A qualitative exploration of factors that influenced health literacy among women diagnosed with breast cancer in Kenya during their cancer journey

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Abstract

Background

In Kenya, there are approximately 6,000 new breast cancer (BC) cases annually and 2,550 deaths. Approximately 80% of patients are diagnosed at advanced stages (III–IV), contributing to the high death rate. Research has shown that BC can be cured when discovered early; thus, providing information and improving BC awareness is essential. Health literacy (HL) is an important skill that can shift behaviour towards better breast health and outcomes, yet little is known about HL experiences among Kenyan patients with BC.

Aim

To explore the experiences and factors that influenced health literacy for women with BC presenting at a public and a private tertiary hospital in an urban area of Kenya.

Methods

A qualitative longitudinal approach using serial semi-structured face-to-face interviews from a purposive sample of 11 women, thematically analysed using Colaizzi's technique.

Findings

Two themes were generated: Information experiences of BC patients and Socio-ecological factors that influenced health literacy. A number of factors influenced HL among patients with BC; these spanned different levels of the SEM and were the forces that influenced how participants accessed, understood and used health information to make decisions in their BC journey.

Conclusions

This study provides a deeper understanding of the HL concept through the literature review, which showed that globally, HL skills are crucial for all stages of the BC journey. Uniquely the study used the SEM in Kenya, which enabled a focus on the circumstantial factors that explained participant's HL behaviour and linkages across the three SEM levels. Rather than using the conventional SEM, policy factors as the dominant influencers should be placed at the fore. Finally, the journey model and qualitative longitudinal approach enabled prolonged engagement with participants and was valuable for gaining a deeper understanding of their experiences; this approach can be used for studying other chronic conditions.

Keywords: Breast cancer; health literacy; cancer journey; socio-ecological model; Kenya

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DEFINITIONS

Term	**Definitions**
Breast cancer survivors	Women diagnosed with breast cancer from the point of diagnosis, throughout and after treatment.
Cancer	Abnormal growth of cells which tend to multiply in an uncontrolled way and in some cases, spread to other body organs.
Cancer literacy	The ability to search for, understand and use health-related information in healthcare decision-making (health literacy) or the knowledge a layperson needs to understand the information and advice the health system offers regarding preventing, diagnosing and treating cancerous conditions.
Cohort	A group of patients receiving treatment (e.g. chemotherapy, radiotherapy) together.
Information need	The term ‘information need’ is often understood as an individual or group’s desire to locate and obtain information to satisfy a conscious or unconscious need.
Literacy	Using printed and written information to function in society, achieve one’s goals and develop one’s knowledge and potential.
Literate	Ability to read and write.
Health literacy	‘The degree to which individuals have the capacity to obtain, communicate, process and understand basic health information and services needed to make appropriate health decisions’ (IOM, 2004, p. 32)
Health seeking behaviour	Any action undertaken by individuals who perceive themselves to have a health problem for the purpose of finding an appropriate remedy.
Information literacy	The ability to access, evaluate, organise and use information to learn, problem-solve and make decisions in formal and informal learning contexts, at work, at home and in educational settings.
Patient education	The process by which healthcare professionals and others impart information to patients and their caregivers to alter their health behaviour or improve their health status.

Patient information	A non-specific term for any information about a condition or procedure, which is intended for consumption by a non-professional audience.
Social networks	A network of individuals (such as friends, acquaintances, and co-workers) connected by interpersonal relationships
Social capital	A network of relationships created by a group of people that helps them achieve common goals and lead a comfortable life.

LIST OF ABBREVIATIONS

Abbreviation	**Expanded Form**
AKUHN	Aga Khan University Hospital, Nairobi
BC	Breast cancer
BSE	Breast self-examination
CBE	Clinical breast examination
HCPs	Healthcare providers
HL	Health literacy
KNH	Kenyatta National Hospital
NCCS	National Cancer Control Strategy
NCCN	National Cancer Control Network
NGO	Non-governmental organisation
RA	Research assistant
RCT	Randomised controlled trial
SDM	Shared decision making
SEM	Socio-ecological model
UK	United Kingdom
US	United States of America
USD	United States Dollar
WHO	World Health Organization

THESIS STRUCTURE

This thesis explored health literacy (HL) as experienced during the cancer journey by listening to women who had been diagnosed with breast cancer (BC) throughout their hospital treatment in Kenya.

Chapter One sets the scene for this thesis and provides an overview of the study topic and its significance in practice and policy. It provides key BC statistics and describes the Kenyan cancer context and key government policy guidelines developed to facilitate activities geared towards prevention, early detection, diagnosis, treatment and end-of-life care. It outlines the Kenyan healthcare system with a specific focus on provision of cancer services and healthcare financing. An overview and definitions of literacy, information literacy and HL are also provided, with emphasis on how they impact BC care. A more detailed critique of HL concept is provided in Chapter Two. The chapter concludes by outlining the research problem, motivation, rationale and significance of this study.

Chapter Two explores the theoretical frameworks that were reviewed to identify the most suitable framework to guide this study. Two health promotion models and three HL frameworks were critiqued for their strengths and weaknesses and suitability for this study. The socio-ecological model (SEM) was identified as the most suitable theoretical framework and adopted for this study.

Chapter Three explores the existing literature relevant to this research study. This included current evidence on cancer-related HL to situate this study within the existing body of evidence on HL by exploring existing research and observing the gaps in that literature. As few HL studies have been conducted in Kenya, the literature review identified contextual factors that influenced HL. It focuses on four broad areas: information needs of patients with BC, sources of BC information, factors that influence HL, and experiences of patients with BC. The chapter ends with a discussion of the lack of qualitative evidence related to the HL experiences of women diagnosed with BC across their cancer journey in Kenya, and concludes by drawing together the literature, highlighting specific gaps and discussing how my study fills these gaps and makes an original contribution.

Chapter Four describes the methodology chosen for this study and outlines the research aim, objectives and rationale for the methodological choices made. It begins with the research design and highlights how my interpretive epistemological position informed the research design. The chapter then addresses the sample access and recruitment procedures, study settings, data collection methods and analysis in detail, and describes the approaches used to ensure that the research was ethical, rigorous and credible.

Chapter Five provides an overview of the research findings, detailing the 11 study participants, and their demographic characteristics. It further presents the findings from the in-depth interviews relevant to the first key theme: Information experiences of patients with BC. Participants' BC awareness and knowledge is considered as well as how they accessed and used cancer information to make decisions, the actual information given by healthcare providers (HCPs), and their perceptions of the information received. Breaking the 'bad news' of a BC diagnosis was described as a terrifying experience that triggered negative emotions because of fatalistic thoughts associated with BC. A comprehensive analysis of the interviews generated the information needs expressed by participants.

Chapter Six presents the data gathered from in-depth interviews that related to the second key theme: Socio-ecological factors that influenced HL. The levels of the SEM are used to organise these factors. In this chapter the factors that were identified as either barriers or facilitators of HL are presented.

In Chapter Seven, the findings are interpreted and discussed in the context of existing literature. As this study generated many findings, the discussion focuses on the socio-ecological factors that influenced HL along the BC journey. This chapter also discusses the limitations of this study and the key contributions to knowledge.

Chapter Eight concludes this thesis and makes recommendations for policy, practice, education and research, which were based on the findings of this study.

CHAPTER ONE: INTRODUCTION

This chapter presents the background information essential to understanding the BC situation in Sub-Saharan Africa, particularly in Kenya, where this study was conducted.

1.1 Overview of BC

BC is the most common malignancy worldwide (Bray et al., 2018), but it is highly preventable and treatable if discovered early. Sung et al. (2021) reported that there were over 2 million new BC cases each year worldwide (24.2% of all new cancer cases) and stated that BC is the second leading cause of death (after lung cancer) in women. Of the 522,000 cancer deaths yearly, 324,000 deaths (62% of total cancer deaths) occur in less developed regions and 198,000 deaths (38 % of total cancer deaths) occur in more developed regions. According to global estimates, over 19.3 million women will be diagnosed with BC by 2025, the majority being from Africa (WHO,2013). BC mortality rates have reduced by 1% per annum in developed countries (Ferlay et al., 2015), whereas they have increased in Africa (Brinton et al., 2014). This reduction is attributed to early diagnosis, whereas the African increase is attributed to the adoption of Western lifestyles, such as delayed childbearing, avoiding breastfeeding, and consumption of an unhealthy diet (Parkin et al., 2010).Furthermore, the African cancer problem is worsened by a lack of standardised BC diagnostic procedures and because women do not seek timely healthcare interventions when they notice abnormal symptoms (Sayed et al., 2016). These delays can further be attributed to the lack of information about BC risk factors and symptoms that women need to report (McEwan,et al.,2014).

The guidelines for cancer treatment in Africa provided by National Comprehensive Cancer Network (NCCN) (www.nccn.org/harmonized) have been adopted from Western countries (Koh et al., 2020). The challenge with such adoption is that the guidelines cannot be fully implemented because of contextual differences; for example, there are few speciality HCPs in Africa to care for the high number of patients with BC, and they may not always have time to gather relevant information to help patients understand their treatment. This is further complicated by a paucity of treatment facilities and resources (Gakunga et al., 2019). This lack of BC treatment resources calls for a greater focus on increasing BC awareness in regard to prevention, early detection, diagnosis and treatment.

A report tabled to the National Assembly Health Committee by the Kenya National Cancer Institute (NCI) CEO Dr Alfred Karagu (Awich, 2019) shows that BC is the most common malignancy in 11 selected regions with the highest incidences of cancer in the country (Table 1). This report was presented in July 2019 with the hope that it would aid the government in allocating resources to fight cancer (Awich, 2019). In Kenya, a country with a population of approximately 50 million people, BC is the leading cause of death, accounting for 12.5% of all cancer deaths (Bray et al., 2018). BC affects 34 per 100,000 women, which offers a clear indication of the threat this type of cancer poses in Kenya. However, these are only estimates, and the numbers could be higher because many cases are unreported, especially those who die at home after seeking traditional healing (Sayed et al.,2019). In addition, cancer registries are not well maintained in Kenyan healthcare facilities (Korir et al., 2018), starkly contrasting to what happens in developed countries. For example, when a patient is diagnosed with cancer in the UK, the information is automatically included in national cancer registry data (https://www.cancerdata.nhs.uk/). Cancer registries provide information about the number of people diagnosed, their treatment and survival rates, which is used to plan and improve cancer services and the lives of cancer patients (Morgan et al., 2018).

Table 1: Population, level of urbanisation, and cancer prevalence rates in selected counties in Kenya (Awich, 2019)

County	**Level of urbanisation**	**Population**	**Male**	**Female**	**Cancer prevalence rate per 100,000 people**									
					Prostate	**Breast**	**Cervix**	**Oesophagus**		**Lymphoma**	**Colorectal**		**Stomach (Men)**	**Mouth and Pharynx (Men)**
					Men	**Women**		**Men**	**Women**		**Men**	**Women**		
Embu	16 %	608,599	304,208	304,367	24.1	31.9	22.7	16.8	6.2				9.7	
Meru	12 %	1,545,714	767,698	777,975	24.5	20.2	17	17.6	9.1				12.5	
Bomet	15 %	875,689	434,287	441,37	18.1		5.6	30.4	21.8			4.3	11.6	
Kisumu	52 %	1,155,474	560,942	594,609	7	11	15.6	9.9	8.6	3.3				
Kakamega	15 %	1,867,579	897,133	970,406	3.2	3.5	7.1	11.7	8.2				1.9	
Nyeri	29 %	759,164	374,288	384,845	4.5	3.5	7.1	7.1	8.2					3.6
Nakuru	46 %	2,162,202	1,077,272	1,084,235	4.5	6.9	6.3	7.1	3.9					3.6
Nairobi	100 %	4,397,073	2,192,452	2,204,376	32.1	37.4	23.7	12.8			10.3			
Mombasa	100 %	1,208,333	610,257	598,046	16.3	36.8	30		8					5.6
Kiambu	61 %	2,417,735	1,187,146	1,230,454	7.9	14.3	11.3	5.7	3.9				4.9	

1.2 Signs and symptoms of BC

BC typically produces no symptoms while the tumour is small, a major cause of delay in seeking healthcare (American Cancer Society, n.d). Common signs and symptoms of BC include: a painless breast lump; swollen axillary lymph nodes; breast swelling or redness of the skin; change in size and shape of the breast; dimpling of the skin; itchy scaly sore or rash on the nipple; pulling in of the nipple; and in more advanced stages, nipple discharge that starts suddenly and pain in one spot on the breast that is unrelated to the menstrual cycle (Langhorne et al.,2007). However, it should be noted that the presence or absence of pain in itself does not indicate a cancer diagnosis. Women are therefore advised to seek further evaluation by a doctor for any persistent abnormalities. Ideally, all women should be taught and encouraged to undergo screening for early detection of BC (Sayed et al., 2016).

Staging of BC

The term staging is used to describe the spread of cancer in the body based on the size of the tumour and whether it has spread to nearby areas, lymph nodes or distant areas of the body (Rakha, Tse, & Quinn, 2023). Staging helps with treatment planning, provides prognostic information, and helps evaluate treatment effectiveness. The tumour, node, and metastasis (TNM) classification system is commonly used for BC diagnosis and screening (American Society of Clinical Oncology, 2018; Hortobagyi et al., 2018). In the TNM classification system, T represents tumour size, N indicates the presence of cancer cells in lymph nodes, and M represents the spread of cancer to other parts of the body (Hortobagyi, et al., & Giuliano, 2018; Vaidya 2014). In Kenya, the TNM staging system is used to describe breast cancer stages (Cserni et al., 2018). There are four stages of breast cancer (Macmillan Cancer Support, 2023):

- Stage I means that the cancer size is less than 2 cm or equal to 2 cm, and is involved in breast tissue (stage1A) or (stage1B) if cancer is found in the nearest lymph nodes It is the earliest stage of BC with a higher survival rate (Macmillan Cancer Support , 2023).

- BC at stage II is when the tumour size has reached or exceeded 5cm with the possibility of lymph node involvement under the arm. Sometimes, the cancer may not be detected in the breast itself, but there are instances when cancer cells have spread to 1 to 3 lymph nodes near the breastbone or in the armpit. (Macmillan Cancer Support, 2023).

- Stage III tumours are of any size and have spread to four to nine axillary lymph nodes, internal mammary lymph nodes, or to the rest of the body (Macmillan Cancer Support, 2023).

- In stage IV, the cancer has spread to other parts of the body (bones, lungs, liver, and brain). This phase is also called advanced cancer, secondary BC, or metastatic BC (Macmillan Cancer Support, 2023).

In sub-Saharan Africa, the percentage of patients diagnosed with stage (III or IV) BC ranges from 30 per cent in South Africa to 98 per cent in Nigeria (Ekpe et al., 2019). In Kenya, 42 per cent of women are diagnosed in stage III and 18 per cent in stage IV (Ekpe, et al., 2019). This starkly contrasts with the US, where only five to eight per cent of patients present at stage IV.

1.3 Screening guidelines for BC

Three types of screening are commonly used for early detection of BC. These are the breast self-exam (BSE), a clinical breast exam (CBE) and a mammogram. In BSE, a woman checks her breasts every month for lumps and any abnormalities in shape and size, whereas CBE involves an HCP examining the breasts to detect tumours and other abnormalities (Langhorne et al., 2007). The most effective screening method is mammography, performed via an X-ray procedure. It detects BC at early stages when there are better chances of successful treatment, reducing mortality. Mammography is recommended annually for women over 50 years and every 2 years for those over 40 years. However, for women with a high-risk BC history, mammography can be performed before the age 40 (NCCN Guidelines Version 2, 2022). In developed countries, screening is organised by the government. For example, the UK has a comprehensive screening programme for women aged 50–71 years who are registered with a doctor. They receive automatic phone messages inviting them for BC screening every three years (Breast Screening Programme, England 2019–2020). However, in Africa, including Kenya, most women are unable to receive mammography because of the cost (range 35–50 USD).

The Kenya National Cancer Control Strategy (NCCS) highlighted activities for early BC detection, but screening using mammography is not included (NCCS, 2017–2022). This can be explained by the lack of screening facilities in some counties. The NCCS (2017–2022) further outlined objectives and activities for BC screening and called on county governments in Kenya to allocate resources for screening. However, this depends on the government's budget allocation for health (6%–6.7%), which is often low in relation to the Abuja Declaration recommendation of 15% (Ministry of Health, 2013). The scarce allocation of funds to the healthcare sector leaves it struggling to provide adequate BC screening, diagnosis and treatment services. Despite budget challenges, there are efforts to create BC awareness both by government and non-governmental organisations (NGOs). For example, the Ministry of Health's (2021) Breast Cancer Screening and Early Diagnosis Action Plan 2021-25 aims to implement the NCCS (2017–2022) and other previous guidelines in developing a comprehensive BC early detection programme in Kenya. The programme will focus on early detection, rapid diagnosis, and breast cancer treatment in a resource-oriented and integrated approach in a population largely naive to screening. It is evident that the majority of those who go for screening usually do so when they find a problem; however, at that time, it is technically not screening that is needed but a biopsy to determine if the breast lump they have is cancerous (Talib 2019 et al.,). Table 2 below provides a summary of the recommendation for screening.

Table 2: Summary of Kenya National screening guidelines recommendations (Ministry of Health (2021) Breast Cancer Screening and Early Diagnosis Action Plan 2021-25)

Age group in years	Recommendation	Interval
25-34	CBE every 3 years Mammography is not recommended	1 to 3 years
35-39	CBE and Ultrasound OR mammography	1 to 3 years
40-55	CBE + mammography	Annual
56-74	CBE + mammography	Every 2 years
75 and older	Consider individual health factors and woman's preference to continue screening	Discuss with patient

1.4 BC awareness

The NCCN guidelines state that awareness is central to decreasing the chances of developing BC and for early detection and treatment. However, Kenya does not yet have a mass BC awareness and screening programme; screening is currently opportunistic and individual-based (Mwenda et al., 2021). BC awareness campaigns in Kenya are mainly led by NGOs; for example, the Beth Mugo Cancer Foundation, Faraja cancer support group, Women 4 Cancer and Kilele cancer support group. There is a need to increase the knowledge level about BC screening among Kenyan women to enhance uptake of available hospital screening facilities. Coupled with low knowledge about BC, factors that may hamper screening and awareness programmes in Kenya, especially for women in rural areas, are the inaccessibility of cancer healthcare services, stigma and women's belief systems (Akuoko et al., 2017; Gakunga et al., 2019; Muthoni & Miller, 2010). Cumber et al. (2017) documented low BC awareness in Sub-Saharan African women, poor understanding of the causes of BC and poor BSE practices (Table 3). They suggested that a lack of knowledge and misconceptions about causes were responsible for late-stage diagnosis in 80% of BC cases. In Jordan, another country without adequate breast care facilities, Othman, Ahram, Al-Tarawneh and Shahrouri (2015) found that when women were empowered with information they practised breast screening behaviour and were diagnosed in early stages when their cancer could be treated.

Table 3: Women's beliefs about the causes of breast cancer and breast self-examination practices (Cumber et al. 2017)

Beliefs about causes of breast cancer	***Breast self-examination***
Putting money under the bra *Attack from the enemy* *Will of God* *Scratching the breast* *When a child bites the mother during breastfeeding* *Prolonged fondling of the breast by a man* *Large breasts* *Small breasts* *Breastfeeding for a long time* *Guinea worm infection*	*Never heard of it* *Heard of it but do not practise* *Heard of it and practise occasionally* *Heard of it and practise monthly* *Don't know clinical breast exam* *Never heard of it* *Heard of it but never had an exam* *Heard of it and had at least one exam*

1.5 Kenyan Government policy on prevention and control of BC

In 2011, the Kenyan Ministry of Health (MOH-Kenya) published the Kenya NCCS 2011–2016, which intended to reduce cancer incidence and improve the quality of life of those affected. The aim was to build a strong force in both public and private networks by investing in cancer awareness, human resources, equipment, surveillance and research. Comprehensive interventions were outlined, complete with objectives and strategies to be implemented by the government and other partners. Some key strategies were: primary prevention of cancers, diagnosis and treatment, palliative care and pain relief, cancer surveillance and research, coordination of cancer prevention activities, and monitoring and evaluation (NCCS, 2017–2022). Although some of the strategies outlined in this strategic plan have been implemented (e.g. tobacco control), a key omission is that the focus remains on HCPs with no mention of patient involvement or HL. For example, the guidelines stipulate what activities stakeholders should perform at the prevention, detection and diagnosis, treatment, survivorship and palliation levels. However, the patient (as a key stakeholder) is not addressed. This could mean that the MOH-Kenya may be reporting the successful implementation of the strategy, yet the intended beneficiaries are left out. If implemented properly, the NCCS may stimulate national policy action, thereby making HL a political priority. In later versions of the strategy document, it is recommended that the patient's voice is included. In tandem with the NCCS, other guidelines were developed to standardise cancer management.

In August 2013, a guideline for the management of cancer was developed by the Director of Medical Services under the MOH-Kenya to implement the NCCS 2011–2016. The guideline is a meticulous document covering site-specific cancers and details the epidemiology, diagnosis, staging, management (including diagnostic procedures), commonly used medicines and prognosis (treatment outcomes). The guideline also stipulated the role of the multidisciplinary team and specified the HCPs mandated to carry out certain procedures to protect patients from exploitation and abuse. These guidelines are similar to those recommended worldwide (e.g. American Cancer Society, Cancer Care Ontario and Oncology Nursing Society) and reflect best practices that would contribute to reducing the incidence of cancer and improving the quality of life for those affected. However, HCPs were advised by the authors to interpret the guidelines carefully based on their context. This could be attributable to the diverse contexts and levels of patients encountered, which ranges from the basic dispensary level to the tertiary referral healthcare institutions. These institutions differ in terms of trained cancer specialists, diagnostic, and treatment facilities.

1.6 BC services in Kenya

Healthcare financing is provided through public, private for-profit and private not-for-profit facilities. Healthcare services are arranged in tiers from the dispensary level to referral hospitals. Financing is mainly paid by the patient, government expenditure and donors (Gakunga et al., 2019). By 2015, there were only two public cancer centres in Kenya: The Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital. However, the major private hospitals (e.g. Aga Khan University Hospital, Nairobi [AKUHN], MP Shah and Nairobi Hospital) also provide cancer services (Kenya Network of Cancer Organisations website: https://kenyacancernetwork.wordpress.com/kenya-cancer-facts/). At public facilities where most Kenyans can afford treatment, the waiting times are long; for example, a woman who was diagnosed with BC in December 2017 was booked for her first radiotherapy in April 2018, which left a long interval during which her disease advanced. The private sector can only serve a small percentage of the population because of the high costs charged, especially as most people cannot afford health insurance (Gakunga et al., 2019). The few patients who have private health insurance or that can access the government-funded National Health Insurance Fund (NHIF) are better placed to receive cancer services. However, insurance companies cap the coverage and avoid taking people diagnosed with cancer (Kimani, et al., 2014). Overall, healthcare financing is provided through private-for-profit and private-not-for-profit public facilities.

After devolving health services, the Kenya government passed a bill in 2012 that sought to establish cancer care centres in all 47 counties in an effort to bring cancer services closer to populations in need, especially those in rural areas. Few counties (e.g., Machakos, Mombasa, Nakuru and Kakamega) have built cancer care centres. Unfortunately, these centres are ill-equipped to offer comprehensive cancer services because they lack specialty-trained oncology staff and appropriate cancer prevention, diagnosis and treatment equipment. Currently, seven private hospitals and two faith-based hospitals have facilities to diagnose and treat cancer (Ngutu & Nyamongo, 2015). Four centres (KNH, AKUHN, Nairobi Hospital, MP Shah, Texas Cancer Centre) in Nairobi, the capital city, and Moi Teaching and Referral Hospital (Eldoret) offer chemotherapy and radiotherapy. Four of these facilities are private and, therefore, out of reach for many Kenyans.

Cancer treatment costs depend on the facility (private or public) and treatment modality. A study by Atieno et al., (2018) reported that the majority of patients with cancer received surgery, chemotherapy and radiotherapy. Chemotherapy alone costs an average of KES 138,207 (USD 1364.3), whereas surgery costs an average of KES 128,207 (USD 1265.6) and radiation costs an average of KES 119,036. (USD 1175.1). The cost is higher for patients who require all three treatments, at an average of KES 333,462 (USD 3291.8) per patient per year. This places treatment out of reach of the majority of Kenyans who live on less than 1.90 USD per day; this causes a considerable financial burden for the families of uninsured patients (Atieno et al., 2018).

In summary, Kenya is among the countries in Africa that is faced with a high burden of BC, with 80% of women with BC presenting to healthcare facilities at an advanced stage. Some reasons for this late diagnosis are lack of BC awareness and the inability of healthcare facilities to offer cancer services. The MOH-Kenya has developed policy documents outlining comprehensive cancer management interventions. Despite these efforts, many challenges continue to be faced including inadequate healthcare finances and lack of a specialty-trained workforce for cancer management. Consequently, there is an urgent need to increase BC awareness through improving HL. Importantly, HL is cheaper and easier to implement than personal finances and workforce training; it is a low hanging fruit that can shift behaviour towards health information access and use.

1.7 HL

Baker (2006) reported that 90 million American citizens faced health challenges because of poor HL skills, with similar reports from Australia and the UK. HL is often misconstrued as the ability to read and write, but there are many factors that influence an individual's HL. Since the 1970s, HL has been considered an important predictor of health behaviour and outcomes, although debate continues as to what constitutes HL, how to measure it and what interventions are cost-effective and most effective in addressing HL-related challenges across various contexts (Rudd, 2015). Different contexts also mean that HL is not a constant; rather it is dependent on several factors. Sorensen (2013) argued that HL can be viewed as a continuum, which changes depending on the circumstances of the individual.

1.8 Historical perspective of HL

The HL movement started in India under Mahatma Gandhi with the aim of supporting groups working in Africa to promote health and education. First used in 1974, the term 'HL' was then described by (Parker & Ratzan, 2010) as health education that met minimal standards for all grade levels. Thirty years later, the definition has evolved with different bodies publishing various approaches. Despite differences in definitions, one commonality exists; that HL involves the need for people to obtain and understand information that helps them to maintain optimum health. The 1990s saw two different approaches adopted for HL, one oriented to public health and the other to clinical care (Pleasant & Kuruvilla, 2008). The clinical approach was developed in the US to help physicians better communicate prescriptions so that patients could understand and adhere to treatment regimens. Conversely, the public health approach takes an empowerment perspective and is more prominent in developing countries in which it constitutes one of the pillars of health promotion.

Despite these differences, both the public and clinical approaches tend to focus on some aspect of an individual’s capacity to obtain and use information for the betterment of their health with knowledge as the core. In the later 20th century, emphasis shifted from health education to understanding the usefulness of socioeconomic and environmental actors as determinants of health (Garcia-Codina et al., 2019). This emphasis led to the focus on HL, which was defined by the Institute of Medicine (IOM) as a person’s ability to access, understand and use information given to them to improve and maintain good health (IOM, 2004). In times of physical and mental distress, such as after a BC diagnosis, patients must make complex treatment-based decisions that are impacted by their HL (Sørensen, 2020). HL is therefore a key priority for many healthcare organisations in the US and other developed countries; however, it remains a relatively new concept in Kenya.

The HL field has seen exponential growth in research and publications focused on the impact of HL and outcomes. Puts et al. (2015), Lee and Hawkins (2010) and Humphrys, Burt, Rubin, Emery and Walter (2019) recommended interventions to address identified gaps in HL. However, the many working definitions of HL mean it is difficult to determine which measures are effective, especially in low resource settings. Trezona, Rowlands and Nutbeam (2018) described HL as a universal challenge that was prominent in the World Health Organization (WHO) agenda spanning two decades. HL is deemed a key pillar for achieving the Sustainable Development Goals as it is crucial in the management of long-term and chronic complex conditions (e.g., BC) that have complex treatment modalities that call for patient engagement and self-management. It has also been argued that HL skills and self-management are strongly related (Kim et al.,2015).

Historically, health education has been used as a means of health promotion and disease prevention, mainly through disseminating large quantities of information. Over time, it became evident that distributing information without considering factors that affected the use of that information was ineffective (Nutbeam et al., 2017). The relationship between individual HL and health outcomes was summarised by Halverson et al. (2015) in terms of three causal relationships that HL may affect: 1) how individuals access and use healthcare; 2) patient-provider interaction, including communication and participation in decision-making; and 3) self-care skills, including knowledge and problem solving. In addition, low HL was associated with delayed diagnoses, problems with the use of preventative services, , understanding one’s medical condition, self-management skills ,adherence to medical instructions, poor physical and mental health and increased mortality risk (Paasche-Orlow & Wolf, 2007).

1.9 HL in Kenya

Although HL research has grown in prominence worldwide since the 1970s, it remains a new concept in Kenya. Some previous research that had elements of HL considered cancer awareness, screening and prevention, with a strong focus on patient education (Alago & Awiti, 2016; Muthoni & Miller, 2010). Interestingly, most healthcare facilities in Kenya include patient teaching as a quality indicator, and statistics are presented every month regarding how well patients are being taught. However, in a country where general literacy levels are deemed low (KNBS & NACC, 2017), it is likely that HL will also be low. As discussed earlier, people with limited HL are less likely to be informed about BC and how to seek related information; therefore, there is a need to devise strategies to actively seek out this group and identify their needs and priorities in terms of BC-related information. HL may be a key factor to help reduce health disparities, and improve BC care and patient outcomes (Buki et al., 2016; Halbach et al., 2016; Kamimura et al., 2016).

A low resource intervention that may impact BC awareness (although not addressed in policy documents) is related to HL. It is essential to introduce the concept of HL and incorporate it into BC care provision activities at all levels in Kenya because women’s understanding of the health information, they receive impacts important decisions about cancer treatment. With the rising burden of cancer and associated mortality in Kenya (Ferlay et al., 2015), knowledge of factors that influence HL may offer valuable insights into interventions that will increase patient involvement in decision-making and improve clinical outcomes, including treatment adherence, management of side effects and general well-being (Kugbey, Meyer-Weitz, & Asante, 2019). In addition, HL skills can empower individuals to take charge of their own health by making appropriate healthcare decisions, improving communication with HCPs and providing them with the knowledge they need to navigate the healthcare environment (Kindig et al., 2004). To consider HL concepts, the following section focuses on literacy and how it impacts BC management.

1.10 Literacy

Literacy is a term used to define the ability to read, write, listen, comprehend and speak a language, but has recently evolved to specifically refer to the ability to read and write at a level adequate for communication (Kindig et al., 2004). Although it seems quite basic, this concept poses a major challenge (Nutbeam, 2017), more so to the average Kenyan woman whose first language is not English, especially as most health communication in Kenya uses English (a foreign language). It is well known that for people to act on what they have read, they need to understand it. Therefore, it can be hypothesised that most Kenyans may not understand health information that is provided in English language (O'Brien & Cadwell, 2017).

The 2014 Kenya Demographic Health Survey rated literacy levels in men at 92% and in women at 88%; however, in the clinical setting, HCPs are faced with many patients with low literacy. Although no available studies have confirmed this low literacy, data from other studies indicated that it is likely to be low; for example, patients with HIV are known to encounter challenges communicating with doctors (Butto et al.,2020). Literacy rates also vary from region to region because of factors such as wealth, urbanisation and culture (e.g. some tribes in Kenya limit the education of females). People with low literacy encounter difficulties with daily activities such as reading a newspaper, the Bible and letters. This is further complicated when they are faced with a chronic illness such as BC that requires a degree of decision-making and self-management (Miller et al., 2010).

In the UK, a report by the National Literacy Trust (2018) highlighted studies that showed the complex relationships between life, socio-economic factors, health and literacy.

- Individuals with low literacy suffered from unemployment and low incomes whereas those with high literacy skills had higher incomes and financial security; therefore, they experienced fewer life stressors that caused poor health.
- A strong link was reported between literacy and health, which highlighted that those with low literacy levels were: three times more likely to experience poor health outcomes, up to 1.8 times more likely to take their prescription medications incorrectly, significantly less likely to comprehend symptoms of a medical illness and mostly rated their health as very poor compared with those with better literacy skills.
- Low literacy skills were linked with increased rates of smoking, drinking alcohol and missed health appointments.
- People with high literacy skills could understand and use health information. They also had higher levels of enjoyment, hope and happiness than those less educated.
- There was a strong correlation between health and HL (WHO, 2013), meaning that people who struggled with low literacy also struggled with low HL, and low general literacy and low HL affect people's health in equal measure.

This section highlighted the relationships among education, literacy, socioeconomic factors and HL. Although the report discussed above was compiled from studies conducted in the UK, the concepts are applicable to Kenya where literacy is inadequate and HL skills are poor.

1.11 The BC journey

The BC journey is complex and diverse, and in this study it encompasses the experiences of BC from prevention, screening, diagnosis, treatment, rehabilitation, and survival. Whereas individuals often enter the BC journey at the point of screening and may never proceed further, others will enter at the point of diagnosis and move through the phases of treatment, rehabilitation, and follow up (Jacobs et al.,2016). Some of those in follow up continue without any further clinical evidence of BC while others will encounter a relapse. In a different scenario, some individuals will enter at the point of diagnosis but require palliative care and eventually die. Death as a result of BC remains the final outcome for more than half of those who have been diagnosed with the disease and accounts for a high mortality worldwide (Buzaid et al., 2020). The five-year survival rate after successful BC treatment is highest in stage I (91 % of all patients),and 85 % at stage II (Arrington et al., 2014).However, the survival rate also depends on the general health, hormonal status and age (Francies et al., 2020).

From the moment a woman thinks there may be something wrong with her breasts throughout the journey of diagnostic investigation, treatment, and follow up care, the experience of living with BC is a continuous one for the woman and her family. The events are embedded in their daily lives and their demands become part of everyday living and decision-making (Jacobs et al., 2016). The BC becomes an ever-present event not a separate entity that can be set aside and ignored. Therefore, the BC related events are connected one to the other for the woman and her family, for example at screening and then diagnosis influences what happens later, and the journey is a continuous one. This is how I have conceptualised the BC journey throughout the thesis.

1.12 Motivation for this study

My interest in BC-related HL originated from several experiences while working in an outpatient chemotherapy clinic and during a BC screening camp. In the oncology clinic, women receiving chemotherapy treatment shared stories of suffering from side effects of the drugs, and an informal interview suggested that the patients did not know how to minimise these side effects. Of particular interest was documentation in the patients’ files that they had been educated on the treatment interventions and side effects. Other patients stated how lucky they were not to experience side effects, although they said that they felt tired after radiotherapy or chemotherapy. Patients felt this tiredness was fatigue, a side effect of chemotherapy and radiotherapy.

Another frustrating experience was when I was working with oncology students in a maternal child health clinic in the outskirts of the city. Students taught the women about signs of BC, demonstrated BSE, and then examined the women. Sadly, 80% of the women refused to be examined, and no persuasion could change their stance. When I asked one woman who had accepted to be examined why the majority had declined, she explained that based on what they had ‘heard’ about cancer, it was better not to be examined and discovered to have cancer because that would kill them ‘faster’. In the screening camp, women were found with big lumps, which they associated with normal nodes because they were not painful. Other breastfeeding women believed the lumps were due to breast milk and that they would go away with time.

An additional motivating factor for this study was the inadequacy of BC awareness programmes in Kenya, meaning patients must access and understand health information and make care decisions on their own. Therefore, through this study, I explored patients' experiences with BC and elicited how they accessed, understood and used health information to make decisions. I also identified key HL events and practices for patients with BC along the treatment journey and how these contributed to their care involvement and management. I explored how HL was conceptualised, with a focus on other players as identified in the SEM and the HL framework adopted for this study, rather than focusing on the patient as portrayed in extant HL definitions.

Despite the troubling BC incidence and mortality statistics in Kenya, an opportunity exists to improve women’s cancer experiences through the provision of information to support the early detection and treatment of BC. A cancer diagnosis is a stressful experience, and having the right information helps patients understand the disease and facilitates their decision-making and coping (Ankem, 2005). My predicament was that we may be overlooking an important factor influencing treatment outcomes, which is HL; this has emerged as an important factor to be included in BC awareness campaigns.

1.13 Problem statement

BC affects many women who are in the most active point of their economic and social lives, causing significant socioeconomic and psychological harm (Akarolo-Anthony, Ogundiran, & Adebamowo, 2010). Patients diagnosed with BC need to access health information in a format that they can understand to help them navigate their treatment journey. In an ideal situation, there should be a system of identifying patients' HL levels, especially as Dumenci et al. (2014) rightfully stated, HL is malleable and can change for each person because of various factors. Many patients have difficulties communicating with HCPs and adhering to instructions because of poor understanding of health terminology and unclear instructions for medication, diagnosis and follow-up appointments. All of these factors can overwhelm patients with low literacy (Akuoko et al., 2017; DeWalt et al., 2011; Alago & Awili, 2016; Rosser et al.,2015). Given the complexity in healthcare, it is important that the process of giving health information is individualised so it can be understood by all patients and improve their cancer experience. This means that patient information materials need be clear and readable. A telling quote is 'It is not about you (healthcare worker), it is about the patient' (Nielsen-Bohlman et al., 2004). This is particularly relevant given that patient information materials are written in English in Kenya, when only 20% of the population speaks that language (Muthwii, 2004). This means the accuracy of take-home messages is buried in medical jargon. HL is a critical skill that could be the difference between life and death. Indeed, patients' ability to perform what may be simple tasks such as adhering to BC treatment regimens, understanding consent forms and education brochures, requires strong HL skills (Ishikawa & Yano, 2008).

A BC diagnosis brings new information demands, anxieties, and feelings of vulnerability, uncertainty, and loss of control (Humphrys et al., 2019). Therefore, the patient needs to learn new skills, access new information, and seek out help from others to meet their knowledge needs (Lu et al., 2020). All of these demands can increase the challenge and distress, thereby adding burden to patients' experiences. If information needs remain unmet, patients experience additional difficulties; therefore, there is need for a consistent approach to provision of BC information (Hofman et al., 2004). Studies from the US, Germany and Australia (Potter et al., 2015; Jordan et al., 2010; Schmidt et al., 2016) showed that patients with BC have preferences in information needs. Similarly, patients with BC in LMIC settings would have information needs and priorities specific to their context. If these are identified, tailored interventions can be developed to ensure that priorities are met.

This chapter provides evidence that the need for appropriate information for patients with cancer is high and must be addressed at the national level. This is because although the Kenya NCCS 2017–2022 and the national treatment guidelines refer to health education as a major strategy, they do not mention HL. This may be why most BC awareness campaigns have been unsuccessful in reversing the high trends of BC. In existing BC awareness campaigns, women are usually taught about how to perform BSE, the changes to watch for in their breasts and what action to take. Without strong evidence, health information related to diagnosis and treatment will continue to be given based on anecdotal rather than actual patient information needs. HCPs need to understand how information practices facilitate people gaining HL as they need to support patients and their families to deal with BC, its treatment and side effects.

Consequently, patients who cannot access, understand and use information to make health-related decisions may find the information irrelevant. In addition to educating women that early diagnosis leads to cheaper treatment and less invasive treatment with a higher chance of success, there is a need to prepare patients for the daunting journey following a BC diagnosis. This is because patients and families are expected to participate in self- and health management during the long treatment period. Additionally, people diagnosed with BC are exposed to complex treatment and follow-up information. For example, the doctor may prescribe chemotherapy, radiotherapy, surgery, hormonal treatment or a combination of treatments. Furthermore, treatment takes a long time (e.g. up to one year). Therefore, giving information to women with a perceived low HL calls for new techniques that would support them in choosing a treatment plan that aligns with their individual needs.

Whilst adding to a worthwhile body of knowledge, these study findings are valuable as the information obtained will assist in reviewing policies on patient/family teaching and aid in developing measures to improve BC-related HL among Kenyan women. Interventions can then be developed that will increase patients’ use of information and involvement in decision-making, thereby improving their treatment experience and quality of life. A previous study noted that a range of communication methods need to be devised and information tailored to suit individual patient needs (van Mossel et al., 2012). The findings of the present study will also contribute to improving nursing standards, as they have potential to identify other barriers to prevention, early diagnosis and treatment of BC. In addition, the findings will be useful in designing successful cancer awareness, screening and early treatment programmes. It is also hoped that this study will support HCPs to understand better and meet Kenyan women's cancer-related health information and care needs. Overall, the rationale for this study is powerful as it introduces the new concept of HL in the Kenyan healthcare space.

This research arose from a grant-funded study where I was the principal investigator (PI) (see Appendix 2 for the full statement about the grant study) with three co-investigators. The funder was CRDFGlobal BIG CAT Initiative (Grant number DAA3-16-62706-0). The aim of the grant-funded study was to identify previously unrecorded information pertaining to the HL status of women diagnosed with breast or cervical cancer.

The research questions that the grant study answered are as follows.

1. What are the HL and awareness levels of women diagnosed with breast or cervical cancer with respect to: cancer awareness and beliefs; warning signs and symptoms; disease types and processes; and understanding nursing, medical and pharmacy instructions?
2. What is women’s ability to: read consent forms and medication labels; understand oral and written information given by HCPs and insurers; and act upon provided information regarding medications, appointment schedules and other aspects related to diagnosis and treatment?

My PhD overlaps the grant-funded study in terms of participants and data collection methods but differs in focus, research questions and depth of analysis, as described in the remainder of this thesis. As the PI in the grant-funded study, I performed the following s**pecific roles.**

- Submitting the letter of intent after receiving the request for proposals.
- Developing the research proposal and all research instruments (e.g. consent form, interview guides).
- Coordinating all grant requirements with various departments (finance, human resources, housing and travel, legal).
- Coordinating the hiring of the research assistant (RA).
- Applying for ethical approval from Aga Khan University, KNH and Kenya National Council for Science and Technology (NACOSTI).
- Responsibility for the overall conduct of the research, monitoring and ensuring that all activities complied to the laws and regulations.
- Sending periodic reports to the funder.
- Compiling the final report, organising for proofreading and sending the report to the funder.
- Sending abstracts to disseminate findings in conferences.

- Presenting the findings in conferences: African Organisation for Research & Training in Cancer (AORTIC) in Maputo, Zambia and the International Conference on Cancer Nursing (ICCN) conference in Auckland, New Zealand.

The four co-investigators played the following roles.

- Prof. Sharon Brownie: Study site advisor and my local PhD supervisor.
- Dr Margaret Barton-Burke: Research mentor.
- Ms. Tayreez Mushani: Interviewed one patient with cervical cancer.
- Peterson Karani Kiraithe: RA who
    - Assisted with checking translation of research instrument.
    - Recruited participants.
    - Conducted one BC and three cervical cancer interviews.
    - Transcribed all interview data.
    - Communicated with participants about follow-up interviews.

The purpose of my PhD study was to explore the HL experiences of Kenyan BC survivors and identify the socio-ecological factors that influenced how they accessed, understood and used information along their BC journey. The research question and objectives of this PhD study were as follows.

1.14 Research questions

1. What are the experiences of accessing, understanding and using health information for patients diagnosed with BC in Kenya?
2. What socio-ecological factors influence the HL of women diagnosed with BC in Kenya?

1.14.1 Objectives

1. To describe the experiences of accessing, understanding and using cancer-related information along the BC illness trajectory.
2. To determine what BC survivors understood about BC in their communication with HCPs.
3. To identify BC-related information needs of women diagnosed with BC.
4. To identify the socio-ecological factors that influenced the HL of women diagnosed with BC.

1.15 Chapter summary

BC is the most common malignancy in women and a leading cause of mortality in Kenya and globally. HL is an important component of healthcare, especially for those with chronic diseases such as cancer. Patients need contextual and appropriate information to support self-management, reduce anxiety and participate in care decisions. Therefore, to provide such information, HCPs must understand what is important, why it is important and at what point in the BC journey it is important. Previous research has focused on patient education in Kenya, but did not consider the HL of patients with BC. Although the level of education is not an indicator of a person’s HL skills, the low general literacy of most Kenyans implies that patients have limited HL and may therefore face difficulties when navigating the healthcare system. This study explored the experiences of patients with BC with a focus on the factors that influenced HL, highlighting their sources of information and perceptions of how the information met/did not meet their needs at various stages of their BC journey. Their experiences as they interacted with various information sources and how these helped them cope are documented. Chapter Two discusses the theoretical frameworks that were considered to guide this study.

CHAPTER TWO: THEORETICAL PERSPECTIVES

2.1 Introduction

Since the 1970s, HL has been presented as an important predictor of health behaviour and outcomes (Brabers et al., 2017). However, the definition of HL is rapidly evolving, given the various ways of transmitting health information and the changing knowledge base of the clientele. Different contexts also suggest that HL is not a constant but dependent on several factors. HL can therefore be said to be on a continuum and changes depending on the individual's circumstances. For example, the information patients with BC need at screening differs from that needed at diagnosis, treatment and survival (Fletcher et al.,2017).

2.2 Definitions and conceptualisation of HL

There are multiple definitions of HL, from basic reading and writing (Shen et al., 2019) to advanced cognitive and social skills that aid people to access health information and make important decisions in diverse settings. These definitions have evolved and developed to include using information for higher-level functions; for example, critical thinking, problem solving and health communication for individual or communal benefit (Plummer & Chalmers, 2017). As the definition of HL varies among researchers, it is important to clarify how various authors use the term.

One of the first people to define HL was Nutbeam and Kickbusch (1998), who defined HL as '…cognitive and social skills, which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (Nutbeam, 1998, p. 357). This definition posited that social skills were important for interaction with other people and society. Although this goes beyond a cognitive explanation, its association with motivation makes HL an action-oriented concept. This means that an individual has to take a deliberate action to access, understand and use health information for the benefit of their health. Nutbeam (1998) further proposed three levels of HL.

- Functional HL involves basic reading and writing skills that enable an individual to know health risks and how to use healthcare services.
- Interactive HL, which is more advanced and combines cognitive and social skills that enable one to understand various forms of communication and apply new information to changing circumstances

- Critical HL is a more advanced cognitive and social skill that enables one to critically analyse information and favourably use it to make decisions in various situations.

The WHO has adopted the Nutbeam definition and is also widely used in research. Plummer and Chalmers (2017) used this definition when they explored the relationship between BC survivors' HL and engagement in physical activity and found women with high HL levels engaged in more physical activity. The definition by Nutbeam takes an empowerment approach to differentiate the levels of HL and how they build on each other. As the population in this study had a perceived low HL, this definition goes beyond its scope. According to DeWalt et al., (2004), the HL describes a set of skills that give the individual a context-specific ability to holistically engage in health-seeking behaviour.

The WHO offered a definition of HL that encompassed the elements of personal empowerment and action: 'Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health' (WHO 1998, p. 10). This definition incorporated personal empowerment and action and viewed HL as an outcome of health education and promotion activities. This calls for higher level skills (e.g. critical thinking and problem-solving) to be used in combination with communication and social skills to empower individuals to improve their health. The advantage of this definition is that it goes beyond healthcare settings into the communities where individuals live and work.

Humphrys et al., (2019) used the definition of HL by Public Health England (2015), who described HL as the 'bridge between people and health settings', reflecting how patients accessed, understood, evaluated and used healthcare information and navigated the services available to them. This definition considers people's ability and skills to: access and use basic health knowledge, practise health-promoting behaviours, competently navigate the health system, communicate with HCPS, select appropriate health services and exercise their patient rights. This definition highlights the diverse settings in which HL is important and is similar to the WHO (1998) definition. It also emphasised the need for HL across the lifespan, demystifying it to an ordinary, everyday occurrence.

The IOM defined HL as 'the degree to which individuals have the capacity to obtain, communicate, process and understand basic health information and services needed to make appropriate health decisions' (IOM, 2004, p. 32). The IOM definition has been adopted for this study as most researchers highly favour it. It appears in many policy documents, including *Health literacy-a prescription to end confusion* (Kindig et al., 2004) and *Promoting health and development: closing the implementation gap* (Kanj & Mitic, 2009: unpublished conference document, 7th Global Conference on Health Promotion. Nairobi, Kenya: October 2009). This definition was also adopted by the US Federal Government for *Healthy People 2010*, the goal of which was to increase quality and years of healthy life and eliminate disparities (Brabers et al., 2017). However, HL as used in that definition leaves the problem of literacy to the individual only and fails to acknowledge the role played by HCPs and other players in the system. In addition, there is no mention of social skills that may be needed to make healthcare decisions. Despite this limitation, the IOM definition is widely used in research.

From the IOM definition, HL can be construed as the possession of reading and writing skills and the ability to perform the knowledge-based literacy tasks (understanding and using information) required to make health-related decisions in various environments (home, community, health clinic). The definitions described above indicate that HL is not just a matter of understanding instructions from HCPs but is multifaceted and also covers the patient's ability to interact with HCPs to secure necessary information (Smith et al.,2009). Four functions are used to actualise this concept: accessing information, understanding information, communicating with HCPs and using the information to make health decisions. Accessing health information is the first step in the HL journey, and there are several ways of achieving this: using language that patients can understand, using simple words and avoiding medical jargon (McCormack et al., 2017). However, the availability of information does not translate to understanding and use of the information, which is the second part in the definition of HL chosen for this study. Patients should be able to access, understand and use health information in real life situations.

Despite its common usage, HL is used in different disciplines to mean different things. However, there are commonalities across the definitions. For example, the definitions highlight the fact that HL represents skills that patients with BC need to meaningfully take actions that will improve their experience during their cancer journey. These skills appear to vary from person to person and are contextual.

2.3 Theory

Imenda (2014) defined a theory as a set of interrelated concepts that structure a systematic view of phenomena for the purpose of explaining or predicting the outcomes of a study. The three major defining characteristics of a theory are that it:

- Is a set of interrelated concepts and definitions that present a systematic point of view.
- Specifies relationships between and among concepts.
- Explains events occurrence based on the specified relationships.

A good theory is one that gives a clear and precise picture of events of the domains it seeks to explain. Anfara Jr and Mertz (2014) postulated that the theory chosen to guide a study should give a clear picture of the domain to be explored; in this thesis it was women's HL experiences in the context of BC.

2.3.1 Purpose of the theoretical framework in this study

In this study, theoretical framework has been used to guide several aspects as follows:

1. Help clearly comprehend the main variables and concepts in the study, including facilitators and barriers related to HL.
2. Provide the general approach for the study, including:
    - Methodology, which was qualitative as my focus was people's experiences, actions, feelings, emotions and behaviours.
    - Target population, which was patients with BC in public and private referral hospitals,
    - Research sample, which comprised a purposive sample of 11 women.
    - Data collection, which used longitudinal semi-structured face-to-face interviews.

A number of theoretical models have been developed to predict an individual's health behaviour and explain why people do/do not engage in various health behaviours (Conner & Norman, 2005). The theories and models contained in this review are among the most widely used in health literacy and health promotion. They are most commonly used in the field of health education and behavioural change interventions. These include the IOM's (2004) framework, the health literacy skills (HLS) conceptual framework, the integrated health literacy model (IMHL) and the health belief model (HBM). The IOM (2004) postulates that HL outcomes are based on how an individual interacts with the information and social demands of their healthcare environment. Although the IOM (2004) team concentrated on the individual, they agreed that HL was based on the relationships between individual skills and various health contexts. The IOM asserts that developing suitable processes, policies and programmes to promote public HL requires a thorough grasp of the problem from a multi-sectoral approach (Sørensen et al., 2012).However, the IOM framework's emphasis on the interactions and responsibilities of three major sectors (cultural and social influences, the healthcare system and the educational system) suggests a causal association, which was not the focus of this study.

Meanwhile the health literacy skills (HLS) conceptual framework describes factors that influence the development of HL skills in an individual and how these multiple factors impact comprehension of information and associated health-related outcomes (Kindig et al., 2004). In addition, it presents other variables that act as mediators of HL. The HLS postulated the association between HL and health related outcomes while demonstrating how HL functions at the individual level. The HLS framework has been critiqued for the inclusion of conceptual categories that allows researchers the flexibility to include mediators, moderators and outcomes. In addition, it does not address the key measurement issues that could affect underlying HL skills. As the present study sought to elicit women's HL experiences, this was not an appropriate framework.

The IMHL was proposed by the European Health Literacy Survey Consortium and integrates direct and indirect pathways between the determinants and consequences of HL (Sørensen et al., 2012). The model arose from a systematic review that examined HL-related issues and public health factors throughout the lifespan (Sørensen et al., 2012). Sorensen and colleagues (2012) established the IMHL to address HL as a dynamic process that occurred within both individuals and populations. The IMHL disregards the fact that personal health literacy abilities can change over time Finally, it does not clarify how some constructs (e.g. SDM and health outcomes) would be operationalised (Sørensen et al., 2012); therefore, the IMHL was not relevant for this study.

Lastly, the HBM was developed by Hochbaun, Rosenstock and Kegels in 1958 in response to a failed free tuberculosis health screening programme, and is a model that is commonly used to understand health behaviour of reluctant individuals (Norman & Conner, 2005). HBM is based on the premise that an individual will take health-related actions if they feel that that there will be a favourable outcome and they can successfully apply the recommended health action. The HBM is a model for the healthy and is therefore appropriate for health screening. However, as this study targeted HL among women already diagnosed with BC, the HBM would not be appropriate. The HBM can address question such as, ‘Why don’t women who know about BC go for screening?’ Although such a question would generate relevant data, it would only address part of my study whose intention is to explore HL experiences across the BC treatment journey spanning across prevention, diagnosis, treatment and follow-up.

The socio-ecological model which was adopted for this study is discussed below.

2.3.2 The Socio-Ecological Model (SEM)

The SEM is a framework for understanding the effect of numerous factors within the complex external environment of the individual on behaviour (Golden & Earp, 2012). Urie Bronfenbrenner initially proposed the SEM as a conceptual model for explaining human development in the 1970s, and it was subsequently structured as a theory in the 1980s (Kilanowski, 2017). Bronfenbrenner’s original idea was represented by nested circles, which set the individual at the centre encircled by various systems. The microsystem, which is the closest to an individual, has the most powerful influence and includes the interactions and relationships with the immediate surroundings. The mesosystem extends beyond immediate contacts and includes others with whom the individual has direct contact, such as workplaces, schools, church and neighbourhoods. The exosystem has no direct influence on the individual but interacts with them in both negative and positive ways, such as through communal settings and social networks. Values and influences from society, religion, and culture are all part of the next level, the macro system. Finally, the chronosystem incorporates both internal and external aspects of time and historical information (Kilanowski, 2017).

The SEM grew from the realisation that the ‘healthy lifestyles’ approach to health promotion did not always improve health. This model acknowledged that health behaviour is influenced by many factors that are beyond an individual’s control (Bronfenbrenner, 1998). An exclusive focus on individual health behaviour was therefore a kind of victimisation for the individual. The conceptualisation in the SEM (Figure 1) makes it easier to identify the influencing factors that would be most beneficial for intervention. In addition, it recognises the relationship between an individual and their environment and provides a basis for understanding the various factors affecting behaviour. With the individual at the centre, the SEM acknowledges the influences of social networks, organisations, the community and public policy on health behaviours. Individuals bear responsibility for the lifestyle changes necessary to improve health, but different factors influence behaviour at various levels. For example, at an intrapersonal level, an individual’s decision not to go for a recommended mammogram may be based on their values, beliefs, personal traits and attitudes. At the interpersonal level, the attending physician may fail to emphasise the need to have a mammogram, or the woman’s friends may discourage her because they do not believe it is important. At the organisational level, getting an appointment may be a problem because of long waiting periods or a shortage of radiologists. At the policy level, a woman may not be able to afford the mammogram because of a lack of insurance or competing needs. McLeroy et al., (1988, p. 355) noted that research that was designed to be consistent with a socio-ecological perspective usually examined multi-level relationships as follows.

- **Intrapersonal:** characteristics of the individual such as knowledge, attitudes, behaviour, self-concept and skills. This includes the developmental history of the individual (micro factors).
- **Interpersonal:** interactions between HCPs and clients or between couples, families and network of friends (meso factors).
- **Organisational:** formal and informal groups that meet certain interests; for example, workplaces, faith and business institutions (macro factors).
- **Community:** relationships among individuals linked by social ties and common perspectives. They may or may not be in the same geographical settings.
- **Policy:** legislation at local, national and international levels.

Figure 1: The socio-ecological model (McLeroy, 1988).

2.3.2.1 Strengths of the SEM

The significance of the SEM is that it portrays the individual as being influenced by and also influencing their social environment. Therefore, it can be used to focus attention on specific areas to create relevant and realistic interventions (McLeroy et al., 1988). In addition, the SEM is valued for its ability to offer behavioural change strategies and environment adjustment as it can help researchers to understand the various factors affecting behaviour. This allows multilevel analyses among intrapersonal (micro), interpersonal (meso) and organisational/community (macro) intervention strategies (Wendel et al., 2015). The SEM has an advantage over other models because it expands the outlook of HL beyond the individual to include the delivery of health information by HCPs, health education materials and resources provided to the public and government policies that impact the healthcare system. Factors at each level of the SEM may act as enablers or barriers to HL; therefore, an approach that focuses attention on these factors can improve HL among patients with BC. These changes will help establish environments that support healthy lifestyle behaviours, offer knowledge on basic HL concepts and stimulate conversations in a patient-centred manner.

2.3.2.2 Limitations of the SEM

A practical limitation of the SEM is the cumbersome and complex multilevel analysis. Multiple layers of influence in the SEM must be considered to yield the most effective solutions, which is a considerable challenge. Interventions, particularly those involving various levels, can be costly. In addition, attempting to act at various layers of the ecological model at the same time may create coordination challenges.

2.4 Adoption of SEM for this study

As HL is not a single level construct, the SEM was considered an appropriate model and adopted to guide the present study, especially as it posits that factors and interventions that may improve HL exist at various levels. Therefore, by appraising factors that influence HL at each level of the SEM, problems can be identified, and interventions implemented, instead of only focusing on individual behaviour. This is important as a person's age and cultural and socio-economic factors have potential to influence HL. This calls for an individualised approach to HI provision, which is also informed by the meso and macro factors. In addition to an individual's HL, challenges may result from the interactions of individual, interpersonal and systemic factors, barriers attributable to healthcare system weaknesses and financial constraints; these may be key factors in attaining optimal HL outcomes (Armin et al., 2014).

The SEM levels used in this study were designed to be inclusive of the individual, interpersonal and organisational factors that influenced HL from the perspectives of the individual women interviewed. As policy and community factors overlap, they have been classified as organisational factors. The terms 'micro', 'meso' and 'macro' have also been used in the findings (Chapter Six) and discussion (Chapter Seven). In this study, the SEM was used to set the scope and focus of the constructs to be studied, supported the problem statement, purpose, research questions and objectives, and provided a road map for the literature review. In addition, the SEM provided a framework for designing the research instruments, conducting the data analysis, and interpreting and presenting the findings. This was one way in which this study made an original contribution to the knowledge base.

2.4.1 Integration of the SEM throughout the thesis

The theoretical framework is the foundation for the construction of all knowledge of research. In addition, the alignment of the theoretical framework to the problem, purpose, and significance is an important part of the thesis process (Grant &Osanloo,2014). Mertens

(1998) adds that the theoretical framework has implications for all decisions made during the research process. It serves as a structure and support for the rationalization of research, problem statements, objectives, significance and research questions.

2.4.1.1 Understanding the research question through the lens of the SEM

As Grant and Osanloo (2014) state, the relationship between research questions and theoretical frameworks is complementary. Therefore, the main research questions took into account the recognizable aspects of the SEM and articulated the theoretical framework concepts in such a way that it can be further explored throughout the chapters of the thesis. Since the theoretical framework connected my study with existing literature, the research questions served as a link between existing knowledge and the problems my study sought to solve. For example, my theoretical lens acknowledges that health behaviour is influenced by diverse factors beyond the individual, my research questions were framed around the concepts of individual breast cancer knowledge, information needs, social interactions and organizational factors that influenced BC health literacy. Thus the research questions, "What are the experiences of accessing, understanding and using health information for patients diagnosed with BC in Kenya? What socio-ecological factors influence the HL of women diagnosed with BC in Kenya?" incorporated the SEM concepts of various levels of influence.

2.4.1.2 Applying the theoretical framework to the literature review

The theoretical framework and literature are intrinsically linked (Grant &Osanloo,2014). In this current study, the SEM was used as a guide to the logical development and understanding of different but interdependent parts of the literature review.

When I first approached the literature review I tried to locate studies that were the same as my proposed study, so that I could pick out the gaps and focus my study on that. I checked the literature to see if there were any such studies but there were none. After getting the grant and then beginning my PhD, I went back and revisited the literature in depth. However, during the initial thesis stages, I started with a less structured integration of the theoretical framework, to refrain from forcing my preconceived ideas into the results. However, I reviewed studies that had used the SEM as their lens (see section 3.10). The reviewed studies helped in the specification of key theoretical principles as applied to my topic of health literacy and enabled me to organize the conceptual subheadings that aligned with the SEM. Additionally, I used the same studies to increase my background knowledge, to identify conflicts and controversies in literature eventually leading to the identification of gaps in existing literature. This identification of gaps helped to refine the aims of the thesis and to develop relevant research questions, as well as justifying the research. As Grant and Osanloo (2014) assert, the alignment of the theoretical framework to the problem, purpose, and importance is an important part of the thesis.

2.4.1.3 Applying the theoretical framework to the research methods

The use of theoretical frameworks was not limited to problem formulation and literature review, but guided the entire work (Torraco, 1997). Often, the theoretical framework dictates the data collection plan and illuminates information within the data. The SEM concepts were used to structure data collection and data analysis plans. Thus, in this thesis the SEM, guided the development of data collection instruments with the interview guide questions addressing the micro, meso, and macro level factors. Though theoretical concepts should be explicitly applied and threaded through all aspects of the study, the SEM in the current study is more explicit in the data analysis stage where SEM guided the identification of significant statements and coding.

2.4.1.4 Findings, discussion and recommendations

The SEM was used as the organizing framework to report the findings and was the organization framework for the discussion that provided an insight and explanation of the factors that influenced how BC patients accessed, understood and used information along the cancer journey. The SEM concepts were integrated in to the literature review and used to interpret the findings, support the discussion, and guide the recommendations which were based on the influences of different levels of the SEM.

2.5 Chapter summary

Common HL concepts that most theoretical frameworks address are communication, health-related knowledge, health outcomes and societal influences. After reviewing the theoretical frameworks, I found that the SEM could adequately direct me to sufficiently answer the present research questions. As the conceptual frameworks were synthesised from a number of concepts, research findings and theoretical perspectives (Sørensen et al., 2012), their strengths and weaknesses have been highlighted. However, qualitative research is characterised by less rigid constraints, which afforded the flexibility to creatively and reflexively apply the SEM to guide this study. The SEM was suitable because it offered the flexibility needed to examine situational and contextual HL factors. This encompassed broad areas of HL, namely accessing, understanding and using health information to make decisions. Chapter Three presents an analysis of the relevant literature reviewed.

CHAPTER THREE: LITERATURE REVIEW

3.1 Introduction

The aim of the literature review was to provide the context and rationale for this study and its findings. It highlights the potential original contribution this thesis makes to the body of knowledge by identifying the gaps in BC-related HL that necessitate further research (Brettle & Grant, 2004), and justifies the methods chosen to conduct this study. This was a traditional review which used a systematic approach (rather than a Cochrane style systematic review) as recommended by Aveyard (2014), which includes: the literature review question; search strategy; method of appraisal and analysis of the studies; critical analysis of the literature; discussion; and recommendations. As per Aveyard (2014), my focus was not to exclude studies based on quality, but to summarise and present literature that was relevant to BC health literacy

3.2 Identification of the literature review question

To develop the literature review question, I undertook an initial literature search on cancer-related HL. I read many papers that helped me to develop my thoughts and ideas and eventually the literature review questions. This also helped me gauge the scope and variety of available literature on HL. At this initial stage, many studies were identified that addressed breast cancer-related HL that were published in accessible journals. After clarifying the research question, I discussed it with my supervisors, colleagues, friends and peers who helped me refine and focus my ideas. An opportunity to present my study at a nurses' conference in New Zealand provided opportunity to discuss my topic areas, which resulted in the design of a mind map (Figure 2) that demonstrated how various aspects of HL related to each other. The question the literature review sought to answer was *How do patients diagnosed with breast cancer experience HL across the cancer journey?* This question takes the larger subject of BC but focusses on just one aspect of it, health literacy and enables the review to incorporate the wide range of elements involved in the question.

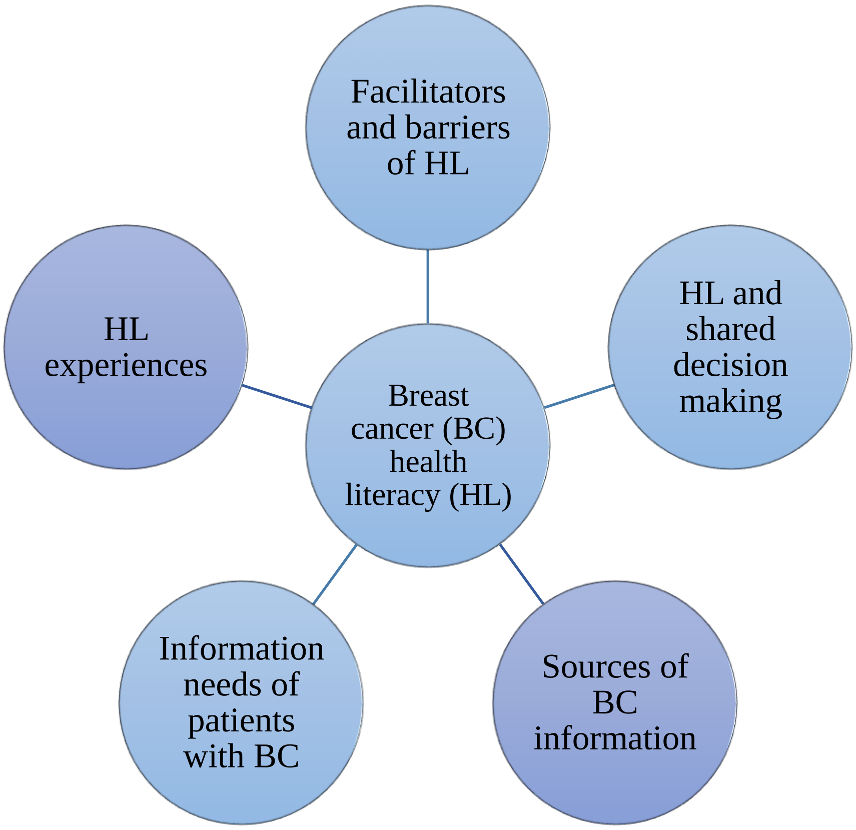


Figure 2: Breast cancer-related health literacy mind map.

3.3 Initial search

The initial literature search was completed between December 2018 and August 2019. The databases searched for relevant literature were MEDLINE, CINAHL and PsycInfo. These databases were found to contain credible, reliable and evidence-based primary sources of cancer research from which resources could be retrieved relating to HL from the medical, nursing and allied health and psychological perspectives (Aromataris & Riitano, 2014). To broaden the search focus, further literature was identified from Google Scholar as well as secondary searches of the reference lists of selected studies (citation tracking) to identify ‘giants’ in the field of HL. These were experts who had published in depth on the topic and their work was frequently referenced. These authors’ names were used to search for seminal works. Grey literature from Internet searches of relevant organisations (e.g., WHO, policy documents, conference proceedings) and the ProQuest library for relevant doctoral theses) was also included.

3.3.1 Search terms

To ensure a comprehensive range of literature was accessed, combinations of key words and phrases were used, including: ‘breast cancer health literacy’, ‘cancer health information’,

‘information literacy’, ‘information needs’, ‘patient education’, ‘cancer’, ‘BC’, and ‘breast neoplasms. Synonyms and MeSH terms were also used. Wild cards and truncation signs were used to cater for different spellings (e.g. health litera* produced results with literacy or literate). Boolean operators (AND, OR) were used to generate new searches.

The search was restricted to papers published in English. Considering the paucity of research in this area, I reviewed studies published between 2005 to 2019 in the first instance to gain a broad understanding on how issues around HL had evolved over time. The initial database search yielded a high number of hits indicating broad interest in the subject of HL. To narrow the results down to a manageable number and after consulting my PhD supervisors, the search filters used were randomised controlled trials (RCTs), metanalysis, systematic reviews (these were high in the hierarchy of evidence and therefore presented a great chance to retrieve high quality research designs and offered overviews of published research) and qualitative research (to inform my qualitative approach). The total number of papers retrieved was 293 (See Table 5 for hits per database, and Figure 3: PRISMA chart).

3.3.2 Screening and selecting studies

Search results were stored in Endnote and duplicates were removed. I then reviewed the abstracts to screen papers whose titles did not include the full terms ‘cancer’ and ‘HL’. This ensured that no relevant papers were missed and revealed papers that included search terms but used concepts related to HL, for example, cancer decision-making and cancer information. This screening was also applied to studies identified through citation tracking. Initial sifting and screening resulted in removal of 166 papers because they were duplicates or did not include cancer HL in the title or abstract. The remaining 127 articles were reviewed for eligibility using the following (Porritt et al., 2014) related questions.

Is the article published in English as specified in inclusion criteria? (See Table 4).

- Does the population in the study meet the inclusion criteria?
- Does the study look at the phenomena stated in the review questions (HL experiences of BC treatment)?
- Does the paper cover attributes of HL; for example, sources of information, information needs, barriers to and enablers of HL, patient education?

This process made the review manageable and established boundaries relevant to the research questions. To determine the studies that would undergo full review, I used specific inclusion/exclusion criteria (Table 4). A further 111 papers were removed leaving 26 articles that were retrieved for a full-text review. Eleven of these papers did not meet the inclusion criteria. These papers and the rationale for their exclusion are detailed in the PRISMA chart (Figure 3). A total of 15 studies remained and were included in this review (see Appendix 5). This approach was consistent with that favoured by Arksey and O'Malley (2005). At this stage, key elements of the papers were extracted and logged into tables in Microsoft Excel worksheets and then later converted into evidence tables (Appendix 5).

Table 4: Studies worthy of inclusion and exclusion

Inclusion	**Exclusion**
Definition of health literacy Assessment of health literacy Adult (18 years and above) Measures of health literacy Breast cancer patients' pre-diagnosis, receiving chemotherapy/radiotherapy/had surgery Lived experiences of breast cancer treatment Patients' cancer awareness Involvement in screening Interventions for promoting health literacy Patient information needs determined by patients/relatives or healthcare providers Factors influencing health literacy Factors influencing patient education Patient/shared decision making Patient involvement Patient attitudes towards breast cancer Culture and beliefs influence on health literacy Sources of breast cancer information Perception towards breast cancer information Nutrition/medication/side effects education Barriers and enablers Studies in a healthcare setting complete with professionals	Other chronic conditions other than cancer Healthcare provider education issues Paediatric and adolescent patients Non-English papers Evaluation of teaching papers Professional and clinical practice issues Conference proceedings/opinion papers Evaluating the validity and reliability of tools Quality of cancer website Randomised controlled trials in progress Papers that were not peer-reviewed

3.4 Updated search

After the initial search, Google Scholar alerts were activated to retrieve any new studies on HL and ensure that the review remained up to date. In July 2021, the combined search strategy was re-run for 2017–2021. This search yielded 82 articles from MEDLINE, PsycInfo and CINAHL, and 70 additional articles (two from hand searching and 68 from citation tracking). The abstracts and titles were screened using the previously described criteria (see

Section 3.3), which left 121 articles. These 121 studies were further scrutinised against the inclusion/exclusion criteria (Table 4) and yielded 31 relevant articles. Therefore 31 articles were retrieved and added to the 15 articles identified initially. In total, 46 primary studies provided the evidence on which I based my review. All additional papers that were added are included in the PRISMA chart (Figure 3). The key elements extracted to form the evidence tables for the updated search included: author, year; location; aim or objective, type of cancer, stage in cancer journey, methods, study sample and key findings (see Appendix 6)

Table 5: Databases search results

Database	Initial search	New Search (July,2021)
CINAHL	n=15	n=5
MEDLINE	n=257	n=57
PSYCINFO	n=21	n=10
Total	n=293	n=82

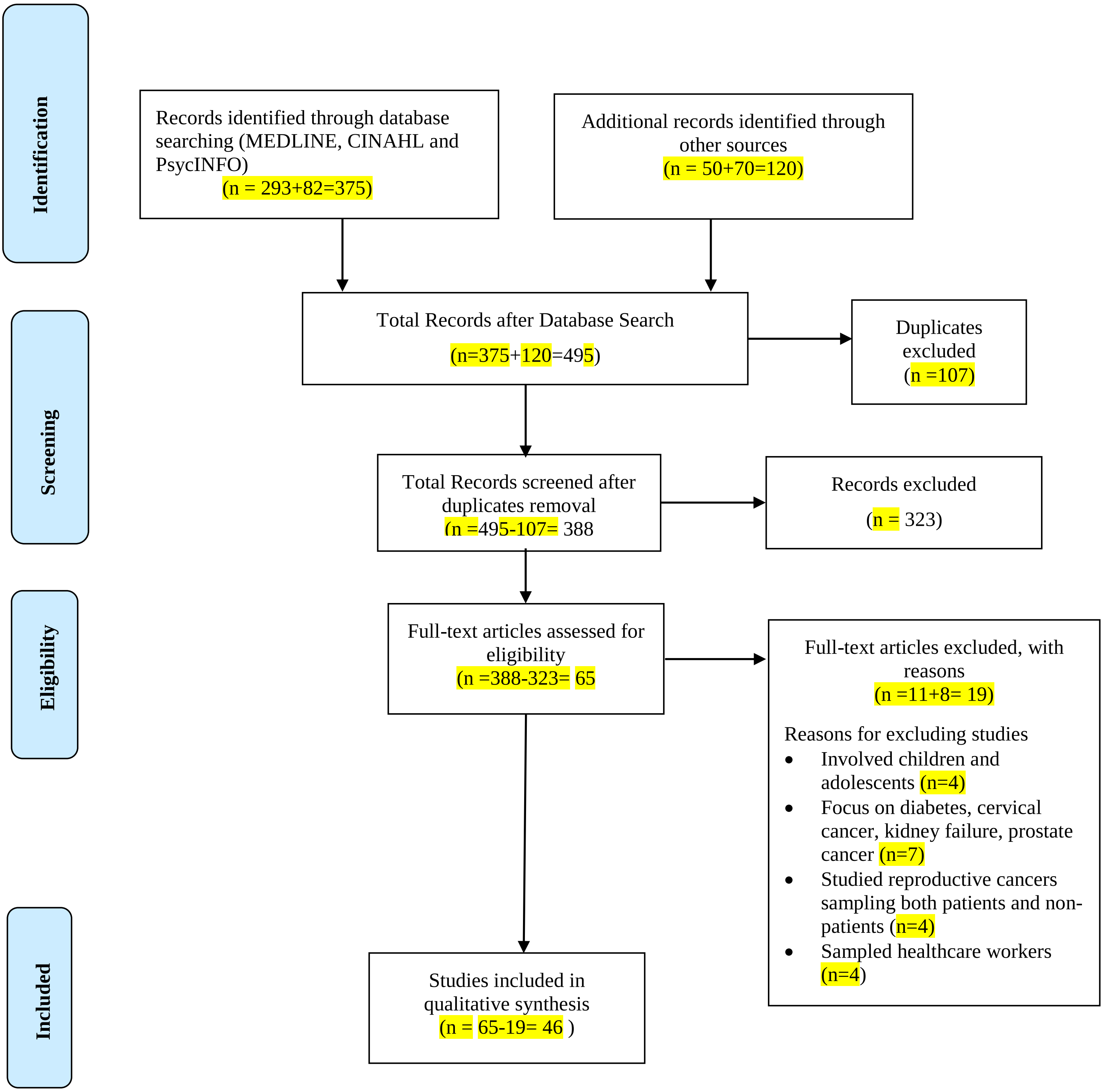


Figure 3: PRISMA chart: Literature search strategy (combined) for cancer-related health literacy.

3.5 Appraisal and analysis of the literature

In total, 46 papers were retrieved and printed for full-text review. My focus was not to assess the studies for quality, but to get topical information about BC health literacy and critique it in relation to my literature review question. Again, the studies were peer reviewed and published in scholarly journals, and this gave me some reassurance me about the quality of the papers included. The appraisal and analysis answered the following questions, as guided by (Aveyard, 2014).

What literature do I have and how relevant is it?
Is the literature I have identified at the top of my own hierarchy of evidence
What are the strengths/weaknesses and gaps of this literature?

3.5.1 Results of the literature review

Forty-six studies published between 2005 and 2021 were selected for this review. Of these, 20 used a qualitative approach and 13 were quantitative. There were seven systematic reviews, five mixed methods, and one scoping review. Most qualitative studies used semi-structured interviews to collect data, with two studies collecting longitudinal data (Halbach et al., 2016; Schmidt et al., 2016). Only three studies used the SEM as their guiding theoretical framework (Leena, 2020; McCormack et al., 2017; McEwan, Underwood, & Corbex, 2014). This confirmed that the SEM was appropriate to explore the topic of HL among patients with BC. Fifteen studies were conducted in the US, four in Germany, three each in Nigeria, Australia, Kenya and Canada, two in the UK and one each in Lebanon, Mali, Iran, Uganda, Thailand, Ghana, the Netherlands, the United Arab Emirates (UAE), Egypt, Jordan, Taiwan and India. Out of the 46 studies reviewed, only 10 were from Sub-Saharan Africa. None of the studies investigated HL experiences in patients with BC across the cancer journey in LMICs.

3.5.2 Main themes and review findings

The literature reviewed was classified into themed areas that constituted the key findings from the analysis of the studies. (See mind map: Figure 2)

- Information needs of patients with BC.
- Sources of BC information.
- Factors that influenced BC-related HL.

- HL and Shared Decision Making (SDM).
- Experiences of patients with BC.

3.5.3 Information needs of patients with BC

An important component of compassionate care for patients with BC is the provision of information, which can only be realised if their information needs are known. As a cancer diagnosis is a traumatic life experience that necessitates patients to make decisions about treatment (Rao et al.,2017), understanding their information needs and the purposes that information se1rves is especially important in a LMIC context. This is because appropriate information facilitates communication between patients and HCPs and allows patients to take control of their own well-being, navigate the healthcare system and advocate for themselves (Kugbey et al., 2019). Consequently, information to empower patients must be specific to their needs. Previous studies highlighted that not all patients have similar BC information needs (Othman et al., 2015).

The stage in the cancer journey has been associated with certain information needs, as identified in previous systematic literature reviews. The systematic review of 112 studies by Rutten et al., (2005) reported 10 information need categories: treatment-related information, cancer-specific information, coping information, prognosis information, rehabilitation information, surveillance and health information, interpersonal information, financial/legal information, medical system information and body image/sexuality information. Most of these needs were similar to those identified more recently by Fletcher et al. (2017) and Tariman, Doorenbos, Schepp, Singhal and Berry (2014), who noted that the information priorities of patients with BC were related to their diagnosis, treatment options and prognosis.

Prioritising patient information needs will guide HCPs to plan for relevant patient teaching. Tariman et al. (2014) conducted a systematic review of 30 studies published from 1966 to 2012 to identify information needs prioritised by patients with different types of cancers (prostate, colorectal, breast, hematologic, lung, gynaecological and other cancers) and describe the trends over time. Their review revealed that the top three information needs were related to disease stage, prognosis or likelihood of cure, and treatment alternatives. That review depicted variations in individual patient information needs as the journey progressed, but it was unclear whether the changes were influenced by the stage of disease, type of cancer, or the patient’s age. During treatment, Tariman et al. (2014) revealed that age could impact patients' information needs; for example, younger patients prioritised sexual attractiveness information, whereas self-care was a priority among older adult patients. Rutten et al. (2005) noted that earlier research had focused on information needs at diagnosis and during treatment, and few studies had examined the whole journey. Although the 10 papers reviewed by Tariman et al. (2014) sampled women with BC, they were cross sectional and collected data at one point in the cancer journey; only four studies were longitudinal. In addition, only studies conducted in English from Europe and North America were included in their review, which limited generalisation of the findings to LMICs.

When HCPs know the priority information needs of patients with BC, they can intervene appropriately and provide information to patients at specific intervals in the disease trajectory. Lu et al. (2020) conducted a systematic review focused on BC, which was published after the data collection for the present study commenced. They discovered that prevalent types of information needs were related to all stages of the cancer journey. Patients desired information related to prevention of BC (especially for their daughters), risk factors for BC, diagnostic procedures, treatment, side effects, finances, prognosis and quality of life. Similar to Tariman et al. (2014), Lu et al. (2020) discovered that patients desired more knowledge about treatment, resumption of normal life and prognosis. Of the 47 studies included in their meta synthesis, only one was from a developing country (Iran), the remainder were from high-income countries (the UK, Australia and Canada). Given that information needs are moderated by various cultural variables (Lu et al., 2020), it is important to undertake studies in a range of cultural contexts, including LMICs, to determine whether the information needs of patients with BC in LMICs differ from those of patients in more developed countries. The following sections present information needs identified in various studies based on the stages in the cancer journey.

3.5.4 Information needs at various stages of the cancer journey

3.5.4.1 Before BC diagnosis

Most information needs before diagnosis related to prevention and screening. Othman et al. (2015) in a survey of 1549 women in Jordan found that they desired information on screening guidelines and when to perform mammography, BSE and CBE. Those authors suggested an exploration of culturally sensitive barriers to screening and incorporation of culturally sensitive HCP-patient interactions (barriers are further discussed in Section 3.10.1 and

3.10.2). However, limitations of the study by Othman et al. (2015) were that both the methods and sample were unclear, and it was not possible to determine whether the included women had BC.

Another area where information needs were important before diagnosis was in breaking the bad news of a cancer diagnosis and explaining the prognosis and treatment. In a study from India that investigated patients’ preferences when breaking the bad news of a cancer diagnosis and the role of family members, Rao et al. (2016) found that most patients desired their family members to be involved. That study also reported that 72% of patients desired disclosure of the BC diagnosis because they did not want to underestimate the severity of the disease, and they also desired to be involved in making decisions about treatment (decision-making is discussed further in Section 3.11. Rao et al. (2016) identified a unique information need in terms of whether or not patients desired disclosure and family involvement. This is an important factor for HCPs to consider in providing care for patients with BC. The systematic review of 55 studies by Puts et al.(2015) found that patients desired information about the risks and benefits of procedures before starting treatment. Lee and Hawkins (2016) in a quantitative study with 122 women in USA reported that patients needed to know about available treatment regimens, and their prognosis or likelihood of a cure. Overall, four studies included in this review (Rao et al, 2016; Othman et al., 2015; Puts et al., 2015); Lee & Hawkins, 2016) showed that information needs varied at different stages of the BC journey. However, these findings were reported in studies that did not focus on the information needs of patients with BC, a gap that will be addressed by the present study.

3.5.4.2 During treatment

Most patients do not have a clear picture of what treatment entails after a BC diagnosis; therefore, the most common information needs were related to the diagnosis and treatment stages. For example, the scoping review by Fletcher et al. (2017) identified that the most common information needs pertained to treatment options, side effects of treatment and their management, diagnostic tests during treatment, survival rates and sources of credible information. Fletcher et al. (2017) discovered that despite receiving conventional treatment, participants also desired information about alternative and complementary therapies. It may be postulated that the desire for information about prognosis relates to preparing for the worst, whereas the need for alternative therapy information may be explained by a desire by to do everything possible to get cured. In addition, that study reported that participants desired information about coping, body image and sexuality, rehabilitation, diagnostic procedures, finances and insurance, end-of-life, the medical system, support services, fertility and clinical trials (Fletcher et al., 2017). They also noted that during treatment, patients desired more information on their body changes, to clarify new experiences and to learn how to cope with the threatening situation of their BC diagnosis. Similar to the study by Lu et al. (2020), these findings highlighted the diverse information needs of patients with cancer at different stages in their journey.

Research suggests that patients with BC desire comprehensive information. Zaid et al. (2016) used structured questionnaires to examine the information needs of 125 women with BC attending treatment in a teaching hospital in Lagos, Nigeria. They found that in addition to treatment information and self-care, women desired to know how they would feel during the BC treatment procedure, the likelihood of a cure and the likelihood of metastasis. These information needs were similar to those identified by Fletcher et al. (2017), particularly those associated with treatment and recurrence. However, Zaid et al. (2016) found that women considered information about the cost of treatment, the benefits of various treatment procedures, type of diet ,adverse effects of treatment, and how best to take care of themselves as less important. In contrast, Fletcher et al. (2017) reported that patients desired information about treatment side effects, costs and nutrition. However, the majority of the studies examined by Fletcher et al. (2017) were conducted in high income countries (e.g. North America and Australia), which may explain the different findings. Although Zaid et al. (2016) presented results from a LMIC context, caution should be exercised in generalising those findings beyond the hospital population and specific treatment intervention, which were limitations noted by those authors.

Information needs specific to surgery are diverse. A quantitative study from Germany (Schmidt et al., 2016) described the information needs of male and female patients with BC 10 weeks after surgery. The priority information needs identified concerned follow-up after discharge from hospital, long-term side effects, insurance matters, disclosure to family, port catheter care, fatigue, coping with fears of recurrence and side effects. Similar findings were reported by Lu et al. (2020); however, a unique finding reported by Schmidt et al. (2016) was the need for information on BC heredity, as patients from families without a previous history of BC were worried that they had ‘introduced’ the cancer into their lineage. Schmidt et al. (2016) acknowledged their study was limited by the use of a questionnaire to collect data, as participants with low HL or that were dyslexic could not participate. Another limitation was the formulated questionnaire with pre-set responses, which did not give participants the option to fully represent their perspectives. This is a weakness of some quantitative studies that a qualitative study could address.

Few studies explored unmet information needs after BC surgery. In Germany, Halbach et al. (2016) longitudinally surveyed 1060 newly diagnosed BC patients' unmet information needs and their association with HL immediately after BC surgery, and at 10- and 40-week intervals. They reported four unmet information needs: medication, side effects, treatment options and medical examination results. These were similar to the unmet information needs reported by Rust and Davis (2011). Notably, unmet information needs were reported by both participants with sufficient HL and those with inadequate HL. Halbach et al. (2016) made a link between unmet information needs and HL, and found that patients with inadequate HL had received less information and were more dissatisfied. This was consistent with Shen et al. (2015), who through a cross sectional study in 511 BC patients in Taiwan found that patients with inadequate HL reported higher unmet needs in treatment options and medical examination results. Overall, Halbach et al. (2016) reported a mismatch between information needs and information provision, with emphasis on provision of tailor-made information appropriate for diverse HL levels among patients with BC. A noticeable limitation of their study that Halbach et al. (2016) noted was the low participation of patients with limited HL; they argued that such patients may have struggled to complete the questionnaires because of poor general literacy. This limited generalisation of their findings to the population with low HL. The studies they reviewed highlighted the variation in unmet information needs of patients with BC but were from high income countries. Therefore, it is necessary to understand unmet information needs in the LMIC context to guide the development of appropriate HL intervention tools.

A qualitative study by Doumit et al., (2010) that explored the lived experiences of Lebanese women with BC identified various information needs. They found women desired to be told the truth, and wished to know the degree of malignancy, what to expect at every stage of the treatment journey and treatment details. Although their focus was on the whole lived experience, a theme that emerged from their data was women's need to know detailed information about their condition so that they could share knowledge with other patients. In Lebanon, cancer is considered taboo or 'something very bad' (Doumit et al., 2010). This is an important consideration given that in some contexts, relatives withhold the cancer diagnosis from the patient with the intention of protecting the patient from the devastating news. The women therefore reported a need for complete disclosure so that they could take control of their lives and share their experiences with others.

Most information needs appeared to be related to the treatment stage. Tariman et al. (2014) identified that patients desired information about treatment options. Another qualitative study involving 44 patients with BC from the US (Weber et al.,2013) reported patients desired information on the duration of treatment and organ-specific side effects. They also reported that younger patients wanted information on the effects of treatment on sexuality whereas others needed information on side effects related to the digestive and urinary systems. Similarly, Rust et al. (2015) in a qualitative study with 24 BC patients in the USA found that they wanted to know how the treatment would affect their daily activities (e.g. driving). All of these studies highlighted the special and context-specific information needs of patients with cancer and the challenges they encountered that HCPs need to be aware of to design appropriate interventions to meet those needs. In a qualitative study among 10 Thai women,Klungrit, Thanasilp and Jitpanya (2019) found that patients with BC desired information about disease prognosis, treatment decisions, life prolonging procedures and foods to avoid. However, as that study recruited a small number of participants from one hospital and only focused on patients undergoing chemotherapy, generalisation of their findings is limited. Klungrit et al. (2019) demonstrated that providing relevant information was deemed as supportive by patients with BC, although that study does not provide an example of a qualitative study undertaken in a LMIC setting.

3.5.4.3 Information needs after completing treatment

The literature showed that patients with cancer had information needs after completing their treatment as well as before diagnosis and during treatment. For example, Shea-Budgell, Kostaras, Myhill and Hagen (2014) surveyed the information needs of 411 Canadian BC patients, and found that the information most sought after was information about their cancer (43.1%), cure or treatment for cancer (29.4%), prognosis (29.4%) and cancer prevention (27%). Interestingly, less frequently sought information concerned the costs of and insurance for paying medical care, where to get treatment and cancer organisations that patients could enrol with. That study concluded that interventions should be tailored to meet information needs according to patients’ preference.

The two reviews described earlier (Fletcher et al., 2017; Rutten et al., 2005) also highlighted the need for information after cancer treatment. For example Rutten et al. (2005) found that after completing treatment, patients desired rehabilitation information including self-care, immediate post-treatment follow-up care ,nutrition during recovery, immediate post-treatment follow-up care, long-term side effects of treatment, recognising or preventing complications following treatment, recovery time and where to obtain medical supplies or medical equipment. Fletcher et al. (2017) indicated that three of the studies they reviewed reported that the greatest post-treatment information needs were related to treatment, prognosis (chance of cure or recurrence, survival rate, effect on future health), medical system information (choosing a doctor, how to interact with HCPs, seeking second opinion, survivor rights) and coping.

3.5.5 Section summary

The reviewed studies identified the core information needs of patients with cancer, and some studies reported core information needs specific to patients with BC. It was noted that information needs varied across the cancer continuum (pre-diagnosis, during treatment and after completing treatment), but most of the individual studies within the reviews focused on information needs at a particular time during the cancer journey (Fletcher et al., 2017; Lu et al., 2020; Rutten et al., 2005; Tariman et al., 2014). In particular, Lu et al. (2020) highlighted this point and suggested that their work provided a model that focused on incentives for getting information, the types of information accessed and moderating variables across the care continuum. However, a majority of the studies concentrated on information needs during treatment (Fletcher et al., 2017; Tariman et al., 2014; Rutten et al., 2005; Rao et al., 2016). Commonly identified information needs concerned: screening guidelines, when to perform mammography, BSE and CBE (Othman et al., 2015); available treatment modalities and prognosis (Puts et al., 2015); side effects of treatment, how to cope and sexuality (younger patients) (Weber et al., 2013); BC heredity (Schmidt et al., 2016); disease phase-specific information (Halbach et al., 2016); and life prolonging procedures and foods to avoid (Klungrit, 2019).

The majority of the reviewed studies were conducted in high income countries rather than LMIC where patients' information needs, and experiences may differ. Most studies collected data at one-time point, which provided data for a snapshot in time. This does not provide a complete perspective of patients' information needs during the BC journey, despite information needs varying at different stages in chronic conditions such as BC. Two studies linked the concept of information needs to the concept of information literacy. Halbach et al.

(2016) noted that patients with lower levels of HL had higher unmet information needs, and Lu et al. (2020) described HL as a moderating factor for information needs. Finally, many of the reviewed studies used quantitative methods, which failed to capture rich, in-depth experiences of participants. These findings suggest that a qualitative study exploring links to information needs in a LMIC setting across the BC continuum is required. The following section presents the literature that identified the information sources used by patients with BC.

3.6 Sources of BC-related health information

Understanding how patients with BC receive health information is essential to support provision of quality care. For example, a mixed method study by Cudjoe et al. (2021) explored how various sources and types of health information influenced information sharing and HL in the context of cervical cancer screening among African immigrant women in the US. The results revealed that the most trusted information source for participants was a HCP, followed by personal experiences of family and friends who made health information more relevant, and lastly the church, which was the least approved information source. These findings concurred with other studies that identified sources of information including HCPs, friends, relatives and social media (Gakunga et al., 2019); HCPs and other women in their social circles (Potter et al., 2015); and television (Chen, 2018). By reporting these factors, Cudjoe et al. (2021) confirmed finding of previous studies (Ilaboya et al., 2018; Muthoni & Miller, 2010); namely, that sources and factors that influence HL span all levels of the SEM (factors discussed in detail in Section 3.10). The mixed method approach used by Cudjoe et al. (2021) allowed for better exploration and understanding of the intimate connection between sources of health information and types of HL.Notably,the majority of those who took part in the qualitative interviews had a high level of HL. Therefore, the themes generated may not be applicable to those with low HL when it comes to cervical, breast and general cancer screening.

A Kenyan quantitative study by Alago and Awiti (2016) investigated preferred sources of information among 393 women in Kisumu County. The results ranked radio, television and HCPs as the most common sources of information, and noted that patients’ friends and HCPs encouraged them to take up positive health behaviour (e.g. BSE and CBE). For some participants, social networks and social media ranked highly for sharing information, whereas others did not want to disclose information to friends or thought these information sources were not credible and found the Internet inaccessible. The reviewed studies revealed that just as patients have diverse learning needs, their preferences in how they receive healthcare information also vary.

3.6.1 Preferences for receiving information

Women with BC have expressed preferences for varying information sources. Cudjoe et al. (2021) (see Section 3.6 above) revealed that the majority of African immigrant women preferred receiving information in a verbal form from HCPs, with pictures being the least preferred method. This was a disturbing finding given that HCPs have been reported to be too busy to teach patients and answer their questions (Ilaboya et al., 2018; Puts et al., 2015); therefore, most health information was given via pre-printed brochures. Those findings also challenged the popular view that patients preferred visual presentation as opposed to text only (Meherali, Punjani, & Mevawala, 2020). This has an implication for HL and raises questions about the readability, language and formatting of patient information booklets, especially as different studies have reported reasons why participants did not use printed materials. For example, a systematic review by Meherali et al. (2020) reported that most participants had no interest in reading printed sources, whereas Potter et al. (2015) reported reasons were inability and insufficient time to read the information. These results showed the diversity of patients’ sources of and preferences for information sources. In contrast, Shea-Budgell et al. (2014) reported that participants preferred materials that were personalised to their lifestyles (e.g. books, magazines, audio CDs, videos). Occa and Suggs (2016) advocated that patient education material should maximise communication and influence behaviour change, which is a HL principle that promotes use of information (Nutbeam & Lloyd, 2020).

In USA ,Otey (2016) qualitatively explored 10 urban African American women’s BC-related knowledge, the communication strategies used during clinical encounters with providers and comprehension of medical information. That study used semi-structured interviews to collect data from older urban American women (aged 60 years and above) who visited a feeding centre twice every day for food. They reported that the preferred sources of information were: scientific databases, written medical information distributed in medical centres, church meetings, friends, family, television commercials, radio programmes, newspapers and the Internet. Interestingly, the women revealed that they were willing to pay for information. This suggested that they valued health information and would exploit all opportunities to get it. However, participants in that study expressed distrust in information from HCPs, stating that they used medical jargon and were not genuinely interested in them but in the financial pay off. Although Otey (2016) sampled older, urban women from a high-income country, some of the sources of information reported were similar to other studies conducted in LMICs (Alago & Awiti, 2016; Zaid et al., 2016; Gakunga, 2019; Gatimu, 2018), which revealed almost similar sources of information. However, Otey (2016) did not use a generalizable sample as they were not patients with BC, although that study offered pertinent information about communication in the healthcare arena. In addition, the context of that study limited transferability to women in LMICs as the sample included women from an urban area who could speak English. As the majority of interview participants reported having a high level of HL, the themes generated may not be transferable to those with a poor level of HL.

It is important for HCPs to understand what motivates patients to seek certain health information. Lee and Hawkins (2010) found that unmet information needs were the main drivers for Internet use. In addition, those in late stages of cancer tended to seek less information compared with those in early cancer stages. Similarly, Potter et al. (2015) in a qualitative study in USA with 31 patients reported that when patients with high information needs were not satisfied, they became innovative and sought information from elsewhere to gratify their need. Lack of emotional support may also lead women to search the Internet, which offers abundant and easily available information (Lee & Hawkins, 2016). A cancer diagnosis causes fear, confusion and anxiety, which complicates patients' lives. The resulting emotional turmoil calls for HCPs to give patients with cancer information specific to their needs and HL level. This is because the ability of HCPs to deliver health information can have a major impact on their patients' ability to access and use information, and navigate the healthcare arena (Humphrys et al., 2019). Furthermore, Muthoni and Miller (2010) reported that most women sought help from influential community leaders, mainly from religious groups, yet these leaders may not have accurate cancer information to aid in decision-making (Muthoni & Miller, 2010). Overall, information from HCPs appeared to be valued and trusted more than information from laypersons. This suggested that patients preferred sources of information that they trust.

3.6.2 Trust in information

Few studies explored whether consumers trust information sources. Chen et al. (2018) conducted a quantitative study using the New Vital Signs (NVS) tool to investigate the relationship between HL, trust and use of health information sources. They found that participants with low HL commonly sought information from social media, television, celebrity blogs and websites in which the quality of information was less likely to be assured. Conversely, participants with high HL sought and trusted information from HCPs (with doctors reported as the most trusted). However, both high and low HL participants accessed and used Internet sources in equal measure. A possible explanation for this is that Internet access among Americans has increased in the last 10 years. Surprisingly, all participants in that study reported that they did not trust information from pharmaceutical companies because this was perceived to serve marketing purposes, and the companies had no genuine interest in the patient’s health. Chen et al. (2018) recommended further research with specific patient populations to elicit more detail on their sources of information. Despite a number of studies (Enzler et al., 2019; Ilaboya et al., 2018; McEwan, Underwood, & Corbex, 2014) reporting that participants used and trusted health information from HCPs, it was concerning that participants in the studies by Chen et al. (2018) and Otey (2016) did not trust health information from HCPs. In almost similar circumstances to Chen et al. (2018) and Otey (2016), some patients in the study by Enzler et al. (2019) felt that HCPs were disconnected from them.

3.6.3 Section summary for sources of health information

The studies included in this review provided useful insights about sources of cancer information. All of the reviewed studies confirmed the need for patients to access credible information sources. The commonly used information sources were: HCPs, family, friends, other patients, peers, church, written brochures, television, photographs, books and support groups (Weber et al., 2013). Interestingly, patients valued and believed information from other patients because they ‘talk from experience’ as opposed to HCPs whose knowledge was mostly theoretical, except for those who were themselves BC survivors (Doumit et al., 2010). In the search for information, some patients become innovative and search the Internet to ensure they have exhausted all available sources (Chen et al., 2018). Seminars arranged for BC survivors were also reported as powerful sources of information (Weber et al., 2013). Although patients in various research projects could differentiate credible and non-credible sources of information, they still used both. Some referred to information from friends, church and community centres as ‘misinformation’ that caused more frustration (Rust & Davis, 2011). The reviewed studies placed emphasis on suitable information sources that eased the decision-making process for patients with BC (see decision-making in Section 3.8). However, although multiple sources of information could be accessed, patients still faced decisional conflict. This conflict highlighted the need for further research focused on identifying the most preferred sources of information, that also acknowledges the challenges patients face as they interact with these sources (Rust & Davis, 2011).

It is imperative that women's sources and use of information is investigated to allow appropriate intervention and ensure they access credible information. Most of the reviewed studies were from high-income countries, with few conducted in LMICs where there is perceived low HL. This warrants an investigation into how women access BC-related health information in a LMIC such as Kenya. In addition, some of the studies examining sources of information used by African women were conducted among women who had emigrated to other countries rather than those within an African context. These immigrants were likely to have different contextual experiences such as medical/living support and high literacy, and their experiences may not be transferable to the Kenyan context. The present study attempted to fill this gap by conducting a BC-specific study to identify the HL experiences of patients across the cancer journey in a LMIC context. A common recommendation in the reviewed literature was that while HCPs need to closely follow patients who acquire information from other sources and discuss its use, they must be aware of the barriers and other factors that influence information use. Therefore, the present study attempted to close these gaps by investigating the health information sources used by patients with BC in Kenya, which will identify contextual gaps and inform communication programmes/strategies and awareness campaigns going forward.

3.7 Factors that influenced HL

Patient information access and use may be influenced by multiple factors. Therefore, it is imperative that HCPs are aware of the facilitators and barriers to HL. Of the eight reviewed studies that addressed this issue, four explored both facilitators of and barriers to HL (Alago & Awiti, 2016; Gakunga et al., 2019; Leena, 2020; McEwan et al., 2014) and four investigated barriers alone (Akuoko et al., 2017; Otey, 2016; Plummer & Chalmers, 2017; Rust & Davis, 2011).

3.7.1 HL facilitators and barriers

Previous studies provided insights into factors that drive HL. Alago and Awiti (2016) conducted a quantitative descriptive study to verify Kenyan women's knowledge of BC risk factors and how best to frame BC messages. Those authors discovered that although some women were exposed to incorrect BC information, others did not access any information on BC. That study also found that how such messages were framed either encouraged or discouraged the women from using it. For example, messages about the benefits of early BC screening were perceived positively, as opposed to those that presented the risks of not performing BSE and CBE. In addition, low literacy levels, lack of infrastructure to access the Internet and lack of resources in the local languages were identified as barriers to information access and use. Although that study was useful because it was based in Kenya, the quantitative approach offered a snapshot view in time, whereas a BC diagnosis is experienced as a journey and HL is a multidimensional construct (Sørensen et al., 2012) with various factors affecting different stages of the journey. In addition, Alago and Awiti (2016) yielded useful information, but the participants were women aged 20–64 years who did not have BC, and therefore lacked a lived experience of the disease. This is a gap that the present study aimed to fill as including BC survivors generated rich experiences and identified factors that influenced HL. The present study addressed this methodological gap by focusing on multidimensional/levels of factors that influenced HL during the BC journey and adopting the SEM as the guiding framework. It is particularly important to identify what SEM factors influence how patients with BC access, understand and use information. This is because a socio-ecological perspective of HL shifts the focus from individual strategies of patient education to how interventions can be supported by other levels of influence (McCormack, 2017). In this way, a more supportive HL environment can be created for women, thereby improving their BC journey experience.

Factors that influence HL also affect BC screening behaviour. Using the SEM, Leena (2020) identified the following factors at different levels of the SEM in a qualitative study of women in the UAE. At the micro level, women's fear of a positive diagnosis was a major reason for their non-attendance at mammography screenings. Fear of pain and radiation exposure during mammography were further deterrents to screening uptake. Moreover, study participants' fatalistic thoughts and their strong belief that cancer was an act of God contributed to the low BC screening uptake. Other factors were lack of information and knowledge about early detection of BC and the mammography procedure. At the meso level, Leena (2020) found that formal and informal social networks provided information about screening and had a significant impact on uptake behaviour. The cooperative behaviour of the nuclear family, particularly the husband, also had a significant influence on BC screening uptake. Alago and Awiti (2016) noted that peers and close friends played significant roles in both women's attitudes towards screening and the type of information and social support they received (Akuoko et al., 2017). At the macro level, community organisations, medical professionals, the media and participants' cultural beliefs influenced women's decision to undergo mammography screening. In addition, Keralite women's attitudes toward mammography were influenced by fear of social isolation and premature death in case of a positive BC diagnosis and limitations imposed by cultural norms; for example, participants expected to be seen by Arabian doctors who could speak their language and understand them, but instead the HCPs were from diverse cultural backgrounds. Similar findings were reported by Othman et al. (2015) where participants cited linguistic, cultural and religious barriers as reasons for not attending BC screening on several occasions.

The socioeconomic factors that affect the uptake of screening are likely to be similar to factors that affect HL, meaning the findings reported by Leena (2020) may be relevant in the Kenyan context. However, the women sampled in that study were expatriates who were educated and had experienced various cultural contexts. Interestingly, despite their education level, they lacked knowledge about the significance of early detection and screening mammography uptake was low. The level of education was considered an important factor (Leena, 2020) and a high education level was associated with increased use of healthcare services (Kugbey et al., 2019) and BC screening practises. Therefore, these results may not be transferrable to the low-resource setting of patients with BC in Kenya. Largely, Leena (2020) postulated that for screening mammography to be widely embraced by the target population in an informed manner, it is necessary to address the influencing factors at all levels of the SEM. Notably, studies that adopted a socio-ecological approach (Ilaboya et al., 2018; Leena, 2020; McEwan et al., 2014) demonstrated that resource provision without adequate information provision and communication did not address all patient needs.

Factors that affect HL occur at all levels of the SEM. For example, McEwan et al. (2014) identified that in addition to HL, health system factors caused delayed BC diagnosis in Egypt. That study attributed the delayed BC diagnosis to HL challenges that arose from participant interactions at the micro, macro and meso levels. Factors that cut across the SEM levels included: lack of knowledge about symptoms, myths and misconceptions about causes of BC (e.g. that BC is caused by anger or sadness and is contagious), modesty and fear of a HCP examining the breast, lack of social support, medical jargon by HCPs, lack of finances and inaccessibility of healthcare facilities that offered BC services. Although that study sampled participants from a larger quantitative study (or what appeared to be a mixed method study), the findings were similar to other purely qualitative studies (e.g. Ilaboya et al., 2018) and can be used to implement patient-centred HL interventions.

Similarly, Gakunga et al. (2019) in four focussed group discussions (each with 6-11 Kenyan women) found that the main barriers to HL were inadequate sources of BC information, insensitive disclosure of BC diagnosis and bad experiences with how HCPs communicated. Their study found misconceptions in risk factor knowledge where women attributed BC to certain practices, including: microwaving food; eating hot food packaged in plastics, spiced food or wheat products; big breasts; wearing brassieres with underwire; wearing tight brassieres; keeping mobile phones next to the breast; keeping money in brassiere or next to the breast; men sucking women’s breasts; wearing of second-hand brassieres without washing; and repeatedly wearing brassieres without washing (Gakunga et al., 2019, p. 1553). Overall, some information was given, but it was not exhaustive, which left the women with unanswered questions, anxiety and fear. These unsatisfied information needs were identified by Shen et al. (2015) as the trigger for patients in high-income countries to search the Internet to find answers to unanswered questions. Unfortunately, most women in LMICs cannot access the Internet and therefore have to rely on information that is easily accessible (see Section 3.6) where sources of information are discussed). Shen et al. (2015) recommended packaging information in different languages so that the rural women could understand and use it. Gakunga et al. (2019) also found that reliable social support, regular access to subsidised awareness and early detection programmes and pleasant HCPs were enablers of HL. However, that study sampled BC survivors who had finished treatment 3 years earlier; because of the chemotherapy side effect ‘chemo brain/fog’ (Gibbons, 2017; Rust & Davis, 2013), there is potential for altered memory, which would introduce recall bias. In addition, the 3 years could have given participants time to reflect on or interact with other sources of information, meaning that they could have given socially desirable responses. On a positive note, this reflection may have made participants appreciate the positive trends in BC treatment and wished that they had experienced them during treatment. The next section reviews literature specific to barriers to HL.

3.7.2 Barriers to HL

Several important factors have been identified in studies that examined barriers to women seeking health information (Doumit et al., 2010; Ilaboya et al., 2018; Lee & Hawkins, 2016; Weber et al., 2013). These factors included: fear of a positive diagnosis and death (Akuoko et al., 2017); fear of cancer recurrence (Doumit et al.,2010); busy HCPs (Gakunga et al., 2019); information overload (Lee & Hawkins, 2016); inability to differentiate credible from non-credible sources of information (Jordan et al., 2010); and hurried doctors' appointments, lack of family support and high cost of treatment (Frie et al., 2018). In Otey (2016), participants provided insight into how HCPs communicated and identified factors that were either barriers or facilitators to communication. Factors such as patient-provider gender discordance, the effect of race and culture on clinical interactions and patients' religion and spiritual views were all offered as potential barriers to effective communication and understanding information (Otey, 2016).

Through focus group discussions in Uganda, Ilaboya et al. (2018) revealed that the barriers to early BC detection spanned the three levels of the SEM. At the micro level, the main barriers were knowledge deficit, fear, poverty and poor health seeking behaviours. At the macro level, barriers included lack of cancer policies, poor allocation of funds to healthcare amid competing burdens of disease, a weak primary healthcare system, long distance to healthcare facilities and limited access to information media. Overall, low knowledge was the most significant barrier that influenced early detection of BC. Ilaboya et al. (2018) concluded that the barriers to early detection of BC were complex and went beyond the individual's behaviour and noted that health promotion activities should increase awareness practices regarding early detection of BC. However, a weakness of that study was that data were collected through focus group discussions at just one-time point, whereas a BC diagnosis sets patients on a journey of many stages. Each individual's BC journey is different based on the contextual issues outlined in the SEM. As HL has been identified as a social determinant of health (Nutbeam & Lloyd, 2020), information provision may be a practical intervention that can be implemented through a multi-level approach (McEwan et al., 2014). To do this, it is necessary to understand how individual women access, understand and use information, which was not explicitly addressed by Ilaboya et al. (2018). The focus group data collection method may also have prevented discussion of sensitive information (Creswell & Creswell, 2017) and participants may not have voiced their opinions as freely as they would in individual interviews. The present study adopted a qualitative approach with a purposively sampled homogenous group with data collected in face-to-face interviews to yield rich information to inform HL interventions, clinical practice, policy, education and further research.

To understand the barriers to early BC diagnosis and treatment, Frie et al. (2018) conducted a qualitative study in Mali, Africa. The main barriers identified were low level of BC knowledge among women, their families and HCPs; fatalistic beliefs; mistrust in healthcare facilities; misconceptions and preference for traditional medicine; economic hardship; limited social support; and the high cost of treatment. Most of these factors were similar to those identified by Ilaboya et al. (2018), McEwan et al. (2014) and Akuoko et al. (2017). Although Frie et al. (2018) used the pathways to treatment model to analyse data, the structure with four time intervals generated barriers that were similar to those identified by studies that used the SEM (Ilaboya et al., 2018; Leena, 2020; McCormack et al., 2017). Frie et al. (2018) qualitatively explored the barriers to BC treatment in Mali, and concluded that to ensure timely access, availability and affordability of BC services for patients in Sub-Saharan Africa, new initiatives to address the identified barriers were required. Although the focus of that study was on barriers causing treatment delay, the findings identified factors that influenced HL.

The patient's knowledge level is significant in HL. In a small-scale survey of 36 participants conducted in Australia, Plummer and Chalmers (2017) explored the relationship between HL and physical activity in women who had recently completed BC treatment. They found a positive association between basic HL abilities (reading and understanding information) and physical activity. This suggested that what was important to these women was an adequate level of knowledge that made them understand the importance of exercise. Notably, participants with low HL levels did not participate despite being invited. That study offered transferable results in that HL was a significant predictor of involvement in physical activity, and that functional HL appeared to be the most important skill (Plummer & Chalmers, 2017). Those authors concluded that sufficient HL and knowledge to make decisions can mean women with BC implement self-care strategies, thereby enhancing their quality of life. This research could be replicated with women from diverse settings, including Africa, to achieve a wide sample that covers participants with a range of HL levels.

A highly cited (92 times) systematic review by Akuoko et al. (2017) found that knowledge and awareness about BC impacted early detection and diagnosis. That study revealed that women in Sub-Saharan Africa had a low level of BC awareness, which was a significant barrier to early BC detection measures. Consistent with another study (Ilaboya et al., 2018), BC health seeking behaviour was influenced by unawareness about early detection, a negative and near fatalistic view of BC and socio-cultural influences such as tradition, beliefs and fear. As reported by Gakunga et al. (2019), there were no significant variations between participants with high and low SES as they reported similar barriers. The finding by Gakunga et al. (2019) and Akuoko et al. (2017) regarding the similarity in perceptions and experiences between higher and lower SES participants supported the finding by Sørensen (2019) that HL in patients with BC is a complex construct that needs to be explored beyond individual factors.

As BC treatment is complex, patients need to understand the regimen so they can adhere to the instructions In a qualitative study (through two focussed group discussions of 12 participants each) in the US, Rust and Davis (2011) explored the level of understanding of medication adherence and the barriers encountered among underprivileged BC survivors who had completed radiotherapy and chemotherapy at least one year before joining the study. Common barriers included: lack of BC information and meetings that would help patients discuss health issues, no opportunities to meet pharmacists, frustration about the inconsistency of and access to information, inability to afford the cost of health services and medication, difficulty understanding medication labels, no information on drug interactions and side effects. Similar barriers were reported in previous studies where patients started chemotherapy without receiving much information from their doctor (Doumit et al., 2010), treatment information was given immediately after breaking the bad news of a cancer diagnosis (Potter et al.,2015) and HCPs were rude and used complex language (McEwan et al., 2014). Because of the barriers identified, most women in the study by Rust and Davis (2011) did not adhere to their prescriptions. For example, one woman stopped taking her tamoxifen (an anti-hormonal drug that helps slow down the growth of BC cells) when she became nauseated, another did not take her medications because she feared side effects and a third forgot to continue with her diabetes drugs when she started chemotherapy. An interesting finding from Rust and Davis (2011) was the inequality in receiving information, with participants who personally knew the pharmacists reportedly receiving more information. This suggested that social capital plays a role in HL. In addition, outspoken patients asked questions, whereas others felt the pharmacists were too busy to be asked questions. Overall, the above factors formed barriers to medication adherence, which appeared to have been caused by inconsistent information and non-attention to HL issues.

Understanding the treatment regimen makes patient confident about their care. BC treatment has unpleasant side effects that require patients to be given appropriate information so they can understand, commit and adhere to their schedule. Previous studies (Doumit et al., 2010; Jordan et al., 2010; Potter et al., 2015; Puts et al., 2015; Weber et al., 2013) identified several barriers faced by people with BC when using information. Those studies showed that many patients were displeased with the information they received from HCPs. Participants alluded to not understanding the medical jargon used by HCPs, but were not assertive enough to ask questions or clarify information (Jordan et al., 2010). At times, they were too upset with their BC diagnosis and any information given was not comprehended (Schmidt et al., 2015). In addition, some were apprehensive about medications and stated that they sometimes did not take medications as instructed because it interfered with their work and routines (Rust & Davis, 2015). Others did not take their drugs because of misconceptions from other sources; for example, a patient who was given Valium (a calming drug) because she was agitated did not take it because she believed it was addictive (Rust & Davis, 2015).

Potter et al. (2015) reported that their participants strongly advocated that health information had to resonate with their beliefs and attitudes and fit in their lifestyles to be used. Various healthcare factors affected patients’ application of information. These included their physical and emotional state when sick (which affected their communication with HCPs) (Jordan et al., 2010), and the time pressure on HCPs (who only allowed 5 minutes per patient) discouraged patients from discussing their health issues in detail (Doumit et al., 2010; Puts et al., 2015). Other barriers to information use included insufficient information (McEwan et al., 2014; Schmidt et al., 2016), poor communication by HCPs (Gakunga et al., 2019), complex language, busy HCPs, little or no counselling upon diagnosis (Potter et al., 2015), high costs, long distances to health facilities (Akuoko et al., 2017; McEwan et al., 2014), medicine unavailability (Rust & Davis, 2011), long waiting periods and information overload (Lee & Hawkins, 2016). These barriers cut across all SEM levels, and some may appear irrelevant to HL. However, they all impacted information access and use. As these barriers were identified from studies whose main objective was not factors that influenced HL, a study that addresses such factors in Kenya is necessary. Factors that influenced HL are summarised and classified under the various levels of the SEM in Table 6.

Table 6: Factors that influenced health literacy

Author	**Micro (Individual)**	**Meso (Interpersonal)**	**Macro (Institutional/societal)**
Akuoko et al. (2017)	Level of awareness about breast cancer (BC) Knowledge about warning signs Knowledge of causes Knowledge about clinical breast examination (CSE) and breast self-examination (BSE) Knowledge about treatment seeking Fear of diagnosis and death	Health practitioners' lack of seriousness about BC	Influence of traditional healers in delaying treatment
Alago and Awiti (2016)	Low literacy levels	Women were exposed to incorrect information; others did not access any information on BC	Lack of infrastructure to access the Internet Lack of resources in the local languages were also identified as barriers to information use
Doumit et al. (2010)		Doctors did not give enough time for the woman to discuss her concerns	
Enzler et al. (2019)		Healthcare provider (HCP) support and understanding of their needs	
Frie et al. (2018)	Low level of BC knowledge among women Fatalistic beliefs	Low level of BC knowledge among families and healthcare providers	Economic hardship, limited social support, high cost of treatment, conceptions and preferences for traditional medicine Mistrust in healthcare facilities
Gakunga et al. (2019)	Misconceptions in risk factor knowledge where women attributed BC with certain practices Unsatisfied information needs	Insensitive disclosure of BC diagnosis, bad experiences with how the HCPs communicated	Inadequate sources of BC information

Ilaboya et al. (2018)	Knowledge, attitudes, beliefs and practices (KABP); health system and policy constraints; structural barriers Prominent barriers associated with KABP were low knowledge, apathy, fear and poor health seeking behaviours	Competing healthcare burdens within the country, lack of a cancer policy and weak primary healthcare	Distance, poverty and limited access to media were identified as the most prominent structural barriers
Jordan et al. (2010)	High cost of treatment	Hurried doctors' appointments Lack of family support High cost of treatment	High cost of treatment
Lee and Hawkins (2016)	Information overload that overwhelmed the patient Difficult to understand health information Worry as a threat to information seeking		
Leena (2020)	Self-efficacy, attitudes, beliefs and knowledge		Cultural beliefs, media, medical professionals, community organisations and BC survivors Healthcare facilities, health insurance, specialised BC screening services and academic institutions
McEwan et al. (2014)	Lack of knowledge about symptoms of BC (ignored small lumps) Fear, myths and misconceptions Not adhering to BSE education as they did not have hereditary risk	Social networks (no support from the husband, others complained of husband insisting to accompany to hospital) Friends provided incorrect information	Sub-optimal communication with HCPs (doctors were rough and used complex language) Misdiagnosis Low socioeconomic status Lack of knowledge by HCPs

			Lack and inaccessibility of healthcare facilities that offered BC services
Othman (2015)	Lack of knowledge about BC screening		
Plummer and Chalmers (2017)	Sufficient HL and knowledge level to make decisions can mean women with BC implement self-care strategies		
Potter et al. (2015)	Some information was difficult to understand, misleading or unbalanced Information was inadequate to make a decision Patients’ information needs were not being met	The information was not adequate to make a decision to have surgery Information given immediately after a cancer diagnosis was not understood Doctors used complicated language and appeared too busy so patients did not ask questions Discrepancy between what the patients and HCPs considered important information	Competitive and adversarial nature of support group
Puts et al. (2015)	Negative experiences and expectations Discomfort of the treatments Fear of side effects	Not enough specific information and too much written information Hurried appointments and talking down to patients	Lack of family support Problems with employment and insurance Transportation difficulties
Rust and Davis (2011)	No access to breast health information	Complicated, wordy medication instructions that were too difficult to read	Inadequate resources to proper healthcare and treatment Cost of medication, on-payment by insurance The readability of the information leaflet with respect to font size and reading level

Shen (2015)		Oncologists responded positively to patient initiated CRII discussions by (1) acknowledging their limited expertise/knowledge, (2) encouraging/approving using the Internet as an information resource, (3) providing information/guidance on the proper use of Internet searches, (4) discussing the pros and cons of relevant treatment options, or (5) giving information Patients reacted to the CRII discussions by (1) indicating that they only used reputable sources/websites, (2) asking for further explanation of information, (3) expressing continued concern, or (4) asking for the oncologist's opinion or recommendation	
Schmidt et al. (2015)	Inability to put their lack of information into proper words, overwhelmed by information, no contact with HCPs after discharge, not enough information to weigh benefits and harms		
Schmidt et al. (2016a)		Patients with BC provided with large amounts of information during their hospital stay, information not targeted to patient needs and may be overwhelming	
Weber et al. (2013)	Fear of recurrence	A lot of information given	

	Differentiating credible from non-credible information		
	Some information difficult to understand, misleading or unbalanced Information was inadequate to make a decision		Competitive and adversarial nature of support group
Jordan et al. (2010)		Use of medical jargon and using difficult terms	Time pressured clinical environment
Schmidt et al. (2016b)		Information was not sufficient to weigh benefits and harm	No contact with HCPs after discharge

3.7.3 Section summary

The reviewed literature identified several factors that influenced HL as either facilitators or barriers. Interestingly, similar barriers were identified in both high-income countries and LMICs. The evidence suggests that while some studies quantified these factors, few studies used qualitative methods to understand these factors, and none investigated factors across the whole BC journey. Therefore, the present study aimed to further discern the contextual nature of HL facilitators and barriers encountered by patients with BC in Kenya using the SEM as a framework to address the gaps identified in the literature. As noted by Lee and Hawkins (2016), understanding barriers can also inform appropriate interventions for maximum benefit for patients with BC. Researchers in the reviewed studies suggested possible interventions that may improve information use. Understanding the barriers to information access and use that are unique to Kenyan women will assist HCPs in developing appropriate interventions to improve BC-related HL and SDM in this population.

3.8 Health Literacy and Shared decision making (SDM)

The NIC dictionary of cancer terms describes SDM as a process where patients and HCPs collaborate to make decisions on the best plan of care for the patient. The effective use of information to make decisions is a concept included in the IOM (2004) definition of HL and is critical for patients’ involvement in their care. Unfortunately, patients with low HL may not participate in decision-making, leaving HCPs to make all necessary decisions. Six studies

(Jordan et al., 2010; Livaudais et al.,2013; Potter et al., 2015; Puts et al., 2015; Shen et al., 2019; Weber et al., 2013) explored decision-making and participation in treatment decisions by patients.

There seems to be a relationship between HL and decision-making. Shen et al. (2019) explored perceived decision-making in relation to three domains of HL among patients with BC in Taiwan. They found that each level of HL was significantly associated with decision-making: functional (ability to find appropriate health information and understand it well enough to know what to do), communicative (ability to actively engage with HCPs) and critical (appraisal of health information). They also found higher SDM scores in women who were younger than 60 years, had an education duration of 12 years and above, were married and had lived with BC for a longer time. Those who had high HL scores were perceived to be more involved in SDM than those who had lower HL scores. These findings suggested that many factors affected SDM among patients with BC and demonstrated that patients with low HL may lack the knowledge and understanding of health information, which reduces their capacity to be involved in making decisions. Although the quantitative approach by Shen et al. (2019) provided key information, the participants’ responses were limited by the questionnaire, and could not offer in depth explanation about decision-making and other constructs (e.g., assertiveness). Other limitations identified by Shen et al. (2019) included recall bias and the possibility that patients would give socially pleasing responses after consulting with their favourite physicians. Therefore, the generalisability of these findings may be limited because participants had a high SES, and the findings may not be applicable to those with a low SES and perceived low HL. Shen et al. (2019) recommended further research involving diverse participants. The present qualitative study conducted in Kenya can identify SDM nuances not reported by the quantitative study.

To enhance HL and participate in SDM, patients need certain key abilities. Jordan et al. (2010) conducted a rigorous qualitative study in Australia to describe what HL represented from the patients’ perspective. Qualitative interviews with 48 male and female patients across three chronic conditions (cancer, arthritis, diabetes), the general community and patients presenting in the emergency department were used to conceptualise HL from their perspectives. Participants identified several key abilities that patients need to enhance HL and participate in SDM: knowing when and where to seek health information; verbal communication skills; assertiveness; literacy skills; capacity to process and retain information; and application skills. Although that study was well conducted, the findings cannot be extrapolated to all patients with BC because the participants had various conditions and diagnoses, and only one had BC.

Following a BC diagnosis, women are faced with the challenge of making treatment decisions amid the turmoil caused by the diagnosis. Weber et al. (2013) explored treatment decision-making styles among American patients with BC through semi-structured interviews. They found that women with high HL made decisions based on high quality information, whereas the low HL group made decisions without evidence. Perhaps the most interesting finding was that some patients with BC deliberately chose not to be involved in SDM and relied on physicians. This finding was supported by Livaudais, Franco, Fei and Bickell (2013), who established that some women felt unduly overburdened by the responsibility to make treatment decisions, particularly those with low HL who had poor treatment knowledge, and expressed regrets about the decision they had made after 6 months. The evidence presented by Weber et al. (2013) suggested that even in high-resource countries such as the US, patients with low HL rarely get involved in finding information about their treatment options and therefore rely on decisions made by HCPs; this means they have the potential to become overwhelmed by decision-making during their treatment. A similar study linking the role of HCPs and other factors that influence decision making would be beneficial in a LMIC setting.

In a quantitative study in USA with 328 newly diagnosed BC patients, Livaudais et al. (2013) found that women receiving adjuvant therapy after surgery regretted their decisions after six months, especially where they felt that the decision-making process was ‘too much responsibility’. Some of the likely reasons for the decisional regret identified in that study were: the women had trouble understanding written material (and the HCPs did not assess their understanding), participants had inadequate knowledge about treatment benefits and lacked decision aids. Other reasons were physician-related and included inadequate training about SDM, as some physicians doubted the patient’s ability to be actively involved in SDM. It is therefore not surprising that some women avoided decision-making, and preferred that others took up the role on their behalf (Weber et al., 2013). Livaudais et al. (2013) recommend the need to find other ways to communicate with patients with low HL. Emphasis was placed on HCPs’ role to ensure that patients understand the treatment options, as sound decisions require a good understanding of available treatment options (Doumit et al., 2010; Livaudais et al., 2013). This could reduce decision regret, especially as breast surgery alters a woman's physical appearance and has been associated with stigma (Tripathi et al.,2017).

Treatment knowledge may change in tandem with SDM skills through the different stages of the BC journey. The finding by Livaudais et al. (2013) that women had insufficient treatment knowledge at the beginning of treatment and therefore could not be actively involved in decision-making complemented that by Shen et al. (2019), that women who had treatment for a long time had higher SDM scores. A possible explanation is that due to their prolonged interaction with various sources of information, the women's HL abilities had developed in tandem. However, this depended on the cancer stage as noted by Weber et al. (2013), that patients in late stages of cancer tended to seek less information compared with those in early cancer stages. Schmidt et al. (2016) suggested that a possible explanation for this was that in the late stages of cancer, there were few treatment options and little probability of cure, meaning patients had probably given up any hope of survival. Surprisingly, Doumit et al. (2010) found that women who felt they had enough information to make decisions about reconstructive breast surgery attributed it to 'good fortune' or luck and not to a routine standard of information provision. This is a factor that HCPs need to be cognizant of so that they can implement HL best practices in consultations and interactions with patients with BC to facilitate SDM (Shen et al., 2019).

Information given to patients with BC should meet their needs if they are to be adequately involved in SDM. Potter et al. (2015) revealed a mismatch between the information patients desired and what HCPs offered before reconstructive surgery. Although patients received a lot of information from the HCPs, most information was complicated, difficult to understand and not adequate to make a decision (Potter et al., 2015). This finding reflected interactions where HCPs give information without assessing the patient's preferences (Rust & Davis, 2011) and decision-making style (Schmidt et al., 2015). In addition, more educated women tend to seek additional information and report immense satisfaction with their decisions (Shen et al., 2019). Similarly, more educated women had higher SDM scores (Shen et al. 2019), and educated women tended to weigh their options and be more involved in decision-making (Weber et al., 2013). Potter et al. (2015) emphasised the need to understand patients' decision-making preferences that range across two extremes: from those who leave the physician as *expert* to make all decisions, to those who embrace patient-centeredness and feel comfortable to get extra information and make decisions. This empowerment is vital for patients with BC who may be overwhelmed with their BC diagnosis but must make decisions on treatment choices (Jordan et al., 2010). HCPs need to understand that patients' decision-making process depends on various factors, which the present study explored from the perspective of Kenyan patients with BC.

For older adults, making cancer treatment decisions can be more challenging. Puts et al. (2015) conducted a systematic review of 38 studies that explored factors that affected decision-making in older patients with cancer. Their results revealed that physician recommendation was a constant reason for patients to accept or reject treatment. Some other factors that were significant for decision-making were: trusting the physician, feeling at high risk because of age, poor communication and scanty information about the treatment risks. As that study involved men and women, it can be postulated that there were gender-based differences in decision-making, and it may be worth conducting a study in same-sex adult populations, not just older patients with cancer. This will be important for developing interventions for SDM to enhance the quality of treatment. Puts et al. (2015) highlighted some weaknesses of their study, including: the findings were limited by the methodological quality of included studies, some of which were old (1975) and conducted when reporting standards were not as high. In addition, the exact numbers of patients who decided to refuse treatment for a particular reason was not known. Despite these limitations, the findings provided pertinent information about factors influencing older patients' decisions to accept or decline cancer treatment in a high-income context. Puts et al. (2015) recommended that further studies consider low HL populations as understanding these factors is of clinical relevance for HCPs to communicate with patients, enrich the treatment experience by reducing errors and improve outcomes. Furthermore, they emphasised the need to understand patients' decision-making preferences, and to empower them appropriately (Potter et al., 2015;Weber et al., 2013). This empowerment is vital for patients with BC who may be overwhelmed by their BC diagnosis but have to make treatment decisions.

3.8.1 Section summary

Overall, the reviewed studies explored the concepts of HL and SDM and outlined the benefits of including patients in decision-making, which comprised improved patient knowledge (Shen et al., 2019), increased patient satisfaction (Potter et al., 2015) and better treatment adherence and quality of life (Livaudais, et al., 2013). The task for HCPs is to ensure that actual involvement in decision-making matches the desired level, keeping in mind that the desire to be involved also changes at various stages during treatment (Shen et al., 2019).

Together, these studies provided important insights into involvement in decision-making (a component of HL) by patients with BC. They lay the foundation for further studies that can clarify the significance of SDM while demonstrating the role of HCPs and factors that influence HL and decision-making. The evidence from these studies suggested that patients with BC are best placed to identify their decision support needs by narrating their needs, wishes and wants in terms of decision-making. This can be achieved through a qualitative exploration of their experiences during the cancer journey. Such knowledge of treatment benefit can improve involvement in decision-making and reduce long-term decision regret. Previous studies (Livaudais et al., 2013; Shen et al., 2019) used quantitative techniques that did not give participants the opportunity to narrate in detail their experiences with decision-making, which was an identified gap. The present study, which is intended to contribute to research on HL among patients with BC in real health situations, probed factors that influenced how patients accessed, understood and used information to make treatment decisions. Furthermore, this study aimed to understand decision-making preferences and styles among patients with BC in Kenya and clarify the assistance they needed to make informed treatment choices.

3.9 Experiences of patients with BC

The reviewed literature suggested that diagnosis with BC was a life threatening incident that altered women’s lives physically, socially, emotionally and spiritually (Halbach et al., 2016; Schmidt et al., 2016; Shen et al., 2019). In a qualitative phenomenological study, Doumit et al. (2010) generated in-depth understanding of the experiences of 10 Lebanese women living with BC. Their findings demonstrated how BC affected and disrupted all aspects of women’s lives. Participating women described the struggle of living with several losses: loss of body parts, loss of hair, loss of social networks and loss of independence. After completing treatment, women lived with feelings of guilt about passing the cancer on to their female relatives (Doumit et al., 2010); this was consistent with the study by Lee and Hawkins (2016) that found women desired information about hereditary factors. Doumit et al. (2010) reported that women had fears of cancer recurrence and uncertainties and rejection by friends but did not fear death because they viewed the disease and death as something planned by the merciful God, whose intentions for their lives was good and who would help them fight BC. Therefore, HCPs should understand the experiences and effect of BC on women so that they can offer appropriate information. Doumit et al. (2010) highlighted the importance of examining the survival rate after a BC diagnosis and illuminated how information contributed to a better quality of life. Although that study was critiqued for its small sample that was not representative and could not be generalised, the focus on women's whole lived experience was a major strength. This informed the design of the present study with its focus on access to and sources of health information and how this information met/did not meet women's needs.

Enzler et al. (2019) conducted a qualitative study in Boston, US that assessed the needs of 37 low-SES patients with BC, and the perspectives of eight HCPs of those needs. They found that patients experienced fear and anxiety, mainly due to financial difficulties, but HCPs assumed that since all patients had state-sponsored insurance, they had no difficulties in accessing care. Enzler et al. (2019) further reported that women who lived far away from the treatment centres could not afford transport costs. These women either missed or delayed their treatment despite having insurance cover. Social support was considered as important as financial support, with some patients stating that their BC diagnosis had emotionally stressed their families and social networks. In addition, some participants indicated their family members made them feel bad about their BC diagnosis and more sick than what they were, which worsened their quality of life. Enzler et al. (2019) offered a perspective that was not offered in other studies in that families and social networks of patients with BC also need emotional support because the effect of the BC may be profound as patients become more dependent on them.

The lack of support from social networks was a major deterrent to patients accessing and affording healthcare. Enzler et al. (2019) recommended that patient populations should be connected to available BC resources via appropriate communication channels, which is a hallmark of HL. In addition, that study highlighted that HCPs should not assume that when free healthcare resources are provided, patients with BC will use them; other personal, interpersonal and organisational factors come into play (as discussed in Section 3.13. Interventions must therefore be tailored to the needs of the individual. Overall, the findings presented in the reviewed studies advocate for a multilevel intervention approach to HL that will lead to collaborations that have advantages over using and relying on one level of influence.

3.10 Summary of the literature review

The purpose of this literature review was to explore existing evidence on cancer-related HL, identify gaps from extant studies and clarify how the present study would fill these gaps. The majority of the studies examined were conducted in high-income countries, with only a few from LMICs. The broad themes identified were information needs of patients with BC, sources of BC information, facilitators of and barriers to HL, HL and SDM, barriers to information use and information experiences of patients with BC. The concepts identified from the reviewed studies illuminated how patients with BC experienced HL, with a focus on how they accessed, understood and used information in making decisions about their cancer treatment. Together, these studies provided important insights into the HL experiences of BC patients and their involvement in decision-making of patients with BC. The gaps identified lay a foundation for the current study that can reveal factors that affect HL, while demonstrating the role of HCPs and other influences. In a LMIC such as Kenya where most participants are perceived to have low HL, this qualitative approach has potential to offer such an explanation.

Overall, the key issue raised by this literature review was that it is incumbent on all HCPs and other communicators to provide understandable health information that patients can comprehend and act upon. It was evident that there is a wealth of work to be done to determine how to best help patients with BC in LMICs to raise their ability to understand, discern and act on accurate, reliable health information. This knowledge will help in developing appropriate interventions.

3.11 Important decisions to the literature review approach

The approach to the literature for this thesis was iterative. As I conceptualised the grant, I searched for literature that existed to find out what had done before and to decide how best to tailor the grant. While the decision to conduct a longitudinal study was already made before embarking on the PhD element of the study, the literature that I found had only looked at HL at one point in time, which on further scrutiny during the PhD justified the need for a longitudinal approach. Rather than embarking on the literature review at the outset of my PhD journey, when I got to the point of reanalysing my findings, I returned and revisited the literature in depth, attempting to be as systematic as possible. At this point I had a greater understanding of the PhD literature review (see reflection in Appendix 1). The new literature guided my decisions on which sources to incorporate into the earlier chapters of the thesis; and is one of distinct differences with the grant project.

3.12 Gaps in the literature

HL is a subject of interest because it is considered to be the bridge between HCPs and patients and has a significant impact on patient health outcomes. Moreover, HL is an important link in increasing positive health behaviour and offers a low resource intervention to improve BC awareness and early detection among Kenyan women. From the evidence presented in this literature review, it was clear that HL is an important skill that is needed by patients with BC as they live and cope with the disease, treatment and side effects. The current body of knowledge about HL among patients with BC from low resource settings is limited. None of the available studies focused on the whole treatment journey, but rather only collected snapshots of data at a single stage. Furthermore, while some studies collected data more than once, it was unclear after how long or at what points in the cancer journey data collection was repeated. The present study maximised the advantages offered by a longitudinal qualitative study (see Section 4.24) by providing prolonged engagement with participants across the cancer journey to fill this gap. Exhaustive BC-related HL studies have not been conducted in Kenya and available literature does not consistently show the HL experiences at all stages of the BC journey. In addition, as contextual and situational issues play significant roles in determining how patients access, understand and use health information, the SEM was an appropriate theoretical framework to guide the present study.

Given that all the included studies were peer reviewed, they were perceived to be worthy of inclusion in the literature review; however, a few had key aspects of the study design, data collection and analysis that were not adequately described or evaluated. However, this highlighted the need to be clear on the aim of a study from the outset and fully describe areas of the study design, including the setting, sampling strategy and inclusion/exclusion criteria. In addition, most available BC-related HL studies were quantitative. An advantage of a qualitative study on this topic is that it gives participants flexibility to fully explain their meanings and experiences.

Largely, the literature review outlined the evidence around BC-related HL and explained why there were gaps, while demonstrating how the present study will contribute to the knowledge base in this area. Based on this evidence, a qualitative approach including women with BC with all levels of HL would yield rich narratives of the experiences and factors that influenced their HL at specific phases of their treatment journey. The reviewed literature identified clear gaps, which formed the basis of this PhD study and informed the research questions, and objectives.

3.13 Research questions and objectives

3.13.1 Research questions

1. What are the experiences of accessing, understanding and using health information among patients diagnosed with BC in Kenya?
2. What socio-ecological factors influence the HL of women diagnosed with BC in Kenya?

3.13.2 Objectives

1. To describe the experiences of accessing, understanding and using cancer-related information along the BC journey.
2. To determine what BC survivors understood about BC in their communication with HCPs.
3. To identify cancer-related information needs of women diagnosed with BC.
4. To identify the socio-ecological factors that influenced the HL of women diagnosed with BC.

This chapter provided an overview of extant HL literature and outlined the rationale for the choice of methodology for this study, which is described in Chapter Four.

CHAPTER FOUR: RESEARCH METHODOLOGY

4.1 Introduction

This chapter outlines the methodological choices and rationale for this thesis, and demonstrates the alignment to the research aim, questions and objectives. It begins with the research design and highlights how my interpretive epistemological position informed the research design. This chapter also addresses the sample access and recruitment procedures, study settings, data collection and analysis, and describes the ethical considerations and how rigour was addressed. In addition, the chapter introduces the participants and provides a profile of their individual characteristics. Overall, the chapter describes how the main purpose of this study was achieved, which was to explore the experiences of BC survivors and describe the factors that influenced their HL during their treatment journey.

4.2 Research design

A possible way to achieve the aims of this study would have been to use a quantitative approach, in which participants would have completed questionnaires. However, this approach would not bring out the salient experiences and health information issues for participants because the questionnaire choices would be restrictive (Tracy, 2019). In the literature reviewed in Chapter Three, many studies (e.g. Shen et al., 2019; Puts et al., 2015; Plummer & Chalmers, 2017) used quantitative approaches to study HL and information-related issues among BC survivors. Although those studies generated useful information, they recommended further qualitative approaches to allow full exploration of participant responses. Sandelowski and Margaret (2000) suggested that quantitative description is somewhat limiting in terms of allowing participants to express their meanings. In contrast, a qualitative approach allows participants to engage in the research issue, which allows them to contribute in detail to the central phenomenon under study (Tracy, 2019). Additionally, a standalone qualitative study would sufficiently answer the research question.

In response to Puts et al. (2015) who recommended large representative samples, it seemed reasonable to take a sequential mixed method approach. True to Shank (2006) who states that the qualitative approach enhances the quantitative results, a mixed method approach would have shifted HL from abstraction to presence and coherence . Furthermore, the mixed method approach would have grounded the qualitative findings more scientifically, thus improving generalizability. According to Gogo and Musonda (2022), the mixed method approach improves quality and rigor of the research and provides more robust validity. Thus, there is double benefit from detailed contextual qualitative data, and more generalizable externally validated quantitative data. However, this approach would have entailed collecting data using questionnaires. The questionnaire is not suitable for a less educated audience because these require good writing skills and verbal ability to express emotions in writing (Tracy,2019). Some participants would have struggled with filling the questionnaire. Questionnaires were prone to misunderstanding and if researcher administered, would have introduced bias (since the researcher may have had to explain HL concepts meaning that the participants' experiences would have been interfered with.

A major consideration as I started planning this study was whether to observe the interactions between patients with BC and HCPs during care in terms of how information was given. This approach would have meant observing participants in their natural settings either at home, work or places of business. Several reasons made me abandon this approach. First, it would be practically impossible to observe interactions with the multidisciplinary team (e.g. doctors, nurses, pharmacists, dieticians, psychologists). Second, observing the interactions may have influenced the way HCPs presented the information; for example, they may have taught patients in an ideal manner when being observed rather than portraying their usual daily practices. Finally, the experiences explored on spanned the care continuum; therefore, it would be impossible to see interactions during screening because the patients had already bypassed that stage and were now in the treatment stage. Observing people's behaviour in their natural settings would also have meant adopting an ethnographic approach (Creswell, 2017), which was not feasible because I was studying participants from diverse ethnic and cultural settings.

Several qualitative HL studies have been published, but they only focused on one stage of the cancer care continuum; for example, Potter et al. (2015) focused on information use after breast surgery and Rust and Davis (2011) sampled patients who had come for chemotherapy on a particular day, despite BC treatment being a lifetime event. This supported my choice to conduct an in-depth qualitative study on BC-related HL experiences to understand how women in Kenya accessed, understood and used information, and the perceptions and meanings of their experiences. The nature of the data to be collected in this research led to the decision of a qualitative approach from an interpretivist perspective. A longitudinal data collection approach using semi-structured, in-depth interviews was adopted to allow interaction with participants at various stages of their treatment and assess any changes in aspects of HL, although measurement of HL was not an aim of this research. This ensured that participants had met with the HCP again or had encountered some new information during treatment so as to get the depth, detail and context of HL in relation to their BC journey. This prolonged engagement also meant participants gained confidence, and during subsequent interviews, they clarified or added HL experiences that they had forgotten to mention.

4.2.1 Qualitative research

Unlike other methods, a qualitative approach allows the researcher to explore the depth, richness and complexity inherent in phenomena (Punch, 2000) by encouraging people to delve into their experiences and realise that it is through their accounts that personal and practical knowledge may be generated (Burns & Grove, 2010). Qualitative methods offer an effective way of exploring and understanding behaviour, beliefs, opinions and emotions from participants' perspective. Mugenda and Mugenda (1999) indicated it was important to note that the subjective knowledge produced through qualitative research approaches does not make a universal claim to be true for everyone and for all things in times and places, nor does it rely on proving things to be true through the objectivity of human senses. However, this is not considered a weakness as qualitative studies do not seek to generalise their findings (Burns & Grove, 2010). The meanings derived from participants in qualitative research are formed through interaction with others and historical and cultural norms that operate in individuals' lives (Creswell, 2017). Therefore, I considered qualitative research as the 'lone' vehicle for in-depth investigation of experiences of how women accessed, interpreted and acted on health-related information to make decisions.

According to Creswell (2017), the main strength of qualitative research is that it yields data that provides depth and detail to create understanding of experiences. Shank (2006, p. 11) likened qualitative research to 'a lantern that helps shed light in dark corners', and qualitative researchers to 'inventors and reconcilers of meaning where no meaning has been clearly understood before'. Therefore, a strength of qualitative research is that it allows the subjects being studied to give rich answers to questions asked by the researcher and may add valuable weight that may be missed by any other method (Earle, 2010). In addition, it may unearth unexpected/surprising findings that can then be explored in subsequent interviews (Bryman, 2008). Overall, qualitative research yields rich and detailed data that allows the researcher to enter and understand the world of the participant (Burns & Grove, 2010).

Based on this guidance, a qualitative approach would yield rich and in-depth data to understand women's HL-related experiences at specific phases of the BC treatment journey. Qualitative studies explore personal and socio-cultural contexts to gain a deep understanding of the people being studied and their experiences (Tracy, 2019). Therefore, context-sensitive qualitative research can highlight nuances not identifiable by quantitative studies. Overall, qualitative researchers value people and the accounts these people give of their experiences (Burns & Grove, 2010). As Polit and Beck (2012) state, that peoples' experiences constitute reality, the present study provides insights into the reality of the world of patients with BC in terms of HL.

A disadvantage of qualitative research is that only small numbers of participants can be studied, and data collection methods are rigorous (Burns & Grove, 2010). This means such approaches have been critiqued for difficulty in analysing data, being subject to researcher bias, and the lack of reproducibility and generalisability of the findings (Punch, 2000). However, steps can be taken to ensure the rigour of qualitative research. The most important step is the need to reflect on the researcher as an instrument that could affect the data collection, interpretation and analysis (Hennink, 2010). O'Brien, Harris, Beckman, Reed and Cook (2014) suggested that further appraisal of quality can be performed using set criteria that are different from quantitative research. These include evidence of triangulation, reflexivity, prolonged participant engagement, member checking and attention to negative cases. The steps that were taken to ensure rigour in this study are discussed in a later section of this chapter (Section 4.9). Throughout this study, the researcher was cognizant of how their background and relationships with the participants may have influenced the study and its findings (See section 4.9 on reflexivity).

4.2.2 Philosophical basis

This study adopted an in-depth qualitative exploratory approach that was considered suitable to explore the HL experiences related to BC for the following reasons. First, the rationale for this research design was that well designed qualitative processes aid in understanding many areas of healthcare in which there are unanswered questions and uncertainty (Creswell, 2007). HL is a new concept in the Kenyan healthcare arena and should justifiably be explored via a qualitative enquiry. This provided a vehicle for deepening my understanding of patients with BC as normal people faced with difficult challenges as they battled a disease. The open-ended and exploratory nature of the research method also allowed participant's own clarifications of their experiences to be uncovered, in which it emerged that they saw themselves as ladies whose lives had been affected by, but not limited to, their BC diagnosis. They experienced themselves as people, not as BC victims.

I believe that truth and sense, understanding and personal experience through interaction in and with the world are built by individuals. To this end, truth exists separately, but the sense of reality does not exist individually or without a human mind, and there are various socially formed representations of reality (Crotty, 1998). This means that there is no single truth in relation to an individual’s experiences, but that the truth is what a person says it is, which is difficult to quantify.

4.2.2.1 Ontology

Patton (2002) described ontology as relating to the nature of reality and a belief in either one verifiable reality or multiple, socially constructed realities. Based on this statement, my ontological stance was subjectivism, given the qualitative approach. I do not agree that one version of truth is truer than another, and I believe that it is possible for all interpretations to lead to a greater understanding of society as a whole. As per my ontological conviction, there are multiple HL realities of patients with BC, which are constantly changing in response to social, political, cultural and power-based factors (Tracy, 2019); therefore, there is a ‘true universe’ that is different from our perception or awareness of it. This contrasts with relativism, which suggests that there is no true world, and that truth is socially constructed and open to individual interpretation (Blaikie, 2007). In explaining social realities, constructivism claims that positivism has more precision or validity, although it does not deny the existence of a ‘real world’ per se (Tracy, 2019). As a nurse educator, a systematic, positivist, empirical analysis supports various aspects of my profession such as drug administration and infection prevention and control. Oncology nursing is supported by positivist empirical procedures; for example, drug calculations and radiotherapy fractions. Therefore, it is inappropriate to try to explain these procedures in cancer nursing using a positivist approach. However, a significant part of cancer nursing is not about science, but is about women, their relationships and their experiences along the cancer journey. Respect, choice and dignity in cancer care are important issues for HCPs to understand. If quantitative, positivist approaches are used, these types of issues cannot fully be understood. To uncover this type of information and construct/interpret the meaning within it, qualitative methods are most appropriate (Lewin& Somekh,2011).

4.2.2.2 Epistemology

My epistemological foundation is interpretivism. The kind of knowledge I presented is women's views, opinions, and perceptions of receiving BC information. My epistemological assumptions are reflected in the research design and how this influenced the research. I wear different hats; I have beliefs and have undergone various experiences. Because I am a nurse, educator, researcher, and a woman who can also get BC and who has had relatives and friends with BC, I actively participated in the construction of knowledge, meaning there was mutual influence. For example, I was angry at some point when participants gave experiences of misinformation by HCPs. This may have influenced how I asked subsequent questions. However, as noted by Tracy (2019), research findings have no meaning until they are interpreted.

4.2.2.3 Axiology

My axiological assumption was value laden, as this study used patients with BC as social actors contributing to the truth. In addition, the stage in the cancer journey (period between diagnosis and the interview time), where the interviews were conducted, and the presence of male relatives may have affected how participants responded to questions. As the women chose to be interviewed on their regular appointment day, there could also have been anxieties about delays. On my end, I questioned if the women were well enough to engage in the interviews, but they were eager to participate and assured me that they were well. Tracy (2019) indicated that the researcher needs to make sense of participants' intentions and emotions rather than only concentrating on their behaviours.

4.2.3 Matching the paradigm and method

The literature (Creswell & Creswell, 2017; Shank, 2006) suggests that researchers who adopt qualitative approaches tend to apply an interpretivist paradigm, whereas the positivist or post-positivist paradigm is used in quantitative research. Various ways of defining positivism exist, but in brief, it is seen as the scientific approach to research (Fulin, Robinson, & Tolley, 2012). The principles that guide positivism are that knowledge is created from facts, and that researchers can objectively measure reality without influencing data collection. This notion separates the researcher from the participants (the researched) and does not acknowledge the co-creation of knowledge by human beings. Positivists postulate that these principles can be used to study phenomena and that this experimental approach forms the core process for social science research, a position that is strongly rejected by interpretivists (Hennink, Hutter, & Bailey, 2010).

The interpretivist paradigm emerged largely as a challenge to the assumptions of positivism (highlighted above) and indicates that knowledge is socially constructed and dependent on other factors, such as age, cultural beliefs and education (Hennink et al., 2010). This approach seeks to understand people's lived experiences, which is called an emic or inside perspective. Interpretivism recognises that people live and experience phenomena in various contexts, and questions whether people's behaviour can really be studied outside the contexts in which they live (Hennink et al., 2010). Interpretivists acknowledge that there can never be one single truth because people's perceptions and experiences of reality are subjective. However, they question the positivist stance that suggests research is wholly value free and that researchers have no influence on data collection or interpretation (Creswell & Creswell, 2017).

Interpretivists acknowledge the subjectivities of both researchers and participants, stating that the values and background of a researcher influence the research data. Therefore, engaging in a process of self-critical reflection (reflexivity) on how my role and personal values may have affected the data collection and analysis was important (Section 4.8). Knowledge of the social world is viewed as being subjective and difficult to predict, and shaped by variable contextual dynamics (Creswell & Creswell, 2017). For example, this study postulated that the use of health information by patients with BC may vary in different contexts and is influenced by various factors (personal, community, organisational, healthcare and policy). The epistemological position I took was interpretive. I believe that to understand a social encounter (in this case cancer-related information), it is necessary to be cognizant of the social and cultural dynamics affecting how it is experienced, understood and enacted. McConnell-Henry, Chapman and Francis (2009) indicated that the interpretivist's knowledge is not fixed but is an understanding that is filtered through the lens of personal, social and cultural factors.

4.2.4 Choice of longitudinal/serial interviews

For this research, participants' HL experiences were best gathered through interviews. Therefore, I used semi-structured longitudinal interviews (two or three interviews at 4–6-week intervals) to investigate the HL experiences of BC survivors and identify factors that influenced their access to, understanding and use of information to make decisions. BC treatment (surgery, chemotherapy or radiotherapy) is not a one-off event, as patients must attend hospital for treatment and follow-up (in case of surgery) for a long period (e.g. up to one year). The longitudinal approach provided opportunities for learning how the participants' HL experiences developed and supports reflection and confirmation of the results of earlier phases of data collection. This design also made it easier to talk about the experiences of subsequent interviews (Boonstra et al., 2021). Interpretivist researchers often use qualitative methods to study social phenomena from the viewpoint of those who are actively living and experiencing it, and interpretation by the researcher. Thus, participants and the researcher co-create knowledge as they focus on gaining insights into how individual actors make sense of their experiences. An important concern for interpretivism is the relationship between researchers and participants. Whereas Saldana (2021) argues that that trust must be established between researchers and participants, the researchers can struggle to balance their objectives while satisfying the need for participants to be respected researchers (Neale,2016).

Social scientists extensively use longitudinal interviews. Murray (2009) advocated for serial interviews, particularly in studies of chronic illness experiences. This gives a more comprehensive picture of participant experiences than a single 'snapshot' interview. Another advantage of longitudinal interviews is that they offer an approach convenient for developing a relationship between the participant and the researcher, thereby allowing sensitive and personal issues to be discussed while exploring changing needs and experiences (Murray et al., 2009). Three interviews at six weeks' interval with each participant were considered important to elicit any time differences or influences on HL and information use, or changes in perception. Again, the six weeks' intervals would allow participants to experience various HCPs so that they would share these in the next interviews. Subsequently, I would elicit any changes in information needs as participants progressed along the journey. Later visits were also used for member-checking, which is defined by Guba and Lincoln (1989) as sharing either the whole findings or a brief summary of the findings with research participants so that they confirm accuracy. This also gave participants a chance to say anything they felt they should have said then and gave the women a position and feeling of power and being appreciated meaning they all felt happy to be participants in this study. A single interview would not facilitate ample narrations about participants' experiences. Through the repeated interviews, I developed rapport and trust with each participant, and they looked forward to the next interview because they said it was 'therapeutic' to talk about their journey. For example, the RA reported that whenever he called participants to remind them of an upcoming interview, they verbalised their happiness. Most participants had never shared their personal experiences and the opportunity to ‘offload’ was beneficial to them.

Murray et al., (2009) explained that repeating interviews has an advantage as it allows narratives to unfold and gives room for participants to highlight perceived gaps in care while suggesting improvement strategies. Trust also develops with frequent contact; this familiarity with the researcher enables participants to speak freely about what was previously seen as sensitive, embarrassing or inconsequential. Murray et al., (2006) also found that repeated interviews allowed participants to mention what was previously unspeakable; this facilitated frank and honest discussions, whereas a single interview might not have yielded the same conversations. In the present study, women who could not discuss sexuality in the first interview brought up the subject in subsequent interviews and asked many questions about how to enhance their sexual experiences. This was attributable to the trust that had developed. Some also requested that I explain issues to their husbands because they would believe me more. Despite the openness, such discussions were not audio recorded, as the women deemed them so sensitive that they requested the recorder was turned off during those discussions. These relationships created fulfilling encounters and suggested that longitudinal interviews enable individual, contextual and sensitive illness experiences to emerge (Silverman, 2016a).

Disadvantages of longitudinal interviews include the emotional burden on the researcher because of the close relationships established with participants, attrition due to advanced disease or death and data overload (Murray, 2009). I encountered all of these challenges during this study. Some participants missed treatment because of lack of finances, some got divorced and others were stigmatised by friends and relatives. Talking with my supervisors and narrating my encounters helped me to debrief, and I realised that ethics in research includes the emotional well-being of the researcher. This was especially so when three participants were lost to follow-up; when the RA called, their family members informed us that they had died. This brought the reality of cancer fatalism so close and made for a devastating encounter. Attrition is common in qualitative longitudinal studies due to the longitudinal aspect (Carduff et al., 2015).However, as I designed the study, I never foresaw the potential of participants dying since the recruitment targeted patients who were clinically stable. I also expected that participants would report more positive HL experiences as they engaged with the HCPs more during treatment.

4.3 Section two: Procedures

The methods, and procedures used in this study are described under several headings: instrument development (interview guide, participant information sheet [PIS] and informed consent form), sampling; recruitment sites; recruitment procedure, conducting interviews, and interview data; data analysis; translation of documents from English to Kiswahili; ethical considerations; and ensuring quality in the research process.

4.3.1 Instrument development (interview guide)

As data were collected in longitudinal semi-structured interviews, I developed an interview guide (Appendix 9) based on current HL literature and the socio-ecological theoretical framework with a focus on the individual (micro), interpersonal (meso) and organisational (macro) influences. Discussions with supervisors, colleagues and fellow PhD students helped develop and refine the interview guide. The contribution by a nurse colleague who is a BC survivor was immense; she helped with replacing the heavy medical jargon with simple English words.

The research questions were phrased in such a way as to dig deep into participants' HL experiences, allow a free-flowing conversation and maximise data generation. As Berg et al., 2004) advised, the questions were open-ended, worded clearly and not judgmental or provocative. The first question elicited information on the pre-diagnosis period and asked how women accessed cancer information. The second question asked participants to describe how they acquired information that eventually led to diagnosis. The third question asked them to describe their experiences of receiving information after diagnosis and what factors affected use of this information. The final question captured participants' perceptions of the information they received. The interview guides for the second and third round of interviews were informed by first interview findings. The initial structured questions were used to identify shifts in HL and add issues that needed to be clarified from the first interviews.

4.3.2 Translation of documents from English to Kiswahili

To accommodate participants who did not speak English, the interview guides, PIS and consent form were translated from English to Kiswahili by a professional translator. Translation between the two languages was challenging and costly. As the RA and myself were both proficient Kiswahili speakers, I discussed this with my PhD supervisors and agreed that we could perform blind-back translation (Malangwa, 2017). This involved translating the professionally translated Kiswahili version back into English to see if the meanings were retained; this was completed by the RA and myself, and I was satisfied that it was mostly accurate. It is important to note that during translation, the translator can face challenges where some words and phrases cannot be accurately translated from one language to the other because of differences in pronunciation and multiple meanings (Malangwa, 2017; Twinn, 1997). In addition, there are words and phrases used in one language that are closely linked with the socio-cultural contexts, and converting them into another language becomes challenging as there is no cultural similarity in the target language (Oliver et al., 2005).

The process of language translation seemed unending, but the pilot exercise (see Section 4.3.3) assured us of correct data capture. Overall, the challenges experienced as we collected data were minimal, as participants appeared to understand the questions and responded appropriately. The same translation process was followed for the PIS, consent form and patient characteristic form. The following sections explain the pilot study, recruitment sites, and procedures.

4.3.3 Pilot study

A pilot study is a small experimentation intended to test and gather information before a larger study to improve the latter's quality and efficiency (Polit & Beck, 2012). Houser (2012) noted that unforeseen problems frequently arise during a project. Therefore, a small-scale pilot study gives researchers an opportunity to identify flaws and weaknesses and make any necessary modifications before the main study.

A pilot exercise with two patients with BC who were not part of the main study was conducted to test and clarify the interview guide questions. The pilot study participants were similar to the target population and were recruited from the private hospital. They responded to the draft interview schedule, and offered suggestions that helped in refining the questions; for example, the starter question that initially read '*...Tell me what you know about BC…*' was reworded to '*…How did you find yourself in the cancer clinic?*' The initial version of the starter question was considered restrictive and would not have initiated a free-flowing conversation in cases when participants did not know much about BC. Overall, the other questions were clear, and conversations flowed freely. These participants were comfortable with their interviews being recorded. The pilot was a useful critique because the final interview schedule helped participants to tell their story with ease. A PhD-qualified colleague also commented that the questions were too structured and leading, after which they were amended to be open-ended. There was also concern about the question of sexuality in the participant characteristic form, with some thinking that it was too intrusive. I chose to leave it in the first instance and would remove if the first three participants in the main study had difficulty answering it. However, all participants responded to that question without any difficulty.

4.4 Sampling procedure

Purposive sampling as used in qualitative research entails choosing participants who possess the capability to offer wide-ranging and detailed information that can answer the research questions and meet the study objectives (Tracy,2019). The target criterion strategy includes recruitment of participants using specific eligibility criteria for sampling (Neale ,2016). Participants who meet the criteria are therefore invited to participate in the discussion of the focus group.

This study sought to interview a purposive sample of 8–15 participants who would offer ‘authentic voices’ (Silverman, 2016 b) and provide rich information that addressed BC-related HL. The 11 women who participated were therefore handpicked because they had the required characteristics (See inclusion criteria in 4.4.1.1) and could provide the information needed (Taylor et al.,2006). All participants who met the eligibility criteria and agreed to participate in the study were recruited, and those who did not meet the criteria were excluded (Section 4.3.4.1). The final number was determined based on data saturation. Purposive sampling is a non-probability sampling technique that allows the researcher to choose participants who will provide ‘rich’ data to meet the objectives of the study (Creswell & Creswell, 2017). Although Houser (2013) indicated a sample size of 2–10 participants was sufficient to reach saturation, a challenge is that saturation is subjective as there is no universal tool to ascertain it (Creswell, 2012).

One of the absolute objectives of continued qualitative data collection and analysis) is to obtain saturation when “no new information appears during coding’(Saldana,2021). Although it varies greatly in different study designs, saturation has a general characteristic (absence of new information, lack of new themes or codes, and replication of the data collected), there is no universal measure for reaching saturation point in qualitative research (Guest et al., 2006). Moreover, data saturation is described by some authors as a gold standard for determining sample size when selecting participants from the study sample (Denny, 2009; Saunders,2018; Sebele-Mpofu, 2020)). Interestingly (Low,2019, p. 131) doubts that information becomes redundant at saturation and refers to it as a ‘problematic and logical fallacy’. This means that a universal level of saturation does not exist and as stated by Fusch and Ness (2015), what may be considered data saturation for someone may be different for another. Hence, thematic and code saturation, should be considered an initial analysis, which forms the basis for a more holistic and comprehensive data analysis, taking into account the relevance and meaning of the subject matter while striving to understand the depth, scope and nuance of the problem. (Hennink et al., 2019).

It is important to say that saturation is a problem for PhD programs due to general limitations imposed by program rules and regulations. The time limit of doctoral degrees is that the course must be completed within a specified period of time. Therefore, this has an effect on the researcher's time in the field because there is a plan to be followed.

However, for this study, conceptual saturation was achieved when the same information was repeated across participants at both study sites. My PhD supervisors and I discussed the various responses and agreed that data saturation had been achieved when the responses became repetitive. At this conceptual stopping point, some participants had only completed two interviews instead of the three scheduled. However, from the transcripts, I had noticed that there were no major differences in the information participants gave in interviews two and three. Vasileiou, Barnett, Thorpe and Young (2018) stated that there is conceptual debate and practical difficulty surrounding the selection of an appropriate sample size in qualitative research; therefore, it was considered reasonable to stop when conceptual data saturation had been reached.

The small sample size in qualitative studies may be considered a limitation, but Creswell (2012) argued that reduced participant numbers allowed for a richer depth of analysis that may be inhibited with a larger sample. However, a danger with small samples is that they do not reproduce the salient characteristics of the accessible population to an acceptable degree (Burns & Grove, 2010). Therefore, transferability may be difficult; this limitation is acknowledged in this study.

4.4.1.1 Inclusion and exclusion criteria

The following criteria were used to choose participants who had attributes that made it possible to accomplish the purpose of this research while maximising diversity.

4.4.1.1.1 ***Inclusion criteria***

a) Kenyan women of Kenyan descent
   - These women were born and raised in Kenya; this helped exclude any foreign influences and therefore presented the true perspectives of Kenyan women's HL experiences.

b) Adults who provided signed consent (aged 18 years and above)
   - Informed consent is a mandatory part of all research, and an ethical requirement for all scientific studies.

c) Women who had a histologically confirmed BC diagnosis
   - The gold standard for BC diagnosis is a biopsy that is histologically reported in the laboratory.

d) Women that could speak English or Kiswahili (Kenya's national language)
   - This ensured the inclusion of usually marginalised data from participants who cannot speak English. Kiswahili is the Kenyan national language and is spoken by most citizens.

e) Women with no cognitive limitation/impairment
   - The interview questions required that women remember HL experiences from the past, and any cognitive impairment might have affected this recall.

f) Women that were newly diagnosed (within the last 6 months) with BC or had an intervention after the cancer diagnosis (e.g. chemotherapy, radiotherapy or surgery)
   - These women would present diverse experiences and delineate specific information needs for each treatment modality.

4.4.1.1.2 Exclusion criteria

a) Women that had a primary cancer that was not BC
   - Those with other cancers may have had different experiences with each cancer that could potentially influence the findings.

b) Women that had not been told their diagnosis
   - A cancer diagnosis needs proper disclosure by a physician (with appropriate psychological support available).

c) Women that were non-Kenyan

    - These women may have different cultural perspectives of illness; they are also perceived to be more knowledgeable about illnesses as they are of a higher SES.

d) Women that were severely sick with symptom distress
    - These women may have cognitive impairment and not able to respond to interview questions. It was also considered unethical to subject them to an interview when they were distressed.

4.4.2 Recruitment sites

Participants were recruited from the oncology clinics at a private tertiary teaching hospital (AKUH, N) and the national public referral hospital (KNH). Although cancer registries are unavailable in Kenya (Kenya NCCS, 2017–2022) and data are scarce, the two selected clinics receive high numbers of patients with cancer based on daily data recorded by nurses for other purposes (staffing related). Diagnoses of new BC cases vary, but the average is five per week at both hospitals.

4.4.2.1 Selection of recruitment sites

AKUH, N and KNH represented private and public tertiary institutions in the capital city of Kenya that are easily accessible and have cancer services attended by large numbers of patients with BC. KNH is also a referral hospital for patients with serious illness from all over Kenya. Many rural women with BC are referred to KNH, which brought the ethnic and socio-economic diversity needed for the study sample.

4.4.2.2 Recruitment procedure at the private hospital

Before participant recruitment, I wrote to the oncology unit managers appraising them of the upcoming data collection activity and attached evidence of ethical clearance and the research proposal. My RA for the grant study, although male, was instrumental in the recruitment exercise; his gender did not interfere with the interactions with participants as they were used to receiving nursing care from male HCPs. Using the established eligibility criteria, the RA visited the oncology clinics and discussed the need to recruit participants with the coordinators and nurses. With help of floor nurses, the RA accessed patients' medical records and identified eligible participants. After identifying eligible participants, the RA invited me to meet these potential participants and I verbally gave information about the study to all participants who met the inclusion criteria. This approach was used because in Kenyan culture, people prefer face-to-face communication rather than receiving papers to read. I then gave them the PIS and consent form (Appendix 7). At the time I met with participants to give them details of the study, I had no information about their diagnosis; this was important as it was part of the data I would collect during the interview (i.e., to ascertain if women had been informed about their diagnosis). This strategy was discussed and approved by my PhD supervisors.

As a cancer diagnosis is a traumatic event (McCann et al., 2010), participants were given enough time (until their next appointment) to think through and decide whether or not to participate. Those who consented to participate brought their signed consent form to their next clinic appointment. Not everyone in Kenya owns a mobile phone; therefore, for those who did not have mobile phones, contact numbers for their closest relatives were collected to aid in communication. Upon receipt of signed consent forms, the RA contacted participants to arrange a convenient time and venue for their first interview. A larger number of participants was initially recruited to cater for any attrition. This was because cancer is a debilitating illness that can lead to high attrition, especially when patients are towards the end-of-life (Murray, 2006). Therefore, 15 participants were recruited and participated in the initial interviews. Sadly, four participants did not complete the interviews; three died and one was lost to follow-up because she relocated back to her village in Naivasha, which is far from Nairobi city.

Accessing participants was not difficult as majority of those approached readily gave consent to participate. Later, I learned that some participants expected financial benefit from this study; however, they expressed satisfaction with the therapeutic effect of the interviews for them, with some stating that this was more beneficial than money. In addition, I explained to those who asked that they would receive a token of 5 USD. Cultural influences and the place of women in Kenyan society clearly emerged during recruitment. As all women were accompanied by male relatives (e.g., husband, brother or uncle), they could not make treatment decisions on their own and had to seek permission from these males. I met most of the male relatives to discuss the study and the level of the women’s involvement and assured them that this was a low-risk study because all I needed was information about their HL experiences. This reassured them and addressed their fears that I would take the women to a laboratory for complex experiments involving collection of blood specimens.

A concern that was raised by participants was the place and time for the interview. Most participants wanted to be interviewed on their clinic days because they had time off from their work or business. Their worry was whether the interview would interfere with their treatment or doctor appointment timings. The clinic nurses were helpful in this regard; we collaboratively tracked the processes to ensure participants’ treatment or appointment was not interrupted. On the interview days, participants had their procedures completed early and they spent less time in hospital, a factor that encouraged them to come for subsequent interviews. This mainly occurred at the private hospital.

4.4.2.3 Recruitment procedure at the public hospital

Although similar procedures were followed for the public hospital, some differences arose in recruiting participants. The women readily agreed to participate, and some were ready to sign the consent form without even reading it. Despite this, I explained the study fully, and encouraged them to take the PIS and consent form home and bring it back on their next visit. Women also informed their friends about participating in the research. Of the four potential participants that were identified by snowballing, one met the eligibility criteria and participated in the interviews. Overall, I achieved good representation of rural women from the public hospital. Although majority of these women had a secondary school education, they could not speak English and preferred to be interviewed in Kiswahili.

4.5 Data collection

In this study, data were collected through semi-structured interviews, which is the most commonly used method of generating data in qualitative research and is lauded for being able to produce rich, in-depth reports (Polit & Beck, 2012). Throughout their interviews, participants had opportunities to explain and justify their actions in relation to the study subject, in this case HL. An advantage of interviews is that they allow participants to clarify, defend and justify their actions when the interviewer asks probing questions (Tracy, 2019). An added advantage of interviews is that they allow the researcher and participant to engage in a dialogue whereby initial questions are modified in light of the participant’s responses. Qualitative interviews can be structured, semi-structured or unstructured (Polit & Beck, 2012). In structured interviews, the interviewer uses an interview schedule with a list of questions that are repeated in the same words and order. Unstructured interviews use an interview guide that serves to stimulate rather than dictate the conversation. In semi-structured interviews, the interviewer has pre-determined questions that allow the interview to unfold in a conversational manner, giving participants a chance to explore what they deem important (Tracy, 2019). The advantage of semi-structured interviews is that complex issues can be probed, answers clarified and the researcher can obtain additional in-depth and sensitive information because of the relaxed atmosphere (Polit & Hungler, 1999). The main disadvantage of the interview method is that there is no anonymity for participants, which may lead to inaccurate responses and unwillingness to participate (Polit & Beck, 2012). Another disadvantage is the amount of time and effort required to set up the interviews, including travelling and arranging for a mutually agreeable time and venue to conduct the interview (Polit & Beck, 2012).

Data were collected through semi-structured face-to-face interviews that explored and described participants' experiences of HL. The interviews were audio recorded with participants' permission, and field notes were used to capture as much detail as possible during the interviews; this provided a means to initially analyse the collected data. Demographic data were completed for each participant as outlined in Appendix 8. The interviews were conducted in English or Kiswahili as per participants' preferences. Semi-structured prompts (see the interview guides in Appendices 10–13) were used to encourage participants to talk about and provide additional insights regarding their thoughts and understanding of BC as well as their personal experiences of cancer in their family and community. At the end of their initial interview, participants were reminded about the second and third interviews in which we would also discuss the first interview findings to confirm that they reflected their experiences.

The initial plan to conduct three interviews changed during data collection depending on the emerging categories. In some instances, participants' experiences had become repetitive by the second interview, and there was no need for a third interview. The interviews lasted between 30 and 90 minutes, with the shortest interview taking 36 minutes and the longest 86 minutes. I had initially contemplated using telephone interviews but preferred face-to-face interviews as they allowed a greater sense of rapport to develop and non-verbal communication to be obtained (Jacob & Furgerson, 2012); for example, long silences, sighs, inappropriate laughter and crying were all witnessed during the interviews and transcribed. Data collection occurred from February 2018 to September 2018 at AKUHN, and October 2018 to January 2019 at KNH.

4.5.1 Individual semi-structured interview approach

Participants were interviewed in a location of their choice; this was usually in the hospital (a quiet room) when they attended for various clinic appointments. However, one participant came to my workplace (she was extremely excited and proud about this) and one participant chose to be interviewed in her home. For the interviews at the participant's home, I was always accompanied by the RA and we informed a colleague where we were, as specified in the University of Salford lone worker policy.

At the beginning of each interview, participants were given a brief explanation about the study; namely, that we were interested in how they accessed, understood and used health information to make treatment decisions. The interviews began by first engaging in general conversations about everyday life (family, politics, business) to establish rapport and make participants feel at ease before delving into the actual research. They were reminded that their responses would be kept confidential and that there were no wrong or right responses or experiences. The starter question that also served as an ice breaker was, '*How did you find yourself in the oncology clinic?*' This question worked well as it encouraged participants to walk their cancer journey in detail. Other questions included pre-diagnosis information sources, events that led to diagnosis, what made them want to see the doctor, information from HCPs in the hospital, their perceptions of that information in helping them make decisions, and their belief systems and how these influenced the information they obtained (See interview guide in Appendices 10–13).

It was necessary to ask probing questions to get information, especially with open-ended questions. Examples of probing questions were '*how is that?*'; '*anything else?*'; '*would you like to elaborate on that?*'; '*in what ways?*'; and '*how did that happen?*'. Taylor, Kermode and Roberts (2006) advised that silence was also an effective way of probing, and I used this technique a lot. Probing questions had been thought out and written beforehand (Polit & Hungler, 1999; Taylor et al., 2006). In the interviews, I gave participants freedom to tell their story; therefore, they guided the flow of questions. The interview flow varied depending on how participants chose to respond; however, I tried to avoid agreeing or disagreeing with the participant's opinions during the interview as much as possible. This was difficult because some participants used this time to ask questions, and others sought approval to determine if they were answering questions correctly. I reassured them that their experiences were important, and there was no correct or incorrect response. Although this encouraged them to continue narrating their experiences, it also caused some discomfort in knowing that as the researcher I needed to 'bracket' my experiences and remain objective and neutral. This challenge was overcome by a strategy I developed whereby at the end of each interview, I switched off the audio recorder and spent an extra 20 minutes with participants to just talk and see if there were any feelings of distress from the interview. This time was also used to answer questions and clarify some issues they had raised during the interview, because although I was the researcher, I was still a nurse. It was an arduous task balancing the separate roles of researcher, teacher and nurse. This highlighted the concept of positionality, which I have explored further under reflexivity (see Section 4.9). As a nurse, I used the opportunity to empower participants with information. This was an intentional action that had been planned based on previous encounters where patients with BC asked many questions during clinical rotations with students.

4.6 Data analysis process

Data analysis refers to the process of systematically searching and arranging the interview transcripts, field notes and any other materials collected by the researcher to increase understanding of the phenomenon under study (Tracy, 2019). The qualitative data analysis process is a dynamic, intuitive and creative process of inductive reasoning that focuses on exploration of values, meanings and experiences that answer the research questions (Tracy, 2019). This process brings structure, order and meaning to the collected data, although there are large amounts of data that need coding and categorising in qualitative studies. Despite these complex processes, Grove et al., (2012) stated that data analysis should follow a logical order and avoid bias whenever possible. In qualitative analysis, the researcher becomes immersed in the entire data by reading and re-reading transcripts and listening to the recorded interviews and thinking about them. Good open-minded questions such as, '*what is happening here*', or '*what strikes you in this data*?' can guide this step and provide answers (Creswell, 2015). As any corpus of rich data can be analysed in different ways, the researcher needs to stay open to the many meanings. A previous study suggested asking the question, '*What is a story here*', rather than '*what is the story*?' (Flick, 2013).

Inductive or deductive approaches are used for qualitative research analysis (Tracy, 2019). An inductive (inside-out) approach involves analysing data based on initial insights from the actual data and specific events from the research; therefore, there is no reference to the specific questions that participants were asked. This raises the possibility of revealing new ideas and explanations (Yin, 2015). Conversely, a deductive approach uses a known theory or predetermined structure in analysing data. In using a deductive approach, researchers start with a set of predetermined codes, and then find excerpts that fit those codes (Tracy, 2019). Although it is a quicker and easier process, the deductive approach has been critiqued for its inflexibility and the potential bias to the whole data analysis because of a pre-determined coding framework. In addition, a major risk associated with deductive coding is the loss of any fresh insights into the real-world problems being studied (Yin, 2015).

This study sought to understand, describe and document people's feelings and thoughts within a 'BC diagnosis' context; therefore, an inductive approach was adopted, and data were analysed thematically guided by Colaizzi's (1978) technique. Colaizzi's (1978) strategy for data analysis is a credible, reliable, rigorous and robust method that allows the researcher to reveal how themes emerged from research data and their interwoven relationships. This process was adopted as it attempts to understand experiences and the meanings those experiences have for participants (Pietkiewicz & Smith, 2014). However, not all phases of Colaizzi's method were relevant to this research, and an adapted version was used. Analysis and collection of data were concurrent, with early analysis of first interviews informing questions asked in later interviews. Based on Colaizzi's (1978) strategy as cited in Shosha (2012), I followed the following four steps (see Table 7).

Table 7: Data Analysis Steps using Colaizzi's (1978) Technique

Steps	**Concept by Colaizzi**	**This research**
Step one	Each transcript should be read and re-read to obtain a general sense about the whole content.	The research assistant transcribed all interview transcripts. I read and re-read each transcript to become familiar with the data, and re-transcribed the interviews informed by my objectives and theoretical framework.
Step two	For each transcript, significant statements that pertain to the phenomenon under study should be extracted. These statements must be recorded on a separate sheet noting their page and line numbers.	Read each transcript, extracted and made notes in the right-hand margin of any significant or interesting statements that pertained to cancer health literacy. I also recorded these on a separate sheet noting the page and line numbers.
Step three	Meanings should be formulated from these significant statements.	Summarised, and identified connections, associations and contradictions in the data and formulated meanings.

Step four	The formulated meanings should be sorted into categories, clusters of themes and themes.	Sorted the formulated meanings into categories, clusters of themes and themes.

4.6.1 Step one: Reading and re-reading the transcripts

I read and re-read the original transcripts to become immersed in the data and get a sense of the whole story. I listened to all of the audio recordings, envisioning the voices of the participants and their pauses, sighs, pitch, silences and any other non-verbal cues. I also saved the recordings on my mobile phone, and listened to them through headphones everywhere, including when doing my house chores and early morning or evening walks. The transcripts became my 'new music' to the extent that when the opening statement was made, I could tell who the participant was and what their story was like; I became familiar with the data in detail. This way, the phenomenon of HL as experienced by participants was explored and construed as their reality and truth (Hennink et al., 2010; Houser, 2013).

During translation of the transcripts, at times, it was a struggle to find the appropriate English term for some words spoken in Kiswahili that would accurately reflect participants' experiences; for example, '*boda boda*' and '*piki piki*' both refer to a motorcycle, which is a popular mode of transport. I chose to translate this as motorcycle taxi instead of '*matatu*' (a motor vehicle that is a means of public transport). I described what I understood as the meaning depicting participants' context, revisited the transcripts to review their statements and at times re-worded or re-structured sentences to capture the participants' stories. This exercise taught me how keenly one has to listen to transcribe accurately and highlighted the advantage of self-transcription.

4.6.2 Step two: Extracting significant statements

The process of coding started at this stage. Coding is defined as labelling parts of the data so as to organise and prepare it for further analysis, and is considered the backbone of thematic analysis (Saldaña, 2021). As my research questions were exploratory and addressed both ontologic (capturing participants' realities) and epistemological (in which I sought to understand the phenomenon of HL from the participants' perspectives) in nature, I used a variety of coding methods (in vivo, descriptive, presumptive, interpretive and evaluation) in the first cycle of coding. This use of multiple coding methods was consistent with Patton (2002), who asserted that just as qualitative research is unique, the analytical approach is also unique; there is no best way to code qualitative data as the relevant information is hidden in the data.

I manually coded the first two interview transcripts from the private and public hospitals to become familiar with the data and generate the initial codes. I then assigned labels to the research questions, which served as anchor codes to help organise the data (See below, anchor codes are in *italics*). I then coded relevant statements and placed the codes under their respective anchor codes. As I coded, I referred to my research problem statement, theoretical framework, research questions and objectives to maintain focus on what I was looking for in the data.

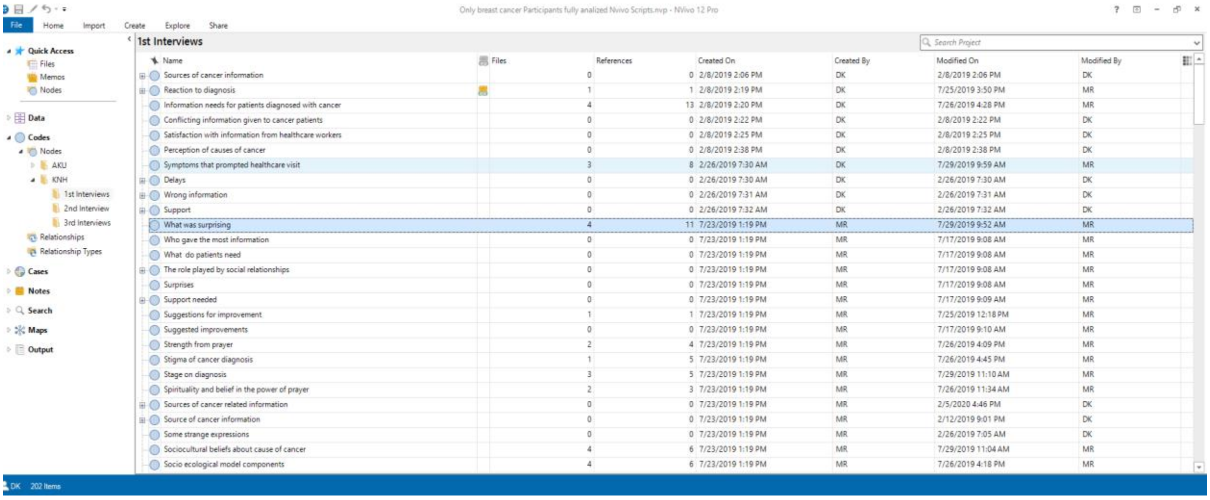
Research questions

- What are the experiences of accessing, understanding and using health information for patients diagnosed with BC? *HL experiences*
- What socio-ecological factors influence the health literacy of women diagnosed with BC? *Facilitators and barriers*

Objectives

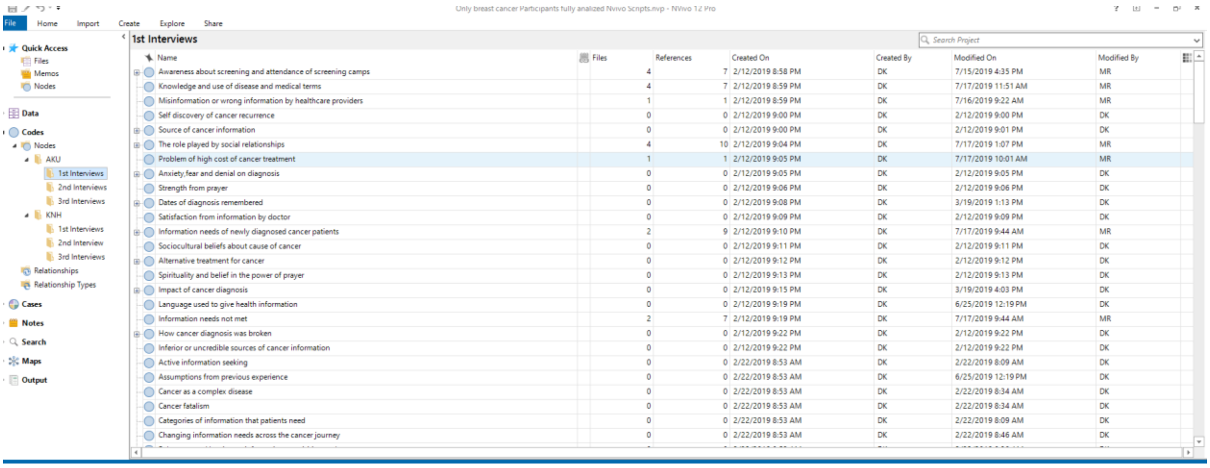
- To describe the experiences of accessing, understanding and using cancer-related information along the BC journey. *HL experiences*
- To determine what BC survivors understood about BC in their communication with HCPs. *Knowledge of BC, communication with HCPs*
- To identify cancer-related information needs of women diagnosed with BC. *Information needs*
- To identify the socio-ecological factors that influenced the HL of women diagnosed with BC. *Facilitators and barriers*

After the initial preliminary manual coding of four transcripts (two from each site) and developing a framework for further analysis, the transcripts were imported into NVivo version 12, which helped with organising data by easing the sorting and data management process. As I had many interviews (30 from 11 participants, see Table 8), NVivo made storage, reduction and organisation of the data more manageable and efficient, which offered an added advantage for coding, sorting, querying and retrieving data by searching. Figures 4 and 5 below show examples of NVIVO generated codes.



Name	Files	References	Created On	Created By	Modified On	Modified By
Sources of cancer information	0	0	2/8/2019 2:06 PM	DK	2/8/2019 2:06 PM	DK
Reaction to diagnosis	1	1	2/8/2019 2:19 PM	DK	7/25/2019 3:50 PM	MR
Information needs for patients diagnosed with cancer	4	13	2/8/2019 2:20 PM	DK	7/26/2019 4:28 PM	MR
Conflicting information given to cancer patients	0	0	2/8/2019 2:22 PM	DK	2/8/2019 2:22 PM	DK
Satisfaction with information from healthcare workers	0	0	2/8/2019 2:25 PM	DK	2/8/2019 2:25 PM	DK
Perception of causes of cancer	0	0	2/8/2019 2:38 PM	DK	2/8/2019 2:38 PM	DK
Symptoms that prompted healthcare visit	3	8	2/26/2019 7:30 AM	DK	7/29/2019 9:59 AM	MR
Delays	0	0	2/26/2019 7:30 AM	DK	2/26/2019 7:30 AM	DK
Wrong information	0	0	2/26/2019 7:31 AM	DK	2/26/2019 7:31 AM	DK
Support	0	0	2/26/2019 7:32 AM	DK	2/26/2019 7:32 AM	DK
What was surprising	4	11	7/23/2019 1:19 PM	MR	7/29/2019 9:52 AM	MR
Who gave the most information	0	0	7/23/2019 1:19 PM	MR	7/17/2019 9:08 AM	MR
What do patients need	0	0	7/23/2019 1:19 PM	MR	7/17/2019 9:08 AM	MR
The role played by social relationships	0	0	7/23/2019 1:19 PM	MR	7/17/2019 9:08 AM	MR
Surprises	0	0	7/23/2019 1:19 PM	MR	7/17/2019 9:08 AM	MR
Support needed	0	0	7/23/2019 1:19 PM	MR	7/17/2019 9:09 AM	MR
Suggestions for improvement	1	1	7/23/2019 1:19 PM	MR	7/25/2019 12:18 PM	MR
Suggested improvements	0	0	7/23/2019 1:19 PM	MR	7/17/2019 9:10 AM	MR
Strength from prayer	2	4	7/23/2019 1:19 PM	MR	7/26/2019 4:09 PM	MR
Stigma of cancer diagnosis	1	5	7/23/2019 1:19 PM	MR	7/26/2019 4:45 PM	MR
Stage on diagnosis	3	5	7/23/2019 1:19 PM	MR	7/29/2019 11:10 AM	MR
Spirituality and belief in the power of prayer	2	3	7/23/2019 1:19 PM	MR	7/26/2019 11:34 AM	MR
Sources of cancer related information	0	0	7/23/2019 1:19 PM	MR	2/5/2020 4:46 PM	DK
Source of cancer information	0	0	7/23/2019 1:19 PM	MR	2/12/2019 9:01 PM	DK
Some strange expressions	0	0	7/23/2019 1:19 PM	MR	2/26/2019 7:05 AM	DK
Sociocultural beliefs about cause of cancer	4	6	7/23/2019 1:19 PM	MR	7/29/2019 11:04 AM	MR
Socio ecological model components	4	6	7/23/2019 1:19 PM	MR	7/26/2019 4:18 PM	MR

Figure 4: NVivo codes from the first interviews at the public hospital.



Name	Files	References	Created On	Created By	Modified On	Modified By
Awareness about screening and attendance of screening camps	4	7	2/12/2019 8:58 PM	DK	7/15/2019 4:35 PM	MR
Knowledge and use of disease and medical terms	4	7	2/12/2019 8:59 PM	DK	7/17/2019 11:51 AM	MR
Misinformation or wrong information by healthcare providers	1	1	2/12/2019 8:59 PM	DK	7/16/2019 9:22 AM	MR
Self discovery of cancer recurrence	0	0	2/12/2019 9:00 PM	DK	2/12/2019 9:00 PM	DK
Source of cancer information	0	0	2/12/2019 9:00 PM	DK	2/12/2019 9:01 PM	DK
The role played by social relationships	4	10	2/12/2019 9:04 PM	DK	7/17/2019 1:07 PM	MR
Problem of high cost of cancer treatment	1	1	2/12/2019 9:05 PM	DK	7/17/2019 10:01 AM	MR
Anxiety,fear and denial on diagnosis	0	0	2/12/2019 9:05 PM	DK	2/12/2019 9:05 PM	DK
Strength from prayer	0	0	2/12/2019 9:06 PM	DK	2/12/2019 9:06 PM	DK
Dates of diagnosis remembered	0	0	2/12/2019 9:08 PM	DK	3/19/2019 1:13 PM	DK
Satisfaction from information by doctor	0	0	2/12/2019 9:09 PM	DK	2/12/2019 9:09 PM	DK
Information needs of newly diagnosed cancer patients	2	9	2/12/2019 9:10 PM	DK	7/17/2019 9:44 AM	MR
Sociocultural beliefs about cause of cancer	0	0	2/12/2019 9:11 PM	DK	2/12/2019 9:11 PM	DK
Alternative treatment for cancer	0	0	2/12/2019 9:12 PM	DK	2/12/2019 9:12 PM	DK
Spirituality and belief in the power of prayer	0	0	2/12/2019 9:13 PM	DK	2/12/2019 9:13 PM	DK
Impact of cancer diagnosis	0	0	2/12/2019 9:15 PM	DK	3/19/2019 4:03 PM	DK
Language used to give health information	0	0	2/12/2019 9:19 PM	DK	6/25/2019 12:19 PM	DK
Information needs not met	2	7	2/12/2019 9:19 PM	DK	7/17/2019 9:44 AM	MR
How cancer diagnosis was broken	0	0	2/12/2019 9:22 PM	DK	2/12/2019 9:22 PM	DK
Inferior or uncredible sources of cancer information	0	0	2/12/2019 9:22 PM	DK	2/12/2019 9:22 PM	DK
Active information seeking	0	0	2/22/2019 8:53 AM	DK	2/22/2019 8:09 AM	DK
Assumptions from previous experience	0	0	2/22/2019 8:53 AM	DK	6/25/2019 12:19 PM	DK
Cancer as a complex disease	0	0	2/22/2019 8:53 AM	DK	2/22/2019 8:34 AM	DK
Cancer fatalism	0	0	2/22/2019 8:53 AM	DK	2/22/2019 8:34 AM	DK
Categories of information that patients need	0	0	2/22/2019 8:53 AM	DK	2/22/2019 8:09 AM	DK
Changing information needs across the cancer journey	0	0	2/22/2019 8:53 AM	DK	2/22/2019 8:46 AM	DK

Figure 5: NVivo codes from the first interviews at the private hospital.

4.6.2.1 Descriptive coding

I assigned topics to aspects of data; for example, any information where the participants talked about God, religion or beliefs was labelled 'faith'. The descriptive coding decisions were also informed by the methodology because I had multiple interviews collected longitudinally over a 12-month period and needed to elicit any changes over time. A review of the raw data showed that many responses could be classified as belonging to more than one topic. For example, if a participant's statement indicated that it was expensive to treat BC and mentioned that their son needed school fees, this statement was classified as 'Financial challenges', 'Impact of BC', and 'Causes of treatment delay'.

Table 8: Number of interviews

Participant pseudonym	**Site (public or private)**	**Number of times interviewed**

Connie	Private	3
Juliet	Private	3
Ruth	Private	3
Lilly	Private	3
Olive	Private	3
Rhoda	Private	3
Debora	Public	3
Naomi	Public	2
Marion	Public	3
Abigail	Public	2
Paula	Public	2
Total	**ALL**	**30**

During coding, I made new discoveries, connections and insights about the participants and their HL experiences. As I read through the interview transcripts and listened to the audio recorded data, I attuned to words and phrases that struck me as strong and relevant statements that needed bolding or highlighting (e.g. fear, faith, family, friends, finances, church and side effects seemed to traverse all transcripts), or where there was vocal emphasis or ironic phrases, metaphors, frequent use of the same words (e.g. God and money) and phrases by participants. With this I demonstrated that I had grasped what was important to the participants, meaning the codes were participant inspired rather than researcher generated (Table 9).

Table 9: Examples of codes generated from participant quotes

	Quotes	**Code**
1.	That day ended, the following and the other week finished, and I saw it nice to go to Aga Khan Hospital to tell them what I'm feeling. *(Juliet, private hospital, first interview)*	Diagnostic delay
2.	I was told, it is just the side effects of chemotherapy, but with the time they will be off.	Information about side effects

	(Connie, private hospital, third interview)	
3.	The card registration money I did not have, 600 shillings (6 USD) for the consultation fee, also I did have. That made me get back home and I stayed for one week as I was looking for the money. *(Marion, public hospital, first interview)*	Finances

The initial coding assisted me to focus on specific areas of the data from the 30 interviews. I read and re-read the transcripts and repeatedly listened to the audio recordings to ensure that no essential information was overlooked/missed out. As I read and listened, I referred to the summary codebook (see Table 10) that I had created, and no new codes arose. The summary table had six columns. The first column is numbered and shows the initial codes. The second column depicts the actual codes, and the third column is the interview stage (first, second or third), which helped to note whether similar concepts were realised in separate interviews. The fourth column shows the site of participant recruitment (public or private), and the fifth column represents the researcher's notes of the thoughts that arose during coding. The sixth column gives examples of participants' statements. The initial coding yielded 47 codes (See Appendix 14).

Table 10: Examples of initial code summary

	Code	Interview stage	Recruitment site	Researcher's notes	Participant statement example
1.	Discovering the lump	First interview	Private	Symptoms that made the participant seek healthcare intervention	How I knew I have got a lump, I checked my breasts every month, so I decided to visit the clinic so that I can get more information when I felt a lump. *(Connie, private hospital, first interview)*

		First interview	Public		I just woke up and found myself with a lump, but I had a child I was breastfeeding. Then after that, I said it was milk, and took it rightly and I stayed for almost a year. But first, before I knew it was a disease, I started losing appetite, and after losing appetite started having back and legs pains. Then I started taking pain killers…later, I lost appetite, and I could not walk. *(Lilly, public hospital, first interview)*
2.	Sources of information	First interview Second interview		How participants accessed information about BC	I had heard about BC, but I had not gone for any check-up, but I had heard about it through TV. *(Lilly, private hospital, first interview)* Now, doctor told me take everything. He told me like meat, it is good for your heart, I cannot remember whether he said heart, but for sugar, you can take because it is good for your brain. Take a lot of water to cleanse the kidneys so that they can work and not be affected by those drugs. (*Debora, public hospital, second interview)*

In this stage, I extracted significant statements and phrases that addressed participants' HL experiences of accessing, understanding and using health information, their information needs and perceptions of the information given by HCPs from each transcript. In addition, factors that were facilitators or barriers to HL were extracted. The notes that answered the research question and objectives were highlighted with marker pens, along with handwritten notes beside the highlight. I recorded what I saw and heard and why I saw and heard it in the data. This was important because every time I listened to the audios and read the transcripts, new perspectives emerged and the notes helped to justify the codes developed.

4.6.3 Step three: Formulating meanings

I reviewed the significant statements and assigned meanings to each. This required the implied and obvious meanings in each statement to be considered. This step involved use of my instincts, analytical skills and critical reading of the transcripts (to help in comprehension and accurate interpretation) and reflexivity, where I moved back and forth between participants' statements and the initial statements extracted in step two. I did this to a point when I was satisfied that the formulated meanings accurately reflected the intended meanings of the participants.

4.6.3.1 Categorizing and generating themes

The codes I created emerged from the data and captured essential elements that answered the research questions. At this stage, I also used knowledge from the literature and theoretical concepts from the SEM to generate categories. The SEM helped in understanding the factors that influenced HL for participants at the various levels (micro, meso and macro). I also clustered the codes that were regular and similar (referred to a specific concept) into categories, which allowed further analysis of connections. As per Saldaña (2021), the essence is to identify an underlying meaning among a group of codes (See example in Table 11). I also wrote analytic memos that explained the codes and the connections between them.

Table 11: From codes to categories

Codes	**Categories**
• Nausea and vomiting • Always tired • Hair fell out	Side effects management
• No money for investigations • School fees for son • Cancer treatment is expensive	Financial distress

4.6.4 Step four: Generating sub-themes and themes

In this stage, I performed a more detailed analysis that involved multiple readings and making notes, transforming notes into emergent themes and seeking relationships and clustering themes (Pietkiewicz & Smith, 2014). After deciding on the formulated meanings, I grouped them into categories of similar experiences to form theme clusters. Each cluster included all formulated meanings related to that group. I ensured that there was congruence between the formulated meanings and the theme clusters by reviewing the sequence of the participant statements, formulated meanings and corresponding theme clusters. Thereafter, groups of theme clusters that answered the research questions or a certain objective were incorporated together into a distinctive theme.

This was a difficult step, because I now relied on my initial notes made from the transcripts and the interpretation. This made me anxious because away from the transcripts, I had to ensure that my interpretation of participants' stories was appropriate and reflected their perspectives. I read and re-read the notes and aligned each possible theme against the phrase. At times I went back to listen to the audios to fully get into the world of a participant. Proceedings and difficulties encountered were recorded for reflection and to help develop further themes. There were interesting discussions for example when a participant said, '*God cannot give me burdens I cannot overcome*', and then later contradicted herself by saying '*cancer belongs to God, He knows why He gave it to me; I will not be afraid*'. Discussions with colleagues helped place this in the appropriate theme but did not compromise participants' confidentiality as the topic was introduced as a general discussion. Another example was a participant who said that cancer was a '*killer disease*', when asked what information she had about cancer. Towards the end of the interview, she was encouraging women to conduct BSE and go for screening because cancer was '*curable if discovered early*'. These two concepts although similar were different and fell under different sub-themes: coping with cancer fatalism and mixed reactions after cancer diagnosis. Fifteen theme clusters emerged, which were later grouped into five emergent themes (See Table 10).

I defined all emergent themes into an exhaustive description, integrating factors that influenced cancer HL and participants' experiences of accessing, understanding and using health information in their cancer journey. These were shared with a colleague who was an expert qualitative researcher. She reviewed the richness and completeness of the findings in adequately describing participants' experiences and confirmed that the exhaustive description captured the perceptions of BC survivors on how they accessed and used cancer related information.

Therefore, two themes were realised: Information experiences of patients with BC along the illness trajectory, and Socio-ecological factors that influenced HL. These themes are discussed in detail in Chapter Six.

4.6.4.1 Developing subthemes

After the two initial phases, I developed a codebook (See example in Appendix 14), which displayed the key codes and definitions that were used throughout the analysis. Later, initial codes were collated and summarised into phrases that formed subthemes (See Figure 6) for an example). In this example, information needs was the subtheme, and information needs before diagnosis, during treatment and after finishing treatment were the initial codes.

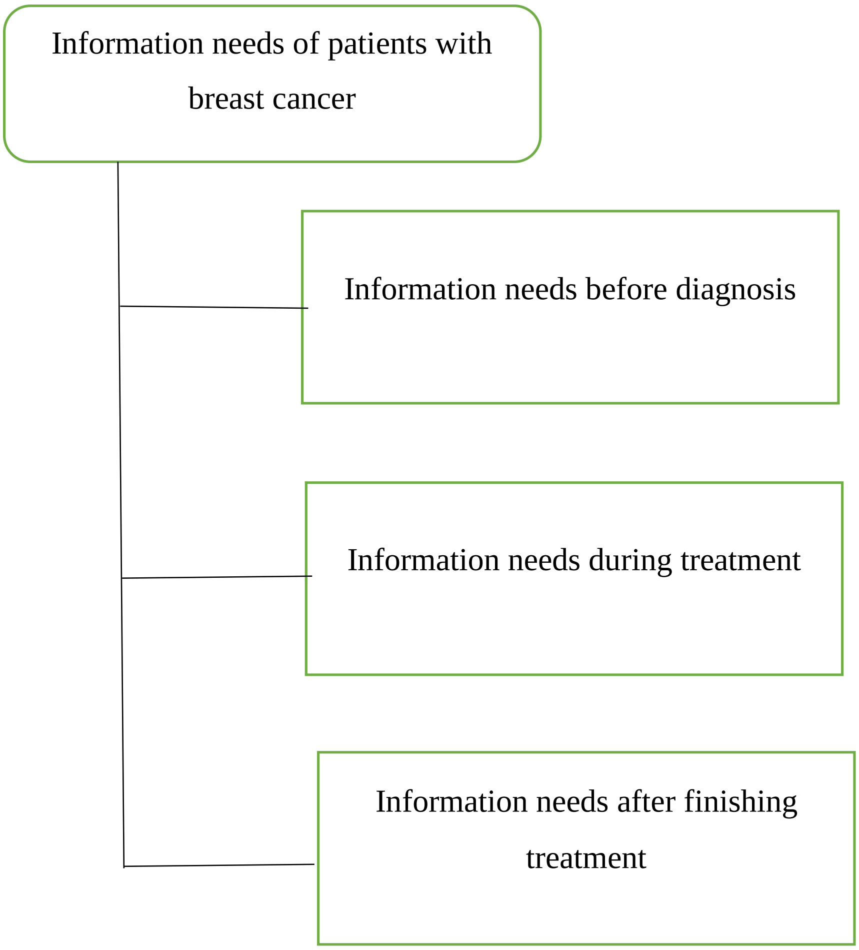


Figure 6: Example of developed subthemes.

Table 12: Developing the codebook

Initial codes	**Subtheme**	**Definition**	**Location of participant quotes in the transcripts**

Participants' needs for specific information about: adherence to treatment, details of specific treatment, expectations before and after surgery, side effects of treatment	Cancer-related health information needs	Participants commented how they desired cancer-specific information to help cope with the BC journey	**Adherence to treatment** Paula, public hospital, first interview Olive, private hospital, first interview Rhoda, private hospital, first interview Juliet, private hospital, second interview Marion, public hospital, second interview **Details about specific treatment** Naomi, public hospital, second interview Olive, private hospital, first interview Abigail, public hospital, second interview Juliet, private hospital, first interview Rhoda, private hospital, third interview **Expectations before, and after surgery** Paula, public hospital, first interview Deborah, public hospital, first interview Rhoda, private hospital, third interview **Side effects of treatment** Juliet, private hospital, first interview Debora, public hospital, second interview Lilly, private hospital, third interview Abigail, public hospital, second interview Juliet, private hospital, third interview

4.6.4.2 Identification of initial themes

1. **Breast lump/swelling as a gateway to health facility:** Participants commented that a lump or abnormal swelling of the breast was the trigger for seeking healthcare.

2. **Church as an avenue for cancer information sharing:** Participants relayed that they received most of their information from church and church-related groups.

3. **Despair and agony at diagnosis:** Participants commented about the negative thoughts, emotions and fear of death that occurred when the news of BC was broken**.**

4. **Doctors as main source of information:** Doctors were the most cited HCPs as giving BC information.
5. **Not understanding treatment regimens:** Participants commented that the BC treatment regimens were complex, and they did not understand them.
6. **Insufficient information on cancer:** Participants commented that HCPs did not give them sufficient information.
7. **Need for patient psychosocial support:** Participants described the need for counselling to help cope with the threatening disease.
8. **Faith in a higher being (God) as a coping strategy:** Participants always referred to God as their strongest support.
9. **Stigma associated with a cancer diagnosis:** Participants commented how they did not disclose their BC diagnosis for fear of stigma.
10. **Cancer treatment financial burden:** Participants commented about the financial implications of BC treatment, and how this deterred them from getting screened.

Further analysis of the data revealed the following themes.

1. **Despair and agony at diagnosis:** Participants commented about the negative thoughts, emotions and fear of death that occurred when the news of BC was broken.
2. **Complexity of decision-making:** Participants commented that they were not involved in decision-making about their treatment, information about treatment was given when patients were still emotional. Socio-culturally, men made the decisions because a BC diagnosis was a serious matter.
3. **Impact of BC diagnosis on self, family and others:** Participants commented how the BC diagnosis affected their spouses, children and parents, and interfered with their ability to work and earn money for their daily upkeep. The treatment for cancer was expensive and this ate into the family finances.
4. **Cancer-related health information needs:** Participants commented how they desired cancer specific information to help cope with the BC journey.
5. **Socioeconomic factors that influenced HL across the cancer journey:** Participants commented how several factors contributed to their access and use of information.

6. **SEM factors:** Participants commented about factors at various level of the SEM that either facilitated or were barriers to how they accessed and used information.
7. **Data that do not fit anywhere:** Participants commented about aspects that did not answer any of the objectives or research questions but seemed important to them. They stated that the interviews gave them a chance to speak about their BC journey and it was therapeutic for them. They gave recommendations of what the government could do to improve breast health awareness and the treatment of patients already diagnosed.

Further analysis of the transcripts was guided by the complicated interactions between objectives, settings, coping methods, time, relevance and prominence of information themes. Throughout, the individual participant and their information needs served as the units of analysis. Both the manifest (visible and obvious components of the text) and latent (relationships that required interpretation of the underlying meaning of the text) content were extracted and coded (Saldaña, 2021) using phrases, words and statements that were substantively related to a specific contextual concept of HL. A senior PhD colleague and independent researcher verified and approved the interconnected groupings of concepts and the interpretation of meaning throughout and verified that the themes emerged and were evident from the data. In addition, I matched the themes and categories to the research questions and objectives. Table 13 shows the themes matched with the categories and research questions/objectives they answered.

Table 13: Themes and categories mapped to research questions and objectives

#	Theme	Categories	Research question answered (in red) / objective met (in pink)
5.	Despair and agony at diagnosis	• Breaking bad news • Cancer fatalism • Doctors and giving information	What are the experiences of accessing, understanding and using health information for patients diagnosed with BC? To identify cancer related information needs of women diagnosed with BC
6.	Complexity of decision-making	• Faith as a major coping strategy • Fear, hope amid fear • Finances • Non-specific symptoms • Lack of knowledge	What are the experiences of accessing, understanding and using health information for patients diagnosed with BC? To determine what BC survivors, understood about BC in their communication with HCPs. To identify cancer-related information needs of women diagnosed with BC
7.	Impact of BC diagnosis on self, family and others	• Side effects management • Stigma • Financial distress • Psychosocial support	What are the experiences of accessing, understanding and using health information for patients diagnosed with BC? To describe the experiences of accessing, understanding and using cancer-related information along the BC journey. To determine what BC survivors, understood about BC in their communication with HCPs. To identify cancer-related information needs of women diagnosed with BC
8.	Knowledge and information expectations of patients newly diagnosed with BC	• Screening for BC • Breast self-examination • Instructions on different types of treatment • Medication indication • Investigations • Post-treatment instructions and follow-up • Patient as best teacher from experience	What are the experiences of accessing, understanding and using health information for patients diagnosed with BC? To describe the experiences of accessing, understanding and using cancer-related information along the BC journey. To determine what BC survivors, understood about BC in their communication with HCPs. To identify cancer-related information needs of women diagnosed with BC.

9.	Socioeconomic factors that influenced HL across the cancer journey	- Faith - Finances - Support - Stigma	What socio-ecological factors influence the HL of women diagnosed with BC? To identify cancer-related information needs of women diagnosed with BC. To identify the socio ecological factors that influenced the HL of women diagnosed with BC.

4.6.4.3 Revision of themes

As I read and re-read the transcripts, I realised that various themes overlapped in meaning. Therefore, I combined some theme categories and revised the titles. Table 14 includes a list of the renamed and final themes that were presented in the findings (See Chapter Five). Categories that had few responses were grouped under one theme and renamed.

Table 14: Revised and final themes

Grouped themes	**Revised title for combined themes**
Despair and agony at diagnosis	**Information experiences of patients with BC along the illness trajectory**
Complexity of decision making	
Impact of BC diagnosis on self, family and others	
Cancer-related health information needs	
Socioeconomic factors that influence HL across the cancer journey	**Socio-ecological factors that influenced health literacy**
SEM factors	
Data that do not fit anywhere	These were not explored further but would be revisited in the recommendations for improving HL in patients with BC in a later section.

4.7 Ethical and institutional approval

Before commencing this study, ethical clearance was sought from the University of Salford Ethics Committee and the ethics committees of AKUH, N, and KNH. For the KNH, in addition to ethics clearance by the Institutional Review Board, the oncology department head had to write a letter to the ward manager signifying approval to collect data. A research permit was obtained from the Kenya NACOSTI. The main concern in this study was participants’ privacy and confidentiality. This was related to the fact that in Kenyan culture, the breast is considered a private part. This meant it was difficult to get participants to agree to be audio recorded as they felt uncomfortable with their very personal narrations and experiences being recorded and analysed. In some instances, husbands insisted on staying in the interview room. This was allowed but the main consideration was to be fair and just to the participants, respecting their wishes and prioritising their needs (Stutchbury & Fox, 2009). After I gave a detailed explanation on how participant confidentiality and anonymity would be maintained, the participating women signed the consent form and agreed to participate. Principles of informed consent, autonomy and confidentiality were all observed (Appendix 7).

Although this study did not seek to elicit painful life experiences, this possibility was eminent because of the unpleasant experiences, complex cancer treatment modalities and distressing healthcare encounters (e.g., death of cohort member). For treatment, patients were organised into groups (cohorts) made up of those who were coming for treatment at the same time. They knew each other and so whenever one died, it affected the whole group. I took responsibility to do no harm to participants or expose them to undue risk, either physical or emotional (Lowes & Paul, 2006). However, it was difficult to avoid the emotional aspect because participants delved into their experiences during interviews, and shared personal, deep, and difficult encounters. My concerns were intensified when some participants broke down and cried. Holloway and Walker (2000) noted that qualitative interviews have potential to provoke painful hidden emotions. This potential to evoke sad emotions was carefully considered and a counsellor contact was always provided to participants before the interviews in case they needed psychological intervention later. Immediately available on the floor were nurse counsellors (among them a BC survivor) who could deal with situations of distress if they arose.

It may be considered unethical to interview women at such a vulnerable time when they have just been diagnosed with cancer, but from the interactions, it appeared that the conversations were therapeutic. Many participants stated that they felt a heavy load had been taken from them and it was a good experience reliving their journey. Again, it may seem unethical to ask women about screening and going for cancer treatment that is not freely provided by the government. My argument is that though this was an important consideration, research evidence generated will help inform government strategic policy documents that are currently *silent* about HL. At one point I also thought I should have focused on the current journey and not retrospective experiences, but then, these participants were the best placed to give their pre-diagnosis health information experiences that could inform policy review.

4.8 Data protection

All participants were anonymised by assigning them an ID code or number (which were later replaced by pseudonyms; see Appendix 8b), and all identifiable information was removed from the transcripts. The transcripts, signed consent forms and study information provided by participants were stored in a locked cabinet at the Aga Khan School of Nursing and Midwifery. Electronic data (audio-recordings, transcripts, analysis, field notes) were protected with passwords and saved on the University of Salford server, which is secure. The files were password protected, saved in Salford one drive, and only accessed by members of the Salford-based research and supervision team.

4.9 Reflexivity and my role in the research process

Reflexivity is a continual process that demonstrates the researcher-participant relationship, and how one affects the other in the research process (Merriam & Tisdell, 2015). Reflexivity in research was explored in this study as it had direct or indirect influence on the study findings (Fontana, 2004). Because of my prior knowledge in the field of BC information, reflexivity was covered to manage the research quality (Berger, 2015). According to Lincoln and Guba (1985), humans are instruments capable of capturing the constantly changing human situation and experiences. Since I was the main instrument in this whole research, it was crucial that I remain impartial as much as possible. However, I know that my ontological and epistemological approach to research would have personal impartialities. My previous personal and healthcare experiences, points of view, and roles may have impacted the interaction and interpretation of the data collection, analysis and findings. This agrees with Creswell (2015) that writing a qualitative text cannot be separated from the author, participants, and the readers since they all read from diverse personal perspectives.

My background is essential to qualitative research because of its subjective nature. It is therefore important to include this aspect because qualitative research involves reflexivity (Bourke, 2014). I am a registered nurse-midwife and lecturer at a school of nursing and midwifery who teaches cancer nursing. I have a master’s degree in nursing and my masters’ thesis phenomenologically explored critical thinking of nurse graduates. I therefore had some knowledge and experience of qualitative research. Before joining academia, I worked in the adult medical-surgical units for over 10 years where I nursed many patients with cancer and witnessed their suffering from treatment side effects. Notwithstanding, I have some faith in alternative medicine, having been treated with traditional African medicine successfully as I grew up. I have also seen patients who were cured using alternative medicine after trying conventional hospital treatment for a long time. Therefore, when participants narrated their engagement with alternative medicine, I flowed with them and may have 'nonverbally' showed approval and encouraged them. My conviction still is that prayers, herbal remedies and other traditional practices have a place in the treatment of chronic diseases. Thus, the participants and 1 co-created knowledge. Since the researcher and the subject under study were interrelated, the following section explains possible ways in which I may have influenced the conduct of this research.

Because of my previous involvement with patients with cancer, I was careful and deliberately suspended my prior knowledge, thoughts, feelings and any ideas that arose so that I would see participants' stories with 'fresh eyes'. Although this was a noble ambition, it was not possible to wholly shed my presumptions given that oncology nursing was my world, in which I instructed students and interacted with patients daily. However, I am an oncology teacher and emphasise to students the need to give patients information so that interventions can start promptly. During data analysis, the phenomenon of HL as experienced by participants was explored and construed as the reality and truth (Hennink et al., 2010; Houser, 2013). Therefore, there was a risk of tilting the direction of the interview towards my personal interests. I overcame this by adhering to the interview guide questions and using probing questions to obtain rich experiences of HL.

As noted by Davis (2020), I needed to reflect on myself as a research instrument that could affect the data collection and analysis. For example, there were times during the interview that I started teaching participants and correcting any misconceptions, they had. I devised a strategy where I debriefed with the participants at the end of the interview and allowed them to ask questions and seek clarification on various issues. I also took field notes and kept a research diary of the activities in the interview room, that would strengthen the interpretation and data analysis. At one point I almost broke down when a participant relived her bad experiences of financial hurdles; this proved the point I mentioned earlier that researchers need emotional care. To overcome these emotions, I shared my experiences with my work colleagues, and they explained how they had also encountered such scenes, and that talking helped to ease the bad feelings. Talking with these colleagues helped me a lot.

At the data analysis stage, I suspended any prior experiences to ensure the validity and rigour of my study. It was not easy to set aside my prior knowledge, assumptions and experiences with patients with BC. It initially seemed an easy activity, as I thought that all I needed to do was acknowledge my biases, put them aside and ensure they did not compromise the interpretation of the participant stories—how naïve I was! Throughout this study, there was some struggle to shelve my existing knowledge and ideas as the study progressed. At times the urge to conduct an audit against the HCPs based on participants' stories was so strong, I started teaching the participants, whereas at other times, I corrected patients on their wrong practices. I recorded these struggles in my research diary for future reflection. This helped me as the research progressed because I was cognizant of my assumptions and their potential to influence the data analysis process.

4.10 Ensuring quality in the research process

In appraising qualitative research, the emphasis is on how well the researcher has provided proof that the descriptions and analysis represent the reality of the circumstances and individuals studied (Taylor et al., 2006). Although qualitative research is carried out in a natural environment, reality is constructed in a contextual and multidimensional manner, variables are not measured, and data is subjective to researcher interpretation (Miles & Huberman,1994; Murphy & Yielder 2010; Roberts & Priest 2006).While quantitative research is linear and uses statistical testing, qualitative research is non-linear, iterative, dynamic, and inductive, and the establishment of rigour seems contradictory (Murphy & Jenner,2010; Tobin & Begley, 2004).Therefore, qualitative research should be assessed using strategies developed for the qualitative paradigm (Cutcliffe & McKenna1999) to mitigate the negative effects of biases (Fetterman1998). The qualitative research approach has specific techniques for conducting, documenting and evaluating rigor. Consequently, it is the responsibility of individual researchers to confirm the validity of research findings (Nowell et al.,2017). In qualitative research, trustworthiness confirms that the research results merit attention (Lincoln,1985), and can be achieved by verifying the criteria of credibility, dependability, confirmability, and transferability (Lincoln &Guba,1985). To guarantee trustworthiness, truth value, and confidence in the findings, interpretation and methods, I used standards for evaluating qualitative research that considered credibility, dependability, confirmability and transferability (Lincoln &Guba ,1985). The steps taken are described below.

4.10.1 Credibility

Credibility refers to the believability of the research findings (Creswell, 2012). The use of clear evaluation criteria and the extent to which the research participants recognise their transcripts described in the research as their own increased the credibility (Taylor et al., 2006). In this study, credibility was achieved by adopting various strategies such as prolonged engagement, peer and member checking, researcher reflexivity (discussed in Section 4.9) and presenting concrete details in the findings.

Prolonged engagement: This referred to spending ample time with the participants to learn or understand their HL experiences and influencing factors. Before actual data collection, I met the participants and their relatives and explained the study ad obtained informed consent. In this way, I developed relationships and established rapport with participants, which facilitated understanding and co-creation of knowledge during the longitudinal interviews (Tracy, 2019). In subsequent interviews, participants had built trust and engaged freely in the discussion.

Peer checking: This was achieved by an experienced colleague analysing some of the data and deriving similar codes This was a way of ensuring that I had analysed the data correctly.

Member checking: Polit and Beck (2012) asserted that member checking (participant validation) ‘is the most crucial technique for establishing credibility’. In subsequent interviews, I clarified any unclear information from previous interviews and completed any missing data. In addition, the transparent data analysis steps and inclusion of verbatim quotes from participants contributed to the authenticity of this study (Creswell, 2012).

Concrete details: I endeavoured to remain as objective as possible and accurately described the themes that emerged from the data analysis so that the experiences of the participants were faithfully represented.

4.10.2 Dependability

Dependability refers to whether one can track the processes and procedures used to collect and interpret the data (Creswell & Creswell, 2017). A technique that lends itself to assessing dependability is the inquiry audit, which includes examination of the data and any relevant documents by an outside reviewer. According to Creswell and Creswell (2017), one or more external research peers view the data separately and conduct two independent inquiries, during which interpretations and conclusions can be compared. I have provided a detailed and thorough explanation of how the data were collected and analysed to provide what is known as an ‘audit trail’ (Polit & Beck, 2012). The audit trail was established through methods described below. All audio recordings, interview transcripts and any participant information were securely stored. All interview data were anonymised before storage. Copies of materials used for ethical approval, the PIS and data collection instruments are attached in the appendixes. Finally, a copy of the proposal is held by Salford University.

As Krefting (1991) advised, two transcripts were coded by a senior PhD-qualified colleague. When we compared findings, both of us had almost similar coding and interpretations. Minor discrepancies were identified, discussed and agreed upon. This confirmed to a large extent that the findings reflected uniformity in interpretation of the reality of the participants. As noted by Taylor et al. (2006), this process of checking the uniformity between raters reduces the probable bias of a single researcher collecting and analysing the data. Paper evidence of the interview schedules, transcripts, coding and theme development also provided a good audit trail to confirm the credibility and trustworthiness of the study findings.

4.10.3 Transferability

Polit and Beck (2012) stated that qualitative research is characterised by ‘thick description’, which is a vehicle for communicating to the reader a holistic and realistic picture. In this study, I provided a rich and comprehensive description of the research setting, interactions and processes observed during the study. According to Punch (2000), transferability in qualitative research is not whether the study includes a representative sample, but rather concerns how well the study has made it possible for the reader to decide whether similar processes would be at work in their settings and communities by an in-depth understanding of how they occurred at the research site. Therefore, transferability refers to the fit or match between the research setting and other contexts as judged by the reader (Taylor et al., 2006).

4.10.4 Confirmability

Confirmability refers to the extent to which the findings stemmed from the ideas of the participants as opposed to the views of the researcher. As advised by Patton (1990), reflexivity of my influence on the research was documented. I kept a reflexive diary of the interview set up, details of other people present, how the participants appeared during the interview, length of the interview, personal feelings about the interview, and initial analytical impressions. Serial interviews ensured prolonged engagement. The findings and discussion/conclusions are presented in Chapters Five, Six, Seven, and Eight, along with rich excerpts of participants' quotes related to the interview questions and extracts from my reflexive journal. These confirmed the authenticity of this study and the relevance of the novel findings and knowledge generated in enhancing BC clinical practice, policy and research.

4.11 Chapter summary

This research adopted an in-depth longitudinal qualitative approach to explore participants' experiences of accessing, understanding and using health information during their BC journey. I chose this approach based on the conviction that HL experiences of BC survivors change throughout the trajectory of their illness. Therefore, this study endeavoured to provide evidence throughout the BC experience (pre-diagnosis, diagnosis, treatment and post-treatment) and not just at one point in time. Eleven participants were recruited for this study from across different age groups (six from a private and five from a public referral hospital). Data were collected via face-to-face semi-structured interviews using an interview guide. Each participant was interviewed two or three times at six week intervals during treatment. The interviews were audio recorded and transcribed verbatim, imported into NVivo and a step-by-step description of Colaizzi's (1978) technique (steps one to four) illustrated in detail how the data were analysed to shape answers to the research questions and objectives. This section also provided a brief profile (Appendix 17 for details) of the study participants, which gives the reader a better understanding of the women who were involved in this study, and provides reality and authenticity to the findings. The next chapters chronicle the journey Kenyan women traversed as they were diagnosed and treated for BC and then entered the time of living with a potentially life threatening and chronic disease. It includes their experiences of how they accessed, understood and used health information to make treatment decisions, and the factors that influenced their HL. The findings chapters are split into two, with Chapter Five presenting the first theme and Chapter Six presenting the second theme.

5 CHAPTER FIVE: FINDINGS

5.1 Introduction

This chapter presents the findings of the study. Participant demographic data is presented followed by a description of the first theme covering information experiences of patients with BC at different stages of the BC journey. The second theme encompassing socio-ecological factors that influenced HL is presented in Chapter Six. The main aim of this study was to describe the HL experiences of Kenyan BC survivors and identify the socio-ecological factors that influenced how they accessed, understood and used information along the BC journey. The collected data depicts how the sub-themes and themes are threaded to convey the main findings of the study. Supporting participant quotes have been chosen from across all the participants and interview stages.

5.2 Participant introduction

This section introduces the participants providing a profile of their individual characteristics. To maintain confidentiality, participants' data and documents were stored under a unique identifying code by the researcher. However, the use of codes dehumanised the participants; therefore, pseudonyms were used to keep participant names private but still refer to them as real people (See Appendix 8b). The introduction includes participants' age, BC stage, treatment modality, language and any other information considered unique in relation to HL and the BC journey. In cases where a participant mentioned a name of either a place or person to illustrate a point, four asterisks have replaced these names (****). See Appendix 17 for a more detailed participant introduction

5.2.1 Participant demographics

Table 15 presents the background characteristics of participating women. These demographic factors influenced participants' access to and use of information and involvement in healthcare decision-making. It is important to note that other factors (e.g. employment status, education levels and wage levels) also contribute to empowerment and health inequalities.

Table 15: Background characteristics of study participants

Pseudonym	Age, years	Level of formal education	Marital status	Religion	Occupation	Residency	Income level	Family history of cancer	Breast cancer stage	Study site	No of interviews
Connie	47	High school, Form 4	Single	Christian	Business lady	Urban	Middle	No	One	Private	Three
Juliet	58	High school, Form 5	Married	Christian	Business lady	Rural	High	No	Did not know	Private	Three
Ruth	41	College	Married	Christian	Teacher	Urban	Middle	No	One	Private	Three
Lilly	28	Primary school class 8	Married	Christian	Housewife	Urban	Low	No	Two	Private	Three
Olive	33	High school, Form 4	Separated	Christian	Casual labourer	Rural	Low	No	Did not know	Private	Three
Rhoda	57	University	Married	Muslim	High school teacher	Urban	Middle	Yes	Two	Private	Three
Debora	37	College	Married	Christian	Secretary	Rural	Middle	No	Two	Public	Three
Naomi	34	High school, Form 4	Separated	Christian	Unemployed	Urban	Low	Yes	Three	Public	Two
Marion	45	High school, Form 2	Married	Christian	Casual labourer	Urban	Low	No	Two	Public	Three
Abigail	61	High school, Form 4	Married	Christian	Retired librarian	Urban	Middle	No	Three	Public	Three
Paula	46	High school, Form 4	Married	Christian	Tailor at factory	Urban	Low	No	Two	Public	Two

Three participants died after the first interview, and though I had indicated in the PIS that I would use the information collected even if participants dropped out, I made a decision not to use the four participants' data, a limitation that I acknowledge. I did not envisage death of the participants, and the non-inclusion could also be related to the African sociocultural belief of not discussing the dead, as they may haunt you. It may also have been unethical to request the next of kins for permission to use the data of the deceased patients.

This study revealed that various factors influenced participants' decisions regarding BC screening, diagnosis and treatment. These factors appeared to affect how women accessed and used cancer-related information. Although most participants had information about BC, the factors described below contributed to how they used the information to go for screening, cope with diagnosis and manage their treatment journey. As the data analysis progressed from interviews to making meaning of participants' experiences, two main themes were generated (Table 11). These were: Information experiences of patients with BC along the illness trajectory and Socio-ecological factors that influenced HL. Some of the associated subthemes appeared to be slightly out of the actual scope of this study, which focused on factors that affected HL, but they had an impact on participants' experiences and perceptions of cancer-related information. The two main themes generated are discussed at length.

This chapter describes the first theme covering information experiences of patients with BC at different stages of the BC journey. The second theme encompassing socio-ecological factors that influenced HL is discussed in Chapter Six. The units of analysis were individual participants and factors that affected various aspects of HL (accessing, interpreting and using HI to make treatment-related decisions). Participants' BC awareness and knowledge is discussed, along with how they accessed and used cancer-related information to make decisions, the actual information given by HCPs and participants' perceptions of the information received.

5.3 Theme one: Information experiences of patients with BC along the illness trajectory

This theme is explored further under subthemes and categories as displayed in Table 16.

Table 16: Theme, subthemes and categories that describe participants' information experiences

Theme	**Subthemes**	**Categories**
Information experiences of patients with BC along the illness trajectory	1. Journey to diagnosis: knowledge and awareness of BC signs and symptoms	Discovering the lump
	2. Experiences of accessing information before and at diagnosis	• Screening camps • Media (television, Internet, books) • Various HCPs • Social networks
	3. Experiences of receiving, understanding, and using information during treatment and follow up (after completing treatment)	• Experiences at treatment stage • Experiences after finishing treatment
	4. Information, knowledge and literacy gaps identified	• Before diagnosis • During treatment • After finishing treatment

These subthemes and categories are discussed below with relevant participant quotes included to support the findings. The term 'participant' refers to the patients who were interviewed at various points in their BC journey. HCPs refers to the healthcare providers who interacted with the patients.

5.3.1 Subtheme one: The journey to diagnosis: knowledge and awareness of BC signs and symptoms

This section considers participants' HL as portrayed by their knowledge and awareness of BC. A breast lump was the main reason for seeking healthcare. Some participants discovered their breast lumps accidentally, and others felt them during routine BSE. A few participants immediately sought healthcare whereas others delayed seeking care, as described below. All participants eventually visited a health facility, and their experiences of obtaining information and how they sought healthcare intervention are presented.

5.3.1.1 Discovering the breast lump

Connie and Juliet discovered their lumps while performing BSE, which indicated that they had knowledge and used it. Connie's was a deliberate act of examining her breasts, but Juliet's was incidental.

> 'How I knew I have got a lump? I checked my breasts every month, so I decided to visit the clinic so that I can get more information when I felt a lump' *(Connie, private hospital, first interview)*

> 'One day, I was sleeping. At night I was caressing my breasts. I felt there was something, a lump to the right side' *(Juliet, private hospital first interview)*

One participant discovered a breast lump after an accident where she fell and hit her breast on a bed. She had broken her leg, which was managed with a plaster cast. During the time she concentrated on her leg, her breast continued swelling but she waited for a while before seeking medical advice. Six weeks later (after her cast had been removed) she went to hospital for a breast examination because the swelling had persisted. She had an ultrasound followed by mammography and a biopsy of the lump, which revealed BC grade three.

> 'I went to hospital, I had a swollen breast; I had been hit by…edge of the bed, I fell on it, and it hit my breast. So, then I decided to seek medication after realising that swelling was becoming bigger after the plaster on my leg had been removed…so I decided to see a doctor*' (Lilly, private hospital, first interview)*

When participants were asked how they learnt how to perform BSE, there were various responses. Some said that they were taught in the antenatal clinic (during pregnancy), in church or via the media, and others thought it was common sense to check their breasts. This delineated the various sources of information and demonstrated that some women implemented what they were taught, but others ignored it. One participant (Rhoda) suspected from the outset that her breast lump could be cancerous because she had lost her sister to BC; she discovered the lump while bathing and went to hospital immediately.

> 'I was bathing when I realised I had a lump in my breast. I went to Aga Khan where a scan was done, and a biopsy revealed cancer stage two. I have a strong history of cancer in the family, my sister died of the same' *(Rhoda, private hospital, first interview)*

Because of her college level education, Rhoda may have been aware that she was at a greater risk for BC because she had a family history of the disease. Her educational level and family history may have raised her BC awareness, meaning she practised monthly BSE. Some participants never thought they could have BC as there was no history of cancer in their families. They believed cancer was only possible as a hereditary condition, as captured by the below statements.

> ‘I never thought I had anything to do with cancer. Yes. It was out of my mind. Since I had not had anyone in my family having that problem, I could not think it was cancer’ *(Connie, private hospital, first interview)*

> ‘I thought I can never get any. I can never become a victim because the information I had was more of it is inherited from the family. And because I knew no one from our family had ever had cancer. So, I thought I was free’ *(Ruth, private hospital, first interview)*

Another participant had associated cancer with individuals’ social status in society.

> ‘I did not put in there in my mind because I know cancers are for the rich people. For those people that have money…[laughter]…I thought it is for only for those people’ *(Olive, private hospital, first interview)*

The majority of participants had no personal health awareness behaviour for seeking medical check-ups or screening for breast or cervical cancers.

> ‘I had heard about BC, but I had not gone for any check-up’ *(Lilly, private hospital, first interview)*

Participants conveyed an attempt to treat the breast lump using local ointments. This highlights the lack of awareness about BC screening, signs and symptoms which could be related to difficulties in accessing BC information.

> ‘I did not take it seriously because from 2013 up to now, 2017 that is the time when I went to the hospital and that is when I…I had that lump’ *(Olive, private hospital, first interview)*

> ‘Then I went and bought that ointment balm and I used to apply and after 1 week it was not reducing but swelling more. Then that is when I decided to do to see a doctor’ *(Marion, public hospital, first interview)*

It could have been due to information deficit that Lilly ignored her breast lump thinking it was breast engorgement. After she stopped breastfeeding, the lump persisted and she went to hospital where an X-ray was performed, which revealed a lump. It was not clear what advice she was given, but she stated that as the lump was painless, she did not take further action. She continued with her work until she developed weakness and back and leg pains, and went to hospital again where painkillers were given. The medication did not help, and she developed breathing and walking difficulties. At this point she was taken to hospital and a breast biopsy revealed stage three cancer.

> ‘I just woke up and found myself with a lump, but I had a child I was breastfeeding. I said it was milk, later, I lost appetite and I could not walk’ *(Abigail, public hospital, first interview)*

Lilly’s narrative indicated that she lacked awareness about BC signs and symptoms, especially as she only had primary level education. In addition, at age 28 years, she may have thought that BC only affected older women. This situation highlighted that using information to make decisions is an important aspect of HL.

In summary, the findings demonstrated a lack of awareness and knowledge about BC signs and symptoms among some participants. It was evident that participants who had no family history of BC tended to adopt a ‘wait and see’ attitude before they sought medical intervention when more severe signs emerged. However, those with a family history of BC and a high level of education had knowledge, practised BSE and promptly sought healthcare when they discovered a lump. This meant that they used the information they had and consequently sought early intervention; using information to make decisions is a hallmark of HL.

5.3.2 Subtheme two: Experiences of accessing information

This subtheme focused on the HL aspect of accessing BC information, with specific attention to the information sources participants used. I used the cancer journey stages (before diagnosis, during treatment, after finishing treatment) as the organising principle for presenting participants’ quotes, which answered the research questions and met the study objective. A focus on participants’ experiences when their BC diagnosis was disclosed entitled ‘*breaking bad news’* is included as it highlighted crucial HL aspects.

In response to the question about how they received cancer-related health information, participants disclosed various sources, including screening camps, television, friends, other patients, seminars, church groups and the Internet. Some participants shared experiences that depicted their awareness and BC knowledge and reported a range of sources of BC information. The sources of information that were frequently mentioned were screening camps, social networks, media, books/magazines and HCPs (doctors, nurses and dieticians).

5.3.2.1 Screening camps

Before they were diagnosed with BC, some participants had attended screening camps where they were taught BC signs and symptoms. Marion, a public hospital participant explained how her awareness of the increasing cases of cervical cancer caused her to attend a BC screening camp when she heard that services were being offered free. This suggested that free services encouraged her to attend the screening camp.

> ‘I come for screening because I had heard that cervical cancer has become rampant but on the side of the breast, I had not heard of breast camp. It is only cervical I had heard. Therefore, when I heard that they were doing free breast screening I showed up’ *(Marion, public hospital, first interview)*

Similar views were shared by Connie, who had awareness about symptoms of BC. When she discovered that she had a breast lump through BSE, she decided to attend a free breast screening camp at the public referral hospital.

> ‘The first time I went to hospital was in mid-June. Whereby there was a free breast screening at hospital ****, so I decided to take up that opportunity’ *(Connie, private hospital, first interview)*

This study revealed that only a few women who had medical insurance went for check-ups in private hospitals where screening was performed. Juliet reported that she had been attending yearly health check-ups, but BC had never been diagnosed. During these check-ups, screening for non-communicable diseases such as cancer was routinely performed. However, it was unclear whether she had any BC screening during her yearly medical examination that was paid for by her private insurance.

> ‘I have been undergoing the medical check-ups every year in September since the year 2012 and there is no time BC was discovered. Even during same year, in September I had been done the check-up’ *(Juliet, private hospital, first interview)*

5.3.2.2 Media

The media referred to by participants included broadcast media (television and radio), print media (books), new media (the Internet) and interpersonal media (social networks). Participants stated that these were important sources from which they received BC-related health information.

5.3.2.2.1 Television

In addition to screening camps and yearly medical check-ups, study participants from both private and public hospitals reported that they gained information about BC from television programmes.

> ‘I had heard about BC, but I had not gone for any check-up, but I had heard about it through TV’ *(Lilly, private hospital, first interview)*

Debora was watching her local television channel *Kameme* when a programme on cancer was aired. In the programme, someone was teaching about cancer and the signs. Although she sought healthcare intervention 1 year after discovering a lump, Debora’s delay was probably attributable to the information she heard on television that cancer was painful. Others learnt about nutrition for cancer patients and symptoms of BC from TV.

> ‘But there is TV [programme] by the name *Kameme*, there was a person teaching…talking about cancer. So, I wanted to know what is cancer? How does one contract cancer? How can one know she has cancer? She was teaching…cancer is painful. So, for me, I know that even when I touched myself and I found I had a lump, I knew cancer is painful’ *(Debora, public hospital, first interview)*

Given that it was a television station that broadcast in the local *Kikuyu* language, it could be that Debora misinterpreted the information, or the presenter did not translate the information accurately from English to the local dialect. Abigail, a participant from the public hospital, had learned about nutrition and diet for patients with cancer from television.

> 'I watched a nutrition programme on how cancer patients feed, how water dissolves in the body and all that’ *(Abigail, public hospital, second interview)*

It was unclear where Paula first learned about BSE, but she described how she listened to television for BC teachings.

> ‘First, I was doing self-examination and listening to the teachings that were being given on TV, and when I realised I had a lump, that is when I went to the hospital’ *(Paula, public hospital, first interview)*

The introduction of solar powered televisions in Kenya increased accessibility of these programmes to many families. It is common for families to congregate in a home that has a television set to watch news or other programmes. The Internet was also found to be a popular information source, especially for those who knew how to use it.

5.3.2.2.2 Searching the Internet

Some participants were active information seekers and searched the Internet to help them understand BC and treatment. They however did not have any specific sites they searched for health information. Paula was also aware the Internet had contradicting information that was not always scientifically correct.

> ‘Yes, so I have also been able to get my own information. because knowledge is power. Whatever I do not understand I go back to the Internet and read about it’ *(Rhoda, private hospital, first interview)*
>
> ‘I am a form four leaver, and I Google for information from mainly Play Store. Besides what the doctors and nurses have told me, of course, the Internet has so much information. OK, there is good and bad information, but I get the good information’ *(Paula, public hospital, first interview)*

Similarly, Ruth searched the Internet for information, but was cautious with the information obtained and always asked her doctor for clarification of such information.

> ‘If I get information, maybe from the Internet, and I do not know whether it is good or bad, I have to come back and ask the doctor’ *(Ruth, private hospital, second interview)*

As noted above, Ruth’s college education may have been an important factor in her decisions about which information to use and when to seek a second opinion, which is a key aspect of HL. In addition, some participants described how they were given books about BC.

5.3.2.3 Information from books

At the public hospital, participants were routinely given books with a summary of BC information (signs and symptoms of BC, the diagnosis, treatment modalities and side effects of treatment). They were also given a folder in which they kept all their prescriptions, investigation request forms, results and any other treatment-related information. This appeared unique to the public hospital. The books guided participants in livings with BC

> ‘When I came here, I told you that I was given a book. I would like to recommend that all the hospitals give such books. That book helped me a lot’ (*Debora, public hospital, second interview)*
>
> ‘The book *is* guiding me on how to live with cancer. It has a good advice in addition to the nurse’s advice’ (*Marion, public hospital, second interview)*

One participant’s doctor also gave her a book about BC, but she encountered challenges reading because it used medical terminology that she could not understand.

> ‘The doctor…when I came here, they give me a book about cancer, but it was for the professionals and the language is totally different. It was written, BC by Doctor ****’. *(Connie, private hospital, second interview)*

This illustrated the need for patients to be given reading materials in simple language that they could easily understand, which is a basic tenet of functional HL. In addition to various forms of media, social networks were another source of information that helped participants both before and after their BC diagnosis.

5.3.2.4 Social networks

Social networks and gatherings were reported to be avenues for obtaining vital BC information. Prominent among them were church prayer fellowships and seminars.

5.3.2.4.1 Church

Most churches in Kenya dedicate one of the worship days as a ‘health day’. On such days, a healthcare professional is usually allocated time to teach the congregants about health. The educator in church encouraged people to check their breasts and also go for breast check-ups in hospital. From the knowledge gained in church Paula sought a second opinion from a different doctor when the mammogram revealed nothing.

> ‘We normally have health days where we get educated about BC. After the advice, I went to the hospital. They checked on me and give me the drugs, then I was told if it fails to clear I get back to hospital. Then I returned to the hospital, they did a mammogram on me which did not show anything, but the thing was not clearing, and I returned again. The second doctor did more tests, which revealed that it was cancer’ *(Paula, public hospital, first interview)*
> ‘Eee…I was in a church seminar. We were taught by a woman who told us that women must be cautious about BC. If you feel any lump coming in between just go to the doctor for check-up. So, for me I did breast examination’ *(Marion, public hospital, first interview)*

> ‘People invited were talking about BC in the church when coming out of prayer meetings. I had always ever heard them talk about being checked, but me myself, I had not taken any initiative. Some church friends have undergone this cancer treatment and lost their breast. But me, I knew it only catches older people’ *(Lilly, private hospital, first interview)*

Despite acting on the information she received from the church seminar, Marion consulted the women’s leader ‘*mama assembly’* when the breast lump was confirmed. She reported that she followed the leader’s advice and applied ointment on her breast lump with no improvement.

> ‘Yes, I went back to our church assembly mother. And she said she did not realise that it was cancer but thought it was just the normal lump. So, when I explained that I have been diagnosed with BC, and I showed her the reports she was so shocked. Even to date she is still shocked’ *(Marion, public hospital, first interview)*

It appeared from this narrative that *mama assembly* was not knowledgeable about BC, and appeared to own up to that fact by her response to Marion ‘*she told me if she knew well the signs of BC she could have been the first one to have helped me*’. This may mean that as the women leaders in church are held in high esteem, they need to be given the right information to enable them give correct advice to their followers.

5.3.2.4.2 Friends

Some participants received information from friends who had family members/close friends diagnosed with and treated for cancer. This encouraged them to continue with treatment and also to have hope. Connie stated that her friend had shared information about an aunt who had BC and she was treated successfully.

> ‘I had a friend who I used to stay with, and she could tell me how I should go to the hospital she had an aunt who had BC and she could tell me she was treated and now she is ok’ *(Connie, private hospital, second interview)*

Connie described how a friend had informed her about free BC screening at the public referral hospital. This suggested that Connie learned about BC symptoms from sources other than screening camps, which contradicted her initial statement.

> ‘My friend had information that there is free screening taking place in Kenyatta so, that friend is the one who made me go to Kenyatta for screening. I did not know whether there was any screening going on’ *(Connie, private hospital, first interview)*

In her third interview, Rhoda described how her friends looked up information on social media and shared with her. One message that a friend sent her was about a patient who had BC but never sought conventional hospital treatment. That patient took some herbal concoctions and was cured after 3 months. Rhoda did not take that information seriously and told her friend so.

> ‘I could not believe that information my friend gave me. I know better…I will continue with my hospital treatment’ *(Rhoda, private hospital, third interview)*

In other cases, friends advised participants to go to hospital for further evaluation when they discovered a breast lump. Olive had lived with a lump for 4 years without any intervention until a friend advised her to see a doctor.

> ‘That was my friend who told me you need to go to the hospital they have to look at the swelling. Because is not becoming small, it is not becoming big, what is that? Go to the hospital and then you will be told by the doctor what is that’ (*Olive, private hospital, first interview)*

This suggested that Olive did not know the signs and symptoms of BC, or she was afraid to go for screening and have a BC diagnosis made. Usually, after a participant disclosing their BC diagnosis, friends offered various advice. Some advice that stood out was to seek treatment from the commercially owned massage machines, Ceragem and Nugabest (these are popular in Kenyan urban cities and are believed to treat all chronic diseases). Connie regretted that she did not go for the Ceragem therapy as advised by a friend.

> ‘Even there is a lady who told me since she knew I have BC, she pursued me on those machines, I really refused’ *(Connie, private hospital, third interview)*

It was evident that friends supplemented information not provided by HCPS.

> ‘All the other information I get from the network of friends, because like the issue after BC surgery, some information the doctor will not give you, like where to get the special bra’ *(Ruth, Private hospital, first interview)*

5.3.2.4.3. Family members and other BC patients

Debora, the third wife in a polygamous marriage, was distressed and worried that her husband would marry another wife because she would have only one breast. However, before her breast removal surgery, Debora’s mother-in-law counselled and reassured her by using the example of a neighbour who had mastectomy and was doing well.

> ‘I worried about the surgery, but my mother-in-law counselled me to some extent, and told me about our neighbour who was well after the operation’ *(Debora, public hospital, second interview)*

Interestingly, participants’ narratives showed how they discussed and shared information with other patients while they awaited treatment. Social networks at the hospital worked well during the treatment stage. As they waited for treatment, participants discussed their cancer diagnosis and treatment experiences with other patients and their relatives. This was particularly evident at the public hospital where patients sat in closer proximity than at the private hospital where they had recliners placed far apart and enclosed in curtains. Patients shared experiences ranging from diagnostic tests (e.g. mammograms) to treatment. The information was cited as helpful.

> ‘Number one of what I have heard from other patients is that there is a scan, the *mammogram* which for me did not show anything. And there is also the other one where they remove a sample to go and test...and here in ****, I have heard that one is never done an operation (meaning surgery) just like that. Mostly they start with *chemo* and finally they come to remove the lump when it has shrunk’ *(Connie, private hospital, third interview)*

A patient with cancer who was also a neighbour taught Abigail about managing the side effects of treatment through diet and exercise.

> ‘I found out that one of our neighbours was sick at home and he explained to me how to feed, what to avoid and to follow the treatment when I work and get tired, I just relax first. I should not overload the body’ *(Abigail, public hospital, second interview)*

Marion appreciated the financial information that another patient had shared with her about hospitals that accepted NHIF and sold drugs at a cheaper rate. That patient had noticed that Marion missed some of her chemotherapy appointments. Marion explained her financial challenges and how the advice was helpful.

> 'When am prescribed the drugs and when I go to town, I find they require much money which I do not have. Then, the other lady sitting next explain to me the issue of Texas telling me to go to Texas cancer centre…and I will fill [in] the NHIF form and I will be issued with the drugs. It helped to know that' *(Marion, public hospital, third interview)*

Overall, participants appreciated how their friends and close family members supported them to access information and medical care and to continue with cancer treatment. In addition to friends and family, seminars were identified as a reliable source of cancer information before diagnosis. Ruth appreciated the information she learned from a seminar that was organised by a group in which people were taught about cancer in general but was quick to warn that women needed to be '*careful because there was a lot of false information out there*'. Ruth's education level (college) and high SES may have helped her to discern credible information, which worked to her advantage.

> 'Like the information that I would get from the seminars, I think it can be important and can be of help and also the support groups. But one needs to be careful with the information' *(Ruth, private hospital, first interview)*

It appeared that information could be gained from a range of sources, but there was some awareness that some information sources are more reliable than others. This highlighted an important consideration when teaching patients with BC.

In summary, social networks appeared to play an important role in providing information about symptoms of BC, encouraging participants to seek healthcare as well as providing encouragement along the treatment journey. Some participants embraced the information and sought healthcare services; others ignored it until they developed overt symptoms of BC.

5.3.2.5 Information from various HCPs

This section outlines examples in which HCPs provided information to participants at diagnosis (termed breaking bad news).

5.3.2.5.1 At diagnosis: Breaking bad news

The initial disclosure of a BC diagnosis to the patient by the doctor was referred to as '*breaking bad news*'. Because BC was envisioned as a 'bad' disease that was expensive to treat, participants expressed concerns about how the news of cancer had been broken to them.

Consistently, participants felt that they needed to have been better prepared to receive the ‘bad news’. This was worsened by the HCPs initiating discussions about treatment when the patients were still in shock after being informed that they had BC. One woman described how she wished the doctor did not directly tell her that she had cancer.

> ‘He just told me the results, this is cancer. So, I was shocked, yes…(pause)…He could have beaten around the bush even try to at least use a good language’ (*Connie, private hospital, first interview)*

This could be related to the sociocultural practice in Kenya where bad news is broken gradually and the person must not be alone. In her case, Connie did not have anyone accompanying her to hospital as her daughter (her only close relative) had gone to school. When she went home, she received more bad news about a friend who had committed suicide because she discovered a lump in her breast. At this point Connie was distressed further, she informed her daughter that she had BC and had considered committing suicide by hanging herself.

> ‘Imagine I have a lump in my breast. Should I take a rope and hang myself?’ (*Connie, private hospital, first interview)*

Connie was the only participant who expressed suicidal thoughts. Fortunately, her daughter was home and encouraged Connie to get treatment. Later in her interview after switching off the audio recorder, Connie said that she was suicidal because she lacked money to pay for treatment. Her situation was later evaluated, and she was enrolled in the welfare programme at the private hospital that catered for all her treatment costs.

Because of awareness about breast lumps as a sign of cancer, participants went to hospital for confirmation and to learn the stage and extent of the cancer. One participant who had a strong family history of BC wished to know how much the cancer had ‘eaten’ her. The anxiety and agony were evident when she spoke of how she received the news from the doctor and was worried about being cured. It may be that she had witnessed family members dying from cancer, which caused her intense distress as evident in her voice.

> ‘I was with doctor **** in her clinic and she told us that it is BC. I was torn. It left me asking a lot of questions what next? Will I be cured?’ (*Ruth, private hospital, first interview)*

Participants were disappointed and cried when the cancer diagnosis was made. Some were emotional, yet others were shocked. This was because of how hopeless they felt, especially those who could not afford treatment. They were terrified; some did not even want to mention the word cancer because of the fear it invoked.

> ‘I even I cried to the doctor. Then I will die. I do not want to remember that thing (the cancer)’ (*Olive, private hospital, first interview)*
>
> ‘When I was told I was positive, I was shocked and even cried. Because I thought, I was dead. You know when we were schooling, we were just saying, ‘cancer is a killer disease’. At that hour I saw, I was dead’ *(Juliet, private hospital, first interview)*
>
> ‘I was shocked because I did not expect to have cancer. I got shocked for I knew my situation is bad for being the breadwinner now my life is ended with cancer…’ *(Naomi, public hospital, first interview)*
>
> ‘I never thought I could have a disease like this’ *(Abigail, public hospital, first interview)*

However, some participants shared that they had received the news from their doctor in a considerate way. Participants appreciated such doctors for being ‘humane’. Some doctors were helpful and offered a lot of information, which made it easier for these participants. It should be noted that Ruth was the only participant who had a university degree and here narrative indicated that she interacted with her doctor at a different and higher level.

> ‘Doctor ****, when we visited the breast clinic with the biopsy results, that is when she started offering the information about the BC treatments, the side effect and everything like that. She gives us all the important information’ *(Ruth, private hospital, second interview)*

5.3.3 Section summary

Overall, when doctors broke the bad news of a positive BC diagnosis, most participants expressed shock, disbelief and apprehension. It appeared that once diagnosed with BC, the participant was put on a death notice. After the initial shock, participants started treatment. As they continued to the treatment stage, they reported their sources of information about treatment. They recalled information given by the doctors, dieticians, nurses and counsellors. It was notable that potential information sources (pharmacists, laboratory and radiology professionals) who form part of the cancer care multidisciplinary team were not mentioned by participants. Their social networks (friends and relatives) provided information and other patients shared their experiences. Participants articulated the information given, singling out doctors as the professionals who had shared the most information.

Largely, participants obtained BC-related information from media (television, radio, books and the Internet), social networks and HCPs (doctors, nurses and dieticians). Other sources were screening camps, other patients with cancer, friends and relatives. Although some participants (with a high education level such as college and high school) mentioned that they accessed the Internet and obtained BC information, they could not name any particular site they had visited. Some participants acknowledged that not all information sources were credible. It was notable that that HCPs were identified as sources of information at the diagnosis and treatment stages but not the pre-diagnosis stage. Most information before diagnosis was obtained from various forms of media and social networks. This suggested that media and social networks should be strengthened and enhanced to provide credible BC information to encourage awareness about BC, self-examination and when to seek professional help. The next section presents participants' experiences of receiving, understanding and using information.

5.3.4 Subtheme three: Experiences of receiving, understanding and using information

This subtheme discusses findings that detail participants' experiences, satisfaction and dissatisfaction with information they received. It was also revealed that patients were more satisfied with health information when it was provided in a simple and easy-to-understand form.

5.3.4.1 Information experiences at treatment stage

Three main treatment modalities for BC were reported by participants (chemotherapy, radiotherapy and surgery), which can be used alone or in combination. Most participants had undergone at least two of these modalities (e.g. chemotherapy and surgery or radiotherapy), whereas others had been treated with all three modalities. This section presents participants' narratives about their HL experiences in regard to: BC treatment modalities, surgery-specific information, diet and nutrition, side effects of treatment, coping with side effects and how information was used (lifestyle changes adopted). In addition, participants' satisfaction or dissatisfaction with the information is presented in cases where this was expressed.

5.3.4.1.1 BC treatment

Some participants were satisfied with the information they had received from HCPs. Rhoda, a high school teacher with college education, was the only participant who was given full information and a choice of either complete breast excision or breast conservation. Full information in this case refers to a comprehensive overview about the BC diagnosis, the treatment options and their advantages and disadvantages. The doctor gave Rhoda and her husband full information, which helped them choose excision of the whole breast over *lumpectomy*.

> ‘The doctor told us that we can do *lumpectomy* to remove the lump only or we can also remove the entire breast. So, we discussed with my husband, and we decided that we can do the entire breast. We were taken through the advantages and disadvantages of the two’ *(Rhoda, private hospital, third interview)*

Rhoda’s education level and career might have had some influence on how HCPs interacted with her and gave her treatment-related information. This reduced the uncertainties as she understood the symptoms and what she was experiencing. In contrast, Paula decried the lack of treatment information after diagnosis. It appeared that her doctor had suggested plastic surgery (reconstructive breast surgery), which did not seem relevant to Paula at that time.

> ‘I would have liked to be told that I will be like this and that...and how one can go about it. But what he was telling me about was the plastic surgery, which I saw it will be a waste’ *(Paula, public hospital, first interview)*

Paula’s narrative highlighted the importance of patients being prepared for the realities of the treatment modality they would undergo. Naomi desired further explanation about the grade and stage of her BC. She had seen grade three written on her clinic card but did not understand; she looked forward to the next visit when she could ask the doctor what the grading meant.

> ‘Then that is why I wanted to come to the hospital so that I may ask the doctor what this grade three means. So, I keep on thinking about what that grade means’ *(Naomi, public hospital, first interview)*

Some doctors at the public hospital went an extra step and encouraged patients to be positive, stop worrying, eat well and take their drugs to get well. They explained to patients about all of the treatment modalities and how they worked. Although the word ‘amputation’ was used incorrectly by Abigail, I understood that the participant meant mastectomy (surgical removal of the breast).

> ‘The doctor told me to accept when I take the drugs that I will get cured. For me I have not been *amputated* the breast but when I will be through with chemo, the lumps will be finished. And if they will not, the remaining will be removed by operation’ *(Abigail, Public hospital, first interview)*

> ‘He told me that this disease, people do get cured, so I should not be sorrowful. I will be encouraged and feed well and I continue following the treatment’ *(Abigail, public hospital, first interview)*

The degree of support perceived by participants was conveyed in the above statement in which the HCPs' communication had a noteworthy effect on the care the participant received and her well-being. Paula was also pleased with her doctor because he gave information about all the treatment modalities before starting treatment.

> 'They explained to me that there is what we call radio, chemo and he prepared me about the effects… (mumbled… '*anga what*', a colloquial used to mean a lot of information) …of chemo and radio. So, I was aware when I was starting the treatment' *(Paula, public hospital, first interview)*

The information they received reduced participants' initial fears and anxiety about cancer as a death sentence. They felt encouraged and were happy when HCPs reassured them that a BC diagnosis was not a death sentence and that people improved after treatment.

> 'Like now there is that information that talks about being sick of cancer and that it is not the end of life. I feel encouraged' *(Marion, public hospital, first interview)*

Naomi was particularly happy and reiterated that she had been given all of the information she needed. The HCPs had emphasised that she needed to understand some key points about BC before starting the treatment. This helped her to cope with and adjust to the demands of treatment.

> 'They explained to me the disease that I have and what they are treating me because you cannot be given the medication and you are not told what is being treated' *(Naomi, public hospital, second interview)*

Ruth also reiterated that she was satisfied with the information she received.

> '…but so far, the information and everything they have done is very ok' *(Ruth, private hospital, first interview)*

Rhoda described how her appointment with her doctor was an open discussion session where she learned a lot about causes and treatment of BC. She was pleased with how the doctor explained to her and wrote notes during the consultation, which she took home and referred to. The doctor also gave Rhoda her telephone number to contact whenever she had a question.

> 'When she was explaining doctor made notes, when am going home, she gives me and tells me, if there is anything you do not understood you can also call me back, she also gives me a phone number' *(Rhoda, private hospital, first interview)*

Doctors did not limit themselves to information about BC, but also advised participants about a proper diet. They emphasised the need to follow instructions about eating well and drinking plenty of water. This was because the drugs were strong, and plenty of water was needed to assist in diluting the drug by-products and facilitate cleansing from the body systems.

> ‘Doctor told me take everything. He told me like meat, it is good for your heart, I cannot remember whether he said heart, but for sugar, you can take because it is good for your brain. Take a lot of water to cleanse the kidneys so that they can work and not be affected by those drugs’ (*Debora, public hospital, second interview)*

Juliet’s doctor also clarified conflicting information about sugar intake as she had been advised to avoid sugar. He advised Juliet to use natural sugars and gave her examples.

> ‘So, the doctor has explained to me to use natural sugar, I should not use refined sugar, but eat fruits like oranges, mangoes pineapple, real honey itself, which has not been refined, just direct from the beehive, which is very good in improving immunity, adding weight and also an appetiser’ *(Juliet, private hospital, third interview)*

In addition to doctors, dieticians provided participants with useful information on diet, which was central to their healing and minimised the intensity of the side effects. Dieticians emphasised the importance of eating well, and taught participants about food portions, frequency of eating and how to deal with feelings of nausea.

> ‘You feed on balanced diet for it will help in fighting diseases in the body and also give you strength to withstand the drugs. Just feed small, small amounts and if you feel like vomiting do not put sugar in your tea...just take it *ndufya* (meaning without sugar)’ *(Marion public hospital, second interview)*

Although this information about diet was important for Marion, it may have been difficult for her to afford a balanced diet because of her low-income level.

Overall, participants from both the public and private hospitals received some treatment-related information from HCPs. Participants reported that this information helped reduce their anxiety and helped them cope as they moved from one stage to another. It also inspired them to take an active role in their own care. Surgery-related information experiences are presented in the next section.

5.3.4.1.2 Surgery related information

When surgery was the treatment modality, participants indicated they were provided with some relevant information. Debora was scheduled for surgery immediately after the doctor received her biopsy report and broke the bad news to her and her husband. The doctor taught her that after surgery, she could not eat immediately.

> ‘When you get out of the theatre you are not supposed to eat anything. You have to relax about 3 hours at least so that your body may get used…’ *(Debora, public hospital, first interview)*

In addition, she was taught about the surgical wound and the catheter drain from the operation site. For discharge planning, the HCPs informed her about wound care.

> ‘After a week they told me that the catheter had stopped removing the dirty content and they removed it. Now I can go home, and I will be going to the nearby hospital where I will be washed the wound’ *(Debora, public hospital, first interview)*

The doctor prepared Debora for the next course of treatment. He informed her that after the surgery she would start another treatment modality (chemotherapy). The way Debora narrated the instructions she had received in detail implied that the doctor had used simple words that she understood.

> ‘Then after healing from the operation (meaning surgery) you will start your chemo which will help to deal with cells that may have spread in your body because it is showing that your cancer has not spread to other parts of the body’ *(Debora, public hospital, first interview)*

Notably, although the majority of study participants had surgery (except Marion and Abigail from the public hospital), it was only Debora who delved into the finer details of her information experiences. Other participants only mentioned surgery in passing and did not appear to have specific information experiences. There are several possible explanations for this. The women may not have been involved in the planning for surgery as the surgeons may have likely explained to the male relatives to give consent. Additionally, the women may have been too emotional, and confused about the BC diagnosis, and the loss of breast that they were in denial.

Participants also reported that they had received information about diet as discussed in the next section.

5.3.4.1.3 Diet and nutrition information

Participants from both the public and private hospitals recalled that information was given to them about the types of food to eat and those to avoid, the timing of meals and the importance of drinking a lot of water. They did not give any rationale but appeared to have followed the advice given by the HCPs.

> ‘Like the feeding well, taking a balanced diet, more of the vegetables and the fruits because they are very good than a lot of meat and also to limit snacks with a lot of sugar. So, to feed well I meant that one should take a lot more fruits and vegetables in your diet’ *(Ruth, private hospital, third interview)*

> ‘They told me that I should not take a lot of starch, like *ugali* (corn meal). I should just take a very little, then vegetables should be more than the ugali. Yes. And a lot of

> water. I take a lot of water. I should take at the right time and avoid the red meat' *(Connie, private hospital, first interview)*

Juliet was clear about the advice to eat small meals frequently. This was after she had complained to me (almost in secrecy) that her husband had been forcing her to eat large amounts of food. This gentleman had earlier insisted on staying for the first interview. He comes from a tribe in Kenya that is associated with cooking a lot of food. He was worried that as Juliet had lost weight, people would accuse him of not feeding his wife; that is why he cooked and supervised her eating. This made her vomit and she detested mealtimes because of the anticipated nausea and vomiting. After her husband had been provided with the necessary information, he changed, and Juliet was happy:

> Yes, I was told to take small quantities of food but many times. *(Juliet, private hospital, first interview)*

Marion gave a positive account of how she was advised about diet and encouraged to be positive. She had been taught about the importance of diet and frequency of eating.

> 'For me, when I started taking these drugs that have a lot of side effects, I feel nausea, lack of appetite such that you cannot eat. Also, for food I should not fail to eat for even when I am vomiting but need to take foods in small bits' (*Marion, public hospital, second interview)*

> 'He advised on the foods to feed on and I stop worrying about the cancer disease' *'(Marion, public hospital, first interview)*

Participants were also given some information about side effects of treatment and how to cope.

5.3.4.1.4 Side effects of treatment and coping

The various cancer treatment modalities bring risks for suffering side effects that cut across all body systems. Information they were given about side effects helped participants to understand and adhere to their rigorous treatment regimens. Rhoda revealed what the doctor had taught her about side effects and how this had helped her cope.

> 'So, my doctor told me on Monday that my palms and the nails will change. I do not have my hair…it is the side effects...because when you are told everything somehow you are able to deal with it' *(Rhoda, private hospital, first interview)*

Similarly, Abigail was informed after diagnosis that the various treatment modalities had side effects.

> 'They explained to me that there is what we call radio, chemo and he prepared me about effects of chemo and radio. So, I was aware when I was starting the treatment' *(Abigail, public hospital, first interview)*

Although most participants did not remember being taught about the advantages and disadvantages of various treatment modalities, they had been taught about side effects. Rhoda verbalised a clear understanding of the side effects of treatment and how they would manifest, which suggested that she had received information about these aspects.

> 'The side effects…they are usually on day five but also the sixth and seventh day of chemo. I also get tired. The level of energy goes down a bit and then it interferes with the taste buds, but apart from that am good' (*Rhoda, private hospital, first interview)*

Participants appreciated being given reliable information early in their treatment as it changed their perception about BC as a death sentence. Consequently, they reported renewed hope, which replaced the initial sense of doom they had felt at diagnosis.

> 'Information of the treatment maybe encouraging to the patient that all is not over, it is not death like the way you were diagnosed with cancer, it is not the end' (*Rhoda, private hospital, first interview)*

Some patients were given information on expected side effects, but never experienced them. This highlighted that not all patients experienced the side effects associated with certain treatment modalities. For example, although Lilly had been educated about nausea and vomiting as a side effect of treatment, she was lucky as she did not experience this. Similarly, Debora had never experienced nausea and vomiting.

> 'The first time she told me the about the side effects and she told me you feel nausea and some people vomit, those kinds of a things but me, I never vomited…' *(Lilly, private hospital, third interview)*

> 'So, you may find yourself not experiencing nausea. Like from me, I have never vomited, even a single time after being administered the drugs' *(Debora, public hospital, first interview)*

The interview data suggested that HCPs gave participants information about the side effects of treatment on white blood cells. Therefore, they questioned the HCP when they said their immunity would be low. Other participants who experienced obvious body changes sought explanations, which the HCPs gave along with advice about coping strategies.

> 'In the past, they told us that this treatment fights with the white blood cells until they go very low, they go very low because of the medication' *(Naomi, public hospital, second interview)*

> 'I asked them one day and they told me that it is the medicine that I take that causes my immunity to go down' *(Abigail, public hospital, second interview)*

> ‘But I was told, it is just the side effects of chemotherapy, but with time they will be off’ *(Debora, public hospital, third interview)*

> ‘When I find myself vomiting, I need to take a lot of water, yes, I force myself in drinking water. When you notice you have diarrhoea you take a lot of water, and you should not ignore it for it may take you to a bad situation’ (*Marion, public hospital, second interview)*

Some participants believed that they were *lucky* to have been informed about side effects of treatment and how to cope. Juliet, in her first interview, stated that she had been informed about her hair falling out. In the subsequent interviews (discussed in a later section), she appeared to blame the nurses for not giving her the right information about hair loss.

> ‘Yes, I had been informed it will fall. It fell with the first chemo. I was told it is like the drugs had affected some of my hair cells’ *(Juliet, private hospital, first interview)*

> ‘Because the doctor had said I will be given drugs to prevent some of those side effects like vomiting’ *(Paula, public hospital, second interview)*

> ‘I have seen the doctor and he has told me that he will give me drugs to reduce the pain’ *(Juliet, private hospital, third interview)*

Overall, participants were given some information about the treatment modalities, their side effects and how to cope. This information gave them hope amid the ‘doom’ of the cancer diagnosis because they started treatment with some knowledge of what to expect. The side effects experienced were nausea and vomiting, skin and nail changes, lethargy, low immunity and hair loss. Equally important was that the side effects manifested after day 5 of treatment and not all patients experienced them. However, although some information was given, the whole range of systemic side effects was not covered. Some participants were able to use the information they received to manage side effects and make lifestyle changes

5.3.4.1.5 Lifestyle changes

Throughout this study, the need for lifestyle changes was highlighted by the majority of participants. This mainly addressed the areas of dietary habits and increased physical exercise. Participants used the term ‘lifestyle change’ to refer to changes in behaviours or habits they had been performing before diagnosis to facilitate recovery and prevent cancer and its recurrence.

5.3.4.1.6 Dietary habits

Participants reported changes in their eating habits such as avoiding red meat, processed foods, cooking with artificial manufactured spices, sugar and sugary things, milk and wheat products. When possible, they consumed natural foods, sour or bitter fruits such as lemons, pineapples and bitter traditional green vegetables. It was also noted by some participants that they needed to eat a balanced diet and increase their vegetable intake. Participants resorted to traditional foods because processed foods were believed to increase the incidence of cancer.

> 'I have reduced taking processed things, meat and sugary drinks. I had been told that sugar is the food to cancer. So, I had to avoid. I also take traditional chicken eggs only' *(Abigail, public hospital, second interview)*

Marion avoided sugary food and reduced her sugar intake in tea. She also stopped eating artificial spices as they were believed to cause cancer. Other lifestyle changes made are evident in the narratives

> 'There are things that I have stopped eating the sugary things, cakes and like… (inaudible words) …even for my tea I have reduced sugar intake…and things like spices I like it a lot but for now, am not supposed to eat like Royco… (a type of synthetic food spice). I have stopped and am not using it' *(Marion, public hospital, second interview)*
>
> 'Like now I make sure that I get the balanced diet but before I was not. I make sure that I get some fruits, and things like that to ensure I eat very well' (*Naomi, public hospital, second interview)*
>
> 'I take food at the right time...after 5:00 p.m. I should not take meals and avoid the red meat' *(Connie, private hospital, first interview)*
>
> 'My feeding now is the best…In fact, am feeding very well. Especially on vegetables…' *(Lilly, private hospital, second interview)*
>
> 'Like for me, I cannot use coffee, I was told the coffee substance, cancer patients cannot use it' *(Debora, public hospital, second interview)*

5.3.4.1.7 Increased physical exercise

The majority of participants reported they had started exercising or increased the amount of physical exercise they used to do before their BC diagnosis.

> 'I do a few exercises and I do them in sitting room; for example, sit ups, so that even though am watching TV, I just stretch' *(Rhoda, private hospital, second interview)*
>
> 'Sometimes I feel very tired and in order to relax, I go for exercises. I either jump or walk. I also carry water jerricans on my back so that my legs may attain strength' *(Abigail, public hospital, second and third interview)*
>
> 'I do exercise now. I do not want just to sleep and take drugs…sometimes I walk a little to go and sit with other women who are selling along the road' *(Marion, public hospital, second interview)*

Overall, participants reported that they made lifestyle changes that continued even after finishing treatment. The most notable were dietary habits and exercise. Most participants avoided meat, processed and sugary foods, ate a balanced diet and increased their vegetable and water intake. They also watched their portion sizes and ate more fruits. Even though they felt lethargic, they embraced exercise, ranging from mild stretching, sit ups and walking to rope jumping. There was also evidence that HCPs gave participants information after completing treatment.

5.3.4.2 Information about follow-up after finishing treatment

Participants described instructions they received after finishing their treatment courses. This included what would happen in the long term and addressed taking drugs, follow-up laboratory investigations and doctors' appointments. The instructions given for follow-up after finishing treatment were considered helpful by participants. Debora was given oral drugs (tamoxifen) to take long-term and an explanation was given of their effect on the body cells. From her narrative, she appeared to understand what the drug would do, and this made her confident.

> 'Today I have been prescribed some drugs to make the cells normal I will not be using the chemo drug but will be swallowing tamoxifen up to continue for 5 to 10 years' *(Debora, public hospital, second interview)*

Juliet was happy with the information she was given in regard to follow-up appointments after her eight cycles of chemotherapy. There was however a tendency to use the medical terms that HCPs used without understanding the meaning. Juliet referred to treatment that involved passing of X-rays, which she called physiotherapy. She later corrected this and said she had radiotherapy.

> 'They have told me I am through with eight cycles, I will continue with the therapy, physiotherapy…no radiotherapy…for 28 days continuously with exemption of Sundays and Saturdays' *(Juliet, private hospital, third interview)*
>
> 'For instance, I will be going back for an appointment on 17th of this month. So that I do a blood test, then I do the Herceptin on 22nd. So unlike before when I was doing a blood test monthly before every chemo so the doctor told me it is not necessary now, I can skip may be a month and then to do a heart ECHO after 3 months' *(Rhoda, private hospital, third interview)*

The information that participants received is summarised in Table 17.

Table 17: Information given to participants

Stage in the breast cancer journey	**Information need**	**Comments**

Screening and diagnosis	Cancer as a disease: causes, signs and symptoms Signs and symptoms of breast cancer (BC), prevention Diagnostics-laboratory and radiological	One patient asked about causes of BC and the doctor explained these to her
During treatment	Treatment modalities • Chemotherapy • Radiotherapy • Surgery	Chemotherapy and surgery were mentioned, but nothing about radiotherapy
	Effect of treatment on the body	Some side effects were mentioned; for example, nausea and vomiting, changes in skin and nail colour
	Side effect management	Mostly concerned diet and nutrition
	Lifestyle changes	Nutrition and diet, exercise, drinking water
Follow-up	Doctor's appointments Laboratory tests (hemogram) Echocardiogram (heart test)	Follow up, taking Herceptin and tamoxifen, follow-up appointments and investigations

From participants' narratives, it appeared that they had been given little or no information about screening, causes of BC and diagnosis by the HCPs. Most of the information from HCPs was given during treatment and revolved around side effects of treatment and how to cope. Almost all participants had received information about chemotherapy and surgery, with only one participant talking about radiotherapy sessions. The next section presents information gaps that were identified as subtheme four.

5.3.5 Subtheme four: Information gaps identified

Although some information was given as described above, both the private and public hospital participants decried the lack of information by HCPS in some key areas. Some participants were not given any information at all and appeared surprised when I asked what they were taught. They did not expect to be given information or even participate in healthcare decisions. To them, what was important was to get treatment, know their next appointment date and book it. A variety of perspectives were expressed in terms of the information participants felt would have helped them along the treatment journey. Some participant quotes in this section are lengthy to capture the essence of their experiences.

5.3.5.1 Before diagnosis

This defines the period between suspicion of BC and confirmation of the diagnosis. Although women were given information that they understood or appeared to understand, they described a number of inaccuracies in the information given. What could not be inferred was whether they were given information incorrectly or they had interpreted it inaccurately.

5.3.5.1.1 Biopsy to confirm BC

A biopsy is minor surgery in which breast tissue is excised and taken to the laboratory to diagnose BC. The procedure is usually done under local anaesthesia where the affected area is injected with numbing drugs. Debora had biopsy without any sedation or anaesthesia being administered. She was also taught that if there were no side effects, it meant that treatment was not working.

> ‘When they drew the sample, I was not anaesthetised because if you are anaesthetised those hormones will die, and they want them while they are alive’ *(Debora, public hospital, first interview)*

> ‘We were told if you seem as though you don’t have any side effects, it is showing that the drug is not working in you’ *(Debora, public hospital, first interview)*

An assumption that may explain this is that HCPs may have used this approach to show patients that the treatment was working to help patients cope with side effects.

5.3.5.1.2 Role of core services (Laboratory and radiological)

Patients emphasised the role of other core clinical services, such as laboratory and radiology, in empowering them with information. They desired an explanation of what laboratory or radiological findings entailed. They recalled how they were asked to undergo diagnostic tests before starting treatment. Most of the time they did not know the significance of these tests and stated that there was need for doctors to explain diagnostic results. Paula was anxious about the long list of laboratory tests in her report, but nobody had explained their relevance.

> ‘Let us say that there is this part of the lab results when you bring them to the doctor. Sometimes they never explain everything to you. They need to explain so that when you are being administered the drugs you be on the same level’ *(Paula, public hospital, second interview)*

There was also a desire for doctors to explain investigation results in detail as this affected the treatment. This would have afforded participants some level of control and thereby reduced their anxiety. Some reported that to-date, they did not understand the interpretation of their laboratory results. Overall, as participants had investigations performed frequently before treatment and doctors’ appointments, it was important for them to be given sufficient information regarding the relevance to treatment

> ‘Mostly I would like to know more about the lab results’ *(Abigail, public hospital, first interview)*

5.3.5.2 During treatment

All participants had been managed with at least one cancer treatment modality (i.e. surgery, chemotherapy, radiotherapy) or a combination of two or all three modalities.

5.3.5.2.1 No information on chemotherapy medication regimens

Participants reported that they did not know the names of drugs, although those from the public hospital had a file with all of their diagnosis and treatment information, which they had been advised to show HCPs whenever they sought healthcare services elsewhere. Participants expressed concern when nurses did not offer information or answer their questions. A nurse’s role is to educate patients about the medication, but this was not evident in some participants’ narratives.

> ‘Even if you ask those giving you the medication, they usually tell you that you will ask the doctor next time that they are not the ones who order the drugs’ *(Naomi, public hospital, second interview)*

Naomi’s words suggested that according to patients, nurses just administered the drugs ordered by the doctor, and that they had no knowledge about them. However, this was not true as nurses are trained to explain and teach patients about all the drugs they administer. When Olive was asked to mention the drug, she was getting, she said:

> ‘I was not told the name of the drug’ *(Olive, private hospital, first interview)*

In a similar instance, Juliet was given different information about taking the same drug. One HCP advised her to take the drug before food while another advised her to take it 30 minutes after food.

> ‘There are some drugs I was instructed to take before food and another one told me to take 30 minutes after food. Then I take the next after 30 minutes’ *(Juliet, private hospital, first interview)*

This lack of and inconsistent information may have caused anxiety and uncertainty as participants were left with unanswered questions. As asking questions is a way of seeking information, participants needed to have been provided with answers to help them cope better. Another information gap was identified in terms of how chemotherapy was administered.

5.3.5.2.2 Routes for chemotherapy administration

Chemotherapy is usually administered through a large vein in the hand or chest. Participants’ narratives suggested that the routes for accessing the veins and how chemotherapy would get into the body had not been explained to them. During one of her interviews, Rhoda described how she saw a patient receiving chemotherapy through the chest and not on the hand like her. She went home and read about it and wished this was used on her too. This was a chemo port that was expensive, but she said she could have afforded it since she had both private and public insurance.

> ‘Because the other time we came I saw a man who had something at his chest. In fact, when I read about that port, I talked with my sister and I thought when I see the doctor, I should ask for the same. So, I think that kind of information should be given to patient’ *(Rhoda, private hospital, first interview)*

When patients have breast surgery, a standing rule is that an intravenous line cannot be fixed on the side of the surgical site because of compromised blood circulation. Therefore, patients needed an explanation about why the HCPS could not insert a needle in the arm on the same side where breast surgery had been performed.

> ‘They told me it is to be inserted not on this hand but to the other hand, which had not been operated on. That also I did not understand’ (*Juliet, private hospital, first interview)*

This was important information as most participants underwent surgery. Participants’ narratives also revealed information gaps during the actual chemotherapy administration.

5.3.5.2.3 Actual chemotherapy administration not taught

The chemotherapy administration time caused anxiety as some HCPs did not ask patients how they were feeling. These HCPs failed to empathise and reassure their patients, and therefore defied the principles of holistic care. From stories participants heard from other patients, chemotherapy was 'harsh', and they expected the nurse to explain in detail what was involved in administration because 'it was not just like any other drug'.

> 'You are injected two first, and then it follows the one they call chemo and then you just get off. There is nothing like being asked what you have felt. I was expecting to be tested *(points to blood pressure measuring machine*), getting tested should not only be done the time of enrolment (*meaning triage*). Lastly, I would like to be tested to know whether I have any reactions, but this is not done. Am only released and told to go home well' (*Juliet, private hospital, first interview)*

Participants expressed their anxiety during the actual chemotherapy administration, especially when checking the drugs with the patient it was emphasised to confirm that they were administering the right drugs to the right patients. This was not done for the other premedication, which worsened their belief that chemotherapy was 'dangerous'.
This caused anxiety because participants suspected the drug was very 'strong', but nobody gave them this information. A probable assumption by HCPs was since the patients had received the treatment before, they knew what was important.

> 'There was no teaching. We just come and sat down, and you are told this is for flushing. You are done the introduction that, that is first for flushing it finishes and it ends the third one. Now the fourth one you are told this is the chemo check your name, the form number whether it is yours, so that we may not give you for another patient. That one now is chemo, when through you are given the fifth one from there you just leave' *(Juliet, private hospital, second interview)*

Many participants had attended the clinic expecting to be taught as a group as they all had cancer, but they were disappointed.

> 'My expectation was that when I come to the clinic as we wait for our turn, I will find people teaching...but I have never heard anything…and you cannot ask another patient about their drugs because they are different' *(Marion, public hospital, second interview)*

5.3.5.2.4 Surgery-related information

Participants expressed a desire for surgery-related information. Details of what they should do to prepare for surgery would have optimised their surgical experience. Paula clearly verbalised the need for detailed information about what to expect during and after surgery.

> 'Before theatre, you ought to be told, when you wake up you will be having the catheter here below and other inserted things (meaning drains). The time it will take;

> how many hours I will be sedated…so that you may be prepared for that operation' *(Paula, public hospital, first interview)*

Participants also verbalised the lack of information on pre-operation procedures and post-operation expectations. Participants who after disclosure of their BC diagnosis needed immediate surgery desired that relatives were also appraised.

> '…. Hmmmm., that is the time I entered the theatre and came out at 3:50 p.m. My family members were so shocked for I stayed in the theatre for long hours, even my husband I was told he was restless' (*Naomi, public hospital, first interview)*
> 'No. they never told me even how the operation will be' (*Paula, public hospital, first interview)*

> 'No. I was not understanding the issue of *mastectomy* or how it will be removed and when removed how it looks like… (participant's laughter) …or how it looks like… (crosstalk…) I came to experience it by myself' *(Paula, public hospital, first interview)*

The post-operative expectations needed to be explained to patients to help manage their anxiety. Deborah raised concerns with post-operative instructions as after the surgery she felt like nothing had been done.

> 'So, I told them am feeling as though there is nothing you have done on me. Then the doctor told me, can you try to raise yourself a little bit. When I tried to raise, I felt a lot of pain' *(Debora, public hospital, first interview)*

The shock of losing a breast was hard hitting, especially as it is an organ that defines femininity, and the thought of having one breast was devastating. Deborah's mother-in-law encouraged her by sharing a story of a village neighbour who had lived without her breast for a long time.

> 'I had never heard that breast could be entirely removed, that is when my mother-in-law called me and told me that so and so from our village they do not have their breast for 30 years' *(Deborah, public hospital, first interview)*

Some participants felt that the information given was inadequate or incomplete and would have preferred a more detailed explanation. For example, when the doctor explained about surgery, Paula did not understand or got confused by the information amid the anxiety of a BC diagnosis (she had just been informed). On her next visit, she asked another patient what cancer grade and stage mean.

> 'I saw as though he skipped a point. He should have started by explaining more. Even the first-time doctor never explained to me. Later, I asked another patient, and these things that are being written 'I don't know stage or grade with numbers, what do they mean?' *(Paula, public hospital, first interview)*

It appeared that most HCPs did not check participants' understanding of the information they were given. After surgery, participants desired information on how to care for the surgical incisions, citing cases where other patients had problems.

> 'You ought to be explained when one gets out of surgery, because even sometimes you will find the wound oozing water, but I saw mine healed well and had no problem. I have heard some women say that theirs stayed without getting healed and had water on the surface' *(Paula, public hospital, first interview)*

5.3.5.2.5 Information about radiotherapy

Sometimes patients did not ask questions because they assumed they knew everything because they had experienced the treatment side effects. One participant stated that the HCPs did not give any explanation on how treatment worked. Rhoda (the most educated participant) described this in reference to radiotherapy, which she had received every day for 30 days.

> 'I went every day. I do not think I was given any explanation. I did not even ask questions because in my mind I already knew it was…everyday but as to the reason …I did not even know or ask. They do not give you information' *(Rhoda, private hospital, third interview)*

5.3.5.3 Knowledge and literacy about side effects of treatment

All treatment modalities have potential to cause side effects. Participants desired to know what the drugs were, their action, possible side effects and coping mechanisms. The side effects reported were emotional, skin and nail changes, fatigue, post-operative lymphedema, pain and artificial menopause. These are discussed below depending on how they manifested.

5.3.5.3.1 Skin changes

Participants desired to have been taught about skin changes caused by chemotherapy and radiotherapy. Without reliable information, most participants panicked when their skin and nails turned black. Participants reported feelings of psychological trauma and negative body image with the hair loss and skin/nail changes, stating that prior information would have prepared them and developed coping skills. Body changes information had not been shared and this was distressing.

> 'I look older, while the face has turned out to be pale, these I had not been explained. First this one...nails are black. Today. And why has it been so? Nobody told me' *(Olive, private hospital, first interview)*

Participants were anxious about imminent body changes. Juliet recalled a male relative who was large sized, but became very thin and dark after a cancer diagnosis and it worried her.

> ‘That is what I keep am asking myself whether I will become thin at that stage. Now you keep asking yourself which stage is that’ *(Juliet, Private hospital, first interview)*

Participants reported feelings of psychological trauma and negative body image with their hair loss and skin/nail changes, stating that prior information would have prepared them to develop coping skills.

5.3.5.3.2 Hair loss/alopecia

Most participants had lost their hair during treatment. They were horrified, stating this was the lowest moment in their BC journey as the hair loss affected their self-image and self-esteem. Juliet recounted how she had beautiful natural long black hair that defined her femininity, but after 3 weeks of chemotherapy it fell out. When it fell out, she felt a deep sense of loss. Her body image changed and her face looked older. Juliet was disappointed with the body changes that no HCP had prepared her about. She was afraid that her new body image would draw attention and people would know that she was sick. Worse still, her eyebrows, eyelashes and pubic hair also fell out, which worsened her feelings. From her narrative, Juliet blamed the nurse for wrong information; she lamented bitterly about the loss and was devastated.

> ‘I did not know my hair would fall off. By the way...*ni vibaya sana* (Kiswahili for it is very bad) ...I was not explained to. It was the mistake of one of the nurse. She told me my hair fell off because I had plaited. I told her she did a bad mistake. You should have told me to shorten my hair’ (*Juliet, private hospital, first interview)*

5.3.5.3.1 Nausea and vomiting

Lilly had been given drugs to prevent nausea and vomiting but was not taught how to take them.

> ‘In that first time also, they never told me that I was going to get drugs to prevent vomiting’ *(Lilly, private hospital, third interview)*

5.3.5.3.2 Fatigue

Most participants appeared and reported feeling tired during treatment (both chemotherapy and radiotherapy). However, they did not associate this with a side effect of cancer treatment; it is likely that they had not been taught about this.

> ‘All the time feeling, I am tired, even if I have not done any work’ *(Connie, private hospital, third interview)*

> ‘Sometimes I feel very tired, but because I accepted myself, I eat well, avoid stress and I take the medication as directed by the physician’ (*Abigail, public hospital, second interview)*

5.3.5.3.3 Post-operative lymphedema and pain

Some participants encountered painful effects of treatment without knowing the cause. Rhoda reported that her arm swelled significantly after surgery, but nobody had informed her about this, and she suffered in silence. The arm swelling is usually due to blockage of lymphatic drainage, especially where the axillary lymph nodes were cleared during breast removal. When she could no longer bear it, she asked the doctor who ordered a pressure bandage that was applied on the affected hand, which reduced the swelling and pain considerably. It worried her that if she did not complain, she could have lost function in that arm.

> ‘What if I would not have been able to use my hand, the numbness, then the swelling would have been excessive that maybe you would have lost it’ *(Rhoda, private hospital, third interview)*

5.3.5.3.4 Artificial menopause

An expressed need by participants was detailed information about effects of chemotherapy on hormones (e.g., how it caused artificial menopause) and the possibility of child bearing after completing cancer treatment.

> ‘Like menopause, like can a person get a child? Why does the menstruation stop? Again, after one undergoes chemotherapy treatment, can they give birth?’ *(Debora, public hospital, first interview)*

One participant narrated how she went through all the chemo cycles without knowing that her monthly periods would be affected. During her third interview Ruth revealed that missing her periods after 3 months of chemotherapy worried her.

> ‘It was a chemo I did the last day of July, and then there was the August, in September that is when the menses stopped. I was worried’ *(Ruth, Private hospital, third interview)*

5.3.5.4 Knowledge and literacy about side effect management

Some participants reported that they were not aware of how they could have prevented or minimised the side effects. Others laid blame on HCPs who did not explain to them how to prevent these effects. Those who understood the treatment procedure well were more comfortable in handling the side effects compared with those who did not understand their treatment from the outset. In addition, the information given was sometimes complex, incomplete and provoked fear. Participants’ expressions and words portrayed suffering that could have been prevented by correct information. For example, Juliet was told by her doctor that at the fifth chemotherapy cycle, her treatment would change, and she would have internal reactions. She expressed a *'fear of unknown'* as she waited for the next course of treatment.

> I was told I will have internal reactions. I was not told beyond that, but the rest… (some silence and deep thinking) ...is what I experienced (said emphatically while shaking her head). When I got home, I called the doctor and he told me when I come next, they will give me pain killers. *(Juliet, private hospital, third interview)*

Later, Juliet realised that she had been given painkillers but unfortunately no one had explained to her what the drugs were and how to use them. Given the emotional changes Juliet had complained about, the HCPs needed to give clear instructions about the take home drugs. However, this may also reflect low functional HL, because drugs are usually labelled, and Juliet could have read and followed the instructions.

Participants frequently expressed that HCPs failed to give them adequate information to understand how chemotherapy caused hair loss. Therefore, some participants thought that eating certain foods would prevent hair loss, which was distressing symptom as it robbed them of their femininity. In an emotionally loaded tone Paula narrated:

> 'They needed to tell us what food would assist in preventing hair falling off such that if you eat it, it will prevent that. You know for the woman to lose hair that is something very big to her' *(Paula, public hospital, first interview)*

Because of minimal information received while undergoing treatment in hospital, some participants had devised their own strategies for overcoming the side effects of treatment. In the public hospital, they described patients shared experiences freely and advised each other on what to do. Unfortunately, some of the advice seemed wrong; however, they reported that it worked for them. Most of these discussions centred around how to manage the side effects.

> 'So, the drugs get to overpower you when you get to the house. There was another one who told me that she normally comes while she had not eaten anything, and she never vomit. And if you do not eat, for me I said I cannot do that, because I know for the drug to work, I need to first eat well. For her advice, I said no' *(Naomi, public hospital, second interview)*

5.3.5.4.1 Side effects-nonspecific but life threatening

The interview data suggested that some side effects experienced were life threatening. Participants recalled incidences where the side effects were so bad that they thought they were dying. Juliet recalled that after her first chemotherapy, she had a near death experience.

> 'When I was given the first drug, I slept as though I am dead, and I continued saying in the house I am going… (meaning dying) …to the extent that my husband decided to call people to come and speak to me' *(Juliet, private hospital, third interview)*

5.3.5.4.2 Knowledge and literacy about nutrition and diet

Information provided about diet was erratic, especially if a patient had a pre-existing condition. For example, a patient who had diabetes felt confused when she was told to eat ‘everything’. It is not clear whether it was the nurse or doctor or dietician who gave this information, mainly because in Kenya, patients refer to any HCP as *daktari* (doctor).

> ‘I asked them about feeding when we started this chemos. In fact, it is my husband who asked *daktari*, how is she supposed to feed? And then she said I can eat everything and also fruits. Hmm…but eat fruits sparingly because they have sugar…you know I am diabetic’ (*Lilly, private hospital, third interview)*

Some participants were happy that they were given information about dietary modification but were confused and frustrated when HCPs gave conflicting information about the same issue. In addition, there were no written handouts to supplement the verbal information given.

> ‘I was told how I will be eating...*tamaka* (a native word that is used when someone is at crossroads). When you are told by somebody else you see as though it is different from the other one’ *(Juliet, private hospital, first interview)*

The conflicting information confused the participants. Some information given needed to be simplified further for patients to use it effectively. For example, the following narrative by Naomi demonstrated further clarity was needed.

> ‘We were told we use carbohydrates and proteins and vitamins, but the vitamins should be more, then followed by carbohydrates and then protein’ *(Naomi, public hospital, second interview)*

Another participant was not given the rationale for not consuming sugar.

> ‘One thing that I have asked is about sugar, because I had been told I was not supposed to take sugar’ *(Juliet, private hospital, third interview)*

This sugar issue appeared to cause Juliet distress such that during her interview, we discussed what she understood. She appeared to have learned from her women’s group that sugar feeds the cancer cells and worsens the patients’ condition. During her third interview, I observed that Juliet’s food tray had processed food. She did not eat any food from that tray as the doctor had advised her to avoid processed foods, sugar and too much oil. Juliet was happy that I witnessed her being served with food the doctor had advised her to avoid.

> ‘I cannot take. There is sausage, maandazi, samosa (deep fried wrapping of wheat flour and minced meat), eggs and bread with eggs cooked with too much oil. In fact, there is nothing I eat because I was told meat should be that of chicken’ *(Juliet, private hospital, third interview)*

I observed that on subsequent chemo visits, Juliet brought her own food from home. This experience may have caused Juliet to distrust information given by HCPs. Another participant stated that it was important to be taught about diet. From her comments it appeared that she had prior information that associated some foods with cancer but wondered about children.

> ‘Even I had to ask myself, what are we supposed to eat? Because if like the food, what are we to eat for you hear even small children they have cancer’ *(Paula, public hospital, first interview)*

5.3.5.5 Knowledge and literacy about financial implications of BC

The need to know about finances was a dominant thread that occurred across all stages of the BC journey. It was mentioned more than 20 times by all participants, more so by those from low SES backgrounds. Participants desired detailed information on the actual money required for treatment. This would help them prepare so that their treatment schedules would not be interrupted, as was the case for Marion.

> ‘To me, in the beginning of BC, I was worried about the money. What is disturbing me mentally is the ways to raise income…other patients we started chemo with they have finished their treatment, but I am still here’ *(Marion, private hospital, third interview)*

Participants regarded financial information as crucial and should have been educated about NHIF as patients did not know that the amount of money NHIF paid depended on the BC stage. The earlier stages (one and two) were allocated more money than the late stages. Some patients found out after being allocated less funds because the doctor had not specified their BC stage.

> ‘Stage one they give 25 thousand Kenya shillings (250 USD) because the NHIF officer told my daughter to tell the doctor to write to her which stage she is because from stage two they give at least give a minimum of 50 thousand shillings (500 USD)’ *(Rhoda, private hospital, third interview)*

In addition, participants were not fully aware of how the NHIF would be used. For example, some did not know that NHIF could be used to purchase drugs.

> ‘For buying medicine, I was not aware if I could use NHIF card. I can also go to buy medicine elsewhere’ *(Naomi, public hospital, second interview)*

> ‘Yes, per month we have been allocated KES 25,000 as the amount one is to use for that month, and you should be remitting the NHIF premiums’ *(Debora, public hospital, third interview)*

Overall, participants needed information about the treatment modality, side effects and how to manage them, nutrition and diet and the financial implications of a BC diagnosis at the treatment stage. They experienced cancer treatment side effects, although some had more side effects than others. Some participants reported that they were not aware of how they could have prevented or minimised the side effects. After presenting the information gaps identified during treatment, the next section describes the gaps identified in how information was presented to participants after finishing treatment.

5.3.6 Information gaps after finishing treatment

Information gaps arose due to absence of information that would have helped participants make decisions after completing treatment. They expected to receive instructions from their HCPs about how often they should come in for check-ups and what kinds of tests they needed to take as part of the follow up visits.

5.3.6.1 Discharge and follow-up

This category was a strong indication of the frustrations the women faced because of lack of information. There needed to be a discharge plan for participants who were ‘graduating’; a term they used for those who had completed treatment. They reported ‘feeling lost’ as there was no information about the next steps, including follow-up, rehabilitation and support groups.

> ‘If the doctors can try and explain to the patient after completing the chemotherapy sessions, they explain more how you will progress and how to control the cancer, this can help those that are affected’ *(Debora, public hospital, third interview)*

Participants were not sure what to do after completing their treatment cycles. They reported that they were not sure whether the cancer cells had cleared from their bodies and desired an assurance. They also needed a detailed explanation on the need for follow up visits.

> ‘But after some time, I realised now since I am done with the treatment does it mean that the cancer is over? So, I was waiting when I come back in August that I should ask that question’ (*Connie, private hospital, third interview)*
>
> ‘I would have liked to be checked whether those cells are over, but none I still have doubts whether I have the cells in my body. Yes, because there is no test, I was done to prove they have gone. Does it mean now that the cancer is over? I was waiting when I come back in August that I should ask that question’ *(Connie, private hospital, third Interview)*

> ‘Again, the doctors need to take the initiative of explaining to the patient that they need to do this and that after finishing treatment’ *(Abigail, public hospital, second interview)*

5.3.6.2 Causes of BC and survival rates

By their third interview, most participants had completed their treatment. However, questions about BC causes and prevention still arose. They emphasised the need to know how to prevent BC and protect females in their lineage. A possible explanation may be that in the treatment phase, they focused more on recovering, and as they completed treatment, then thoughts of BC prevention crossed their minds.

> ‘The causes of cancer, that one has not yet been clear to me…really what causes cancer? How one can prevent and save herself and others from getting cancer’ *(Ruth, private hospital, third interview)*
>
> ‘I keep asking myself where this disease is coming from. What is causing this disease?’ *(Marion, public hospital, first interview)*
>
> ‘Let us say for example like for the HIV. For HIV it was said that we need to use condoms. Now for cancer how are you going to protect yourself? Because it is not an airborne disease nor sexually transmitted’ (*Debora, public hospital, third interview)*
>
> ‘The area, the causes of cancer, that one has not yet been clear to me really what causes cancer. How can one prevent and save herself from getting cancer?’ *(Rhoda, public hospital, third interview).*

Juliet was hopeful of recovery and expressed a desire to know about survival rates of BC patient, but it seems she did not know how to ask for this information.

> ‘You know I am not the first one to get sick, and I know many have recovered. I believe I will be among those who recover. I wish I knew how many survive’ *(Juliet, private hospital, second interview)*

The participants appeared to have a strong belief that diet, and nutrition played a key role in prevention of BC.

> ‘If the doctors can try and explain to the patient after completing the chemotherapy sessions, this can help because they can know the type of food one is supposed to eat’. *(Deborah, public hospital, third interview)*

When HCPs gave conflicting information about cancer recurrence, it confused participants. Paula, whose BC recurred, had been given an explanation that seemed to confuse her. Paula had delayed starting chemotherapy by 5 months because of a doctors’ strike at the public hospital.

> ‘One told me maybe the cancer was not removed all of it…and another that I had stayed for long before I started the chemo. I had stayed since the 5th month to the 10th month because of the doctors’ strike’ *(Paula, public hospital, second interview)*

The above articulates the need for HCPs to give comprehensive information to patients with BC across all the stages of the journey.

5.3.7 Summary of information gaps identified

Most of the gaps in knowledge and information appeared to occur during the treatment stage and were related to the treatment modalities and side effects that caused untold suffering. Though some BC information was given, crucial information was missed out or the participants did not understand the information. For the majority, no information was given about what side effects to expect for the treatment modality they were receiving (chemotherapy, radiotherapy or surgery) and how to minimise or cope with these side effects. Participants desired information about treatment schedules, laboratory and radiological investigations and how to minimise the probable nutritional, respiratory, gastrointestinal, sexual and general body image complications. If information was given in a way they understood, it would likely have helped them to understand, anticipate, recognise and prevent side effects. Subsequently, this would have put them more in control, reduced their anxiety, uncertainty and improved their treatment experience. Various information needs of patients with BC were identified from participants’ narratives of their interactions with HCPs or events that happened during the cancer journey. The information needs of the participants at each stage of the journey have been collated from the findings and are presented in Figure 7.

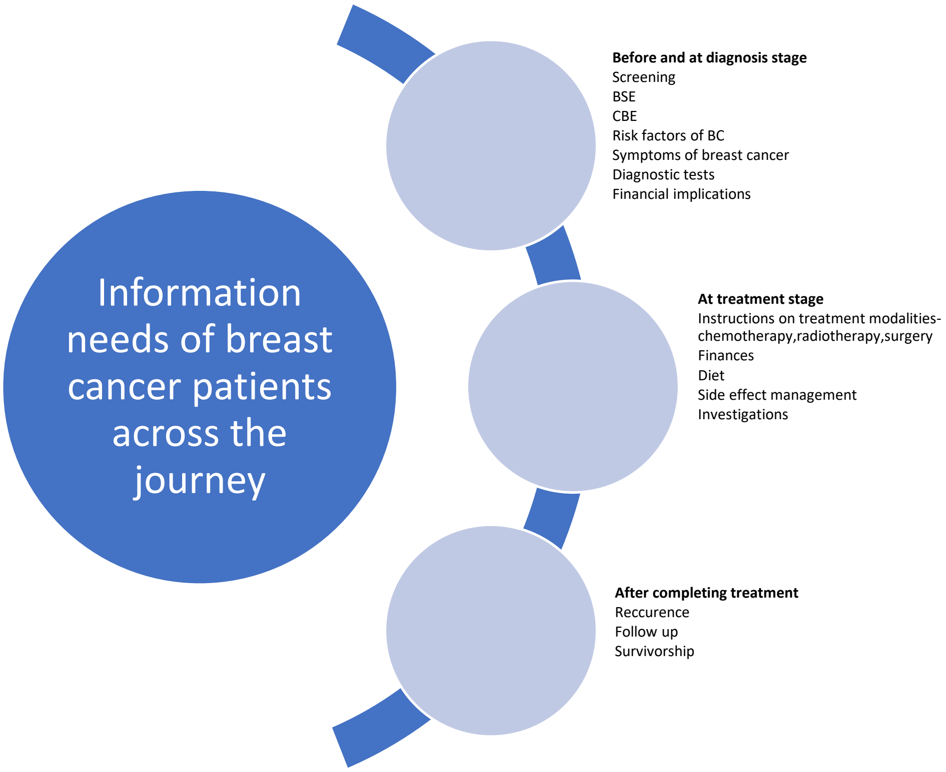


Figure 7: Information needs at different stages of the breast cancer journey.

The factors that influenced how participants accessed, understood, and used health information (theme two) are presented in Chapter Six.

CHAPTER SIX: THEME TWO: SOCIO-ECOLOGICAL FACTORS THAT INFLUENCED INFORMATION ACCESS AND USE AMONG PATIENTS WITH BC

6.1 Introduction

This chapter explores the findings from the interviews regarding factors that influenced how participants accessed and used health information. The SEM concepts (individual/micro, interpersonal/meso and systemic/macro) provided a contextual understanding of the factors that influenced participants' HL during their BC journey and formed the organising principle for this chapter. This was because the SEM recognises the relationship between an individual and their environment and provides a basis for understanding various factors that influenced participants' access to and use of information. Participants' narratives indicated that the HL challenges they encountered resulted from interactions of micro, meso, and macro factors. The socio-ecological factors that influenced HL in patients with BC and their descriptors are shown in Table 18 below.

Table 18: Socio-ecological factors that influenced health literacy among patients with breast cancer

SEM level	Factor	Descriptor
Micro	Emotional status after BC diagnosis	The mix of emotions (anger, anxiety, fear, crying) after the doctor had broken the bad news of BC diagnosis.
	Faith in God	A belief in a higher spiritual being, which is frequently used interchangeably with 'religion' in referring to a certain belief system.
	Financial distress	The stress caused by insufficient income to pay for treatment and investigations, bus fare, accommodation and meet other family needs (e.g. school fees, food, rent).
	Prior BC awareness	Pre-existing exposure and knowledge of BC disease
	Socio cultural beliefs about BC	Common traditions, habits and patterns that have the power to dictate how people approach BC and their attitudes about causes, prevention, and treatment.
	Education level	Individual participant formal schooling
	Positive attitude and the power of self	Being optimistic about situations, interactions and self
	Socioeconomic status	The social standing of the participant
	Return to pre-cancer body	When the side effects of BC treatment had worn off and participants' image returned to normal.
Meso	Medical jargon	Medical jargon is the language used by medical professionals to communicate and can cause confusion and weaken understanding between HCPs and patients
	Busy HCPs	The workload of HCPs that interfered with sharing BC information
	The prohibitive nature of instructions	HCPs mostly gave information forbidding patients from doing certain things (Always started with do not….)
	Social support and networks	The perception and actuality that one was cared for and had assistance from other people and was part of a supportive network.
Macro	Institutional policies	Policies that govern how BC patients are taken care of including how information is shared with them and their families.
	Written information seen as useful	Some patients were given brochures and printed information about their treatment.

	Health care financing	A function of the ministry of health that allocates money to meet the healthcare needs of the populations.

6.2 Subtheme one: Individual (micro) factors

At this level, individual factors that influenced how participants accessed and used health information are considered. Fundamental to this was the presumption that individuals make choices based on some abilities and inherent characteristics. Identifying these factors was beneficial as they can inform the design of appropriate interventions to improve the experiences of patients with BC.

6.2.1 Emotional status after BC diagnosis

Most participants were shocked that they had been diagnosed with BC, and the majority perceived that they would die. Even so, doctors immediately gave them treatment information. Participants may not have understood the information given.

> ‘You know even though I was explained there before, I did not get it well because I was shocked’ *(Juliet, private hospital, third interview)*

The following extracts offer examples of the emotional reactions other participants experienced after being diagnosed with BC, which may have interfered with how they received and understood information. Participants knew BC was a ‘bad’ disease and never thought that they would be in this situation.

> ‘I did not know whether I could ever have such a sickness. Even I do not know what I can explain. You can start seeing it like death’ *(Naomi, public hospital, first interview)*
>
> ‘When I was told that I have BC for sure I got a shock. I was shocked because I did not expect to have cancer’ *(Marion, public hospital, first interview)*

Participants conveyed emotional upset and their thoughts about death instilled anxiety and fear. These emotional upsets influenced how they processed the BC information. Connie used the term ‘*finished*’, *a* word that is used contextually in a hopeless situation. She then remembered God, which helped her relax.

> ‘I felt I was finished and that was…I thought that would be the end of me, but as time went on I just relaxed…uhmm and asked God what to do’ *(Connie, private hospital, first interview)*

The agony and despair after receiving news of a BC diagnosis could mean that the participants did not pay attention to the initial instructions about treatment. Later, it appeared that individual faith helped the women to cope with the agony and despair. They had hope that their BC diagnosis was a trial that would be overcome if they held strongly to their faith in God.

6.2.2 Faith in God

For the purpose of this study, faith is defined as a belief in a higher spiritual being, which is frequently used interchangeably with ‘religion’ in referring to a certain belief system. In addition to participants perceiving faith as important, they saw it as central to their BC diagnosis and treatment experience. After their BC diagnosis, faith and spirituality appeared to meet their need for inner peace. The majority of participants alluded to their faith as a major coping strategy when receiving cancer-related information. Participants consistently referred to God as a guide, protector and helper; they believed that God gave the disease and would provide a cure. Combined with the right attitude, this meant that participants seemed confident of positive outcomes.

> ‘Let me say I thank God because I lack that fear. I have kind of placed it in the hands of God and I also believe that prayers and right attitude do work’ *(Rhoda, private hospital, first interview)*

In related findings, cancer was seen as a special opportunity to demonstrate how God enabled people to find meaning in their suffering. Participants lived with hope for the future and trusted in the mighty power of God, even when everything seemed futile. Olive explained how being positive helped her cope with her illness. In an interesting conversation, she reported how in an act of faith she spoke to the chemotherapy and commanded it to work only on the cancer cells in her body. This was because the doctor had taught her that the chemotherapy drugs destroyed both normal and cancer cells.

> ‘But when you see that medicine, you speak to it by faith; ‘you medicine when you get inside my body, make sure that everything that is not important in my body is cleared’ *(Olive, private hospital, third interview)*

All participants reported they believed in a higher being (e.g. a spiritual being, God), which helped them to find inner peace, even when they were anxious about their condition. Several reported that believing in God had helped them to withstand the emotional agony in a way that could not have been attained through any other form. This withstanding of emotional agony helped them to adhere to BC treatment instructions and hope for recovery.

> 'I normally pray, though at times I feel no breakthrough of my prayers. Yes, So I just contact some people to continue praying for me. Yes' *(Connie, private hospital, second interview)*

> 'I can say there are stable, also God helped them to be stable not to lack strength and also they have given me a lot of support' *(Lilly, private hospital, second interview)*

In addition, faith helped remove the fear of cancer and its effects after being informed about the BC diagnosis. Their strong belief in God gave patients a sense of relief. Paula used the words '*Jehovah heals*' instead of BC and reiterated the familiar statement that *'doctors treat but God heals*'.

> 'Then when I went home I said that the doctor has just put the name cancer, but I have replaced those words with 'Jehovah heals' so I went home, and I have never had fears or worries. I only say one word that doctors treat but God heals' *(Paula, public hospital, first interview)*

These findings suggested that some participants dealt with losses by trusting that it was God's will in their lives. The sense of trust, hope and reliance on their faith gave participants strength to cope immediately after being informed of their cancer diagnosis. When Paula's hair fell out after chemotherapy, although the doctor had educated her about this, she comforted herself that it was God's will. As she spoke of this experience, she acted as if she was talking to God face-to-face.

> 'Even if my hair has fallen recently…God, I told you I do not want to see this hair fall. But if you have seen it worthy for it to fall, it is ok. After all, disease is of God and there is no way we can do about it, but to be get treated' *(Paula, public hospital, first interview)*

Lilly, the participant who had ignored the pimple on her breast until it became a wound, became stronger as she received information and started treatment. Her faith, belief in God and fervent prayer life strengthened her.

> 'And now am strong because I have been a firm Christian and a believer in the word of God, so I had not lost my strength…I continue to be prayerful' *(Lilly, private hospital, second interview)*

The belief that God knew why they were suffering with BC encouraged participants to adhere to treatment instructions and helped them to cope. With such an attitude, Rhoda looked strong, and described how other people told her so.

> ‘But there are other people who say I look so strong. I just tell them it is God. I feel that God cannot give you a burden that you cannot carry. It does not matter what condition you are in’ *(Rhoda, private hospital, third interview)*

Even as they affirmed how their belief in God complemented the information received as they battled BC, most participants experienced considerable distress because of the financial implications of their BC diagnosis.

6.2.3 Financial distress

Cancer treatment in Kenya is expensive for patients and their families. A strong thread across the interviews was the fear of not being able to afford to pay for treatment. Participants with low SES (e.g., Marion) reported interruptions in their scheduled treatment. Their cancer treatment had interfered with the household budget, which suggested that without a proper financial plan, the information received would not have been useful.

> ‘This disease has brought a lot of uncertainty in my house for I have been the breadwinner. Now it is hard to place food on the table, paying the rent and even the school fees. I see the cancer disease has brought problems to my family’ *(Marion, public hospital, third interview)*

The lack of finances interfered with information use and appeared to leave participants feeling desperate. All participants had NHIF that partly covered their treatment costs. However, some had missed their treatment because they had not paid insurance premiums. Marion emotionally spoke about how other patients who had money had finished their treatment and she was left behind. No financial assistance was forthcoming from relatives as they asked her to use her NHIF cover, which was not fully paid up.

> ‘…I am the only one left. When I ask relatives for their help, they tell me to use the NHIF card…’ (*participant talked very softly and the rest of her statement was not audible*) *(Marion, public hospital, second interview)*

The above extract highlighted that it was not the BC per se but the expensive treatment that was an issue in this regard. Participants saw other cohort members defaulting from treatment because of lack of money. Rhoda, who had a high SES, recalled how a fellow patient had defaulted treatment because of a lack of finances.

> ‘So one of the ladies stopped treatment because she kind of said she could not afford treatment’ *(Rhoda, private hospital, third interview)*

Even when they were given information, the fear of not being able to afford treatment interfered with use of that information. Participants recounted in emotional tones how the financial burden of BC treatment had caused separation from her husband, and also interfered with family projects.

> ‘Like from the side of my husband, it seems like a burden. He acts differently and other times he ignores me. When I got sick, I went back to my father’s house because I saw my husband could not afford my treatment’ *(Abigail, public hospital, second interview)*
>
> ‘It has affected my family on the side of finances and the projects that were underway had to stop for a while’ *(Abigail, public hospital, second interview)*

Marion, the participant who experienced significant financial challenges, lamented that the BC had damaged her body and rendered her unable to do the menial jobs that had earned her money for daily survival. It seems that for Marion, the need for finances to meet the treatment costs superseded the need for information. This suggests that giving information without addressing the patients’ priority needs may not be beneficial. The financial setbacks caused hopelessness in those without paid-up NHIF as they knew that without treatment, their cancer would advance and affect the whole breast.

> ‘Before I was diagnosed with cancer I used to do menial jobs and get money, I would wash cloths, sweep houses, hawk clothes as I walk but for now, it is very hard like the one for hawking. (Inaudible words) …’ *(Marion, public hospital, second interview)*
>
> ‘Even though I am not the only victim of this disease some fellow victims are poor, and they that cannot afford the cancer treatment. Am saying I have been late for drugs it seems like I will be amputated the entire breast. Sometimes I find myself swollen at my armpits and those are the damages I have witnessed’ *(Marion, public hospital, second interview)*

There are several tests needed to confirm a cancer diagnosis, with some requiring long durations before results are available. In addition, some participants had travelled long distances to reach a hospital that provided comprehensive cancer services. For example, Debora had to travel 300 kilometres to the city for diagnostic tests and treatment.

> ‘You see from all the way from ****, that bus fare is too high, there are also accommodation costs, for it is not that you are coming to Nairobi for one day. So I would like these treatments to be brought to the nearby public hospitals so that treatment may be easy’ (*Debora, public hospital, second interview)*

Financial distress related to treatment and associated costs was evident for all participants regardless of their SES. However, despite the financial challenges, prior awareness and knowledge about BC also influenced how they accessed and used information.

6.2.4 Prior BC awareness

It was evident that some participants had prior knowledge about BC, which appeared to determine how they used information. They described what they knew about BC before they were diagnosed and their expectations. The interview data confirmed that those who had a family history of cancer had higher BC awareness and sought medical help faster than those without a family history. They had also performed their BSE and visited hospital immediately when they discovered a lump.

> ‘After I did myself examination I realised that I had a lump on my left…eee…breast that is when I came to this clinic’ (*Ruth, private hospital, first interview)*

Those without a family history of cancer tended to wait and ignore initial symptoms until more life interfering signs emerged. For example, a pimple on her breast did not worry Naomi until it became a big wound. Similarly, Marion expected BC to manifest like a wound. This may mean that participants could have discovered their breast lumps much earlier but failed to seek medical intervention. This failure to act demonstrated a knowledge deficit of BC symptoms.

> ‘When I saw the pimple on my breast was becoming bigger, I talked with a friend. I only told my mum when it became a wound’ *(Naomi, public hospital, first interview)*

> ‘I thought that cancer is like a certain wound. That is what I knew while I was growing like a little girl, I saw a woman with cancer of the breast, but hers were wounds’ *(Marion, public institution, first interview)*

Lilly had delayed going for medical intervention and was diagnosed at an advanced stage (stage three). She was breastfeeding her child and mistook a breast lump for milk. This was despite having other symptoms, such as lack of appetite and generalised body pains.

> ‘Before I knew it was some disease, I started losing appetite, having back and legs pains. I had the lump, but I thought it was milk that had *clotted* in my breast’ *(Lilly, public hospital, first interview)*

These findings demonstrated that participants were unaware of BC signs and symptoms and did not realise that early medical intervention increased the chance of cure. Throughout the interviews, it emerged that participants’ individual beliefs about causes of cancer influenced how information was accessed and used.

6.2.5 Socio-cultural beliefs about BC

Participants' knowledge about BC was also influenced by religious and socio-cultural practices and beliefs. They held diverse beliefs on the causes of cancer, with some saying it was thought to have been as a result of '*being bewitched*', '*punishment from God for wrongdoing*' or '*an abnormal cell dividing as a result of infection*'. Others thought it could be '*because of environmental pollution*'. This was evident in the following statements.

> 'Yes, that I am bewitched, things like that' *(Naomi, public hospital, first interview)*
>
> 'I have understood that is being caused by these things that we are feeding on' *(Debora, public hospital, first interview)*
>
> 'Cancer, I understand it is dividing of infected cells which are abnormal, and they form a tumour and then this tumour interferes with the body functioning' *(Ruth, private hospital, third interview)*

Based on what participants had heard from other people, varying discourses emerged in regard to causes of BC. One participant was worried that tomatoes that were sprayed and taken to the market almost immediately could be causing cancer.

> 'So they spray let us say even tomatoes today and on the following day, they take it to the market. You see now that chemical is still on the vegetables that we are cooking' *(Debora, public hospital, third interview)*

According to some participants, BC was some kind of witchcraft. In Kenyan culture, anything that is complex and cannot be explained is associated with witchcraft. This was especially so in rural (upcountry) areas where most people do not have access to credible health information. In such a situation, information given would not be used as individuals would be likely to seek the services of a witch doctor or traditional medicine man.

> 'This cancer disease there in the upcountry people are getting oppressed Like from our tribe…western Kenya and Nyanza, you know they run to other things saying it is witchcraft, the traditional medicine and other thing but those things, I do not believe on them' *(Marion, public hospital, first interview)*

> 'I started seeing as though I have been thrown at that wound… (meaning bewitched) …But I reached a point and said that I will not think of such things, and I started to pray' *(Naomi, public hospital, first interview)*

Other individual factors that influenced how participants accessed and used heath information that do not fit in any of the above categories above are discussed below. These are participants' characteristics, positive attitude and return to their pre-cancer body.

6.2.6 Participants' characteristics

All participants had received some information from the HCPs, but how they used it differed. This was likely influenced by some individual characteristics which impacted how they accessed, understood, and used health information. The characteristics presented here are level of education, a positive attitude, degree of involvement in decision making

6.2.6.1 Level of education

Whenever they needed extra information, participants who had a high school level of education were confident to ask their doctors for further information, and also asked questions when they experienced side effects. Those who were literate appeared to have the ability to find their own information and actively engaged with HCPs. They proactively searched for information and asked their HCPs questions. This was especially evident among educated participants who had many questions about treatment schedules. They reported confidence in the information shared by the HCPs.

> 'Yes, I asked the doctor, and he told me that it is these chemo drugs that are causing that and the moment I will stop them it will just improve' *(Abigail, public hospital, third interview)*
>
> 'The other one I asked questions is the pharmacist, I told her to explain to me how I will be administered the injectable drugs…yes, I asked her how I will be injected' *(Juliet, Private hospital, first interview)*

Participants also described the impact of a positive attitude about the BC diagnosis and the treatment information.

6.2.6.2 Socio economic status

This study found that participants' knowledge about cancer increased with their progress through cancer treatment and contact with HCPs. The analysis showed that participants with a high SES (e.g., Rhoda and Abigail) were able to make decisions on what they had been advised, whereas those with low SES depended on what their doctor to decide for them. It was notable that HCPs were used by participants to validate information obtained elsewhere, and they depended on the knowledge and experiences of HCPs in deciding what to do for their treatment. Participants accepted the decisions made by the HCPs without any further thought. They had no information to refer to or they may not have understood the information they were given. However, participants reiterated the need to be given information gradually and be granted enough time to review treatment alternatives and make an informed choice.

> ‘The only different way you must change is what you are doing to pass the information to people to understand, maybe you need to find ways of passing that information’ *(Ruth, private hospital, first interview)*

Most participants showed little understanding of BC treatment, with several reporting that it was the doctor or nurse who made decisions for them. Juliet and Connie communicated fluently in English and Kiswahili but appeared to have relegated decision-making to the HCPs. This non-involvement in decision-making could reflect their inability to appraise health information, and confidently make decisions based on their knowledge.

‘For me, I cannot comment on that. The doctor is the one who will decide…That is what has been bothering me. Sometimes…I ask myself what type of cancer do, I have. Even today I have a question to ask, how many cycles I will go through’ *(Juliet, private hospital, second interview)*

Coupled with a positive attitude and inner motivation, completion of treatment provided hope and confidence that the BC treatment worked. Most of the participants reported that on completion of treatment, the side effects had worn off and their bodies looked normal again, just like before treatment. This was deemed more encouraging than the information they were given.

6.2.6.3 A positive attitude and the power of self

Most participants reported the need for a positive attitude during BC treatment. They emphasised that staying with positive minded people reduced stress and depression. Rhoda and Juliet both indicated that only then would the cancer information they were given make sense and be useful:

> ‘When you have the right attitude and making sure that I also surround myself with people who have what a kind of a right attitude’ *(Rhoda, private hospital, second interview)*
>
> ‘Yes, I see it changing…with right attitude…I will get well’ *(Juliet, private hospital, second interview)*

Participants who had a positive attitude that they would get well tended to use the information they were given, especially by counsellors. As Debora continued with treatment, she had accepted her BC diagnosis and looked well. Debora described how people she met would ask if she still had cancer because she looked fine to them.

> ‘So I did as [I was] advised, am on the 7th chemo and I have accepted myself. Even when I walk on the road people normally ask me, are you still the sick one?’ *(Debora, public hospital, second interview)*

Olive emphasised positivity, saying that if patients were positive, then the treatment information would help.

> ‘If you take it positively, you will walk but if you take it negatively, even the chemo that you are going about will not be able to be help because you are doubting the information’ *(Olive, private hospital, third interview)*

Although information was regarded as crucial, a positive attitude was understood by participants to enable them a to internalise the information better and hope for good outcomes. This may have been an important factor in their decision-making.

6.2.6.4 Return to pre-cancer body enhanced information use

It was interesting to see how participants changed their perceptions as they progressed through their BC journey. Participants who had seemed afraid earlier on and were devastated by their BC diagnosis became increasingly confident to ask questions. For example, Connie had struck a rapport with her doctor and could ask questions.

> ‘Whether I need to continue with clinics, I forgot to ask since the doctor told me I do not have any problem I thought that I was okay’ *(Connie, private hospital, third interview)*

As participants finished treatment, they received information about BC and saw their bodies transform to a pre-cancer state. Their hope and that of their relatives was restored when they resumed their roles in society. This came as a pleasant surprise as no one had informed them that their hair would grow back, and their nails and skin would return to normal after finishing treatment. They changed their initial perception of cancer as a death sentence and shared BC information with other women.

> ‘I am very much okay in fact people are very much encouraged that to be diagnosed with cancer is not the end of life. I teach in church, my work place and also my family, I’m very much okay’ *(Ruth, private hospital, third interview)*

Olive shared her son’s reaction when her hair started growing and her nails resumed their normal colour:

> ‘Now, my son keeps on looking me. ‘Hi mum, now your hair has start growing. Your hair is good mum You see’, then he says ‘let me look at your nails. Ha…even your nails are now getting cleared’ *(Olive, private hospital, third interview)*

Eventually, they verbalised that BC was a disease like any other in contrast to what they had felt on diagnosis, that it was a ‘death sentence’. They gave accounts of their new perspectives.

> ‘Cancer is like any other disease. The way am seeing people are getting treated and getting healed I see it will come to end’ (*Paula, public hospital, second interview)*
>
> ‘Me I say, cancer is like any other disease’ *(Juliet, private hospital, third interview)*
>
> ‘Cancer is like any other disease, and one has to put faith first’ *(Abigail, public hospital, third interview)*
>
> ‘Cancer by the way I say it is like any other disease and any one can get it’ *(Debora, public hospital, third interview)*
>
> ‘I see cancer is like any other disease could infect you, but the difference is that its treatment cost. Cancer is treatable when it is known at an early stage, yes cancer is treatable’ *(Marion, public hospital, third interview)*
>
> ‘That when even though you have been told that you have cancer that is not end of your life’. *(Olive, private hospital, third interview)*

Invoking the power of God, Naomi encouraged other patients newly diagnosed with BC the following words.

> ‘What I can tell someone who has been diagnosed with BC is not to see death, for cancer is like any other disease like malaria, if you have God it is like any other disease that one can contract’ *(Naomi, public hospital, first interview)*

From participants’ narratives, it was evident that BC and its treatment affected them as individuals in a number of ways. It evoked emotional, psychological, economic and spiritual changes. Dealing with these changes created challenges for participants. Some participants manage the challenges well by seeking information and using it to cope while others experienced difficulties and distress. When information was given and used, it reduced the anxiety, fear and confusion and assisted in decision-making.

6.2.7 Section summary

Overall, there were many individual factors that influenced how information was accessed, understood and used during participants’ BC journey. Women shared diverse experiences and highlighted how finances, faith, personal traits, a positive attitude and ability to make decisions influenced their cancer journey. It was also evident that certain factors enhanced participants’ HL, with key factors being education and SES levels. Across the categories, women who were literate actively searched for information, engaged HCPs and had a better experience. Once they started treatment and felt better, participants had renewed hope that they would go back to their pre-diagnosis state. However, they still referred to the cost of treatment as a major deterrent, and as a topic about which information was needed from the outset. They emphasised the need to be told the exact amount of money treatment would cost.

The financial aspect was a major deterrent to screening as participating women stated that it was futile to know you have BC if you could not afford the treatment. After commencing treatment, most patients found hope of being cured and living again. They remembered what they were taught, that BC was curable if diagnosed early. Having discussed the individual (micro) factors, the next level in the SEM, the interpersonal (meso) factors are presented below.

6.3 Subtheme two: Interpersonal (meso) factors

Based on the SEM, the meso factors identified in this study included communication skills and social support. Notably, social support factors involved the participants' social networks, whereas communication skills factors were HCP-related.

6.3.1 Communication and provision of information

Depending on methods of communication and provision of information, participants perceived this as either supportive and helpful or as an added burden. The factors presented are medical jargon, busy HCPs and prohibitive nature of instructions.

6.3.1.1 Medical jargon

From participants' narratives, HCPs taught what they deemed important and did not provide information according to the needs patients expressed. As BC treatment is complex and takes a long period of time, patient information should be tailored to a level that the patient understands. Most participants reported they had problems understanding the information they were given, such as diagnostic results and disease grading. Some reported that even to-date, they did not understand the interpretation of their results; they would have liked a simpler explanation of the tests they had received. The medical terms used have been bolded.

> 'The doctor told me that that test is supposed to be done to check whether the drug that they are administering is for…I do not know if it shows **triple positives** am not supposed to use that drug…' *(Debora, public hospital, first interview)*
>
> 'Now I was told that there are patients that they can be treated with drugs, if they can't tolerate chemotherapy, but mine because is **triple O negative** I was told…with drugs I was told it will work' *(Juliet, private hospital, first interview)*

The treatment information provided by their doctors was technical and participants often did not appear to comprehend.

> 'They have told me when I am through with these **eight cycles**, I will continue with the therapy, physiotherapy…no **radiotherapy**…for 28 days continuously with

> exemption of Sundays and Saturdays. I will just come...they know better' *(Juliet, private hospital, third interview)*

Further on in her treatment journey, Debora was reminded about the need for a certain test that she was unclear about. The use of the vernacular term '*ndiowe*' reflected a situation when one has become resigned to fate.

> 'The doctor told me that that **FIS** (correct term should be fluorescence in situ hybridisation or **FISH**) test is supposed to be done to check whether the drug that they are administering is for…*ndiowe* (native for I do not know) …if it shows **three positive** am not supposed to use that drug' (*Debora, public hospital, second interview)*

In the examples above, triple positive referred to a more aggressive BC type that requires additional treatment. A FISH test is used detect genetic abnormalities associated with cancer and is useful for diagnosing some types of the disease; for example, triple positive BC which is sensitive to hormones and is aggressive.

When Rhoda came for her chemotherapy, the nurse had difficulties accessing the veins for administration of the drugs. Later, Rhoda narrated the instructions about Herceptin, an oral BC drug which is taken for 5 years after completing chemotherapy.

> 'The time for **cycle three** when I came for chemo, when the nurse checked my hand but said, the **veins have collapsed'** *(Rhoda, private hospital, first interview)*
>
> 'For instance, I will be going back for what an appointment on 17th of this month. So that I do a blood test the I do the **aceptin** on 22nd. And to do a heart **ECHO** after 3 months' *(Rhoda, private hospital, third Interview)*

Participants felt that they had no choice but to adhere to the treatment protocol even if they did not understand. However, although they faced challenges, they chose to focus on their cure. Comprehending complex medical terms and information was difficult and confused patients. HCPs used medical terms that patients claimed to understand, although their facial expressions suggested they did not.

> 'On my side, that information of ***mastectomy*** shocked me and in my mind, I had thought I will be done the **chemo** and **radio** and it will be over' *(Marion, public hospital, second interview)*

> 'I understood because he told me, because that is in **stage I** it will heal well' *(Olive, private hospital, first interview)*

Although the HCPs did well by giving patients information booklets about BC, unfortunately, the language used was complex and participants did not understand the messages. However, they carried the books around with them and would give them to their friends or relatives to read and explain to them. Lilly raised this concern at her third interview, which indicated that all along she did not understand the information.

> ‘I read but I could not understand and even now I cannot remember. I move with the book everywhere just in case I got to a place I show them so that they may read it’
> *(Lilly, private hospital, third interview)*

Some terms used were vague but perceived as scary and caused anxiety for participants.

> ‘Telling you that there is some food you must eat because the drugs are very ***strong*** and if you fail to follow what is instructed by the doctor you will ***hurt*** yourself’
> *(Deborah, public hospital, first interview)*

These findings suggested that when HCPs used medical jargon, participants did not understand the instructions. Again, it was evident that participants used the terminology they heard from HCPs without understanding the meaning. This calls for HCPs to use simple language that patients can understand if they are to engage meaningfully with the information. Having described how medical jargon interfered with information use, the next section describes the busy schedules of HCPs and how this influenced HL.

6.3.1.2 Busy HCPs

Most participants complained that HCPs were always in a hurry and did not provide opportunities to ask questions and seek clarification. They desired individualised information tailored to their stage of BC and treatment modality. As HCPs appeared very busy, participants more often discussed issues with other patients and learned from each other.

> ‘Unless you personally ask the question, but to be explained, nothing you are told’
> *(Juliet, private hospital, second interview)*

There was an expressed need for time to be created for patients to ask questions Some participants may have been lucky because their doctors prompted questions, which was appreciated.

> ‘It is the doctor normally asks; she ask me if I have any questions? And she also asks my children if they have any questions concerning their mum. She is of great help’
> *(Lilly, private hospital, third interview)*

Participants’ narratives indicated they needed time to ask questions; therefore, opportunities should have been created for them to ask questions. When talking about this issue, Marion pointed out that when she asked questions, it seemed like she was burdening the doctor more as he had other patients waiting to be seen.

> ‘Every time we see the doctor he is in a hurry and if you ask more questions is like you are wasting his time…for there are other patients waiting to be seen’ *(Marion, public hospital, first interview).*

The ability to ask questions is a critical component of HL that demonstrates the patient’s ability to interact with HCPs. It was apparent that participants did not know that they could ask the HCPs questions or request written information. Patients’ questions can be considered an expression of their unmet information needs. Rhoda and Ruth were both educated and asked questions, whereas less educated participants did not ask. Participants commented that they desired time to seek clarification or ask the HCPs questions. Juliet, who had a secondary school education, always asked me questions during her interviews, stating that she forgot to ask the doctor.

> ‘Like today I had a question to ask the doctor about what am expected to eat. But there was no time’ *(Juliet, private hospital, second interview)*

A unique but unfortunate finding in terms of how instructions were given was raised by Rhoda. It appeared that HCPs only focused on aspects that the patients were not supposed to do, which was deemed as restricting and prohibitive.

6.3.1.3 The prohibitive nature of instructions

When giving instructions, HCPs focussed more on prohibitive aspects, which left participants feeling hopeless. Rhoda decried the use of the word ‘don’t’ in every instruction given. Patients interpreted this to mean that they had very few options in life and this was frustrating.

> ‘The nurses are trained to give you the information. But the way they tell you, it can weigh you down. It is as if you are putting your life at a stop. Then in the booklet, it is don’t, don’t, do not! Do not eat this, do not wear this, do not mix with people, do not do this do not do that, although they have a point because of the low immunity’ *(Rhoda, private hospital, third interview)*

She added that after receiving information, she chose what to implement and what to ignore.

> ‘You are being advised, but in a way, there is room for somebody to make their own judgment’ *(Rhoda, private hospital, third interview)*

This suggested that patients decided which information was relevant and useful based on their interpretation and specific needs. HCPs need to be cautious about how they give information as some of it sounded scary and discouraged participants. After chemotherapy, Rhoda was scheduled for radiotherapy; when she was taught about the 30 cycles, she was scared and feared how she would finish all of them.

> ‘He gave me information that I felt it was very scary…when he talked about the side effects…how it would affect my hand, I was not so sure that I would go through. I told my sister, ‘I do not think if I will do it’ *(Rhoda, private hospital, third interview)*

Although the narratives above were all Rhoda’s, they highlight fundamental issues that other participants may have failed to raise. Apart from communication, social support factors that influenced access to and use of information were identified.

6.3.2 Social support and networks

In this level, I report the social networks or links that women diagnosed with BC used or interacted with, because they helped them access, understand and use health information, or provided support that enhanced their HL in the BC journey.

6.3.2.1 Family and friends

Family and friends either impacted participants’ understanding of information or adherence to care and treatment. They supported participants in enduring the complex diagnostic and treatment procedures, and understanding and coping with the side effects and attending clinic follow-ups. The majority of participants reported they had disclosed their cancer diagnosis to someone close to them, such as nuclear family members, friends, workmates, church leaders and church members. These individuals had offered psychosocial support that enabled participants to access medical care and receive financial support for cancer treatment and other daily needs. Moreover, as cancer treatment extends beyond 1 month, several participants felt supported by those to whom they disclosed their condition. For example, these people would accompany them to the clinic, or remind them about taking their drugs or clinic appointments or offer support in making treatment decisions or seeking more information about cancer and its treatment. This was highlighted by the below statements.

> ‘In fact, they are treating me like a baby. They are always on my side, and they care very much about my feeding. And also they ensure I take these drugs’. *(Lilly, private hospital, second interview)*
>
> ‘I would go for treatment with my sister all the time. And we would discuss information further with my sister and if we don’t understand we will ask the doctor next time’ *(Rhoda, private hospital, second interview)*
>
> ‘My husband has been very, very supportive, I have always been visiting the clinic with him starting from the investigations. So we discussed with my husband, and we decided that we can do (remove) the entire breast’ *(Ruth, private hospital, third interview)*
>
> ‘I have a very sharp (bright) child. She is the one who normally brings me the drugs, and she asks me, mum have you forgotten to take your drugs?’ *(Debora, public hospital, third interview)*

> ‘The support I have got from my husband and my children. They have also stood still, and this is what has given me a lot of strength’ *(Juliet, private hospital, second interview)*

> ‘My feeding now is the best because of the support of my family members. In fact, am feeding very well especially on vegetables and fruits’ *(Lilly, private hospital, second interview)*

Different people encouraged participants to continue with treatment. For example, Olive received a lot of support and encouragement from her family and friends.

> ‘I just appreciate because when I am talking with my friends, with mummy and my brothers. It makes you move on, and you see there are still people who are thinking of you’ *(Olive, private hospital, second interview)*

However, some comments from family members were very frustrating:

> ‘My husband told me that, my hands are like that of thin cattle even if it is slaughtered you cannot have the meat. So that…(laughter)…now that the one made me to feel very bad… (participant’s laughter)’ (*Juliet, private hospital, second interview).*

In the above example, the husband’s comment could be related to a lack of insight about cancer cachexia, and prior information could have prevented this. Overall, it was evident from participants’ narratives that socio-psychological support offered by close family members and friends was pivotal for participants accessing BC services and encouraging and ensuring that they adhered to treatment. However, other participants were not willing to disclose their diagnosis to other persons because of stigma and fear.

6.3.3 Section summary

The meso factors that influenced HL cut across social networks and HCP-related factors (use of medical jargon, not giving instructions and information) which was distressing. Social support from relatives, and friends enabled access, and use of information. The findings aligning with organisational (macro) factors as per the SEM are presented below.

6.4 Subtheme three: Organisational (macro) factors

Organisational level factors refer to aspects of health facilities and associated activities that are geared towards facilitating individual behaviour. This includes HL policies, best practices and any effort geared towards enhancing patients’ information experience at all stages of the BC journey. At this level of the SEM, the influential factors identified from this study were institutional policies, patient/family education programme, and healthcare financing. The differences between the private and public hospitals were evident from the interviews and are also discussed.

6.4.1 Institutional policies

A recurrent finding across the interviews, particularly for public hospital participants, was the mandatory pre-treatment counselling. This counselling was not mentioned by any participant from the private hospital. Before commencing any treatment modality, the participant and their close relatives paid for a counselling session (2 USD) in which all treatment information was shared they were allowed to express their fears and ask questions. They appreciated this counselling as it helped them accept their BC diagnosis and upcoming treatment.

> 'Before I was administered the drugs, I had sessions of counselling that a patient is taken through' *(Deborah, public hospital, first interview)*

It emerged that this counselling helped patients to prepare for treatment and altered their fatalistic beliefs about BC.

> 'I got someone who can give me good counselling and not threaten me with bad news about, 'when you get cancer, cancer kills and cancer can't be cured' *(Marion, public hospital, second interview)*

While the information received overall changed their perception of cancer as a death sentence, counselling had increased their acceptance of the disease.

6.4.2 Written information seen as useful

At the public hospital, it was routine for patients to be given a file with all their diagnostic and treatment information. A participant from the public hospital described the file with all of her reports, which she had been instructed to carry around when seeking health services. Although she could not comprehend what was written in the file, she always carried it because other HCPs could get information about her treatment from it.

> 'I read the file I was given but I couldn't understand and even now I can't remember. I move with the file everywhere just in case I got to a place I show them so that they may read it' *(Lilly, private hospital, third interview)*

This was a good practice as it would alert other HCPs that the patient was on BC treatment. This way they would avoid giving drugs that would cause drug-drug interaction adverse effects. Although participants found the written summary helpful, they complained about the financial challenges, especially with the NHIF.

6.4.3 Healthcare financing

Financial ability was a dominant thread in the interviews and cut across the levels of the SEM. At the macro level, the focus was on the government insurance (NHIF), and how it catered for cancer treatment. It is important to note that NHIF does not cover all the treatment costs, meaning participants had to pay for part of the costs.

> ‘For me, I thank God because I had an insurance cover although at one point during radiotherapy we exhausted the cover’ *(Rhoda, private hospital, third interview)*

> ‘By the way, this NHIF card you need to have paid money every month, 500 (5 USD). But there are some who are down in the rurals who cannot pay for NHIF’ (*Debora, public hospital, second interview)*

6.5 Chapter summary

Overall, many factors cutting across all levels of the SEM influenced how participants accessed, understood, and used health information. In their narratives, participants identified enablers and barriers to information access and use, and gave recommendations, which if implemented, could optimise the BC illness journey experience. These factors are discussed in Chapter Seven.

7 CHAPTER SEVEN: DISCUSSION

7.1 Introduction

This chapter discusses and interprets the findings of the present study in relation to existing literature. The main aim of this study was to describe the HL experiences of Kenyan BC survivors and identify the socio-ecological factors that influenced how they accessed, understood and used information along their cancer journey. The discussion is grounded in the assumptions of the SEM, which recognises the relationship between an individual and their environment and provides a basis for understanding the various factors affecting behaviour (Bronfenbrenner, 1998). This study found that several factors influenced how patients accessed, understood and used health information to make decisions. These factors spanned the tenets of the SEM and acted as either facilitators or barriers to HL. Therefore, there are micro, macro and meso factors that influence HL, and at times they overlap. Across the three levels, finance was a dominant factor that determined whether participants postponed or sought healthcare. The themes generated from the interviews provided ample evidence (see Table 19 below) that all levels of the SEM played key roles in influencing HL among patients with BC and addressed the gaps in extant literature identified and discussed in Chapter Three.

7.1.1 Meeting the study objectives

The purpose of this study was to explore the experiences of Kenyan BC survivors and identify the socio-ecological factors that influenced how they accessed, understood and used information along their BC journey. This study achieved its objectives, and also clarified the need and potential for further investigation on this subject, particularly with patients with BC and HCPs. Table 19 below maps out how the findings meet the study objectives.

Table 19: Mapping objectives to the research findings

#	Objective	Findings
1.	To describe the experiences of accessing, understanding and using cancer-related information along the BC journey	Provision of the right information helped participants to cope better with the daunting journey of a BC diagnosis and ensuing treatment. The ability to cope was shaped by the information received and how participants perceived it. The information was drawn from various sources: media (television, radio, Internet), social networks (friends, and relatives), HCPs (doctors, nurses, and dieticians) and books. Other sources were screening camps and other patients with cancer. Participants with a high education level (college and high school) searched the Internet for BC information, although they could not name any particular site they had visited. Despite accessing information from various sources, some participants acknowledged that not all sources were credible. It was notable that HCPs were identified as sources of information at the diagnosis and treatment stage but were largely absent pre-diagnosis. Most information before diagnosis was obtained from media and social networks. This suggests that media and social networks should be strengthened and enhanced to provide credible BC information. One cannot ignore the suffering evident in participants' narratives related to the lack of information about side effects and how to manage them. In addition, there was variation in how side effects were experienced; especially in that not all patients experienced side effects. Surprisingly, the physical side effects (those that affected the body image such as hair loss, skin and nail changes and weight loss) were not as devastating as emotional side effects. All participants had some information about BC, but there was no awareness and knowledge about the signs and symptoms among some participants. This was especially evident among participants who had no family history of BC and tend to adopt a 'wait and see' attitude until more severe signs emerged before they sought medical intervention. However, those with a family history of BC and a high level of education (except Abigail, a librarian) had knowledge, practised BSE, and promptly sought healthcare when they discovered a breast lump. These participants accessed and used information and consequently sought early medical intervention for their symptoms, which is a hallmark of HL (i.e. using information to make decisions). However, participants that had no previous family history of BC felt guilty that they 'introduced' BC to the family.
2.	To determine what BC survivors understood about BC in their communication with HCPs	BC diagnosis invoked extreme fear among the participants, with most referring to it as a 'death sentence'. Moreover, the manner in which the diagnosis was broken shocked participants. Notably, doctors gave them treatment information while in the shocked state. This could be the reason that most participants did not know about BC treatment, side effects and management. It was evident that HCPs used medical jargon, which patients used in turn without understanding. There may be an assumption that patients

		who use medical terms understand those terms, but the findings showed this was not the case. Participants avoided asking questions because HCPs seemed busy. Doctors provided the most information, and participants expressed dissatisfaction when they asked nurses any question as they always referred patients back to the doctor. This suggested that nurses did not have specialty cancer training and capacity to give appropriate information. Therefore, there is need for appropriate and readily available BC information. The findings revealed how the instructions given by HCPs added to participants' feelings of hopelessness. All instructions seemed to focus on what participants should not do. (e.g. Rhoda complained that everything was 'don't, don't, don't'). In hospital, the instructions given to patients were violated; for example, Juliet was served with processed food despite being advised against it.
3.	To identify the information needs of women diagnosed with BC	This study found that participants had unique needs at every stage of their BC journey. However, the need to know about the causes of BC arose even after completing treatment. This suggested that participants desired to have information so that they could prevent BC recurrence. Priority information needs were related to specific treatments and related side effects, coping with side effects, investigations and survival after finishing treatment. Participants valued information from other patients as it was based on real experience and suggested that sessions could be planned for patients to share their experiences. Participants also valued and trusted information from HCPS but resorted to other sources when their information needs were unmet.
4.	To identify the socio-ecological factors that influenced HL among women diagnosed with BC	Several factors influenced how patients accessed, understood, and used health information to make decisions. These factors spanned the levels of the SEM and acted as either facilitators or barriers to HL. These were micro (BC awareness, attitudes towards BC screening, BC fatalism, apprehension after 'bad news', physical and psychological condition), meso (medical jargon, social capital, SDM) and macro (institutional policies, provision of medical reports, information booklets, counselling services) factors that influenced HL and at times they overlapped. Across the three levels, finance was a thread that determined whether participants postponed or sought timely healthcare.

The first part of this chapter focuses on the major findings of this study and how they relate to the SEM, which was the guiding theoretical framework (See Chapter Two). The implications of the results are explained in the context of healthcare policy and practice, patient education and HL. This study discovered various socioeconomic and ecological factors that influenced how women accessed, understood, and used health information to make treatment decisions. These variables were categorised into three levels according to the SEM: micro (individual) factors, meso (interpersonal) factors and macro (societal and organisational) factors (Figure 8). However, this division did not imply a separation of these levels as there was considerable overlap between these factors in this study. Previous studies (David, 2020) reported that the boundaries of the SEM were indistinct and bi-directional; for example, factors at the macro levels were also expressed at the micro level. Some factors (e.g., financial resources) traversed the three SEM levels. These factors are discussed in detail at the level at which they appeared to influence HL the most. This section presents a detailed discussion of the factors that influenced each level.

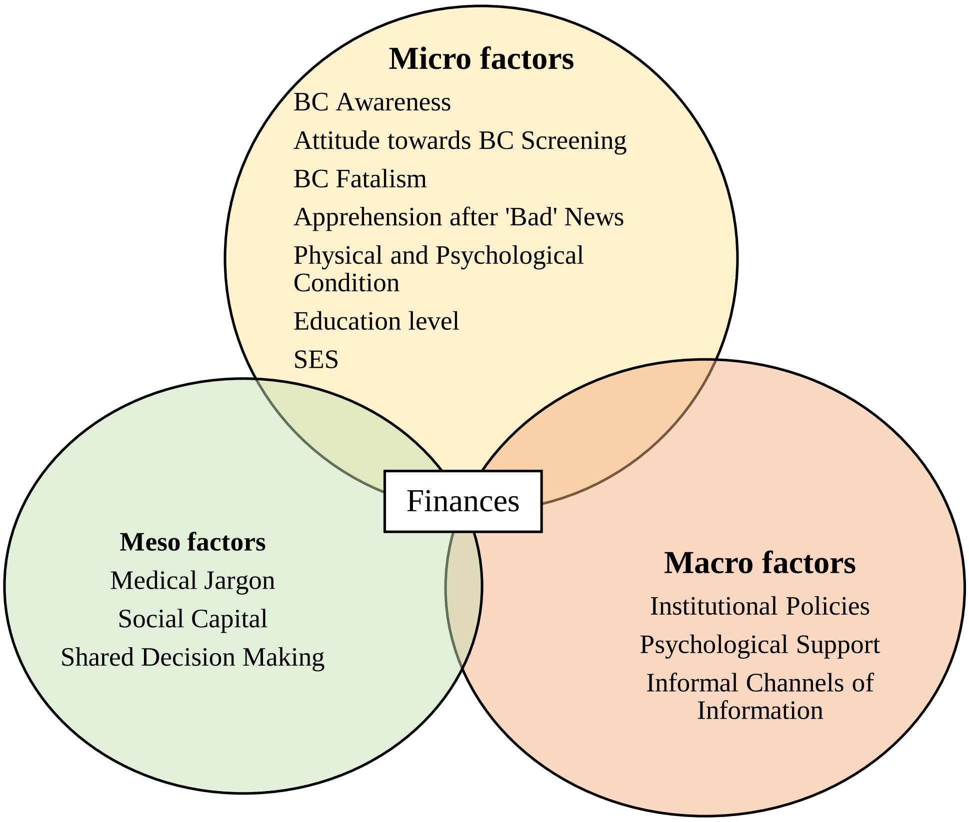


Figure 8: Socio-ecological factors that influenced health literacy among patients with breast cancer.

7.2 Micro (individual) factors that influenced HL

This study found that the individual factors that influenced HL were the women’s knowledge, awareness, beliefs and attitudes towards BC and their information needs.

7.2.1 BC awareness

Analysis of participants’ responses revealed that although the women in this study had some knowledge that a breast lump was a bad sign, they did not routinely go for screening. Few women (e.g., Rhoda and Paula) practised monthly BSE. Similar findings were reported in previous studies from countries such as Iran (Haghighi et al.,2015), Jordan (Othman et al., 2015), Indonesia (Iskandarsyah et al., 2014), Germany (Schmidt et al., 2015) and Nigeria (Adedimeji et al., 2017). Women’s inability to recognise BC symptoms, disease severity and the need for medical attention appeared to result from a lack of BC awareness and inadequate knowledge about signs and symptoms of the disease. This finding was consistent with previous research from other developing countries (Adams et al.,2009; Adedimeji et al., 2017; Iskandarsyah et al., 2014; McEwan et al., 2014), which highlighted that a lack of awareness and knowledge about BC screening was a significant predictor of BC presentation delay. Several issues, such as a lack of health awareness and education, limited health education programmes, particularly in rural or isolated areas, and insufficient information provided by HCPs may contribute to this lack of knowledge (Armin et al., 2014).

Media campaigns, such as public announcements on television, radio and in newspapers, have been found to be an effective way in increasing breast health awareness, educating women how to conduct BSE and improving breast screening practices (Dadzi & Adam, 2019). Findings reported by Khan et al., (2015) had some similarities with the present study in that women had a good awareness of BC and practised BSE; however, they did not have in-depth knowledge, and did not use this knowledge to seek timely healthcare intervention, which led to delays.

Most participants in this study were aware that a breast lump was a bad sign. However, their overall lack of awareness about BC and the importance of early detection along with other socio-ecological factors, including the uncertainty a positive BC diagnosis brings, and the strong belief in fate, negatively impacted their decision to undergo BC screening. Despite knowing that a breast lump was a danger sign, most participants feared seeking healthcare intervention. For example, Connie thought of committing suicide after discovering a lump.

Her friend encouraged her to go for testing and even introduced her to another friend who was an HCP. Avis-Williams et al., (2009) assessed the knowledge, attitudes/beliefs and practices toward BC screening and clinical trials among underserved African American women in Mississippi and documented similar findings. They found that patients had little knowledge of the risk factors for BC, only mentioning family history and lifestyle. In their focus group discussions, Avis-Williams et al. (2009) reported that women mentioned smoking, use of food preservatives (similar to some comments in this study) and injury to the breast (Abigail in this study attributed her injury from falling as the cause of her BC) as risk factors. In addition, women in that study did not appreciate the importance of early detection and screening for BC. Similarly, Sub-Saharan African, and Chinese women have been reported to avoid discussing cancer, with Chinese women associating it with an increased risk of developing it (March et al., 2018). This current study supports previous evidence that women in LMICs lacked BC awareness, did not know the risk factors, signs and symptoms, and the majority did not practise BSE. However, the majority knew that a breast lump was a bad sign, although perceptions about the lump may have caused diagnostic delay, meaning the BC had progressed to a later stage by the time they sought medical intervention.

In this study, participants had knowledge of BC signs, but were frightened to go for screening. Some, like Paula, Ruth, and Rhoda, had knowledge of and practised BSE. These findings differed from a cross-sectional study by Dadzi and Adam (2019) that found significantly low levels of BC awareness in Ghana. That study recommended educating women, especially in rural areas, on BSE as a preventive measure for BC. However, in this study, even though Juliet had yearly health check-ups paid for by her private health insurance, the breast lump was not detected. From her statement, it was unclear whether mammography was included in the yearly check-up, as she was diagnosed with BC in November, but her yearly medical check in September of the same year had not pointed to the possibility of BC. This raised questions about what the yearly medical check entailed. In contrast, Abigail had never gone for BC screening, but she learned from her church group how women with BC had their breasts cut off and this scared her. This fear of losing her breast may have contributed to her 1-year delay of diagnosis because she thought that her lump was breast milk engorgement. In addition, at 28 years, Abigail was young and outside the ‘normal’ age range for BC (80% of newly diagnosed BC patients are aged 45 years and above). None of the participants in this study described undergoing routine mammography screening, with Lilly, Connie and Juliet only having this screening after a lump had been found.

This study demonstrated variation in participants' knowledge and understanding of symptoms of BC and routine practice of BSE; some knew what to do and others did not. A possible explanation for these findings may be individual socioecological influences. For example, women's education level and SES appeared to be important factors. These finding suggested that HL was positively associated with literacy and SES, which was consistent with a systematic review by Humphrys et al., (2019) that investigated how HL influenced the journey to cancer diagnosis. The present study reported that factors which influence HL may affect a patient's ability to access and understand BC symptoms information, appraise this information in relation to bodily changes and navigate the healthcare system to access the specialised care required to obtain a diagnosis. It is therefore likely that the positive connection between education level, SES and HL may have enabled participants such as Rhoda and Juliet to perform BSE and go for BC screening. BC awareness was also influenced by meso and macro factors, which are discussed below.

7.2.2 Attitude towards BC screening and a positive diagnosis

Many participants were particularly concerned about the results of their diagnostic test, the immense financial resources needed for treatment (Marion, Paula, Rhoda, Olive) and the inability to afford the treatment. One participant's suicidal thought (Connie, see Section 7.2.1) was an unexpected finding that may need further investigation to clarify the association between a BC diagnosis and suicide. This suicidal feeling depicted the powerlessness and hopelessness that a BC diagnosis confers on women and calls for holistic intervention and a sensitive approach to sharing information following a BC diagnosis. Although some of these attitudes are considered typical among patients diagnosed with a chronic illness in low resource settings, similar findings were described in the studies reviewed in Chapter Three (Akuoko et al., 2017; Ilaboya et al., 2018; Leena, 2020; McEwan et al., 2014) and in other socioeconomic classes . The following is a detailed analysis of these perceptions of fear.

The fear of a positive BC diagnosis overwhelmed Debora as she collected her results, whereas Marion and Olive narrated their fear of death and leaving their families. Juliet feared the side effects of treatment and how her body image would change. This fear arose from an experience with a close relative who was treated for cancer and who lost much weight, his skin colour darkened, and he later died. Overall, there was a fear of the unknown as participants did not have information and did not know what to expect. These findings were consistent with those of previous studies where fear, personal values and attitudes were significant factors in BC awareness in the UAE (Leena, 2020), Germany (Schmidt et al., 2015), Egypt (McEwan et al., 2014) and the US (Weber et al., 2013). This suggested that the factors associated with attitude affect women in high- and low-income settings in the same measure. The results of this study identified several personal attitudes held by participants that affected their willingness to undergo BC screening. These attitudes were barriers to HL and suggested that the participants had an overall slightly negative attitude towards and fear of BC screening, which was generally characterised by apprehension and fatalistic thoughts.

7.2.3 BC fatalism

Fear of a positive diagnosis of BC and the fatalistic thoughts discouraged women from participating in screening because a positive diagnosis was perceived as a ‘death sentence’. Indeed, for many patients, a positive cancer diagnosis is culturally stigmatised and can contribute to social isolation (Gakunga et al., 2019). For example, other members of the community may believe that cancer is the product of a ‘sin’ committed by the patient (Rosser, Njoroge, & Huchko, 2016). Therefore, irrespective of the diagnostic outcome, that person would be looked at with suspicion. This stigma and negative connotations attached to a BC diagnosis are pervasive and cut across countries, cultures and communities (Mutebi & Edge, 2014). Similar findings were reported by Nyblade et al., (2017), who conducted two qualitative exploratory studies in Karnataka, India; one focused on cervical cancer and the other on BC. Based on in-depth interviews and focus group discussions, cancer stigma was defined as both experienced (enacted) stigma, such as isolation or verbal stigma, and anticipated (fear of) stigma if a cancer diagnosis was disclosed. In this current study, Marion suffered social isolation, and Juliet had anticipated stigma and relinquished her church treasurer role because of fear that people would know about her BC diagnosis. For women with symptoms, stigma was a feared outcome of a cancer diagnosis, and described as a barrier to screening, early diagnosis and treatment seeking. This highlighted that stigma was a common phenomenon in Kenyan communities, which is a key factor in BC screening, and is a terrifying outcome of a cancer diagnosis (Carreira et al., 2018). Participants such as Juliet kept their diagnosis within their nuclear family for fear of stigma. Stigma was therefore a major barrier to women with symptoms seeking screening, early diagnosis and treatment, and may explain why there is hesitancy in seeking BC screening services.

The present findings also concurred with prior research from Sub-Saharan African countries (Meacham et al., 2016) and expanded understanding of how stigma impacted care engagement. For example, Meacham et al. (2016) found that stigma prevented survivors in Uganda from seeking help and discouraged them from staying in care until treatment was completed. Contrary to expectations, Meacham et al. (2016) showed that social support for patients with BC in Uganda was rare, particularly from husbands. This differed from the present study, where most married women were supported by their husbands. This suggested that the presence of social support can help women participate in BC care services. A detailed discussion on social capital and support is provided later in this chapter (See Section 7.3.2). Although more research on cancer-related stigma is needed, an examination of the driving factors and stigma indicators can help HCPs to better understand how to reduce stigma, improve access to information, screening and treatment, and support patients' overall quality of life (Carreira et al., 2018; Güth, et al., 2011).

Another explanation for the fear of a positive diagnosis was closely related to femininity. A positive BC diagnosis is often followed by surgery in which part of or the whole breast is removed (mastectomy). Nine of the 11 participants in this study had undergone surgery and had either partial or total mastectomy. Mastectomy is seen as disfiguring as it involves a permanent change in the physical appearance of the woman. The alleged loss of feminine beauty and elegance is not only agonising but is also seen as a disgrace. It is surprising that in the present study, participants did not directly voice concern about the loss of a breast, but anxiety about the loss could be inferred from their narratives. For example, Debora conveyed how the doctor advised her husband against marrying another woman and mistreating her because she had only one breast. This suggested that though the women did not voice concerns about losing a breast, they were struggling with the loss of this symbol of femininity internally. Chuang et al., (2018) highlighted that across cultures, the breast is the symbol of femininity (representing beauty, sexuality, and food for babies). Therefore, thoughts of losing a breast have been reported in other studies as distressing, and the psychological effect is severe for many. The fear of the implications of a positive diagnosis that prevented women from undertaking screening mammography was consistent with the findings of a previous study (Kobeissi et al.,2014) that explored Iranian immigrant women living in Southern California. That study investigated the effect of BC knowledge and attitudes on screening.

Although women in that study had access to mammography screening services, most feared the outcomes of a positive BC diagnosis. Those authors concluded that personal attitudes (values, fears, perceptions) influenced the use of mammography among immigrant Iranian women in the US.

A possible explanation for the fear of a BC diagnosis among women in the present study was their lack of knowledge about the disease, treatment and how to cope with the perceived consequences of the diagnosis, which may have been a consequence of low HL. This was evident from the more optimistic reports made by participants who had dealt with survivors of BC, or who had gained adequate details on the disease and benefits of early detection and confirmed the argument that HL plays a role in the motivation to use health services (Kamimura et al., 2016). It can be postulated that the fear experienced by the women in this study affected their cognition (Gibbons, 2017), and was barrier to HL. However, even those with a high HL and good access to quality information were still scared of having BC. Although this might not necessarily have prevented them from screening or taking action, they were still terrified because of the treatment and potential long-term consequences. When developing health interventions for BC awareness, the focus should be on enhancing personal attitudes to improve BC screening and early detection, which in turn could eliminate or reduce the fear and anxiety on suspicion of BC.

7.2.4 Fear and suspicion of BC

In the present study, suspicion of BC when a lump was discovered caused immense fear, and the interval between sample taking and getting results caused tension and anxiety. Debora, a public hospital participant, described her worst time as waiting for the biopsy results. Many questions went through her mind, and she wondered what would become of her if she was found to have BC. It is almost certain that appropriate information provided by the HCPs would have reduced this anxiety (Halbach et al., 2016). Previous studies (Azami-Aghdash et al., 2015; Pineault, 2007) demonstrated that in BC screening programmes, nurses can make a big difference by assessing patients’ anxiety and providing the necessary informational support. They can also provide the necessary follow-up and personalised support while a patient waits for a diagnosis. In this study, the period between participants discovering a lump and confirming the BC diagnosis was described as devastating. Most participants expressed fear, anxiety and uncertainty at the possibility of having BC. Brown et al. (2017) identified the fear of BC as a major cause of anxiety and found that providing social support to women awaiting a diagnosis reduced this anxiety. Moreover, Brown et al. (2017) showed that while emotional support from family and social networks (such as a spouse, family or friends) was comforting, it did not alleviate anxiety; even though the women were satisfied with the assistance they received, their anxiety did not decrease. Only the support provided by HCPs alleviated their anxiety because it included emotional and informational components that were critical in calming women while they waited for a diagnosis. In the present study, the majority of women desired emotional support from HCPs to be accompanied by information. These findings were consistent with other research that concluded that with HCPs, patients get an opportunity to express their concerns and get professional assistance (Keyzer-Dekker et al., 2014). Keyzer-Dekker et al. (2014) further concluded that women diagnosed with BC experienced high levels of anxiety and distress during the diagnostic process and required a tailor-made protocol for support. The important role of HCPS was also highlighted by Adam and Korateng (2020), and is further discussed with the meso factors of the SEM (See Section 7.3.1). In addition to their anxiety on discovering a lump, participants in this study reported feeling apprehension when they received the ‘bad news’ of a BC diagnosis.

7.2.5 Apprehension after receiving the ‘bad news’ of a BC diagnosis

In this study, when the ‘bad news’ of the BC diagnosis was broken, most participants harboured fatalistic thoughts. They cried, prayed and wondered why God had chosen them to have cancer. These heightened emotions after receiving the BC diagnosis were worsened by the financial challenges and fear of not being able to pay for the treatment costs. Previous literature confirmed that how the BC diagnosis was broken to a patient impacted their emotional well-being (Rao et al., 2016). This study offers insights into how the participants felt after a BC diagnosis. Given their emotional upset, it may be difficult to give a patient information, but the course of management needs to be discussed with them. For example, Debora received her BC diagnosis, and surgery was planned and performed the following day without detailed pre- and post-surgery instructions. This means that while she was still struggling with the emotions of a positive BC diagnosis, major decisions were made in a short period of time without providing her with opportunity to reflect. In this case, she underwent a mastectomy (breast removal surgery) within 24 hours of receiving the ‘bad news’; this was overwhelming.

According to Halbach et al. (2016), patients with BC are habitually given a lot of information at diagnosis while they are in hospital, but the emotional upset at diagnosis prevents patients from taking in the doctor's instructions. However, participants in the current study appeared to feel better after starting treatment when they interacted with other patients and exchanged information, and by their final interviews, they perceived BC to be like any other disease. This was consistent with a study by Akbolat et al., (2021) from Turkey that found that the heath information needs of patients with BC changed over time. Furthermore, the present findings corroborated those of Choi (2021), who concluded that providing simple information customised to match patients' needs was essential as it helped them cope with a BC diagnosis.

Rao et al. (2016) found that after 'breaking the bad news' of a BC diagnosis, '*cancer*' was the last word that the women heard, and any information given after that was not understood. Notably, the women in this study who had a higher level of education (e.g., Rhoda, Naomi, Ruth) desired full diagnostic and prognostic information. This showed that despite their apprehension, women benefited from relevant information that met their needs (Schmidt et al., 2016). Almost all patients want more information about their condition, particularly about immediate medical issues such as treatments or side effects, as opposed to long-term or non-medical issues (Schmidt et al., 2016). In this study, most patients with BC wanted their disease to be disclosed, but a smaller group did not wish for disclosure of their cancer diagnosis for fear of stigma (Described in Section 7.2.3). Regardless of differences in the desire for disclosure, both groups wanted the same specific information about their cancer and preferred the involvement of close family members in decision-making (Schmidt et al., 2016). Further research examining the impact of factors such as disease stage or family relationships could aid physicians in breaking bad news. The present findings support the findings of other studies in which patients reported positive outcomes if their information needs were met. Relevant information that meets the patients' need increases coping, reduces stress, and improves well-being and compliance with treatment (Ormandy, 2011).

The present findings were also consistent with Corless et al., (2015), who found that patients newly diagnosed with HIV in Botswana described the HL challenges of being given information immediately after finding out their positive status. That study identified denial and psychological challenges as major barriers to learning new information and recommended that patients are always accompanied by someone from their support network. Ormandy (2008) also alluded to this when a patient in her chronic kidney disease study in the UK stated that the doctor explained about treatment when she was still very emotional. This poses a challenge and raises a question for HCPs regarding the right time to introduce information. The present findings showed there is a need for information right from the time of diagnosis, but other factors, especially the patient's emotional status, also come into play. A recommendation to overcome this would be to break the bad news, allow the patient and their significant others to internalise, and then start an education programme before treatment. Such processes and measures have been developed in high income countries and found to be beneficial for patients (McElroy et al., 2019). At diagnosis, the doctor should avoid large quantities of information and focus on high quality or high priority needs, as noted by Ormandy (2011). In that study, the needs identified were similar to those in the present study, and included treatment modalities, finances and side effects (discussed under information needs in Section 7.4.7.2.71). Therefore, there is a need for HCPs to assess patients' readiness to learn so that teaching can start as soon as the patient and family are ready, instead of immediately after 'breaking bad news'. It is important to provide appropriate information to patients with BC as this helps them cope with the new situation (Schmidt et al., 2016). The above sections focused on attitudes towards and fears about BC, and the following section discusses how participants' physical and psychological conditions influenced their HL.

7.2.6 Participants' physical and psychological condition

The findings from this study presented an account of the side effects women experienced due to the complex BC treatment regimens. These side effects manifested physically, emotionally and psychologically and may have affected how participants accessed, understood and used health information. Many participants experienced emotional or psychological stress as well due to the difficulty in coping with BC, a major illness. The findings also suggested that participants lacked knowledge and understanding of the possible side effects they would encounter.

7.2.6.1 Physical

Common physical side effects experienced by study participants were nausea and vomiting, skin and nail changes, lethargy, amenorrhea, low immunity and hair loss. Equally important was that the side effects manifested after day five of treatment and not all patients experienced them. Side effects of cancer treatments have a significant impact on health literacy. Patients treated with chemotherapy and radiation may have fatigue, nausea, hair loss, and other uncomfortable symptoms, making it difficult to concentrate on medical information or retain the information discussed at the appointment (Rust, & Davis. 2013). Long-term therapy can also lead to cognitive problems and reduced mobility, which further complicate the situation (Bolton & Isaacs, 2018). Similarly, these aspects of cancer care also affect patient participation in healthcare decision-making.

Participants acknowledged that although some information had been given, the whole range of systemic side effects was not covered. There were similarities between the concerns raised in this study and those reported by Rutten et al. (2005), who found that patients were primarily interested in learning their specific diagnosis, including the disease stage, treatment options and the side effects associated with those options, during the diagnosis and treatment phases. Similarly, Carreira et al. (2018) reported that long-term iatrogenic effects of treatment affected a large percentage of BC survivors, including fatigue, persistent pain, lymphedema, vasomotor symptoms and infertility, all of which can have a negative impact on quality of life and mental health. These side effects can also hinder information access and use, whereas appropriate information provision and use by patients can improve the patient experience (Ormandy, 2011). Therefore, information provision is a coping strategy that improves the quality of life of patients with BC (Fletcher et al., 2017; Tariman et al., 2014; Tucker et al.,2017). Specific information needs are discussed later in a separate section (7.2.7.2).

7.2.6.2 Psychological

Anger, anxiety, despair, helplessness, fear of death and suicidal thoughts were emotions reported by women in this study. All of these emotions may have affected the women’s ability to learn new information and use it to make treatment-related decisions. This is especially true for patients with BC who have undergone chemotherapy or radiotherapy because of ‘chemo brain’ or ‘chemo fog’, a phenomenon where brain function is affected by the treatment (Gibbons, 2017). A previous descriptive phenomenological study (Gibbons, 2017) investigated the lived experience of chemo brain by women after undergoing BC chemotherapy. That study confirmed the existence of cognitive changes during and after chemotherapy, as well as the effects of these changes on daily life, such as fatigue, emotions and the importance of support. Participants in the present study may have experienced chemo brain/fog, which may have interfered with their attention and recall of information they were given earlier in the treatment phase. For example, Connie gave different accounts of how she was diagnosed with BC. At one point, she stated that she routinely performed BSE, which depicted some BC awareness, whereas she stated in a subsequent interview that her breast lump was discovered during a screening camp.

This dissonance in information could be explained by the chemo brain effect (Gibbons, 2017). Connie struggled to clearly recollect the chronology of her BC journey, which had implications for her ability to process information given to her. This places patients who have undergone chemo or radiotherapy in a special ‘information needs’ category, meaning they cannot be taught just like any other patients. Therefore, for many patients with BC, the usual ways of providing information may not be effective because of the major psychosocial and cognitive changes. This was reflected in a qualitative study from the US noting that nurses needed to provide education and support for patients experiencing chemo brain (Rust & Davis, 2013). This means the timing and content of teaching are critical to ensure patients’ and families’ understanding, coping, compliance and acceptance, and can help improve their quality of life (Adam & Koranteng, 2020). Therefore, it is critical for HCPs to ensure that patients with BC comprehend the information they are given.

This study highlighted the importance of educating HCPs, patients and family members about the cognitive changes associated with chemotherapy and how to cope with these changes. Other long-term psychological challenges identified by Carreira et al. (2018) included difficulties readjusting to professional, social and intimate relationships, as well as coping with future uncertainty. Some of these factors were reported by the present participants; for example, Debora stated that she was stressed after her BC diagnosis, and this stress affected her performance at work, and colleagues noticed that she had changed. In contrast, Naomi reported that she did not allow herself to be stressed. Several other participants reported feelings of anxiety in case the BC recurred. Having considered the micro factors that influenced HL, the section below extends individual experiences of accessing, understanding and using health information.

7.2.7 Education level

Education seems to be a major factor in BC health literacy, as it can have an effect on the amount of information individuals are exposed to regarding BC and its risk factors. As Park, et al., (2018) assert, education is one of the strongest predictors of health behaviours. Thus, those who lack education may not know much about BC or how certain lifestyle choices, such as smoking and alcohol consumption, could increase their risk for developing the disease. On the other hand, those with higher levels of education may be better equipped to understand medical jargon used when discussing possible treatments and be more likely to incorporate additional health measures into their treatment regimen(Park et al.,2018). This was evident in Rhodah and Ruth who seemed to interact well with HCPs and also sought additional information from the internet. Education also impacts socioeconomic status which can then impact access to lifetime opportunities to learn more about health issues including BC prevention methods and diagnosis techniques. This way the more educated can make more informed decisions related to treatment options navigation decisions.

7.2.8 Socioeconomic status (SES)

SES is one of the main factors influencing cancer health literacy. It affects access to healthcare, educational materials, and information about risk factors (Kritsotakis & Gamarnikow, 2004). Individuals with low SES are more likely to experience a lower level of knowledge pertaining to cancer prevention, diagnosis, treatments, and the latest research developments in this field. Additionally, cultural norms can also play an important role in influencing cancer health literacy. For example, some cultures may place greater importance on alternative therapies than traditional medical care when it comes to managing both preventive and treatment-related aspects of cancer care. In this study, Marion hinted that some patients sought traditional medicine in addition to the conventional medical treatment. It is well known that knowledge obtained through family members or religious beliefs may prevent individuals from actively seeking evidence-based treatments as well as recommend preventive measures for their personal health behaviors (Kim et al.,2015).

Having considered the micro factors that influenced HL, the section below extends individual experiences of accessing, understanding, and using health information

7.2.9 Experiences of accessing, understanding, and using information

The women in this study learned about BC from mass media (television, radio and the Internet), social networks, HCPs (doctors, nurses and dieticians) and books. Other sources included cancer screening camps, other cancer survivors, friends and family members. Although some participants (college and high school graduates) stated that they used the Internet to obtain BC information, they were unable to name any specific sites they had visited.

7.2.9.1 Accessing BC information: Sources of information

7.2.9.1.1 Television

Data from this study showed that most women learnt about BC signs and symptoms from the television. Television is one of the most effective forms of media to disseminate news about BC in Kenya. However, this information is usually approached with suspicion as people feel that most television stations have an agenda to ‘sell news’, and the information can either be believed or not. Although most women in this study learned about BC from television, it remained unclear whether they believed this information. However, it was possible that this information was not internalised and used because even after hearing about BC screening and BSE from television, Lilly, and Debora did not take any action to seek healthcare. It therefore appeared that although television was a popular source of information, most of the information was not trusted, which was also reported by a previous study (Enzler et al., 2019). One participant from the private hospital recommended that the hospital ran BC information adverts on television screens while patients await treatment or consultation. However, David (2020) indicated that women do not trust such information, especially in a private hospital because they think it is a marketing gimmick but would trust the information if it was in a public facility.

7.2.9.1.2 Healthcare providers

Most women in this study reported that HCPs’ advice and knowledge was more valuable than that provided by friends, family, media and other social networks. It appeared that doctors gave the most information, although they used complex language at times that participants did not understand (discussed in Section 7.5.1.1). Mwanri et al. (2020) conducted a systematic review on the HL environment of breast and cervical cancer among black women and concluded that HCPs could help women navigate the barriers encountered along the cancer journey. However, they can only do this if they understand the obstacles to information access and use. As shown in other studies (e.g. Beaver et al., 2006; Doumit et al., 2010; Othman et al., 2015; Shen et al., 2019), patients attach great value to and trust the information and advice offered by medical professionals rather than a lay person. Beaver et al. (2009) evaluated a telephone intervention administered by specialist BC nurses that aimed to meet patients’ information needs and reported that women considered these BC nurses as a prominent source of information.

An unusual finding from the present study was participants’ perception that most health information was given in a prohibitive manner, which was discouraging. Rhoda recounted that this modality of giving instructions made patients feel hopeless. She criticised the use of the word ‘don’t’ in every instruction given, stating that this made patients feel they had very few choices in life. In a way, this magnified the ‘BC monster’ and increased their anxiety and uncertainty.

It can be concluded that HCPs have a key role to play in providing information that will raise BC awareness, which will help to foster a culture of early BC detection among women in Kenya. However, they must present the information in a manner that encourages patients to use it. In addition, their role in providing contextualised information along the BC journey cannot be underestimated. Previous studies highlighted various strategies that HCPs can adopt to improve information provision (Bickes et al.,2021). Some of these strategies (e.g., teach-back method) are discussed in the next section. Overall, barriers to developing HL and practising HL skills were personal to the participants' characteristics or were created by some HCPs who worked in ways that did not support the development of those HL skills. Teaching methods that can communicate accurate BC information to various patient populations are needed (Winefield et al.,2003), and HCPs must ensure clear communication to promote HL.

7.2.9.1.3 Other patients and religious leaders

Analysis of the present findings identified women religious leaders as key influencers of how BC information was accessed and used. Unfortunately, some of them did not have credible information; for example, Marion was advised to apply *Robb* (an over-the-counter ointment) to a breast lump by her *Mama Assembly* (a respected woman religious leader). Marion applied the ointment for more than a month but decided to seek healthcare intervention when there was no improvement. In the present study, participants indicated they trusted information provided by local community members and leaders. This finding matched that observed in other studies where it was evident that people tended to trust the information provided by religious and local leaders (Gakunga et al., 2019). This implied that BC survivors, religious and local community organisations complement HCPs in terms of playing an important role in HL. A possible explanation for this trust could be the shared cultural values and customs, which can inspire their female group members to engage in healthy behaviours such as BC screening (Cardarelli et al., 2011; Jonathan et al., 2018; Macnamara & Camit, 2017).

In this study, participants (especially at the public hospital) also shared information with other patients as they waited for or during treatment (chemotherapy). It was evident that when patients shared their experiences, especially those who had finished treatment, it was reassuring to those who were still receiving treatment. This further supported Juliet's sentiment that patients trusted information from fellow patients who had 'walked the BC journey'. This calls for innovative ways to organise patient-to-patient information sharing sessions in the presence of an HCP to correct any misconceptions. BC survivors can therefore be trained and used as advocates to disseminate BC information and encourage other women to seek healthcare interventions early.

Participants indicated that they would trust the messages delivered to them by survivors of BC, particularly because they would relate to the point at which they were diagnosed, the side effects they encountered and the importance of early detection. For example, Juliet’s comments showed she valued other patients’ experiences and trusted their information more than that provided by HCPs. There are several possible explanations for this. Fellow patients may have broken down the information to a language other patients could understand. In addition, as they had walked the BC journey and experienced the effects of treatment, participants felt it was easier to trust them. Finally, these patients were living evidence that BC was not a ‘death sentence’. This finding was consistent with Shen et al. (2015) who also reported participants valued information from BC survivors. Another study (Enzler et al., 2019) reported that HCPs’ and patients’ priorities differed when it comes to information needs, with HCPs dwelling more on the treatment rather than the patients’ information needs. The same study revealed that although HCPs assumed that they had met patients’ information needs, patients reported unmet information needs.

An observation from this study was that women with lower HL were less likely to verify the accuracy of health information sources, despite an important aspect of HL being the ability to understand and use the information (Halbach et al., 2016). It is therefore important that the patient verifies the credibility of the source of information. There are several possible explanations for this finding. It may be that the women lacked the necessary skills to access information, and some might not have known how to differentiate credible information given that they received information from their social circles. It is possible that the people in their social circles did not have access to credible information too. Kugbey et al. (2019) also reported the challenge of delivering credible BC information to women in LMICs. This suggests that HCPS should make effort to reach patients with BC with high-quality information across networks they trust and use (Alago & Awiti, 2016). This may require capacity building training for religious and other community leaders because they appear to be trusted sources of information, despite the credibility of their information being unknown.

7.2.9.1.4 Internet

In this study, a few participants (with high education levels; college and high school) accessed the Internet and obtained BC information. However, they could not name any particular site they had visited. It must be acknowledged that countless health alerts, including those that address BC, are posted to the Internet every day (Hawkins et al., 2010). Many of these seem untrustworthy and do not sufficiently cover the subjects they purport to cover, which reduces their value and relevance. However, some social media sites provided useful information, as reported by Ure et al., (2020), who found that women with BC gained self-efficacy and felt ready for the subsequent stages of treatment because of interacting with others in different social media platforms.

To improve the usability of information sources, Alago and Awiti (2016) recommended that collaborative efforts need to be made so that women access BC information through their preferred channels. Such communications should include the contact information of an individual or organisation that can be referred to. Even so, it was noted that most messages with contact information appeared to be inaccurate (Alago & Awiti, 2016), suggesting that health messages on social networking sites in the Kenyan context were not to be believed despite being accessible to many women. Shen et al. (2015) recorded different findings from patients with BC in the US who accessed credible sites on the Internet, shared these with their physicians and used the information as a basis for decision-making. It may be that those women were educated and had Internet access to specific sites provided by official agencies (Shen et al., 2015). In Kenya, most women do not know how to navigate the Internet and lack money to buy Internet bundles, and those who can access Internet may search any site for health information. For example, Paula stated that she accessed information from Google Play. The study by Lee and Hawkins (2016), although very different from this study, covered aspects of a trend in information use that many Kenyans have adopted, which was searching the Internet. Lee and Hawkins (2016) recommended HCPs should screen websites for credibility and recommend trustworthy sites to patients in what is termed ‘Internet prescription’. This could work well in Kenya if patients were taught about specific sites from which they could access BC information, or if the MOH-Kenya provided reliable information. In addition, HCPs should provide informal workshops for newly diagnosed patients. In such workshops, patients can be taught based on identified information needs. Fletcher et al. (2017) noted that an important component of effective supportive cancer care was providing appropriate information to people affected by cancer. Therefore, further research is needed to investigate satisfaction with the Internet and other sources of BC information, especially in low resource settings. Having discussed the various sources of information used by study participants, the information needs that were elicited are considered in the next section.

7.2.9.2 Information needs of patients with BC

A common concern raised by participants was the lack of adequate information to help them cope with the challenges of their illness journey. They reported suffering the side effects of treatment without proper knowledge of how they could minimise them. Nausea and vomiting were mentioned as the most common and debilitating side effects. Diarrhoea, dizziness, hair loss and skin and nail colour changes were other commonly cited side effects. In the absence of adequate information from HCPs, participants resorted to other information sources, such as searching the Internet and asking fellow patients, friends and community opinion leaders. From the interview transcripts, it appeared that most of the information they acquired was inaccurate and did not warn them to expect side effects. Participants desired health information from HCPs to help them cope with their cancer treatment. An example of this was given by Rhoda as she talked about her post-surgery complications and by Juliet with her hair loss. Rhoda experienced post-surgery lymphedema, which she had not been taught about. Her hand kept swelling and became numb, but she only went to hospital when her arm could not fit in her clothes, where she was informed that it was a surgical complication. Juliet was unhappy that the HCPs did not prepare her for her hair falling out. Similar findings were reported in the literature in that patients with cancer reported unmet information needs about side effects of treatment (Matsuyama et al.,2013).

A previous study (Matsuyama et al., 2013) investigated patients’ information needs within the first nine months of cancer diagnosis, and reported strong indications that patients wanted information to help them better comprehend their cancer, make decisions and cope with treatment. This was consistent with the study by Halbach et al. (2016), which investigated unmet information needs among patients newly diagnosed with BC over the course of treatment and the association with HL. Their results indicated a mismatch between the information provided and patients’ needs over the course of treatment. In addition, patients’ information needs were higher after diagnosis, but decreased as they continued with treatment and became more optimistic about recovery. Furthermore, even if patients with low HL received the same amount of information as patients with high HL, they required more information or preferred different dissemination methods (Kent et al., 2012). This is because simply providing information does not guarantee that patients will be able to comprehend and retain it. For example, participants in this study reported that they did not understand their blood reports (Abigail) and radiotherapy appointments (Rhoda).

To meet the information needs of patients with BC that have a perceived low HL, information must be tailored to their abilities to process the information (Luker et al.,1996). Previous research found that patients with lower HL perceived that they received less information and were more dissatisfied with that information (McCormack et al., 2017; Reid, McKenna et al., 2009). In the present study, although participants appreciated the efforts by HCPs to give them information, they encountered challenges such as their information needs were not assessed, complex medical language was used and there was an assumption that '*one size fits all'*. In the oncology clinics at the study sites, it is standard practice to give out booklets with cancer information, which some participants had received, and others (e.g. Juliet) had not; those participants requested the booklets after our interview. At the public hospital, participants were routinely given files with all the treatment information. They reported that the HCPs did not explain the contents, but they were advised to show the file to the doctor in any hospital they visited for non-BC related treatment. This suggested that all patients were given the same information despite their diverse needs and the fact that different treatment modalities (surgery, chemotherapy and radiotherapy) and stages of treatment require tailored information (Lu et al., 2020). Consequently, the information received did not help them as much it should have. In the worst-case scenario, the information was deemed meaningless as the use of medical jargon meant the intended message was not clear.

7.2.9.2.1 Priority information needs

The present findings showed priority information needs for participants were BC as a disease, necessary investigations, treatment modalities, treatment side effects and how to cope, finances, follow-up instructions after finishing treatment and survival. These information needs persisted throughout the BC treatment journey, and by their third interviews, participants expressed a desire to know what caused BC and why they got it. This may be because information needs changed along the cancer continuum. This was consistent with the finding reported by Kassaman et al., (2022) that at diagnosis, women with BC desired information about survival. However, at diagnosis, the fear and apprehension may interfere with comprehension and patients may assume that HCPs will give them all the information they need, but then realise at the end of their journey that there were information gaps. Nurses may also make assumptions about patients' priority information, which are often inaccurate

(Luker et al., 1996). For example, at the end of treatment, Rhoda (the most educated participant) and Debora still desired information about causes of BC, highlighting an unmet information need. This finding differed from previous studies (Li & Guo, 2021; Luker et al., 1996) that showed that highly educated patients had a better grasp of information and demonstrated more confidence to seek, appraise and understand health information. Most participants in the present study lacked knowledge and understanding about the causes of cancer and how they could have prevented it. They associated the BC with various causes; for example, Debora related cancer to the food people ate (red meat, sugar) and agrochemicals used on farms. It was apparent from participant responses that they did not understand what caused BC even as they finished their treatment course. This differed from the study by Alago and Awiti (2016) in which women from Kisumu county in Kenya mentioned keeping money or cell phones in their bra as risk factors for BC. That study recommended appropriate education about BC risk factors using appropriate channels.

Study participants desired information about specific BC treatment modalities (chemotherapy, radiotherapy, and surgery). The course of treatment was long, meaning they needed information on the choices of treatment modality, specific side effects and how to cope. This resonated with a German study by Halbach et al. (2016) that reported the priority information need for patients with BC concerned treatment. During treatment, participants in this study reported a large number of unmet information needs, including information about treatment, side effects, medication and investigation results. Participants needed information about routes of chemotherapy administration, pre- and post-operative surgery instructions, and radiotherapy (modelling and tattoo details). They desired information on the effects of their treatment on their bodies and how they would manifest. When they spoke about the side effects, they had experienced, one could not ignore the suffering they underwent. Most had gained insight about side effects from personal experiences and other patients. A notable finding from this study that was consistent with the NHS website (https://www.nhs.uk/conditions/chemotherapy/side-effects/) was that chemotherapy side effects were unpredictable and that not all patients experienced them. For example, only two participants experienced pain and some never experienced nausea and vomiting, yet these are common distressing side effects reported by most patients with cancer (Custodio et al., 2016). Juliet reported experiencing mood swings, whereas Deborah developed self-hatred despite appearing ‘normal’ and teaching other women about BC.

In the present study, it appeared that all women had similar information needs at the same stage of their cancer journey. Furthermore, BC treatment modalities caused anxiety and fear, and participants stated that information about the treatment plan, side effects and how to cope would have reduced their suffering. HCPs providing the right information at the right time, or information that was tailored to participants' needs would have reduced their anxiety and they would not have resorted to inferior sources of information. Chemotherapy side effects needed to be discussed and understood so that participants could report if they experienced more severe symptoms than expected after going home. It was evident that participants had insufficient information; for example, Debora wondered if she would get pregnant after the treatment, Ruth queried why her periods had stopped and Paula believed that some foods could prevent alopecia. Another participant (Juliet) was advised by one HCP to take her medication 30 minutes before food, while another had advised her to take it 30 minutes after food; this left Juliet confused and frustrated. In terms of eating, Juliet's husband forced her to eat a lot of food because she appeared thin. Similar findings were reported by Reid et al. (2009) where family members perceived that the patient's weight loss was due to loss of appetite, and could be reversed by eating. This supported other studies that noted the role of HCPs was to identify the needs that were relevant to their patients' current situation and educate them accordingly (Hepworth & Harrison, 2002; Timmins 2005; Rutten et al., 2005). Ormandy (2008) found that information needs arose because of inadequate knowledge, which led to dissatisfaction with existing conditions. These information needs may be expressed or unexpressed; from this study it appeared that some patients were not aware of their health information needs. Similarly, Halbach et al. (2016) reported that patients with limited HL were disadvantaged in that their health information needs may not be met during the course of cancer treatment.

The qualitative longitudinal approach used in this study confirmed that BC-related information needs among Kenyan women were not static, but rather changed over time. This original contribution to the knowledge highlighted that there is need for an ongoing process of providing information from diagnosis throughout the treatment stages. This study found that most information was provided on a crisis basis, and not according to specific patient needs. Needs assessment could have been performed by HCPs to elicit the priority information needs of patients with BC.

7.2.9.3 Information overload as a barrier to information use

In the context of this study, information overload referred to a situation when there was so much relevant and potentially useful information available that it became a hindrance rather than a source of support. The present study found that doctors gave participants a lot of information over a short period of time, especially immediately after breaking the bad news about the BC diagnosis. For example, Paula received information amid the emotional turmoil after being told she had BC; this could have caused the confusion she reported. After starting treatment, chemo brain/fog could be an associated factor that interfered with participants' memory and ability to use information. Although it was not verbalised, there appeared to have been an information overload at diagnosis, which means the women could not use that information. This information overload is a predictor of low HL (Brabers et al., 2017). Participants in this study demonstrated a clear preference for simple information devoid of medical jargon. These findings were broadly consistent with those of other researchers such as Pilkington et al. (2017), who emphasised that HCPs needed to balance the depth and breadth of information to overcome information overload, especially for patients with perceived low HL such as Kenyan women. This was consistent with a study conducted 25 years ago by Luker et al. (1996), which found that patients with cancer were too frightened to take in a lot of information at the point of diagnosis. Another explanation could be the assumption that in a threatening situation such as a BC diagnosis, patients desire and seek a lot of information initially, but this information seeking reduces at later stages as patients learn to cope (Halbach et al., 2016).

7.2.9.4 Fear of asking questions

The shame of being illiterate may mean patients are embarrassed to say they do not understand information; therefore, they shy away to the extent that even if they do not understand, they do not ask for clarification. In this study, some women, especially those with low level of education and low SES, did not know that they could ask questions of HCPs. Those who knew they could ask were deterred by 'busy' HCPs and felt they would waste their time if they asked questions. This was a barrier that may have left participants with unanswered questions. Previous studies revealed that a patient's ability to read and write was often mistaken for proficient HL, but these skills are not true indicators of adequate HL (McCormack et al., 2017). For Kenyan patient/family education tools, a common assessment performed by HCPs is whether the patient understands English or Kiswahili and can read.

While Speros (2009) asserts that HL is much more than reading and writing, (Sørensen et al., 2020) emphasizes its role in empowering individuals to participate in healthcare decisions. This study recommends the use of a quick checklist like what Dumenci et al. (2014) developed to assess patients' HL. The checklist can be used to screen patient's HL and intervene appropriately. This may overcome conventions established among HCPs in Kenya that a patient who can speak English or Kiswahili will understand health information.

This section discussed the intrapersonal (micro) factors that influenced HL, and the following section presents relevant interpersonal (meso) factors.

7.3 Meso (interpersonal) factors that influenced HL

In the present study, meso factors referred to the formal and informal social networks or support systems that influenced how patients with BC in Kenya accessed, understood, and used health information to make decisions. These included family and social networks, other patients and HCPs. This study identified that the main influences on interpersonal relationships were family members, participants' roles as breadwinners, peers, friends, friends of friends and the HCPs that were involved in participants' care (nurses, doctors, counsellors, pharmacists, radiographers, laboratory technicians and radio-oncologists).

7.3.1 HCP-related factors

This study revealed that participants had received some cancer-related information from HCPs. However, they could not clearly articulate what they had been taught. Juliet spoke of how she suffered in pain but had been given painkillers in hospital that no HCP had explained to her. It appeared that HCPS focused more on clinical care delivery and paid less attention to participants' individualised information needs. This was consistent with a previous Kenyan study (Gakunga et al., 2019) in which patients with cancer were highly satisfied with their clinical care, but dissatisfied with information provision. Similarly, a US study (Enzler et al., 2019) observed that BC survivors with low SES had special information needs beyond their medical care. Interestingly, many HCPs believed that patients information needs were being met, but participants' experiences suggested the opposite. This calls for HCPs to tailor information provision to meet the individual needs of patients with BC. When patients are given information through effective patient education, they acquire knowledge about symptom management, self-care and treatment decisions (Martin et al., 2014).

The present findings supported previous studies that found that before diagnosis, there was no formal structure for information provision but thereafter, the HCPs provided some information. This calls for efforts to structure information provision to women before they are diagnosed with BC, which means that prevention and early detection education should be taught to patients. Gakunga et al. (2019) concurred with this notion, noting that BC outcomes were dependent on early detection, diagnosis and prompt access to high-quality treatment and palliative care. Conclusively, patients must comprehend information, otherwise the women with low HL are not likely to benefit from BC awareness campaigns and health education. Emphasis should also be placed on providing financial information for women and families, so they understand that earlier diagnosis is likely to lead to less expenditure. In the absence of such strategies, patients are less likely to acquire new BC knowledge, leaving their HL to be shaped by personal experiences, beliefs and information from their social circles and community networks. This perpetuates the negative beliefs and fatalistic thoughts about BC (discussed earlier under micro factors), which are barriers to women seeking breast health services.

7.3.1.1 Medical jargon

Participants in this study described the medical jargon that the HCPs used as a barrier to information use. It appeared that the women in turn used this jargon without understanding what it meant. For example, Juliet was informed about triple tests (which involves patient history and CBE, mammography/ultrasound imaging and non-excisional biopsy), but in her interview, spoke about ‘triple O negative’. Similarly, Debora spoke about the need to perform a ‘FIS test’ that the doctor had explained to her (the correct test is a FISH test), and when asked if she understood what the test was about, she responded in her vernacular ‘*ndiowe*’, meaning ‘I do not know’. This use of medical jargon could deter patients from seeking information or asking questions of HCPs. Similar issues were reported in Turkey where patients with cancer experienced difficulties conversing with HCPs because of the use of complex medical terms (Akbolat et al., 2021). Clinical practice in BC care often involves the use of difficult diagnostic and treatment terms (e.g., biopsy, fine needle aspirate, lumpectomy, mastectomy, tumour markers, CT scans); at some point, patients with BC encounter these terms and have to make decisions. The literature suggests that there is a general assumption that patients who speak medical jargon understand it (Thomas et al.,2014), yet the opposite is true; such patients experience difficulties and do not understand the complex words they use.

Surprisingly, previous studies reported that HCPs were oblivious to their use of medical jargon, which made communication with patients difficult (Pitt & Hendrickson, 2020). Even so, patients with sufficient HL also encountered difficulties understanding complex cancer treatment information (Halbach, 2016). As patients with limited literacy are more likely to wholly depend on their HCPs for health information, this information should be broken down to a level that patients understand. Tariman et al. (2014) recommended simplifying information to a grade three level to ensure patients could understand. It is important that HCPs use plain language and give simple messages that patients can understand. A needs assessment (which includes identifying patients who 'do not know what they do not know') is necessary for patients to indicate priority information needs. HCPs should also develop innovative strategies to assess whether patients have understood the information they give them. Fernández-González and Bravo-Valenzuela (2019) advised that HCPs should always anticipate that the patient will misunderstand information and ask questions such as, 'When you go home, how will you take your medications?' and 'What will you tell your family about today's instructions?' For example, a participant in this study explained how she took her 'three times a day' medication with breakfast, lunch and supper. This has potential to cause medication errors (wrong timing) because the time intervals between breakfast, lunch and dinner were not constant, thus information provided by HCPs has profound implications for patients. Still, Kessels (2003) found that up to 80% of medical information that HCPs gave patients was forgotten as soon as they left the office and 50% of what they remembered was remembered incorrectly.

In this study, patients could not name their medications; although cancer drugs are complex, one would expect patients to have a record of their drugs and most participants did not have this information. Simmons et al. (2017) recommended that HCPS should be given extensive HL training to help them decrease medical jargon and advance patient education by using plain language, easy-to-understand written materials and teach-back methods. They should also design plain language written materials with visuals to provide more culturally and linguistically appropriate health education for patients with BC. Universal principles of health communication also recommend that HCPs should treat every patient as if they do not understand the information they are given (Hadden & Kripalani, 2019). HCPs should ask questions in a patient-centred manner, and not merely ask patients if they 'have any questions. Simmons et al. (2017) recommended that HCPs invite questions from patients so that the patient knows that the HCP expects questions at every encounter and may come with pre-determined questions. Plummer and Chalmers (2017) added that HCPs should use plain language and limit information to one to three key ‘need to know’ items. Rafie et al., (2015) encouraged using the teach-back method to confirm learning. One way of doing this is for the HCP to ask the patient to tell them how they would explain to a person at home what they were taught. HCPs can then assess the match between the information given and patients’ understanding (Cadet et al., 2021). The teach-back method was investigated by Bickes et al. (2021) and found to be an effective method for reinforcing or confirming patients’ understanding of what was taught. In this study, all participants also placed a high value on their social ties, which influenced how they accessed and used information. This is discussed in the next section.

7.3.2 Social capital as a promoter of HL

This study used the World Bank (1999) definition of social capital, which encompasses the institutions, relationships and norms that shape the quality and quantity of a society’s social interactions. Social capital is not just the sum of the institutions that underpin a society but is the ‘glue that holds them together’ (World Bank, 1999). In this study, this concept referred to ‘who do you know who knows who’. Study participants received a lot of information from their religious circles; for example, Lilly learned about BC from women in her church. Some participants had broader social networks than others; for example, Connie and Rhoda had family and friends who worked as HCPs. Such participants demonstrated a better understanding of their diagnosis and treatment. However, all participants placed a high value on their social ties, which influenced how they accessed and used information. Those with broad connections received large amounts of information, some of which was incorrect. For example, Olive noticed a lump in 2013, but her friends advised her that it would disappear by itself. Instead, the lump continued growing and in 2017, she consulted yet another friend who advised her to seek healthcare intervention. Others (e.g., Marion) chose to seek the opinion of a women’s religious leader. These findings were consistent with the results of other studies (Gakunga et al., 2019) in which opinion leaders were found to be influential sources of knowledge. This suggested that the type of social capital available to a patient has an impact on the type of information they access.

Social capital is therefore a mediator of HL for integrating skills and abilities needed to search for information (Berens et al., 2018) and then using those skills to ask questions, discuss with their doctor (Farias et al., 2017), search the Internet (Shen et al., 2015) and question their care. McKenna et al., (2020) indicated that the networks that comprised social capital often served as channels for the flow of useful knowledge that aided the achievement of health goals. Individuals’ lives can often be improved by social capital, which works through psychological and biological processes. Growing evidence suggests that people with a high level of social capital cope better with adversity and can fight disease more effectively (McKenna et al., 2020). This ability to cope better may be explained by enhanced social cohesion interactions, companionship and a sense of belonging (Kritsotakis & Gamarnikow, 2004). As community ties are bound in strong kinship ties, they have a major impact on peoples’ lives in measurable and well-documented ways and are significant in enhancing HL. This study provides evidence that social capital was a core factor in how women accessed, understood, and used health information.

It was evident that participants’ HL developed through their social networks. Some participants’ initial information was drawn from their social networks, which helped them make decisions to seek healthcare interventions. This study showed formal and informal social networks or social support had a major impact on the uptake of BC screening. Husbands were supportive and tended to accompany their wives to the hospital. Similar to other cultures, the cooperative behaviour of the family, especially husbands, had a marked impact on the BC journey. The strong kinship bonds common in African families are associated with enhanced coping and well-being amid external attacks such as chronic diseases (Guidry et al.,2003). In this study, peers and close friends had a major influence on participants’ attitudes towards screening, and on the type of information and social support they received.

A previous study reported similar findings and clarified that social networks were a valuable asset and that relationships mattered (Hulett et al.,2015). For example, Rhoda’s husband, sisters, and children were supportive, whereas Marion suffered isolation because family members avoided her. It may be possible that because she did not have to worry about finances, Rhoda accessed more information and used it to cope with the side effects as she did not have to worry about finances and other utilities. Conversely, Marion experienced financial difficulties and isolation, which were barriers to information access and use. These findings were consistent with a previous study (Hulett et al., 2015) and suggested that social determinants of health (e.g. SES, education level and support) were key influences on HL. Conclusively, financial, and emotional support play key roles in how Kenyan women accessed and used health information and attend BC awareness, screening, diagnosis, and treatment services.

7.3.3 SDM

SDM is defined as:

> Shared decision making is a collaborative process that involves the person using the service working with the HCP to reach a joint decision about their care, now or in the future (for example, through advance care planning). It involves HCPs working together with people who use services and their families and carers to choose tests, treatments, management, or support packages, based on evidence and informed personal preferences, health beliefs, and values. This involves making sure the person has a good understanding of the risks, benefits and possible consequences of different options through discussion and information sharing (UK, 2021, p. 3).

The data from this study suggested that although participants adhered to their treatment regimen, they would have benefitted from complete information that would have enabled them to participate in making treatment decisions. Other studies (Katz et al., 2017; Leppin et al., 2015) showed that HCPs played an important role in helping women to find and use information, and supporting them to make decisions (Rutherford et al., 2017). However, there was weak evidence regarding this support from HCPs in the present study, which was unable to demonstrate that HCPs supported patients in decision-making. However, the findings were consistent with other studies that suggested that in a BC diagnosis, information provision is considered a key support (Rutherford et al., 2017; Spittler et al.,2012; van der Heide et al.,2015). For example, when Juliet was feeling harassed by her husband to eat a lot of food, teaching given to her husband about the need for small, frequent portions changed her experience and enhanced her well-being. A phenomenological study by Adam and Korateng (2020) conducted in Ghana concluded that having a BC diagnosis was hard enough without being ‘bombarded’ with information. In that study, there were positive impacts on the lives of patients with BC who had informational, emotional, financial, and social support. The prognosis and overall quality of life for those who received support also appeared to be more promising and well-adjusted than for those who did not receive any support. Rutan (2021) noted that HL affected how people behaved in the health system. For patients to be actively involved in decision-making, they require sufficient knowledge about their illness and treatment options (Sak et al., 2017).

The need for patients with BC to have access to information that enables them to make treatment decisions and achieve the best possible quality of life has previously been emphasised (UK, 2021). It is a common stipulation in hospital policies that before commencing any BC treatment, the patient should sign an informed consent form. It is at this point that comprehensive information should be given to the patient about the treatment options, benefits, risks, possible side effects and prognosis (Zhao al., 2018). However, patients are often presented with incomplete information about treatment options and follow the advice of HCPs even when they may have wished otherwise. In this study, no participants mentioned having signed a consent form; this suggested that they may have just signed the form without understanding it, or that their male relatives signed on their behalf, although this cannot be proved as I did not review their medical files. In addition, none of the study participants conveyed knowledge of their prognosis during their interviews; this could be related to a socio-cultural fear of discussing death (especially for patients who came at stage III). It is therefore inconclusive whether this was an indicator of lack of provision of prognostic information by the HCPs or attributable to the African cultural practice of not discussing undesirable outcomes (e.g., death) when one is suffering from a chronic illness. However, it highlighted the need for patients to be given comprehensive BC information by HCPs to enhance their decision-making. Sak et al. (2017) reported that the severity of the disease influenced patients’ involvement in decision-making, with less involvement seen in life-threatening illnesses such as BC. This calls for understanding and decisional support by HCPs as this improves the quality of life of BC survivors. Interestingly, Luker et al. (1999) reported that even patients who did not want to be involved in making treatment decisions desired detailed information. Therefore, all patients with BC should be given comprehensive information to support them in making decisions about their treatment.

As evident in this study, most participants adopted a typical patient role and left decision-making to doctors or male relatives. This passive role may be related to their lack of knowledge that they could be involved in making decisions, not having adequate information to make informed treatment choices or cultural factors. Socio-culturally, a Kenyan woman should not ask questions randomly, especially if accompanied by a male who provides for her upkeep. Most participants (except Marion) were accompanied by their husbands, uncles, or

other male relative. The findings in this study were consistent with an American study (Burton et al., 2016) in which older patients with BC trusted their doctors to make treatment decisions for them. A major difference between the two studies was that the American women were given all relevant information unlike the Kenyan women in this study. The non-participation in decision-making could be related to the language and the possibility that SDM is a new concept that is not yet entrenched in Kenyan healthcare policies and practice. Most HCPs communicated in English, but some participants understood *Kiswahili* only. In such instances, the women's husbands/male relatives received the explanation which they later translated for the participant. Therefore, if the woman was alone for her doctor's appointment, there was risk of information overload (see Section 7.2.9.3). Kamara et al., (2018) advocated that information given to patients with low English proficiency should be organised into short- and long-term goals to avoid overload and improve usability.
In some cases, this study suggested that some decisions were made in consultation with family, especially male relatives (husbands, uncles, cousins) who always accompanied the women to the hospital (e.g., Rhoda, Paula, Juliet). In other cases, decisions were made after consulting opinion leaders from religious groups (Marion) or family, friends, and friends of friends (Connie). It is commonly assumed that patients with a high SES and education level participate more in decision-making. However, in this study, participants' SES and education level did not appear to have a direct influence on their involvement in SDM; therefore, this study can neither support nor refute the notion that those with lower SES and education levels do not participate in decision-making. In addition, this study did not elicit whether the women were satisfied with the healthcare decisions made; however, given their dissatisfaction with lack of information in some areas there was likely to have been some dissatisfaction. For example, Rhoda would have opted to receive her chemotherapy through the port and not the peripheral intravenous line, but she was not given that option. Rhoda's dissatisfaction was evident in her statement, '*I think the patient should be given a choice. Not the doctors to make the choice for the patient*'.

A question that remains to be answered is 'how do patients get involved in making decisions if they do not understand the information?' Furthermore, active involvement requires a patient to have sufficient information about their illness, treatment options and all related procedures (Farias et al., 2017). In contrast to this study, women in a study from the US (Farias et al., 2017) reported a high degree of self-efficacy, felt empowered and participated in their care because their physicians communicated key information and involved them in decisions about their care. Similar findings were reported by Murugesu et al. (2021), who used in-depth interviews to explore the HL skills and support needs of women in relation to SDM in maternity care in Netherlands. That study found that SDM required adequate HL skills for clients to obtain, appraise and apply health information to various situations. Furthermore, Brabers et al. (2017) noted that in terms of patient participation in medical decision-making, it was possible that a high level of HL allowed patients to take a more active role as they were presumed to be capable of obtaining, comprehending, evaluating and applying information necessary for medical decision-making. Therefore, preparing women for consultations (e.g., agenda setting) and assisting them in understanding information in a timely manner are important ways to facilitate participation in decision-making. In dealing with HL challenges (Livaudais et al. , 2013) proposed that HCPs should develop new ways to interact with patients with low HL to allow them to assume a comfortable level of decision-making responsibility.

In this study, acquiring information was seen as a way of coping with the BC diagnosis, which promoted well-being. Similar findings were reported in a study in Germany by Vogel et al., (2009) who examined the impact of BC patients' experiences with physician–patient communication and participation decision-making on depression and quality of life three and six months after primary treatment. Patients who participated as much as they wanted in the decision-making process were happier with their outcomes than those that did not. Vogel et al. (2009) concluded that offering information and involving patients in decision making helped them to cope better with their chronic illness.

The feelings of stress after receiving the bad news of a BC diagnosis can cause a state of uncertainty regarding making decisions. This study showed that without information, anxieties emerged, and participants felt vulnerable and had a sense of loss of control over their lives. For example, when Paula, Juliet and Rhoda were anxious about changes in their treatment regimen, their involvement in decision-making may have made them feel more in control and thereby enhanced their well-being. Similarly, Cadet et al. (2021) found that women lacked the self-efficacy to make a decision about BC mammography screening, and relied heavily on their doctors' opinion. Although that study explored older women's (above 75 years) ability to make decisions, the recommendations can be applied to the Kenyan context. Cadet et al. (2021) found that a decision aid modified for those with low HL improved their interaction with HCPs and increased their overall involvement in making decisions. Further research about use of decision aids is feasible and may help increase participation in decision making and reduce decision regrets among patients with BC (Roberto et al., 2018). Another study (Spittler et al., 2012) that investigated BC survivors' information needs and decision-making in the US found that women were advised to '*Go with your gut feeling*' and '*Don't let anyone change your mind*'. This means the emphasis was on the patient taking charge of their illness and being given time to make decisions, including being allowed to delay or postpone some decisions. These results were not described by participants in the present study, which may be explained by cultural differences as in Kenya, important decisions are made by men who also control the family finances.

7.3.4 Financial challenges

Financial inadequacy was a recurrent tread raised by participants in this study at all levels of the SEM. For most participants, the cost of treatment included the money they must pay for each BC session and the costs of laboratory and radiological investigations, consultation fees for each session, hospitalisation (if they needed admission for any procedure), food and medications. These costs varied per facility, with private facilities being more expensive than public facilities. This scenario was worse for patients who lived in rural regions that had to travel to the city (mostly via public transportation) to access the treatment facility. Specifically, most participants did not have sufficient money to pay for treatment, insurance premiums, transport, accommodation, and drugs while also meeting their family's needs. There also appeared to be competing family interests; for example, Marion's priority was her son's school fees over her own BC treatment. This caused a considerable treatment delay that made cohort members call her to find out why she was missing chemotherapy sessions. This suggested that even though information may be provided, and patients were involved in making decisions, financial issues may hinder the use of information. Therefore, financial counselling should be given to help patients decide about starting treatment, instead of starting treatment and exhausting the family income, then having to sell off property and eventually default (or worse still, die). Participants' narratives suggested that some suffered poor experiences because they had inadequate financial resources. This finding was consistent with other research that investigated factors that impacted BC outcomes and demonstrated that financial resources were a significant cause of diagnostic and treatment delays (Bowser et al., 2017; Gakunga et al., 2019; Leena, 2020). This highlighted the need for full financial disclosure after a BC diagnosis (Sharp, et al., 2018) as this improves patients' overall health-related quality of life.

The women in this study described cases where patients had started BC treatment, but then exhausted their NHIF and other financial resources and had to sell off their property to get finances for treatment, but still died, even after all that trouble. This could be a reason why women associated BC with death and cried at the news of their cancer diagnosis. They labelled the BC diagnosis a ‘death sentence’ knowing that they possibly could not afford treatment and may die. However, once they started treatment, most women verbalised that diagnosis of BC at an early stage resulted in better outcomes and they overcame their death anxiety.

The findings of this study suggested that participants were not aware of the significance of early detection and its contribution in easing the financial and emotional burdens for their families, despite evidence that early diagnosis reduces the overall cost of treatment (Akuoko et al., 2017). The extraordinarily high cost of BC services means individuals must purchase health insurance before seeking medical intervention. In Kenya, insurance providers play an important role in promoting access to healthcare, but this depends on an individual’s ability to pay 500 KES (5 USD) per month for premiums. In addition, free healthcare services are only provided at the dispensary level (Kimani et al., 2014), which do not have capacity to offer BC treatment services. Consequently, without sufficient insurance coverage, the expense of BC treatment is prohibitive for many women. Some participants in this study did not know that the amount of money covered by NHIF depended on the BC stage, with a higher amount allocated for earlier stages. It is therefore imperative that HCPs educate patients about health insurance and follow up to ensure that their medical reports highlight the BC stage, because this forms the basis for the insurers’ decision-about the amount paid. Often, the amount of money needed for the whole treatment journey surpassed the NHIF limit, meaning patients had to raise the rest of the money themselves. Similar to other studies (Adedimeji et al., 2017; Akuoko et al., 2017; Bowser et al., 2017; Byrne et al.,2018), women in this study stated that BC treatment was out of their reach and recommended that the government introduced free BC services from screening to treatment and rehabilitation.

As the main hurdle in early healthcare access is finances, which is largely controlled by males in Kenya, female financial independence may empower women and grant them freedom of choice and autonomy to make their own healthcare decisions (Abeje et al., 2019; Green, et al.,2019). Ironically, women in this study that were educated and employed (e.g., Rhoda), would not be allowed to spend their money without their husband’s permission. This is a cultural concept that was also identified in previous studies (George, 2013; Green et al., 2019).

The following section discusses the macro (organisational) factors that affected women's HL.

7.4 Macro (organisational factors) that influenced HL

In this study, macro factors represented the intersection and linkage a patient had with social institutions and organisations that have rules (formal and informal) and regulations for operation. These included institutional practices and policies, socio-cultural factors, and healthcare financing. The information exchange between patients and HCPs must be as productive as possible to ensure that being health literate must be the new organisational norm for the delivery of care. Organisations must therefore incorporate HL into their standard operating procedures while adopting scientific principles (Schillinger, 2020).

7.4.1 Institutional policies

This section discusses the provision of education, psychological support services and informal channels of sharing information by BC patients.

7.4.1.1 Provision of information booklets and file with patients' reports

At the public hospital, patients were given books with treatment and diagnostic information. Debora advocated for this as a helpful practice because she could refer to the book as needed. When asked what they were taught, patients at the public hospital would show the file with all their treatment details. This system of giving patients their treatment reports is laudable because if a patient attended healthcare services elsewhere, it alerted other HCPs that they were receiving BC treatment. This is important because some side effects of treatment may present as illness; for example, neutropenia is a side effect that presents like febrile illness, and patients with BC are given a document (fever letter) to show HCPs anywhere that they seek healthcare. In this study, no participant mentioned the fever letter, suggesting that they were not aware of it. Both the public and private hospitals had patient education policies that stipulated how teaching should be done. However, participants' narratives indicated that what was outlined in the policy was not put to practice. This theory-practice gap has been reported in previous studies in the US (Lee & Hawkins, 2010), Egypt (McEwan et al., 2014) and Uganda (Ilaboya et al., 2018). This highlights that the theory-practice gap is an international concern and may imply that HCPs do not implement policies fully.

Current patient education programmes appear to be the tip of the iceberg, as evidence shows that much more needs to be done. For example, people need a choice of languages (Lee & Hawkins, 2010). McEwan et al. (2014) suggested the involvement of patients in the interdisciplinary discussion of their illness, and treatment plan and that patients should access their medical records. All of these efforts aim to ensure patients can understand information and contribute in their treatment decision-making.

7.4.1.2 Psychological support and counselling services

Some participants voiced concern that psychological intervention was not available to those diagnosed with BC, especially at the private hospital. At the public hospital, patients reported that after the doctor had shared the bad news of their BC diagnosis, the patient and her close family were taken through counselling and given some information about treatment. Participants comments indicated that the counselling was meant to help them to be positive about their diagnosis and accept treatment to support positive outcomes. All participants from the public hospital stated that this initial counselling had helped them a lot as they started treatment. At the private hospital, none of the participants reported being counselled by a psychologist, and this may be a significant gap. These participants (e.g., Debora) indicated that a psychological intervention assisted them and their families to understand BC treatment.

In the present study, only one participant had attended a BC support group. However, the support group did not meet her information needs because the women there were discussing how they received treatment in India. Naomi could not afford the costs of treatment in India, and therefore found the support group irrelevant to her needs. In other studies, support groups have been reported to be reliable sources of information as patients share their real-life experiences. For example Winefield et al.,(2003) found that cancer survivors who had been through similar experiences explained things differently than the HCPs. In addition, patients gained strength to continue with treatment knowing that they were not alone in facing hardships.

7.4.2 Informal channels of information sharing by BC patients

This study showed that after starting treatment and feeling better, participants (e.g., Debora and Paula) used local forums to educate other women about BC. Debora stated that as her body did not change much physically when she started treatment, most people in her village and church did not believe that she had BC; they only believed after she showed them the mastectomy scar, although she had improvised a prosthesis that she wore. Debora was therefore given a role to speak to women about BC at church and other social gatherings. In Kenya, women meet frequently at various avenues such as the marketplace and in religious and women's groups (*chamas*). If anyone had screening or had been diagnosed with BC, the members of these small groupings are usually informed at informal meetings. It may be a positive idea that a BC survivor such as Debora shared their experiences and encouraged other women to undertake BSE and screening. However, a challenge would be the credibility of the information because in her talks, Debora referred to information that she had come across during her treatment as well as her experience with treatment. This resonated with what participants stated in their first interviews, that even though they accessed information from the media, friends, and relatives, they believed HCPs more. This was similar to a previous study (Shea-Budgell et al., 2014) that found patients with cancer trusted information from HCPs the most. Consequently, it would be prudent for HCPs to provide information to patients with BC and refer them to trusted Internet sites (for those who can browse) that provide appropriate information. Other strategies would be to replicate what has been done in the UK for patients with chronic kidney disease (Greater Manchester Kidney Information Network) (Vasilica et al.,2020) ,Face mums for pregnant mothers (McCarthy, 2018),and WoMMeN for BC screening (Galpin et al., 2017).These are online social media platform projects where HCPs and patients share information in an online community of practice.

7.5 Chapter summary

The findings of this study showed that there were several factors that influenced HL among patients with BC. These factors spanned different levels of the SEM, and were the forces that influenced how participants accessed, understood, and used health information to make decisions in their BC journey. These factors were bi-directional and at times overlapped. Across the three SEM levels, financial challenges were a dominant thread that determined whether participants sought timely healthcare. At the individual level, fear of a positive diagnosis was a major reason for women's lack of participation in BC screening. In addition, fear and lack of finances were additional individual-level barriers to BC screening. The findings showed that HL was not an individual construct, but a process and an outcome of various interactions and criteria.

7.6 Limitations of the study

Although the present findings contributed new knowledge to the understanding of the HL experiences of patients with BC in Kenya across the cancer journey, they may not be transferable to other contexts because of some limitations.

Lack of transferability: The characteristic small purposive sample used in qualitative studies cannot be generalised to the whole population. However, the transferability of these findings should not be based on criteria used for quantitative approaches. This is because the aim of the research was to explore the experiences and factors that influenced HL for women with BC, which was achieved through semi-structured interviews, and the study did not seek to generalise the findings.

Study sample: The study sample included women who were receiving treatment in two referral hospitals in Kenya’s capital city; therefore, the views of the women who reside in rural areas were underrepresented. There are likely to be differences in how rural women experience BC-related HL, and their stories would have further enriched this study. In addition, there could have been information and recall biases because of disease stages and side effects; for example, chemo fog may have influenced women’s responses. There may also have been self-report bias as participants may have exaggerated to make their experience seem worse, or under-reported experiences to finish the interview and get on to other business.

One of the inclusion criteria was clinical stability with no obvious signs of distress or cognitive impairment, thus majority of the participants were in stage I and II. It may be that those with stage III or IV were not clinically stable, or were too sick and were left at home to die peacefully. Given that the majority of BC diagnoses in Kenya are at stage III and IV, these patients’ views warrant further exploration.

Possible researcher influence: My role as the researcher in this study may have influenced the interviews and interpretation of the findings. In addition, my professional background, experiences, values, and emotions as I interviewed the women may have influenced the research. Although I was conscious of these factors and tried to detach and play a researcher role (discussed in the reflexivity section in

Chapter Four), my personal biases and presumptions could have influenced the research process.

Others: The present study did not involve the HL perspectives of HCPs, which may have provided a different viewpoint on their HL practices as they are the ones that provide BC services. Further research should explore HL from HCPs' perspectives.

7.7 A reflection on methodological choices

I recruited 15 participants in the study, and during data collection, three died, and one defaulted due to financial challenges. During data analysis, I did not include their data in the study. In addition, the information I had gathered from these interviews did not change/add differing themes to the themes that were developed. I recognise the ethical implications of excluding these participants in my analysis. Various reasons are offered to explain my decisions. The first is that the PIS stated that the information collected would be used until the point of withdrawal from the study. My interpretation of this is that what the PIS referred to was 'willingful' withdrawal; death and lack of finances to continue treatment were not 'willingful'. As Gordon and Prohaska (2006) recommend, the researcher must include and clearly explain a 'withdrawal from the study' process. This is a limitation I acknowledge, but with lessons learnt about accurately framing ethical statements in the PIS, for correct interpretation and meaning. Secondly, I used the second interview for member checking in data collection. Through member checking, I verified my understanding of the data by consulting with participants and ensuring that I had correctly understood and conveyed their emotions, ideas, and HL experiences. This way, participants provided feedback and identified any potential omissions or misinterpretations that could affect the study's findings' accuracy, objectivity, and reliability. Without member checking, I would not be confident that the participants' voice was being represented truthfully.

I have also acknowledged participants' deaths and default as a limitation in the discussions section. Conclusory remarks for future researchers will include a recommendation to have a larger sample when dealing with similar groups of patients to cover up for sudden deaths.

On reflection, I would have included a family member to help participants narrate their experiences. This way, I would have used them to validate the first interviews of the deceased participants. However, this is debatable since the relatives may not have accepted for their late kins' information to be included and may seem unethical. These are lessons learned for future research.

7.8 Contributions to knowledge

This study made original contributions to the knowledge in several ways. First, a deeper understanding of the HL concept was achieved through the review of relevant literature, which showed that globally, HL skills are crucial for all stages of the BC journey. However, most of the reviewed studies were quantitative and focused on one stage of the BC journey. Therefore, this study contributed to the literature by describing the HL experiences of Kenyan patients with BC throughout the various stages of the disease using a journey model and socio-ecological perspective. This study exposed the challenges encountered by patients with BC who are in a healthcare system that has resource limitations, in that even if they received information about BC, financial burdens prevented the use of that information. The study also highlighted the changing information needs of patients with BC at each stage of the journey and emphasised the need for an individualised approach so that patients make informed choices and participate in treatment decision-making.

The study also made several noteworthy contributions in highlighting the information sources for patients with BC. Popular sources were media, social networks, other patients and HCPs. This information was important because evidence-based practice emphasises individualised, patient centred care. Another unique contribution of this study was the methodology that used a journey model. This demonstrated that a qualitative longitudinal research approach offers a creative and insightful way of prolonged engagement with participants and is valuable for gaining deeper understanding of the experiences of patients suffering from a chronic illness such as BC. Therefore, this approach can be used for studying other chronic conditions. Previous research focused on quantifying HL by labelling it as adequate or inadequate, and collected a snapshot of data at one stage, whereas this qualitative approach illuminated changing information needs at various stages of the BC journey and clarified factors influencing HL skills. This will enable identification of meaningful interventions at each SEM level. The semi-structured interviews also gave participants a chance to speak about their lives and provided insights into how information given either met or did not meet their needs.

Furthermore, this study made an original contribution in that no previous study has been identified in Kenya that used the SEM. In this study, the SEM set the scope and focus of the constructs to be studied, supported the problem statement, purpose, research questions and objectives, and provided a road map for the literature review. In addition, the SEM provided a framework for designing the research instruments, data analysis, interpretation, and presentation of the findings. Application of the SEM in this study was pivotal in understanding HL in a LMIC context and enabled me to focus on the circumstantial factors that explained people’s HL behaviour or performance and provided a framework to see linkages across the three levels. The study clarified that HL in patients with BC in LMICs is influenced by socio-ecological factors at individual, interpersonal and organisational levels. The factors identified are multidimensional, correlated and interwoven; for example, the finance factor traversed the three SEM levels. It appeared that if a woman has financial challenges, her desire for BC information is affected, meaning financial needs have to be met for health information to be useful. These factors may be the root causes of the perceived low HL and need to be addressed; for example, there should be interventions (at the organisational level) to overcome financial challenges. Therefore, even if patients possess abilities to seek, understand and use health information, other factors may hinder the HL process; this was a unique contribution of this study. To enhance the BC HL of women in Kenya, it is crucial to adopt an evidence-based SEM model. The research suggests a departure from the conventional framework that prioritizes micro, meso and macro factors. Instead, I suggest placing policy factors at the forefront as they are dominant influencers according to the study findings. Provided that complimentary screening and affordable breast cancer services are made available to women in Kenya, they may not have apprehension about discovering their BC diagnosis and will be encouraged to seek early interventions. Additionally, if easily obtainable breast cancer health education is provided, it can deter women from turning to untrustworthy sources like the ones noted in the study results. Strategically addressing these macro factors can exert a direct influence on the community and organizational (meso) as well as individual (micro) factors, ultimately enhancing women's ability to access and utilize breast cancer information. The proposed model is shown in figure 9 below. Overall, the study findings support the premise that all levels of the SEM play key roles in influencing women’s BC-related HL.

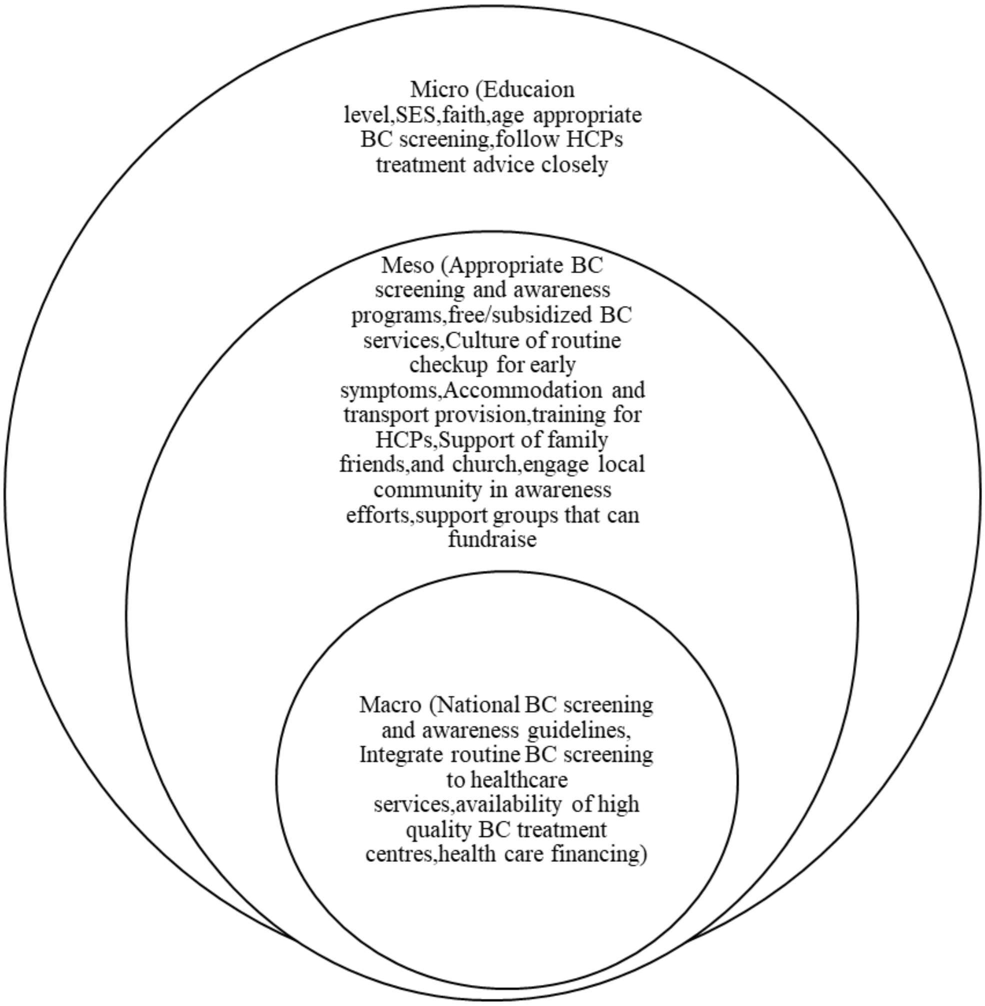


Figure 9: Bottom-up socioecological model of factors that influence Breast cancer HL

Contextually Kenyan women face major socioeconomic challenges against a background of low resources and inadequate BC healthcare services. The findings of this study may inform development of new forms of the SEM unique to women in low resource settings. For this reason, HCPs must first identify influencing factors and implement HL best practices and strategies that can improve the treatment experience and enhance the quality of life of patients with BC. Overall, the key issue raised by this study is that it is incumbent on all stakeholders to embrace best HL practices and provide understandable health information that women can comprehend and act upon. Even so, it is evident that a wealth of work remains to be done to explore how best to help patients with BC in LMICs and develop appropriate interventions to improve their ability to understand, discern and act on accurate, reliable health information.

This study also made an original contribution to the knowledge by illuminating the BC journey of women in Kenya and demonstrating that HL in this journey was contextual. From the moment a woman thinks there may be something wrong with her breasts throughout the journey of diagnostic investigation, treatment and follow-up care, the experience of living with BC is continuous for the woman and her family. These events are embedded in their daily lives, and their demands become part of everyday living and decision-making. The cancer becomes an ever-present event for the woman and her family, not a separate entity that can be set aside and ignored. This means that what happened at screening and then at diagnosis influences what happens later in the continuous journey. As patients with BC are products of their social contexts, information provided should not only focus on health, but include other SEM factors as discussed in Chapter Seven. The collated and analysed voices of participating women provided a Kenyan-specific reality that HCPs can consider optimising treatment, meet patients' expectations and provide health information more effectively. This study highlighted the need for provision of detailed information on BC to women at all stages of their cancer journey to enable them to make informed choices, participate in decision-making and improve the quality of their treatment experience.

By exploring the HL experiences of patients with BC, this study adds previously unknown evidence from an LMIC context to the body of knowledge and illuminated the crucial role of information in the BC journey. This new knowledge is an original contribution that will be published, and inform practice, policy, education, and further research. Appendix 18 illustrates what was known from the literature review compared with the present findings.

The last (Chapter Eight) presents suggestions for further research, practice and policy based on evidence collected from participants' narratives. It offers new insights and strategies that can strengthen the provision of BC information to Kenyan women based on participants' recommendations and the findings of this study.

CHAPTER EIGHT: CONCLUSION AND RECOMMENDATIONS

This thesis explores and describes the HL experiences of Kenyan BC survivors and identifies the socio-ecological factors that influence how they access, understand, and use information along their BC journey. This study demonstrates the broad scope of HL and highlights women's information needs and priorities at various stages of the BC journey. From participants' narratives, it is apparent that HL goes beyond the individual and encompasses other factors, for example, psychosocial support and HCPs' competence. The evidence from this study indicates that in the Kenyan context, HL does not necessarily depend on formal education but on other factors, such as faith, fear and emotions, finances, social support, and the availability and accessibility of healthcare services.

The interaction between different socio-ecological factors is manifest in this research.
The results show that women living with BC resort to diverse sources of information about their condition, with the three most noticeable being HCPs (doctors and nurses), television and radio. Given they are the main information source, HCPs need to be aware of HL and the impact of the information they provide on their patients. However, reliance on the radio and television for information suggests that there is the need to restructure the quality of information on BC provided by these media channels. It was also found that a substantial number of women use non-health professional sources of information about treatment and alternative therapy, which suggests there is a need for contextual interventions based on the information needed. Most participants showed little understanding of BC, diagnostic processes, and treatment modalities. The HL factors identified are the same across high-income countries and LMICs, although there is a stark difference in financial challenges. For example, cancer services are free in the UK, whereas in Kenya patients pay from their own pocket or through insurance. The UK also has well established BC information channels; women are informed (through a phone or email alert) when they are due for BC screening. As a result, the current trend in health behavioural change requires much more than addressing and educating people (Leena,2020; McLeroy et al., 1988). I concluded that individual choices matter; patients should be given all the information and then left to make the decisions for themselves: *It is all about the patient and the choices they make…but they need to be*

informed choices! Nevertheless, they can only make informed choices if issues relating to HL are addressed.

Interventions are more likely to be successful and problems resolved if root causes are tackled first. This study provides invaluable insights that challenge traditional approaches and presents HL as a social construct; therefore, in a low resource setting, some social values need to be addressed when BC information is disseminated. BC is a disease that presents with vague symptoms, is distressing when diagnosed and has complex treatment regimens. Therefore, a BC diagnosis is a daunting one that affects women and their families. It is clear from this study that a BC diagnosis is overwhelming, and patients need to be taught credible sources of information before they even get to HCPs, as they only encounter HCPs once diagnosed. Effective interventions necessitate an understanding of the identified HL barriers and facilitators. The provision of health information is crucial in understanding and making decisions about BC. Overall, the present findings can be used to improve healthcare education and practice and inform further research and policy to ensure that women in Kenya receive appropriate information about BC. The next section presents a summary of the recommendations that emerged from this study, and provides suggestion to improve current practice, policy, education, and future research.

8.1 Implications for practice

Based on the findings, the following recommendations are made for clinical practice.

- Needs assessment should be performed by HCPs to elicit the priority information needs of patients with BC. This assessment could be used to design educational materials to help meet patient information needs. To be most effective, the material itself must be adapted specifically to LMIC patients in terms of language and simplicity. For example, specific education brochures, highlighting the signs and symptoms of BC, treatment modalities, and survival information should be provided in different languages.
- HCPs need to provide the right health information to the right patient at the right time throughout the whole BC treatment journey.
- There is need to implement strategies that encourage patients to ask questions, such as displaying flyers that advise patients to ask questions at every encounter with HCPs.
- HCPs need to find alternative ways of providing information to support patients with BC along the BC journey. For example, they should develop a treatment-specific protocol for information that patients should be given at each stage of their journey.
- HCPs need to give information at a pace that is comfortable for the patient, repeat information and ask the patient to teach-back the information; these simple techniques enhance patient understanding. HCPs need to hold tailor-made education programmes focused on improving patients’ BC-related HL. Kenyan women need accurate information from reliable sources on all aspects of BC, from recognising alarming symptoms to understanding the benefits of early detection and navigating the technical aspects of BC screening.
- Improve communication of health information with patients with BC by avoiding medical jargon and using plain language. The information should be individualised to specific patient information needs.
- Healthcare institutions should be ‘health educators’ and host websites with credible sites for patients to access health information. This can be borrowed from developed countries where hospitals have social media accounts through which they share information with the public. They also have websites, for example, Medline plus (https://medlineplus.gov/), which has an encyclopaedia with pictures; drug formation portals such as digital.gov (https://druginfo.nlm.nih.gov/drugportal/); and the breast

screen Australia programme (https://www.health.gov.au/initiatives-and-programs/breastscreen-australia-program).

- Promote patient-centred care by providing standardised but culturally sensitive information that respects patients' opinions and choices.
- Information should be provided about healthcare financing for BC treatment, and the consequences of defaulting treatment. Prognostic and survival information should also be provided to patients.
- Provide structured mass education and create awareness about the causes, symptoms, prevention, diagnosis and treatment of BC in Kenya. This is particularly needed among rural populations where most people are likely to have low HL and may lack BC knowledge.

- Implement a patient navigation programme that can eliminate barriers to care and ensure timely sharing of information, access to services and care. According to Freeman (2012), this navigation should encompass all phases of the BC journey as this enables timely care across the continuum. Patient navigation programmes are a foreign concept in Kenya (although a pilot has been started at the KNH with patients with prostate cancer), but are well established in the UK and US (Dalton et al., 2019; Jacobs et al.,2014; Marshall et al., 2016) and have been found to reduce the financial resources needed for treating advanced cancer as most patients re diagnosed at an earlier stage of the disease, which is usually cheaper to treat (Freeman, 2012).

8.2 Implications for healthcare policy

Based on the research findings, the following recommendations are made to improve healthcare policy in Kenya.

- The Kenya Government Breast Cancer Screening and Early Diagnosis Action Plan (2021-2025) provides guidance on strategies that can ensure early diagnosis and treatment of BC. Though the framework emphasizes the need for appropriate education and awareness campaigns, there is no focus on HL. This means that the traditional methods of creating awareness, may not work. The awareness plan should therefore encompass various approaches that address the socio-ecological factors which will promote HL. For example, the action plan while promoting early BC diagnosis acknowledges that screening is largely opportunistic due to lack of appropriate resources. A possible solution is private public partnerships in which government and non-governmental organizations can work together to provide health education materials in local languages and ensure that they are culturally appropriate.

- The Kenyan Government needs to change the current health policy and include all cancer services (screening to treatment) in the NHIF programme so that those who cannot afford to pay have access to healthcare services. In addition, there is need to equip the dispensaries and health centres (classified as levels two and three) with resources to provide breast health services in rural areas. Enhancing Kenya's NHIF may significantly boost BC screening and early detection among women with low SES. This way they can access screening facilities from select private healthcare services, which are accredited by the MOH-Kenya as BC service providers.
- There is need for large-scale cancer awareness campaigns (both by government and NGOs) where the public should be taught about signs and symptoms of BC, stages and the advantages of early detection and diagnosis. This must include messages that it is easier and cheaper to treat early-stage BC. However, any cancer-related information shared with the public must be vetted by the MOH-Kenya before it is released for public consumption. Communicating the right information is not enough; HCPs must deal with patients' values and emotions and other SEM factors, including how people consume information, and how they make decisions. Another strategy can borrow from The Word of Mouth Mammogram e-network (WoMMeN) project in the UK (Galpin et al., 2017).This way, a social media hub can be created where women (both health professionals and lay) can interact, get information about beast health and offer peer support to patients.
- Invoking the role of the MOH-Kenya, there is need for the government to organise more education sessions through media throughout the year, and not only in October (international BC awareness month). In addition, support from wider society, religious groups and opinion leaders could be used for BC awareness, but they also need training in providing accurate information
- As outlined in the Kenya Government Breast Cancer Screening and Early Diagnosis Action Plan (2021-2025), the community strategy of creating awareness is proposed. Community leaders are often trusted by their communities and can help disseminate accurate health information. Governments and non-governmental organizations can work with community leaders to organize health education programs and promote HL. To execute the community strategy, there is need to increase engagement with

Kenyan citizens to develop measures of HL that are culturally and contextually relevant for a low resource setting. For example, ‘*chamas*’ can be used to reach out to women with BC awareness messages. Community leaders (e.g., *nyumba kumi*), if empowered with knowledge, can be positive influencers for improving BC-related HL. *The nyumba kumi* initiative, a strategy to improve security in Kenya, may be an effective approach to share information. In this initiative, citizens are organised into clusters of 10 families who live in the same neighbourhood and encouraged to know the activities in each household. This way information about BC prevention and early detection can easily be shared and trusted as the people are in the same neighbourhood. In addition, the church (religious leaders are very influential and have a large following) and employers should take an active role in disseminating accurate BC awareness messages.

8.3 Implications for education

Based on the research findings, the following recommendations are relevant for improving education about BC and HL in Kenya.

- It is necessary to train more HCPs in oncology who can spearhead and audit the breast health programmes at level one and two facilities to ensure efficiency and identify gaps to initiate quality improvement processes.
- Research has demonstrated that healthcare professionals who possess an understanding of health literacy principles yield more favourable results in the care they provide to patients as opposed to those who lack such awareness. Consequently, having a good understanding of HL is crucial for healthcare practitioners to effectively evaluate and address their patients' HL requirements. To help with this, healthcare organizations should organise educational initiatives regarding HL among nursing staff. Additionally, continuing education programs should offer training on how best to communicate relevant BC information to patients in a way that promotes comprehension and utilization of the information. HL training should be a mandatory topic in the new nurses’ orientation, while the more experienced nurses can have in service sessions.
- From basic school level, HCPs should receive professional training in HL, communication and language, and be aware of various cultural beliefs that affect provider-patient interaction. It seems prudent to improve their knowledge as this will enhance the quality of information they provide to patients with BC. There is need for

focused HL awareness and education for HCPs and the public. Nurses should incorporate HL in patient education programmes and raise awareness of the issues associated with limited HL among various HCPs. Nurses should also become familiar with HL screening tools and techniques used to assess patients with low HL.

- Appropriate HL content should be included in the curricula at all levels of education, from basic to university, with a requirement for students to enrol in consumer health information and education courses. There is need to customise programmes that teach nurses how socio-cultural diversity affects HL and the multi-level health awareness interventions needed to enhance outcomes for patients with BC.
- Schools are an excellent platform for promoting health literacy among children and adolescents. Health education should be integrated into the school curriculum, and teachers should be trained to deliver health education effectively. This will not only improve the health literacy of students but also their families and communities.

8.4 Implications for research

The study raised issues that are relevant for further research. The following suggestions encompass researchable areas.

- There is a need for in-depth research that seeks to understand the complexities of accessing, understanding, and using health information, especially among the rural populations who may not understand English or Kiswahili. In addition, there is need to measure the HL levels of Kenyan women. This way individualised HL interventions can be tailored to cater for the needs of the women in the rural areas. investigations; for example,
- Investigation of HL knowledge among HCPs.
- Exploration of HL experiences in relation to patient family education and perspectives of HCPs working in cancer services.
- Exploration of decision-making styles of patients with BC as this is an outcome of HL.
- A larger quantitative study can explore the relationships between HL and other clinical and psychosocial factors that affect the participation and well-being of patients with cancer. From the findings, best evidence-based practices can be developed to provide contextual HL interventions.

- Progress in the field will in turn improve the design of effective interventions and help adjust the format and select appropriate instruments to measure the impact of HL in the prevention, diagnosis and treatment of BC based on the characteristics of specific patient groups.

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APPENDICES

Appendix 1: Reflections

The BC journey

The BC journey started with 'fear of unknown' when the lump was discovered, followed by diagnosis, then the 'bad news' was broken, a point that the women felt a death sentence had been passed on them. Later, they started treatment and as they improved, this raised their hopes and changed the notion of BC as a death sentence.

The stress of a cancer diagnosis

A cancer diagnosis is a stressful experience that affects the patient and her family in many ways. A woman is not only the pillar of the home, but she plays various other roles. She is the organizer of family events, she plans the meals, and she manages the house routines and nurtures her children. At individual level, the toxic side effects of treatment render her energy less. She is constantly faced with nausea and vomiting, fatigue and other physical symptoms. The taunting journey of treatment increases the stress levels of the woman and her family. Given that she may have surgery, followed by chemotherapy, and radiotherapy the side effects she experiences are immense. The financial implications of the BC diagnosis places great strain on the family resources. It is not uncommon to hear that a woman deferred treatment due to lack of money while their families abandon others. Women who have been diagnosed with BC have told stories of 'living with losses': Loss of health, loss of hair loss of strength, loss of independence, loss of family and loss of self-esteem. Consequently, it is imperative that the government considers this and allocates a special fund for a national campaign to increase BC awareness. Some effort has been seen with some NGOs organizing campaigns at county level. This awareness campaigns will disseminate information that will enable women discover breast lumps at an early stage. When discovered early, the treatment is cheaper and the probability of cure is high. The campaign slogan can be: woman, know your breasts, woman touch your breasts every month, woman look at your breasts in the mirror, woman what are your breasts saying? Using media that is easily accessible for example radio and television will ensure a critical mass of people is reached. In conclusion, BC is a stress full condition, which affects the individual and her family, it strains the family income 'it causes untold stress and suffering to the women and is associated with many *'losses'. Concerted efforts need to be implemented to increase awareness and capture the cancer at an early stage that has a high cure rate.*

The intrigues of data collection

There was one particular gentleman who categorically stated that he knew there was money for cancer projects and so the wife would only participate if they were given money. Needless to say, they did not consent to the study. Though this practice puts to question the autonomy of the participant, (Kuczewski, 2001) in his interesting article Informed Consent: Does It Take a Village? The Problem of Culture and Truth Telling suggests that informed consent should no longer be an individual issue but a responsibility of the individual and those close to them for example, husbands and children. Well, in Kenya it is already happening.

In another incident, my RA informed me of a patient who met all the inclusion criteria, but from looking at her demeanour, she wore an aura of richness mixed with some kind of aloofness and arrogance. Her nonverbal cues seemed to be shouting, 'LEAVE ME ALONE'! The RA discouraged me from approaching her saying she would definitely not accept to be a participant. Not to be swayed, I gathered all the courage I needed and called her into a side room where I explained about the study, and how I wished she could participate. This lady opened up, invited me to go to her home for further discussions and actually volunteered a lot of information even before I asked. I considered her amongst the "special populations" in research that my supervisor had referred to in one of our discussions. She proved our misconceptions wrong because she was a pleasant lady to talk to and she appreciated that I took time to think about her. Anyway, let me end her story by saying, when it was time to go to her home for the interviews, all the calls and text messages went unanswered. A decision was thus made not to pursue her unless she called back to reschedule, which she did not. She thus did not participate in the study; it would have been interesting to hear her BC HL experiences from a perspective of the rich.

Reflection on literature review process

Giant Monster subdued? Maybe, maybe not!!

One peculiar aspect of my research is that I have been doing it upside down (directly translated from my mother tongue-Luhya of Western Kenya region). What I mean is that I have never been in the same milestones with my cohort members. The reason is that, by the time I started *my PhD, I was the Principal Investigator (PI) in a grant funded study that was investigating health information needs of cancer patients. Therefore, my concept paper only needed some cleaning up before proceeding to ethics, which was granted within a reasonable period. I did not therefore have time to engage with the literature because I started collecting data, then analysing and before I knew it, it was time for the Interim assessment. These delays in doing a proper literature review earlier on may be responsible for the hardships I had, which I can now gladly refer to as past tense.*

Lit review to me has always been a monster. Difficulties with Lit review…it was huge. I did not understand until I read, listened to you tube videos and had several sittings with my supervisor Prof Alison. I remember one night that I sat up on the table figuring out the lit review, I did evidence tables. However, I felt it was not right. So as raw as it was, I sent to Prof Alison, switched off the computer and went out for a walk to calm my nerves; and guess what, she said, I was on the right track.

When eventually I understood what I needed to do, I could not stop writing. The monster has been subdued. Thanks Prof Alison. I have learnt new HL knowledge and expertise is setting in.

I now understand why a literature review is vital to a study…. I understand why some authors say. Engage with the literature. It is not a collection of studies and summarizing their strengths and weaknesses.

What I did was an intense exercise, a thread that weaved through my whole thesis. First roadblock was attempting to do a systematic review, yet I had clearly stated that I would use a systematic approach. I was so stuck at this roadblock until I explained to Prof Alison and she managed to get the green lights on…and off I speeded. The mistake I was making was that I was looking for my study in the literature, which I could not get.

I now understood that I needed to look for various categories of studies in order to identify the gap and justify my original contribution to the body of HL knowledge. With this in mind, it was excitement, fun and joy all in one word…fantabulous! In a single day I learnt so much about Cancer health literacy and I rubbished what I had presented before as literature review because it was just a summary of studies that had been done. Therefore, I looked for papers that answered the following questions:

1. *What studies justify the need for my study? What did they say and why do they say my research is needed?*

2. *What studies are similar to mine but do not do exactly what I will do? What are the gaps in these studies and why is this important?*
3. *What studies might my research speak back to? What is the problem with these studies?*

Overall, why these studies and not others?

Answering the questions above was the key to fighting and overcoming the monster. I feel proud of what I have achieved, and I know that though it is not perfect yet, I am much better in literature review than most of my peers. Thanks to my supervisors!

Appendix 2: Statement regarding PhD candidate's independent contribution

Beginning Investigator Grant for Catalytic Research (BIG Cat) Vs PhD

The following extract from the grant call highlights why I was the principal investigator for the project.

IV. ELIGIBILITY

1.Principal investigator (PI) must be a beginning investigator, defined as a clinician or scientist who received his or her highest degree of study within the past seven years. An earned academic (or research) doctorate [such as a Doctor of Philosophy (Ph.D.)], or medical degree [such as a Doctor of Medicine (M.D.), Doctor of Osteopathy (D.O.), or Bachelor of Medicine Bachelor of Surgery (MB ChB, MB BS, BM MCh, etc.)] is considered the highest degree of study in most countries. When an investigator has received multiple terminal degrees, the calculation will be based on the date of award of the most recent degree. The funding is also open to those with a Master of Public Health or its equivalent. No exceptions to this requirement will be considered.

2. Each PI's institution at which he or she is employed should serve as the Principal Institution1 designated on the application.

3. The PI must commit at least 15% Level of Effort (LOE) of his/her fulltime work to the project.

4. Projects may include additional investigators as part of the project team at the discretion of the PI. However, all funds must be spent in Africa or to benefit African research capacity building.

5.PI must be having legal living status in Africa.

6. PI must reside in and be conducting research in Africa with particular relevance to the African cancer burden on the continent.

7. Proposals may only be submitted by PI's invited by CRDF Global upon submission of a responsive LOI. Each PI can submit only one proposal for this program that must match the project outlined in the responsive LOI submission.

8. Each project is evaluated independently and therefore should not be part of, nor depend on the success of other projects submitted to this program. Early-career African clinicians and scientists (with a terminal academic degree within last seven years) who reside in and will conduct cancer research in Africa relevant to the African cancer burden

Scope

Grant awards will be made to institutions of selected early-career African investigators to support two-year projects up to **$50,000 USD total** ($25,000 USD per year, with second year funding contingent on research progress from the first year). If justified near the end of the second year, up to a six month no cost extension may be permitted." Awards are intended to catalyze subsequent application for funding from NCI and/or other sources, not to support longer term research. The grants are not intended for principal investigators outside of Africa, although collaborative research projects are encouraged. All funds provided must be spent in Africa with the exception of limited support for travel to international scientific meetings and conferences. BIG Cat funding is intended to support RESEARCH PROJECTS i.e., not to enhance or improve healthcare services directly.

This research arose from a grant-funded study in which I am the Principal investigator (PI) with three other co-investigators. The funder is CRDFGlobal BIG CAT Initiative (Grant number- DAA3-16-62706-0).

	Grant	**PhD**
Investigators	• Dinah Kassaman - Principal investigator • Prof. Sharon Brownie-Study site advisor • Dr Margaret Barton-Burke-research mentor • Ms. Tayreez Mushani-interviewed one cervical cancer patient • Peterson Karani Kiraithe-Research Assistant	Dinah Kassaman This research arose from a grant-funded study in which I am the Principal investigator (PI) with three other co-investigators. The funder is CRDFGlobal BIG CAT Initiative (Grant number- DAA3-16-62706-0).
Aim	To identify previously unrecorded information pertaining health literacy status of women diagnosed with breast or cervical cancer.	To explore the experiences of breast cancer survivors and describe the factors that influenced their HL during their treatment journey
Research questions	1.What are the health literacy and awareness levels of women diagnosed with breast or cervical cancer with respect to: cancer awareness and beliefs; warning	3. What are the experiences of accessing, understanding and utilizing health information for patients diagnosed with breast cancer in Kenya? 4. What socio-ecological factors influence the health literacy of

	signs and symptoms; disease types and processes; understanding nursing, medical and pharmacy instruction? 2.What is the ability of the woman to: read consent forms and medication labels; understand oral and written information given by health care providers and insurers; act upon provided information regarding medications, appointment schedules and other aspects related to diagnosis and treatment?	women diagnosed with breast cancer in Kenya?
Objectives	Only had the above research questions.	1. To describe the experiences of accessing, understanding, and utilizing cancer-related information along the breast cancer illness trajectory. 2. To determine what breast cancer survivors understand about breast cancer in their communication with healthcare providers. 3. To identify cancer related information needs of women diagnosed with breast cancer. 4. To identify the socio ecological factors that influence the health literacy of women diagnosed with BC.
Sample size	**18 women** 12 breast cancer survivors 6 cervical cancer survivors	**11** Breast cancer survivors

Specific roles as PI in grant project

- Submitted the Letter of Intent (LOI) after receiving the Request for Proposals (RFP)
- Developed the research proposal, and all the research instruments –consent form, interview guides
- Coordinated all the grant requirements with various departments (Finance, human resources, housing and travel, and legal).
- Coordinated the hiring of the research assistant.
- Applied for ethical approvals from Aga Khan University, Kenyatta National Hospital and Kenya National Council for Science and Technology (NACOSTI).
- I was responsible for the overall conduct of the research, monitoring and ensuring that all activities complied to the laws and regulations.
- Sent periodic reports to the funder.
- Compiled the final report, organised for proof reading and sent to the funder.
- Sent abstracts to disseminated findings in conferences.
- Presented the work in Aortic and the ICCN conferences
- Led in publishing one article (Kassaman, D., Mushani, T., Kiraithe, P., Brownie, S., & Barton-Burke, M. (2022). Fear, faith and finances: health literacy experiences of English and Swahili speaking women newly diagnosed with breast and cervical cancer. *Ecancermedicalscience, 16*.)
- Second manuscript in progress in which I am the second author (In their voices: Kenyan women's experiences with cancer treatment-related side effects)

Roles of the RA

- Assisted with checking translation of research instrument.
- Recruited the participants.
- Conducted three cervical cancer and two BC interviews.
- Transcribed all the interview data
- Communicated to the participants for follow up interviews.

	Independent/unique contribution	**Joint contribution**
Title	A qualitative exploration of the factors that influence health literacy in women diagnosed with breast cancer in Kenya during their cancer journey	"Despair, agony and complexity": Breast cancer survivor's lived experience of health literacy during their treatment journey in low resource settings, the case of Kenya
Study idea	Conception of study idea, developing proposal, study tools and seeking collaborations	Prof Sharon (20 %), Tayreez (20%)and Dr Margaret (30 %) contributed to the design, write up, and commented on the drafts and final proposals.

	necessary to implement the study, applying for ethics..	
Data collection	Data collection-interviewed 9 participants (BC patients)	Tayreez interviewed one cervical cancer patient. Peterson interviewed participants (two breast cancer patients)
Transcription	Re-transcribed the data for BC patients	The RA transcribed the interview data (90 %).
Data analysis	Analysed 100 % of the data for BC	-

Appendix 3: Search terms

Key words	Alternative words
Cancer	OR “neoplasm” OR “tumour”
BC	OR “breast neoplasm” OR “breast tumour”
Information needs	OR “patient education”
Health literacy	OR “health knowledge” OR “consumer health
Filters	Randomised Controlled Trials Meta-analysis Systematic reviews Qualitative

Appendix 4: Updated database search history in July,2021

https://ovidsp.ovid.com/?T=JS&NEWS=N&PAGE=main&SHAREDSEARCHID=5r9Qx81Syc5YdqAgGeyOKmARiUgZHwnbNR5PAxAXxYm2ekxoPVZUdTYWLc73avCKP

Ovid MEDLINE(R) <1946 to August Week 3 2021>

1 BC.mp. or exp Breast Neoplasms/ or Breast Carcinoma.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 357665

2 health literacy.mp. or Information Literacy/ or exp Consumer Health Information/ or (exp Consumer Health Information/ or exp Patient Medication Knowledge/) [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 14788

3 exp Health Literacy/ 7320

4 1 and 2340

5 1 and 3157

6 limit 5 to (english language and female and full text and humans and yr="2018 -Current") 12

7 limit 6 to (english language and female and yr="2018 -Current") 12

8 limit 7 to (english language and humans and yr="2018 -Current") 12

9 Kenya.mp. or exp Kenya/ 20942

10 limit 9 to (english language and humans) 15958

11 1 and 2 and 9 0

12 Africa.mp. or exp "Africa South of the Sahara"/ [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 284607

13 1 and 2 and 124

14 BC.mp. or exp Breast Neoplasms/ or Breast Carcinoma.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 357665

15 health literacy.mp. or Information Literacy/ or exp Consumer Health Information/ or (exp Consumer Health Information/ or exp Patient Medication Knowledge/) [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 14788

16 exp Health Literacy/ 7320

17 14 and 15 340

18 14 and 16 157

19 limit 18 to (english language and female and full text and humans and yr="2018 -Current") 12

20 limit 19 to (english language and female and yr="2018 -Current") 12

21 limit 20 to (english language and humans and yr="2018 -Current") 12

22 Kenya.mp. or exp Kenya/ 20942

23 limit 22 to (english language and humans) 15958

24 14 and 15 and 22 0

25 Africa.mp. or exp "Africa South of the Sahara"/ [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 284607

26 14 and 15 and 25

APPENDIX 4- INITIAL DATABASE SEARCH HISTORY IN DECEMBER 2018-AU

PsycInfo search history sorted by search number ascending

☐	# ▼	Searches	Results	Type	Acti
☐	28	23 and 27	5	Advanced	More
☐	27	phenomenology.mp.	6352	Advanced	More
☐	26	limit 23 to (english and randomized controlled trial)	170	Advanced	More
☐	25	limit 23 to (english and meta-analysis)	7	Advanced	More
☐	24	limit 23 to (english and "systematic review")	17	Advanced	More
☐	23	16 and 20	2365	Advanced	More
☐	22	limit 21 to (english and "systematic review")	2	Advanced	More
☐	21	18 and 20	320	Advanced	More
☐	20	exp Breast Neoplasms/	254428	Advanced	More
☐	19	limit 18 to (english language and english and "systematic review")	14	Advanced	More

☐	18	15 and 16 and 17	1338	Advanced	More
☐	17	Health Education/ or exp Consumer Health Information/	62300	Advanced	More
☐	16	Health Knowledge, Attitudes, Practice/ or exp Health Literacy/	101470	Advanced	More
☐	15	exp Neoplasms/	2903996	Advanced	More
☐	14	9 and 13	5	Advanced	More
☐	13	phenomenology.mp.	6352	Advanced	More
☐	12	limit 9 to (english and randomized controlled trial)	170	Advanced	More
☐	11	limit 9 to (english and meta-analysis)	7	Advanced	More
☐	10	limit 9 to (english and "systematic review")	17	Advanced	More
☐	9	2 and 6	2365	Advanced	More
☐	8	limit 7 to (english and "systematic review")	2	Advanced	More
☐	7	4 and 6	320	Advanced	More
☐	6	exp Breast Neoplasms/	254428	Advanced	More

☐	5	limit 4 to (english language and english and "systematic review")	14	Advanced	More
☐	4	1 and 2 and 3	1338	Advanced	More
☐	3	Health Education/ or exp Consumer Health Information/	62300	Advanced	More
☐	2	Health Knowledge, Attitudes, Practice/ or exp Health Literacy/	101470	Advanced	More
☐	1	exp Neoplasms/	2903996	Advanced	More

Medline search history sorted by search number ascending

☐	# ▼	Searches	Results	Type	Actions	Anno
☐	38	limit 35 to 1600 qualitative study [Limit not valid in Ovid MEDLINE(R); records were retained]	406	Advanced	Display Results More	
☐	37	limit 35 to 1200 meta-analysis [Limit not valid in Ovid MEDLINE(R); records were retained]	406	Advanced	Display Results More	
☐	36	limit 35 to ("0830 systematic review" and english) [Limit not valid in Ovid MEDLINE(R); records were retained]	406	Advanced	Display Results More	
☐	35	limit 34 to ("reviews (best balance of sensitivity and specificity)" and english and human)	406	Advanced	Display Results More	
☐	34	31 and 32	2847	Advanced	Display Results More	
☐	33	29 and 30	348	Advanced	Display Results More	
☐	32	(BC or breast neoplasm).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	202498	Advanced	Display Results More	
☐	31	exp Health Education/ or exp Health Information/	219560	Advanced	Display Results More	
☐	30	exp Health Literacy/	4645	Advanced	Display Results More	
☐	29	exp Neoplasms/	2903996	Advanced	Display Results More	
☐	28	23 and 27	5	Advanced	Display Results	

					More	
☐	27	phenomenology.mp.	6352	Advanced	More	Display Results
☐	26	limit 23 to (english and randomized controlled trial)	170	Advanced	More	Display Results
☐	25	limit 23 to (english and meta-analysis)	7	Advanced	More	Display Results
☐	24	limit 23 to (english and "systematic review")	17	Advanced	More	Display Results
☐	23	16 and 20	2365	Advanced	More	Display Results
☐	22	limit 21 to (english and "systematic review")	2	Advanced	More	Display Results
☐	21	18 and 20	320	Advanced	More	Display Results
☐	20	exp Breast Neoplasms/	254428	Advanced	More	Display Results
☐	19	limit 18 to (english language and english and "systematic review")	14	Advanced	More	Display Results
☐	18	15 and 16 and 17	1338	Advanced	More	Display Results

☐	17	Health Education/ or exp Consumer Health Information/	62300	Advanced	More	Display Results
☐	16	Health Knowledge, Attitudes, Practice/ or exp Health Literacy/	101470	Advanced	More	Display Results
☐	15	exp Neoplasms/	2903996	Advanced	More	Display Results
☐	14	9 and 13	5	Advanced	More	Display Results
☐	13	phenomenology.mp.	6352	Advanced	More	Display Results
☐	12	limit 9 to (english and randomized controlled trial)	170	Advanced	More	Display Results
☐	11	limit 9 to (english and meta analysis)	7	Advanced	More	Display Results
☐	10	limit 9 to (english and "systematic review")	17	Advanced	More	Display Results
☐	9	2 and 6	2365	Advanced	More	Display Results
☐	8	limit 7 to (english and "systematic review")	2	Advanced	More	Display Results
☐	7	4 and 6	320	Advanced	More	Display Results

☐	6	exp Breast Neoplasms/	254428	Advanced	More	Display Results
☐	5	limit 4 to (english language and english and "systematic review")	14	Advanced	More	Display Results
☐	4	1 and 2 and 3	1338	Advanced	More	Display Results
☐	3	Health Education/ or exp Consumer Health Information/	62300	Advanced	More	Display Results
☐	2	Health Knowledge, Attitudes, Practice/ or exp Health Literacy/	101470	Advanced	More	Display Results
☐	1	exp Neoplasms/	2903996	Advanced	More	Display Results

CINAHL search history

```
Set   Search                                              Results
------------------------------------------------------------------------
001   exp Neoplasms/                                          80577
002   Health Knowledge, Attitudes, Practice/ or exp Health Literac    4715
      y/
003   Health Education/ or exp Consumer Health Information/          1426
004   1 and 2 and 3                                           79
```

005	limit 4 to (english language and english and "systematic review")	3
006	exp Breast Neoplasms/	8239
007	4 and 6	18
008	limit 7 to (english and "systematic review")	0
009	2 and 6	105
010	limit 9 to (english and "systematic review")	1
011	limit 9 to (english and meta analysis)	1
012	limit 9 to (english and randomized controlled trial)	4
013	phenomenology.mp.	297
014	9 and 13	0
015	limit 14 to updaterange="medl(20190724200454-20190731102604]"	0

Appendix 5: Initial (December,2018-August,2019)-evidence tables

Study Reference	Country	Focus/Aim	How HL is defined	Methods and sample	Type of cancer and stage	Findings
Shen, H.-N., Lin, C.-C., Hoffmann, T., Tsai, C.-Y., Hou, W.-H., & Kuo, K. N. (2019). The relationship between health literacy and perceived shared decision making in patients with breast cancer. Patient education and	Taiwan	To explore the relationship between patient-perceived shared decision making (SDM) and three domains of health literacy (HL) in patients with breast cancer.	Health literacy has been conceptualised, by the European Health Literacy Consortium, as an individual's competencies to access, understand, appraise, and apply health information to make judgments and decisions concerning healthcare, disease prevention, and health promotion contexts to maintain	Quantitative Cross sectional convenience of breast cancer patients from breast surgery clinics or wards	Breast On treatment	Factors important for declining cancer treatment included concerns about the discomfort of the treatments, fear of side effects and transportation difficulties. Although the reasons why older adults with cancer accepted or declined treatment varied considerably

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
counseling, 102(2), 360-366. doi:http://dx.doi.org/10.1016/j.pec.2018.09.017			or improve their quality of life.			
Shen, M. J., Dyson, R. C., D'Agostino, T. A., Ostroff, J. S., Dickler, M.	England	To observe the processes of patient–physician communication when cancer-	Not provided	Qualitative-Observation and audiorecording of patients and oncologists	Breast stage 1-4 On trreatment	Patients approached oncologists as experts who could advise them about the information they found on the internet. Most patients approached oncologists

Study Reference	Country	Focus/Aim	How HL is defined	Methods and sample	Type of cancer and stage	Findings
N., Heerdt, A. S., & Bylund, C. L. (2015). Cancer-related internet information communication between oncologists and patients with breast cancer: a qualitative study. Psychooncology, 24(11), 1439-1447.		related health information(CRII) was discussed.				collaboratively and asked for their expert opinions and recommendations. The information they looked up was from a reputable website.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
doi:10.1002/pon.3752						
Weber, K. M., Solomon, D. H., & Meyer, B. J. (2013). A qualitative study of breast cancer treatment decisions: evidence for five decision-making styles. Health Commun,	USA	To study factors that impact the decision-making and how the decisions were actually made among breast cancer patients.	None provided	Qualitative In-depth interviews with 44 women	Breast All stages	Women used a variety of sources to make decisions. Some women left decision making entirely to the doctors. Others weighed different options and asked their doctor to substantiate % decision making styles came out

Study Reference	Country	Focus/Aim	How HL is defined	Methods and sample	Type of cancer and stage	Findings
28(4), 408-421. doi:10.1080/10410236.2012.713775						
Potter, S., Mills, N., Cawthorn, S., Wilson, S., & Blazeby, J. (2015). Exploring information provision in reconstructive breast surgery: A qualitative study. Breast,	USA	To use in-depth qualitative methods to investigate patients' and professionals' perceptions of information provided for decision-making in reconstructive breast surgery with particular	None provided	Qualitative Semi structured interviews with 35 health care providers (HCPs) and 31 patients		There was a discrepancy between what the patients and HCPs considered important. Patients' information needs currently were not being met. The information was not adequate to make a decision to have surgery. Information given immediately after a cancer diagnosis was not understood. Doctors used complicated language and appeared too busy that patients did not ask questions

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
24(6), 732-738. doi:10.1016/j.breast.2015.09.003		reference to the provision of information to facilitate procedure choice				
Jordan, J. E., Buchbinder, R., & Osborne, R. H. (2010). Conceptualising health literacy from the patient perspective. Patient education and counseling, 79(1), 36-42.	Australia	To identify and understand what health literacy represents from the patient perspective and identify potential constructs for a broader measure of health literacy.	The term health literacy encompasses an individual's ability to seek, understand and utilise health information.	Qualitative 48 individuals who had chronic illnesses. Face to face and telephone interviews	Not specified but cancer patients were recruited.	Most participants needed a trigger to seek healthcare services. Knowing where to seek help was an ability patients needed. Importance of clearly explaining symptoms to the doctor. Time pressured clinical environment interfered with getting information from HCWs. Patient emotions and disposition when sick interfered with how they communicated. They identified other community and healthcare factors that interfere with information use.

Study Reference	Country	Focus/Aim	How HL is defined	Methods and sample	Type of cancer and stage	Findings
Lee, S. Y., & Hawkins, R. P. (2016) Worry as an Uncertainty-Associated Emotion: Exploring the Role of Worry in Health Information Seeking. Health Communication, 31(8), 926-933. Retrieved from http://ovidsp.o	USA	To understand what leads women with breast cancer to consult the Internet for health-related information.	None provided	Quantitative-cross sectional 122 women participating in a RCT.	Breast Newly diagnosed	Unmet information needs drove patients to the internet. Patients in late stages of cancer tended to seek less information compared to those in early cancer stages. The more educated used internet more. Those with unmet need for emotional support spent more time on online support services.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
vid.com/?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med12&AN=26752071						
Othman, A., Ahram, M., Al-Tarawneh, M. R., & Shahrouri, M. (2015). Knowledge, Attitudes and Practices of Breast Cancer Screening Among	Jordan	To explore women's perceived reasons for performing breast cancer screening, mammography and CBE in particular.	None provided	Not explicitly stated but could be a mixture of patients and non-patients- Survey, but reports that 54 field workers did in depth face-face interviews with 1549 women. A	Breast Early detection	Though HL and lived experiences not explored, the study explores women knowledge attitudes and practices in relation to breast cancer screening. Most women knew that Clinical Breast Exam should be done every year at age 40 and above. They knew that mammography should be done every year. They however undertook CBE and mammography erratically. While they knew that mammography was for screening, others had it for follow-up of a lump detected previously or on physician advice.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
Women in Jordan. Health Care for Women International, 36(5), 578-592. doi:10.1080/07399332.2014.926900				structured questionnaire was used. Could have been a mixed method - though does not expressly indicate so.		
Halbach, S. M., Ernstmann, N., Kowalski, C., Pfaff, H., Pfortner, T. K., Wesselmann, S., & Enders, A. (2016).	Germany	To investigate unmet information needs in newly diagnosed breast cancer patients over the course of cancer treatment	None provided	Quantitative	Breast -on treatment	Unmet information needs on side effects and medication and medical examination results and treatment options were high and increased during the first 10 weeks after breast cancer surgery. Considering health promotion and social issues, unmet information needs started high and decreased during post-treatment.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. Patient Educ Couns, 99(9), 1511-1518. doi:10.1016/j.pec.2016.06.028		and its association with health literacy				Patients with limited health literacy had higher unmet information needs.

Study Reference	Country	Focus/Aim	How HL is defined	Methods and sample	Type of cancer and stage	Findings
Humphrys, E., Burt, J., Rubin, G., Emery, J. D., & Walter, F. M. (2019). The influence of health literacy on the timely diagnosis of symptomatic cancer: A systematic review. European journal of cancer care, 28(1), N.PAG-	Australia	To evaluate the influence of health literacy on the timely diagnosis of symptomatic cancer.	Bridge between people and health settings," reflecting how patients' access, understand, evaluate and use healthcare information and navigate the services available to them.	Systematic review 26 papers	Any cancer	Poorer health literacy increased delays. HL seen as an important pathway to cancer diagnosis and could help develop targeted awareness campaigns and early screening and diagnosis.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
N.PAG. doi:10.1111/ecc.12920						
Olayide, A. S., Halimat, A. J., Samuel, O. A., Ganiyu, R. A., & Soliu, O. A. Level of Awareness and Knowledge of Breast Cancer in Nigeria. A Systematic	Nigeria	By aggregating available data, we aimed to assess what still constitutes poor breast cancer awareness in Nigeria in order to suggest how to allocate resources	None	Systematic review- Studies conducted on Nigerian populace from 2000 to date were reviewed systematically	Breast cancer	In general, low awareness of breast cancer may not be the direct and foremost driver of persistent late presentation in Nigeria. The knowledge of risk factors for breast cancer was higher than the knowledge of symptoms. The percentages of respondents who performed breast selfexamination regularly as screening procedure were higher than those who performed mammography (Table 3) as recommended in practice for the appropriate age brackets.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
Review. Ethiopian Journal of Health Sciences, 27(2), 163-174. Retrieved from http://ovidsp.ovid.com/?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med13&AN=28579712		to reverse the paradox				

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
Wanchai, A., Armer, J. M., & Stewart, B. R. (2010).	Thailand	The purpose of this literature review is to summarize research as it relates to CAM use among women with breast cancer	None	Systematic review	Breast cancer on treatment	Many women use CAM as a complement to traditional therapies.
Rust, C., & Davis, C. (2011). Health Literacy and Medication Adherence in Underserved African-American Breast Cancer		To explore the importance of health literacy and medication adherence from a qualitative perspective.	Health Literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate	Qualitative-Two Focussed group discussions of 12 participants in each	Breast cancer on treatment	Four themes emerged from the transcribed interviews: inequality of access to health information, acquisition of medication information, medication usage and adherence, and barriers to access to medications

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
Survivors: A Qualitative Study. Social Work in Health Care, 50(9), 739-761. doi:10.1080/00981389.2011.585703			health decisions" (U.S. Department of Health and Human Services, 2000, pp. 11–20).			
Livaudais, J. C., Franco, R., Fei, K., & Bickell, N. A. (2013). Breast cancer treatment decision-making: are we	USA	To evaluate factors associated with patients' perceived responsibility for decision-making in women receiving adjuvant therapy after surgery.	None provided	Quantitative 328 newly diagnosed after a surgical intervention who were participating in a RCT. Telephone surveys	Breast Newly diagnosed and had surgery	Insufficient treatment knowledge at the beginning of treament.Low literacy was seen in the less educated who also voiced too much responsibility of decision making.Trust and communication by the physician plays a big role. Knowledge of treatment benefits increased participation in decision making.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
asking too much of patients? J Gen Intern Med, 28(5), 630-636. doi:10.1007/s11606-012-2274-3						
Plummer, L. C., & Chalmers, K. A. (2017). Health literacy and physical activity in women diagnosed with	Australia	To explore the relationship between health literacy and physical activity in women diagnosed with breast cancer	Health literacy has been defined by Nutbeam24(p357) as "…cognitive and social skills, which determine the motivation and ability of individuals to gain access to,	Quantitative 36 women Through telephone interview	Breast 6-8 months after treatment	HL is a significant predictor of physical activity in women diagnosed with breast cancer. Of the 3 levels of health literacy proposed by Nutbeam,functional health literacy appears to be the most important component in this relationship

Study Reference	Country	Focus/Aim	How HL is defined	Methods and sample	Type of cancer and stage	Findings
breast cancer. Psycho-Oncology, 26(10), 1478-1483. doi:http://dx.doi.org/10.1002/pon.4318			understand and use information in ways which promote and maintain good health			
Doumit, M. A., El Saghir, N., Abu-Saad Huijer, H., Kelley, J. H., & Nassar, N. (2010). Living with breast cancer, a Lebanese	Lebanon	To provide in-depth understanding of the experience of Lebanese women living with breast cancer.	None provided	Qualitative-Phenomenology 10 purposively sampled women	Breast (Stage 1-111 On treatment	Women described experiences of living with losses:loss of body parts,loss of hair,loss of social networks.They lived with guilt feelings of passing on the cancer to their female relatives.The had fears of cancer recurrence and uncertainties,fear of rejection by friends,fear of death.They had a great need for knowledge and felt they could share their knowledge with newly diagnosed cancer patients.

Study Reference	**Country**	**Focus/Aim**	**How HL is defined**	**Methods and sample**	**Type of cancer and stage**	**Findings**
experience. European Journal of Oncology Nursing, 14(1), 42-48. Retrieved from http://ovidsp.ovid.com/?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med7&AN=19815459						

Appendix 6: Updated (July 2021)-evidence tables

Author, year	**Location**	**Aim and/or objective**	**Type of cancer studied, and Stage in cancer journey**	**Methods**	**Study sample**	**Key findings**
Brown, T., Dyck, I., Greenhough, B., Raven-Ellison, M., Dembinsky, M., Ornstein, M., & Duffy, S. W. (2017).	London	To evaluate the effectiveness of a breast awareness DVD.	Did not have cancer	Mixed method Focus group discussions for qualitative data	101 black women	From the video it seemed BC was a disease of white women. The DVD lacked feeling and emotion, the use of the term aggressive in describing BC in black women increased fear. It would have been important for the DVD to portray a patient journey with

						BC, so that the participants could lean from the experiences. The DVD increased BC awareness and prompted the women to sensitise their family members, they were keen to know if BC would be passed to their daughters.
McEwan, J., Underwood, C., & Corbex, M. (2014)	Egypt	The aim of the present study was to deepen our understanding of women's experiences with, and interpretations of,	Breast Treatment	Qualitative	Women at stage 3 and 4 with treatment delay	Intrapersonal factors-fear,BC awareness and misintepretation of symptoms,HL and causation beliefs, Modesty (shyness about HCP

		diagnosis and treatment delays and highlight nuances not identifiable in the quantitative study.				touching their breasts),lack of knowledge and low socioeconomic status. Interpersonal factors-social networks-family, friends ,neighbours provided information. Organizational-Sub optimal communication with doctors, low economic capacity, inefficiency in diagnosis and referral.

Yiqing Huang et al 2019	Singapore	To determine the prevalence of CRC screening among non-colorectal cancer survivors, and identify factors that may influence the uptake of CRC screening	Non-colorectal cancer survivors Treatment	Cross-sectional Study	Non-colorectal cancer survivors Male and female	In our study, there was high knowledge of CRC amongst cancer survivors. More than 80% knew the symptoms, screening tests and risk factors for CRC. However, despite the high knowledge and a personal history of cancer, close to half believed there is ‘little need’ or ‘no need’ for CRC screening

Kirsten M. Weber , Denise Haunani Solomon & Bonnie J. F. Meyer 2013	Pennysylvania USA	we studied potential differences in the weighting of factors by patients based on their own decision-making needs, preferences, or styles.	Breast cancer survivors All stages	Qualitative	Breast cancer survivors	Through an interpretive analysis, we identified five treatment decision-making styles: (a) medical expert, (b) self-efficacy, (c) relationship embedded, (d) inhibition, and (e) constellation of information, which are differentiated by two dimensions: (a) low versus high information needs and (b) self-versus other preferences.

Puts, M. T. E., Tapscott, B., Fitch, M., Howell, D., Monette, J., Wan-Chow-Wah, D., . 2015	Canada	To determine if the factors influencing older adults' decisions to accept or decline cancer treatment varied by cancer stage, cancer type, cancer treatment, and age (younger old (65- 74) and older old (75+)).	All cancers After diagnosis- does not specify stage	Systematic review	10 databases	Factors important for declining cancer treatment included concerns about the discomfort of the treatments, fear of side effects and transportation difficulties.
Khan, T. M., Leong, J. P., Ming, L. C., & Khan, A. H. (2015	Malaysia	Aimed to understand and evaluate the level of in-depth breast cancer knowledge in terms of clinical breast examination and	Breast Screening	Systematic review	All women	Women in Malaysia generally have good awareness about breast cancer and on screening with BSE. There are serious deficits in in-depth

		breast self-examination, and other important aspects such as side-effects and risk factors in Malaysian females.				knowledge, however, which creates misconceptions and delays health-seeking behaviour.
Sheppard, V. B., Christopher, J., & Nwabukwu, I. (2010)	USA	We convened two focus groups to: (1) explore African women's knowledge and attitudes towards breast cancer practices and (2) identify potential intervention targets.	Not specified	?qualitative Just says focus groups	Immigrants in Washington DC. Women were primarily from the western region of Africa (e.g., Nigeria, Ivory Coast), but there were representatives from the southern (e.g., Zimbabwe) and eastern	Findings indicated that women's knowledge and exposure to breast cancer prevention and screening were limited, and common explanations for breast cancer were that it is a boil or is a

					(e.g., Ethiopia) regions as well	punishment from God.
Shen, M. J., Dyson, R. C., D'Agostino, T. A., Ostroff, J. S., Dickler, M. N., Heerdt, A. S., & Bylund, C. L. (2015).	USA	The goal of the present study was to observe the processes of patient–physician communication when cancer-related health information(CRII)was discussed.	Breast Stage 1-4 Treatment	Qualitative-Observation and audiorecording of patient oncologist	21 breast cancer patients	Patients approached oncologists as experts who could advise them about the information they found on the internet. Rather than directly challenging the oncologists [13], most patients

						approached them collaboratively and asked for their expert opinions and recommendations. This finding fits in line with previous research indicating that patients who discuss internet health information with their physicians report a reliance on their providers for decision-making [11]. Patients also often explicitly expressed that the information they looked

						up was from a reputable website.
Connie L. Arnold, PhD 1; Alfred W. Rademaker, PhD2; James D. Morris, MD1; Laurie Anne Ferguson, DNP, APRN, FNP-C3; Gary Wiltz, MD4; and Terry C. Davis, PhD1 2019	Louisiana, USA	To compare the effectiveness of a health literacy education strategy to promote CRC screening among patients at rural community clinics using the fecal immunochemical test (FIT)	Did not have cancer	RCT	Male and female on routine clinic visit	Providing FIT kits and literacy-appropriate education at regularly scheduled clinic visits with a follow-up telephone call when needed was found to increase CRC screening among low-income, rural patients. The

		combined with 2 telephone follow-up strategies: an automated telephone call (AC) or a personal call (PC).				lower cost automated call was just as effective as the personal call The results of the current study indicated that the perception of barriers to screening was low in our vulnerable patients and self-efficacy regarding completing the test was high. It is interesting to note that our health literacy–informed education and

						follow-up strategy was equally effective among patients with limited literacy in promoting FIT completion. In the current study, approximately 60% of patients completed the FIT without needing a follow-up telephone call.
Enzler, C. J., Torres, S., Jabson, J., Ahlum Hanson, A., & Bowen, D. J. (2019)	Memorial Sloan Kettering Cancer Center USA	To assess the needs of low-SES breast cancer patients from the perspective of the	Breast On treatment or post treatment	Qualitative Grounded theory	Low-SES breast cancer survivors (n = 37) and medical personnel (ie, physicians, nurses,	Low-SES breast cancer survivors reported many unmet needs, including transportation,

		patient and the provider			and navigators; n = 8)	housing, health literacy, and language, among others. Many providers feel that these needs are being met, but patients have more diverse experiences.
Wanchai, A., Armer, J. M., & Stewart, B. R. (2010).	Thailand	The specific questions about women with breast cancer were (a) which types of CAM were reported, (b) what were the sources of information about CAM, (c) what factors	Breast On treatment	Systematic review	33 quantitative studies	Sources of information about CAM use for women with breast cancer vary widely, including family, friends, mass media, healthcare providers, CAM providers, and self-help groups. Sociodemographic

		contributed to CAM use, and (d) why did women decide to use CAM?				factors that appear to be related to CAM use were younger age, higher education, higher income, married status, involvement in a support group, and health insurance. The reasons for CAM use reported by women with breast cancer were to help healing, to promote emotional health, and to cure cancer.

Cooney, M. A., Culleton-Quinn, E., & Stokes, E. (2013	Ireland	The aim of this study was to present what is known about the prevalence, location, intensity, nature, and temporal factors of the pain experienced by patients after breast cancer treatment.	Breast On treatment	Systematic review	26 articles	Pain is confirmed as a prevalent treatment-related symptom experienced by 13%-51% of women in several different anatomic locations. The onset is variable, ranging from immediate to 24 months, highlighting the need to assess for pain at every evaluation interval. Little is known about the nature of the pain, but descriptors used (tenderness,

						soreness) suggest that the type of pain may not be confined to neuropathic pain. Reported average numeric intensity is low, but no study measured the impact ofpain on functio
Waljee, J. F., Rogers, M. A., & Alderman, A. K. (2007)	Boston USA	To comprehensively review the literature regarding decision aids for the surgical treatment of early breast cancer, and estimate summary	Breast Treatment Surgery	Systematic review	11 articles	Decision aids significantly improved patient knowledge regarding treatment options, and increased patient satisfaction with the decision-making

		effects of decision aids on the type of breast cancer surgery chosen and patient knowledge of breast cancer treatment.				process. Finally, decision aids were well received by both surgeons and patients across all studies.
Jennifer L. Hay a,∗, Kevin D. McCaul b, Renee E. Magnan 2006	USA	To examine the direction and effect strength of the prospective evidence connecting cancer worry to subsequent breast cancer screening.	Breast Did not have cancer	Meta analysis	12 prospective studies	

Demir, F., Donmez, Y. C., Ozsaker, E., & Diramali, A. (2008). Patients' lived experiences of excisional breast biopsy: a phenomenological study. Journal of clinical nursing, 17(6), 744-751. doi:https://dx.doi.org/10.1111/j.1365-2702.2007.02116.x	Turkey	The purpose of this study was to explore the lived experience of patients undergoing an excisional breast biopsy.	Diagnosis-had excision biopsy of breast done	Qualitative-phenomenology-face to face interviews	20 participants	Three themes were identified: need for information, fear, spiritual needs. Fear that the lump was cancer, fear of surgery and fear that their breast would be removed.Patients needed information about the surgery by the physician who examined them when they learned that they would have an excisional biopsy. Patients trusted their physician and felt more relaxed and at

						ease. Thought surgery would be conducted under local anaesthesia and learned that it would be under general anaesthesia in the operating room. patients did not adequately understand the postoperative discharge education; that the education was given to them before they had fully recovered from anaesthesia, or that their anxiety level was so high

						that they could not understand what was said to them. Desired that this education to be given both verbally and in writing .Participants prayed including non-believers.
Underhill, M. L., & Dickerson, S. S. (2011)	USA	The primary aims were to (a) recognize the common meanings and shared practices of managing hereditary breast cancer risk, (b) understand the	Pre diagnosis	Qualitative Hermeneutic phenomenology	9 women with hereditary breast cancer risk	All women discussed a need for accurate information, support, and guidance from healthcare providers. Results demonstrate that healthcare providers

		practical knowledge women apply to living with risk, and (c) appreciate the value of available resources (e.g., online resources, healthcare providers).				are lacking the necessary tools to help care for high-risk women, which causes women to become their own experts.

Buki, L. P., Yee, B. W., Weiterschan, K. A., & Lehardy, E. N. (2016	USA	Specific goals were to use qualitative inquiry to create a measure that would (a) help advance theoretical conceptualizations of health literacy, (b) assess the influence of cultural and conceptual knowledge on cancer disparities, (c) assist in identifying areas of focus for	Breast and Cervix Pre diagnosis	Qualitative Indepth Interviews	49 women	The final measure included 129 items that assess beliefs, attitudes, knowledge, emotions, and contextual factors related to breast and cervical cance

		psychosocial interventions, and (d) evaluate psychosocial interventions designed to improve breast and cervical cancer health literacy levels among medically underserved women.				
Potter, S., Mills, N., Cawthorn, S., Wilson, S., & Blazeby, J. (2015)	UK	The aim of this study was therefore to use in-depth qualitative methods to investigate patients' and	Women who had breast surgery Treatment stage	Semi-structured interviews	35 professionals and 31 women who had breast surgery	Information provision is inconsistent and there is a mismatch between patients and professionals' perceptions of the

		professionals' perceptions of information provided for decision-making in RBS with particular reference to the provision of information to facilitate procedure choice.				adequacy of information provided, (2) patients' information needs currently arenot being met. There is a disparity in the quality of information provided by breast and plastic surgeons and improvements are needed.

Farias, A., Ornelas, I., Hohl, S., Zeliadt, S., Hansen, R., Li, C., . . . Li, C. I. (2017)	USA	To explore, from the patient's perspective, how physicians communicate with them about all aspects of adjuvant endocrine therapy (AET) treatment.	Breast Treatment	Qualitative Interviews	22	Four themes:(1) information exchange, (2) decision-making to take and continue AET, (3) enabling patient self-management and monitoring potential side effects, and (4) emotional support. Physicians exchanged information with patients in a way that they understood and enhanced patient's health literacy regarding the

						benefits and knowledge of AET. Physicians empowered patients to make decisions about their care. Patients expressed trust and confidence in their physician which helped them seek care when needed. Patients reported a high degree of selfefficacy to self-manage AET and were continuing treatment despite potential side effects.

Ramirez, A. S. (2013). Effects of ethnic targeting on the perceived effectiveness of cancer prevention messages among latinas and non-latina white women. J Health Commun, 18(10), 1256-1273. doi:10.1080/10810730.2013.778362	UK	This study tested the relative efficacy of English-language messages targeted to Latinas, compared with general-market messages, among highly acculturated Latina women and non-Latina White women.	All cancers Did not have cancer	Quantitative	1419 participants	In 1 of 2 experiments ethnically targeted messages were rated relatively more effective for the intended audience and equally effective for the general audience
Obiodun, O. A., Olu-Abiodun, O. O., Sotunsa, J. O., & Oluwole, F. A. (2014). Impact of health education intervention on knowledge and perception of cervical cancer and cervical screening uptake among adult	Nigeria	This study aimed to determine the effect of health education on the awareness, knowledge and perception of	Cervix Early detection	Quantitative	350 women	Multiple media health education based on a movie is effective in creating awareness for and improving the knowledge and

women in rural communities in Nigeria. BMC public health, 14(1), 814.		cervical cancer and screening among women in rural Nigerian communities.				perception of adult women about cervical cancer and screening

Humphrys, E., Burt, J., Rubin, G., Emery, J. D., & Walter, F. M. (2019). The influence of health literacy on the timely diagnosis of symptomatic cancer: A systematic review. European journal of cancer care, 28(1	UK	This systematic review aimed to evaluate the influence of health literacy on the timely diagnosis of symptomatic cancer	Colon, rectum and pancreas), cervical and breast cancer. Pre-diagnosis	Systematic review	26 papers	Poorer health literacy increased delays. HL seen as an important pathway to cancer diagnosis and could help develop targeted awareness campaigns and early screening and diagnosis.
Secginli, S., Nahcivan, N. O., Gunes, G., & Fernandez, R. (2017). Interventions Promoting Breast Cancer Screening Among Turkish Women With Global Implications:	Turkey	To systematically review the scientific evidence on the effectiveness of various strategies	Breast Screening	Systematic review	23 papers	

		aimed at improving screening behaviors for breast cancer in Turkish women.				

Shen, H.-N., Lin, C.-C., Hoffmann, T., Tsai, C.-Y., Hou, W.-H., & Kuo, K. N. (2019). The relationship between health literacy and perceived shared decision making in patients with breast cancer. Patient education and counseling, 102(2), 360-366.	Taiwan	To explore the relationship between patient-perceived shared decision making (SDM) and three domains of health literacy (HL) in patients with breast cancer.	Breast Treatment	Quantitative	511 Breast cancer patients from breast surgery clinics or wards	

Adedimeji, A. A., Lounsbury, D., Popoola, O., Asuzu, C., Lawal, A., Oladoyin, V., . . . Adebiyi, A. (2017)	Nigeria	To assess and describe cancer-related knowledge, opinions, perceptions and behaviors of Nigerians by obtaining pertinent information about community members' knowledge, attitudes and practices regarding cancer risk reduction and actions to maintain healthy lifestyles.	Did not have cancer	Qualitative Focussed group discussions	Men ,women,and young adults(total of 80)	Participants demonstrated awareness of cancers and mentioned several risk factors related to individual behaviors and the environment. Nonetheless, myths and misconceptions as well as micro, meso and macro level barriers impede prevention and control efforts. Intrapersonal/individual barriers, which increase susceptibility to cancers, include

						low educational attainment, low socioeconomic status, old age, unhealthy lifestyle and lack of access to information Young people noted that parents and older family members were unwilling to provide information about cancers linked to sexual behavior. Health system factors such as poor services, low skilled personnel, outdated equipment and

						inadequate infrastructure were most often mentioned as the most significant barriers.

Alago, S., & Awiti, J. (2016).	Kenya	To verify Kenyan women’s knowledge of the various risk factors associated with breast cancer, their preferred framing of the breast cancer messages and their preferred channels for receiving those messages.	Breast Did not have cancer	Quantitative	Three hundred and ninety-three (393) women aged 20-64	Findings revealed that (a) information deficiencies in relation to breast cancer is a factor that needs to be addressed, (b) gain, loss and mixed frames are used and (c) the most preferred sources of information were radio and health facility personnel and, to a low extent the internet and television. Other sources that participants mentioned were: family members,

						friends, newspapers, and seminars
Frie, K. G., Samoura, H., Diop, S., Kamate, B., Traore, C. B., Malle, B., . . . Kantelhardt, E. J. (2018).	Mali Africa	This study analyses barriers throughout a breast cancer patient's pathway from symptom recognition to treatment	Breast Post treatment and others did not have cancer	Qualitative	8 breast cancer patients, 17 healthy women	The main barriers during the appraisal interval were a low level of breast cancer knowledge among women, their families, and medical professionals, and during the help-seeking interval, mistrust in the community health care centers and economic hardship. Barriers during the

						diagnosis interval were low quality of health care services and lack of social support, and during the pretreatment interval high costs and lack of specialized treatment facilities

Leena, R. D. (2020).	United Arab Emirates (UAE)	To identify the socio-ecological factors that affect the uptake of screening mammography among Keralite women living in the UAE	Breast Screening	Ethnography	Five focus group discussions comprised of two populations: Population 1: Keralite women residing in the UAE those who had undergone screening mammography and Population 2: Keralite women residing in the UAE who had not undergone screening mammography were the participants. Socio ecological Model	The individual level socio-ecological factors were identified as self-efficacy, attitudes, beliefs, and knowledge. The community level factors were cultural beliefs, media, medical professionals, community organisations and breast cancer survivors. The organisational factors were health care facilities, health insurance, specialised breast

						cancer screening services, and academic institutions.

Makurirofa, L., Mangwiro, P., James, V., Milanzi, A., Mavu, J., Nyamuranga, M., & Kamtauni, S. (2019).	Zimbabwe	To assess breast and cervical cancer knowledge, attitudes and practices of women of reproductive age, in Mudzi District, Republic of Zimbabwe	Breast and cervical cancer Pre-diagnosis	A cross-sectional community-based survey was conducted. A total of 409 survey household questionnaires were administered to women of reproductive age (15-49 years) in 2014.	Though post-menopausal women also develop cancer, this study focused only on women of reproductive age. Moreover, this study was conducted in only five/18 wards of one district. Analysis of the results did not account for the survey's complex sampling design and results are only generalizable to the study population.	This study revealed a lack of awareness and comprehensive knowledge about breast and cervical cancer. It also revealed low self-risk perception, low uptake of cancer early detection services and low capacity of the local health institution in offering cancer services

Lu, H., Xie, J., Gerido, L. H., Cheng, Y., Chen, Y., & Sun, L. (2020).	China	This paper aims to systematically identify, evaluate, and synthesize existing primary qualitative research on the information needs of breast cancer patients.	Breast cancer Across the cancer continuum	Systematic review	Eligible studies included qualitative or mixed-methods studies focusing on the information needs (across the cancer continuum) of breast cancer patients or their social networks	Three themes, 19 categories, and 55 concepts emerged: (1) incentives (physical abnormality, inquiry from others, subjective norm, and problems during appointments); (2) types of information needs (prevention, etiology, diagnosis, clinical manifestation, treatment, prognosis, impact and resumption of normal life,

						scientific research, and social assistance); (3) moderating variables (attitudes, health literacy, demographic characteristics, disease status, as well as political and cultural environment). The studies revealed that the information needs of breast cancer patients were triggered by different incentives. Subsequently, the patients sought a variety of

						information among different stages of the cancer journey
Sayed, S., Moloo, Z., Ngugi, A., Allidina, A., Ndumia, R., Mutuiri, A., . . . Dawsey, S. M. (2016).	**Kenya**	The objective was to conduct a pilot breast cancer awareness and diagnosis program at three different types of facilities in Kenya.	Breast Before diagnosis	Mixed methods	1094 women of child bearing age	A total of 1,094 women were enrolled in the three breast camps. Of those, 56% knew the symptoms and signs of breast cancer, 44% knew how breast cancer was diagnosed, 37% performed regular breast self-exams, and 7% had a mammogram or breast ultrasound in the past year. Of the 1,094 women

						enrolled, 246 (23%) had previously noticed a lump in their breast. A total of 157 participants (14%) had abnormal CBEs, of whom 111 had ultrasound exams, 65 had FNAs, and 18 had core biopsies. A total of 14 invasive breast cancers and 1 malignant phyllodes tumor were diagnosed

Tucker, C. A., Martin, M. P., & Jones, R. B. (2017).		To explore the question: What information exists in the literature about the information needs, source preferences, engagement behaviours and associated sociodemographic and situational factors (such as disease-related or treatment-related factors) of women ≥18 years with mBC at different time	Breast cancer Treatment	Protocol for a scoping review		Results yet to be published

		points of the cancer care continuum?				

Kugbey, N., Meyer-Weitz, A., & Asante, K. O. (2019)	Ghana	Therefore, this study examined 1) the main sources of breast cancer information among the women, their access and satisfaction with healthcare information and 2) the direct and indirect effects of health literacy and access to health information on quality of life among women living with breast	Breast Treatment	A cross-sectional survey design was employed. The interviewer-administered instrument included the health literacy scale, questions on access and satisfaction with healthcare information	205 women living with breast cancer and receiving treatment at a teaching hospital	Women living with breast cancer relied on information about their illness from health workers (80%), television (66.8%), radio (53.7%), newspapers (13.2%), Mosque/Church (13.2%), community meetings (7.8%) and schools (3.4%). However, 33.2% of the women indicated that they sought information from non-health professionals and

		cancer through depression and anxiety (which are significant risk factors for poor quality of life).		, depression and anxiety scale, and the Functional Assessment of Cancer Therapy-Breast Cancer		the information were mainly on treatment (83.6%), alternative therapy (65.7%), self-care (65.7%), symptoms (50.7%) and diagnosis/ prognosis (46.3%)..Access to health information and health literacy had significant indirect effects on quality of life through depression and anxiety. Whereas health literacy had direct influence on quality of life after

						controlling for other factors, access to information had no direct influence on quality of life.The result further showed that 89.8% of the participants were satisfied with the amount of information received, from health care professionals 91.7% were satisfied with the quality of health care information and 79% indicated that their concerns had been

						adequately addressed.Responses on access to health care information showed that only 7.3% of the participants rated their access to healthcare information to be poor.
McCormack, L., Thomas, V., Lewis, M. A., & Rudd, R. (2017)						

Akuoko, C. P., Armah, E., Sarpong, T., Quansah, D. Y., Amankwaa, I., & Boateng, D. (2017). Barriers to early presentation and diagnosis of breast cancer among African women living in sub-Saharan Africa. PLoS One, 12(2), e0171024. doi:10.1371/journal.pone.0171024	N/A	This review aimed to appraise the contributing factors to delayed breast cancer presentation and diagnosis among SSA women.	Breast Diagnosis	Systematic review	Fourteen (14) quantitative studies, two (2) qualitative studies and one (1) mixed method study merited inclusion for analysis.	Factors • Level of awareness in BC • Knowledge about warning signs • Knowledge in causes • Knowledge in CSE & SBE • Knowledge about treatment.seeking • Infrequent screening activities • Difficulty in assessing healthcare–disadvantaged by living in remote areas. Misconception and misinformation

						about breast cancer • Fear of diagnosis and death. • Health practitioners lack of seriousness about breast cancer • Influence of traditional healers in delaying treatment
Adam, A., & Koranteng, F. (2020). Availability, accessibility, and impact of social support on breast cancer treatment among breast cancer patients in Kumasi, Ghana: A qualitative study. PloS one, 15(4), e0231691.	Ghana	To assess the availability of social support for breast cancer patients receiving breast cancer treatment at Komfo Anokye Teaching	Breast cancer All women receiving BC treatment	A phenomenological study design	Qualitative data were collected through in-depth interviews with 15 BC patients receiving treatment	**Informational support** Almost all the 15 participants reported receiving information they considered useful especially from the health professionals they encounter in

		Hospital (KATH) in thT				their treatment journey. The information received covered issues such as the type of food to eat, medication adherence, and self-care. Support received from family members and HCWs.They were taught about BC ,diet,side effects of treatment

Meherali, S., Punjani, N. S., & Mevawala, A. (2020).	Canada	The goal of this study was to identify and synthesize the evidence on HL interventions to improve HL and health outcomes in LMICs.	No specific cancer	Systematic review. The reviewers systematically analyzed the data from 23 published research studies, including 20 quantitative, 1 qualitative, and 2 mixed-method studies, on HL	23 studies: 20 quantitative I qualitative 2 mixed methods	The reviewers identified four themes: traditional HL interventions, art-based HL interventions, interactive learning strategies, and technology-based HL interventions. The researchers of a few studies also used multicomponent interventions to improve the HL of the population. Much remains to be done to improve HL in LMICs in this era of sustainable

				interventions to improve the health outcomes in LMICs.		development goals. Many effective interventions that involve multiple strategies are required to deliver health-related information. Evidence from this systematic review shows the effectiveness of a range of approaches to HL delivery.

Latifi, M., Sedaghat, M., Barahmand, N., Fahimnia, F., & Allahbakhshian Farsani, L. (2020).	Egypt-Africa	Therefore, the aim of this study was to identify the health information-seeking barriers for women with breast cancer after mastectomy.	Breast Treatment-after surgery	Qualitative, data were collected through semi-structured face-to-face interviews .	17 women with breast cancer after mastectomy.	Seven main themes were introduced as three individual barriers, including fear, shame and embarrassment and inadequate health literacy and four contextual barriers of economic status, physicians and medical staff, lack of accessibility of information sources and the behavior of those around them that were the underlying factors to explain the barriers of health information seeking

						in mastectomized women.

Burks, A. C., Doede, A., Showalter, S. L., & Keim-Malpass, J. (2020)	Mali Africa	To understand the perceptions of risk, benefit, and the informed consent process after enrolling in and completing a phase 2 clinical trial using intraoperative radiation therapy (IORT) for earlystage breast cancer, and to determine how perceptions varied based on women's health literacy levels.	Breast cancer On treatment	Nested Qualitative- A qualitative descriptive study was conducted using structured interviews	A convenience sample of 20 participants consisting of women aged 45–90 years	Women with lower levels of health literacy reported feeling confident enough in the provider to make the decision to enroll in the clinical trial during the initial consultation, and, in general, women reported relying heavily on provider recommendation for enrolling in the clinical trial.They sought information from friends,doctors,internet,family members

						and patients who had BC to help in decision making.

Klungrit, S., Thanasilp, S., & Jitpanya, C. (2019).	Thailand	This study was conducted to explore supportive care needs of Thai women with breast cancer undergoing chemotherapy.	Breast On treatment-undergoing chemotherapy	Qualitative approach.	Purposive sampling of ten women with breast cancer who were undergoing chemotherapy	Results indicate that communication and useful information are prioritized very highly. There are also needs for facilitating communication about the disease prognosis and treatment decisions, life prolonging procedures, and practice for self-care, particularly regarding appropriate foods to take and those to be avoided. Moreover, telephone counselling and

						home visiting services are recommended to support the women when they face problems at home that could not be solved after each cycle of chemotherapy. These findings provide evidence to guide health care professionals in the best ways to provide information to women with breast cancer undergoing chemotherapy.

Otey, D. T. (2016). Health communication & the medical encounter: Perspectives of urban African American women. Dissertation Abstracts International: Section B: The Sciences and Engineering, 76(8-B(E))	USA	The primary aim of this pilot study was to explore urban African American women's perspectives about the communication utilized during clinical encounters with providers via the use of semi structured interviews.	Did not have cancer	Qualitative semi structured interviews	Participants were 60 + who came to the centre for food twice a day	Themes identified: 1) Doctor's Provision of Information 2) Doctor's Provision of Time 3) Doctor is unaware of patient's difficulty understanding information 4) Doctor's Demeanour 5) Patient's demeanour, attitudes, and beliefs 6) Patient's comprehension of information 7) Patient's trust and confidence 8) Patient's reluctance

						to seek care 9) Patient’s difficulty remembering information 10) Respect 11) Religion and spirituality 12) Complementary and Alternative Medicine (CAM) Use 13) Race and Culture 14) Age 15) Gender 16) Patient’s use of additional information 17) Advocacy during the clinical encounter 18) Patient’s compliance with

						medical recommendations. In addition to information about participants' health literacy scores from the literacy assessments, final results included demographic information, preferred sources of health information, and information about those factors that women viewed as either impediments or facilitators to effective

						communication with doctors and with other health care providers both in and outside of the medical appointment.

Halbach, S. M., Enders, A., Kowalski, C., Pfortner, T. K., Pfaff, H., Wesselmann, S., & Ernstmann, N. (2016). Health literacy and fear of cancer progression in elderly women newly diagnosed with breast cancer--A longitudinal analysis. Patient Educ Couns, 99(5), 855-862. doi:10.1016/j.pec.2015.12.012	Germany	This study aims to investigate the distribution of health literacy levels and the association of health literacy with fear of cancer progression (FoP) over the course of cancer treatment in a sample of elderly women newly diagnosed with breast cancer.	Breast Treatment	Quantitative	1359 patients from 98 breast cancer centres	About half of the elderly breast cancer patients in our sample were classified as having limited health literacy (inadequate and problematic levels). Inadequate and problematic health literacy were significantly associated with higher levels of FoP in the elderly breast cancer patients.

Halbach, S. M., Ernstmann, N., Kowalski, C., Pfaff, H., Pfortner, T. K., Wesselmann, S., & Enders, A. (2016).	Germany	To investigate unmet information needs in newly diagnosed breast cancer patients over the course of cancer treatment and its association with health literacy	Breast Treatment	Prospective, longitudinal, multicentre cohort-study	1060 patients from 98 breast cancer centres	Unmet information needs on side effects and medication and medical examination results and treatment options were high and increased during the first 10 weeks after breast cancer surgery. Considering health promotion and social issues, unmet information needs started high and decreased during post-treatment. Patients with limited health

						literacy had higher unmet information needs.

Ilaboya, D., Gibson, L., & Musoke, D. (2018). Perceived barriers to early detection of breast cancer in Wakiso District, Uganda using a socioecological approach. Globalization and Health, 14(1), 1-10.	Uganda	This study investigated the perceived barriers to early detection of breast cancer in Wakiso district, Uganda using a multilevel approach focused through a socioecological framework.	Breast Pre-diagnosis	Qualitative- Focussed group discussions and semi-structured interviews	Our findings indicate that especially during transition from	Barriers to early detection of breast cancer are multifaceted and complex, cutting across individual, interpersonal, organizational, community and policy barriers. The major themes that emerged from the study included: knowledge, attitudes, beliefs and practices (KABP); health system and policy constraints; and structural barriers. Prominent barriers

						associated with KABP were low knowledge, apathy, fear and poor health seeking behaviours. Barriers within the health systems and policy arenas were mostly centred around competing health care burdens within the country, lack of a cancer policy and weak primary health care capacity in Wakiso district. Distance, poverty and limited access to media were identified as

						the most prominent structural barriers.

					inpatient to outpatient care as well as after treatment completion, it is important that patients have specific points of contact who provide them with adequate information and support them in navigating through the health care system and in returning back to their daily-lives.	

Rao, A., Ekstrand, M., Heylen, E., Raju, G., & Shet, A. (2016). Breaking bad news: patient preferences and the role of family members when delivering a cancer diagnosis. Asian Pacific Journal of Cancer Prevention, 17(4), 1779-1784.	India	To investigate patient preferences regarding cancer disclosure, and their perception of the role of their family members in this disclosure, and how patient preferences differed from those of their family members.	All cancers Treatment	Structured interviews of 127 participants	127 men and women and family members	A majority wanted their families to be involved in the process. Patients who had wanted and not wanted disclosure differed with respect to their preferences regarding the particulars of disclosure (timing, approach, individuals involved, role of family members). Almost all patients wanted more information concerning their condition, about

						immediate medical issues such as treatments or side effects, rather than long-term or non-medical issues.
Leydon, G. M., Boulton, M., Moynihan, C., Jones, A., Mossman, J., Boudioni, M., & McPherson, K. (2000). Cancer patients' information needs and information seeking behaviour: in depth interview study. Bmj, 320(7239), 909-913.	UK	To explore why cancer patients do not want or seek information about their condition beyond that volunteered by their physicians at times during their illness.	All cancers Treatment	Qualitative indepth interviews	Men and women in a cencer centre	While all patients wanted basic information on diagnosis and treatment, not all wanted further information at all stages of their illness. Three overarching attitudes to their management of cancer limited patients’ desire for and subsequent

						efforts to obtain further information: faith, hope, and charity. Faith in their doctor’s medical expertise precluded the need for patients to seek further information themselves. Hope was essential for patients to carry on with life as normal and could be maintained through silence and avoiding information, especially too detailed or “unsafe” information.

						Charity to fellow patients, especially those seen as more needy than themselves, was expressed in the recognition that scarce resources—including information and explanations—had to be shared and meant that limited information was accepted as inevitable.

Fletcher, C., Flight, I., Chapman, J., Fennell, K., & Wilson, C. (2017). The information needs of adult cancer survivors across the cancer continuum: A scoping review. Patient Educ Couns, 100(3), 383-410. doi:10.1016/j.pec.2016.10.008		To provide an updated synthesis of the literature that investigates the self-reported information needs of people diagnosed with cancer across the cancer continuum.	All cancer All stages	Scoping review	104 studies(Concurrent-66,prospective,11,retrospective 22,mixed designs,5) Qualitative-33 Quantitative-58 Mixed methods-13	The most common information needs at the diagnosis/ treatment phase were related to treatment (37.7%). At the post-treatment phase of the cancer continuum, information about treatment (23.1%), rehabilitation (13.5%), and body image and sexuality (12.2%) were most frequently cited. Only 3 studies included in the review assessed the information needs

						of people at the recurrence/metastasis phase; at this stage, information relating to treatment was of greatest need (33.3%) closely followed by prognosis information (29.2%). Studies that assessed the information needs at the end of life most often reported information needs specific to end of life care (44.8%), medical system information

						(12.1%), and coping (9.5%).
Tariman, J. D., Doorenbos, A., Schepp, K. G., Singhal, S., & Berry, D. L. (2014). Information Needs Priorities in Patients Diagnosed with Cancer: A Systematic Review. J Adv Pract Oncol, 2014(5), 115-122. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/24910808		The purpose of this review article is to: 1. Summarize relevant studies that have examined information needs priorities in patients with various types of	Various types of cancers After diagnosis	Systematic review	30 studies	Overall, the top three information needs priorities among cancer patients are information related to prognosis or likelihood of cure, disease stage, and treatment options. This review

		cancers. 2. Identifying the prioritized information needs across the studies. 3. Summarise the association of age with patients' priorities of information needs and describe the trend over time.				revealed that age could influence patients' information needs in terms of prioritizing sexual attractiveness in younger patients and self-care in older adult patients. There is a common belief that the younger the patient, the more likely he or she is to put more importance on sexuality and the impact of cancer on sexual relationships.

Tucker, C. A., Martin, M. P., & Jones, R. B. (2017). Health information needs, source preferences and engagement behaviours of women with metastatic breast cancer across the care continuum: protocol for a scoping review. BMJ Open, 7(2), e013619. doi:10.1136/bmjopen-2016-013619	Prospective study	The aim of this study is to explore the question: What information exists in the literature about the information needs, source preferences, engagement behaviours and associated sociodemographic and situational factors (such as disease-related or treatment-related factors) of women ≥18 years with mBC at different	Metastatic breast cancer Post treatment	A scoping review will be performed using the guidelines of Arksey and O’Malley	Prospective study	Prospective study

		time points of the cancer care continuum?				
Rutten, L. J. F., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). Patient education and counseling, 57(3), 250-261.		This review seeks to address the following objectives: (1) identify cancer patients' information needs during their cancer journey, (2)identify the sources cancer patients use to obtain cancer	Diverse cancers (Breast,prostate,other sites. All stages	Systematic review	112 articles	The 10 information need categories were as follows: cancer specific information, treatment-related information, prognosis information, rehabilitation information, surveillance and health information,

		relevant information, and (3) examine whether, and to what extent needs and information sources sought vary by phase of the cancer care continuum (diagnosis, treatment, posttreatment/survivorship, relapse/recurrence, and end-of-life).				coping information, interpersonal information, financial/legal information, medical system information, and body image/sexuality information.

Ankem, K. (2005). Types of information needs among cancer patients: A systematic review. Libres, 15(2), 1.		To find (1) the ranking of importance that cancer patients attribute to specific information types, (2) the effect of such demographics as age, education, and gender on the need for a particular type of information among cancer patients, and (3) the effect of such patient situations as time since diagnosis, stage	Diverse cancers All stages	Systematic review	18 studies	The information ranked highest in need by patients emerged to be that related to the illness itself. A need for illness-related information was cited more frequently than any other type of information. Patients rated several aspects of their illness as most important: information about diagnosis, chances of cure, spread of disease, prognosis, and signs of

		of illness, type of treatment being received, and preferred role in decision-making on the need for a certain type of information.				recurrence. As for the impact of patient situations on the need for a specific type of information, patients who prefer to be active in decision-making during illness want more information about their illness. Although some evidence existed to indicate that patients who are closer in time to their diagnosis need to understand the disease by wanting more information

						about their illness, the stage of cancer does not affect the type of information needed.

Zaid, Y. A., Egberongbe, H. S., & Adekanye, A. E. (2016). Needs and sources of information for women in the treatment and management of breast cancer in Lagos State, Nigeria. Information Development, 32(2), 175-185.	Nigeria	The purpose of this study was to examine the needs and sources of information women with breast cancer found helpful during the treatment procedure.	Breast Treatment	Quantitative	125 women	The result shows that the women expressed a great need for almost all types of information(information about: how they will feel during the breast cancer treatment procedure (63.9 percent); what the treatment plan means (55.4 percent); the spread of the cancer (52.6 percent); types of treatment available (55.4 percent); the likelihood of cure (54.6 percent); and whether the cancer

						will grow back (53.6 percent)); but those with higher levels of education indicated a greater need to know the reasons that their doctors had for suggesting treatments. The data indicated that personal doctors, oncologists, family and friends, mass media and leaflets and brochure were important information sources utilized by respondents; but the major sources of

						information respondents found very helpful were personal doctors, oncologists, family and friends
Swoboda, C. M., Walker, D. M., & Huerta, T. (2021). Odds of meeting cancer prevention behavior recommendations by health information seeking behavior: A cross-sectional HINTS analysis. Journal of Cancer Education, 36(1), 56-64.	USA	The purpose of this paper is to assess how different sources of health information influence likelihood of meeting cancer	All cancers Prevention	Quantitative	USA adults	Those who seek health information from doctors, the internet, or publications had higher odds of meeting more cancer prevention guidelines than

		prevention behavior guidelines.				those who do not seek health information. Those who used healthcare providers as an initial information source had higher odds of meeting diet, cervical, and colon cancer screening recommendations, while using the internet as an initial source of health information was associated with higher odds of meeting diet, smoking, and colon cancer screening

						recommendations. No health information source was associated with meeting either exercise or mammography recommendations
Shea–Budgell, M. A., Kostaras, X., Myhill, K. P., & Hagen, N. A. (2014). Information Needs and Sources of Information for Patients during Cancer Follow-Up. Current Oncology, 21(4), 165-173. Retrieved from	Canada	To identify the information needs of patients being seen in a follow-up clinic and to assess whether those information needs varied according to demographics, primary cancer site, or time since	Mixed site cancers Had finished treatment	Quantitative	411 men and women	The most frequently reported types of information sought included information about a specific type of cancer (43.1%), treatment or cures for cancer (29.4%), prognosis or recovery from cancer (29.0%), and

		last treatment. The study also aimed to identify patient preferences for the means of receiving health information.				prevention of cancer (27.0%). The least frequently reported types of cancer information sought included where to get medical care (3.4%), paying for medical care or insurance (4.6%), and cancer organizations (5.4%). Their doctor or health professional was overwhelmingly the most trusted source of cancer information, followed by the

						Internet, family, and friends. The least trusted sources of information included radio, newspaper, and television. Patients most preferred to receive personalized written information from their health care provider.
Cudjoe, J., Gallo, J. J., Sharps, P., Budhathoki, C., Roter, D., & Han, H.-R. (2021). The Role of Sources and Types of Health Information in Shaping Health Literacy in Cervical Cancer Screening Among African Immigrant Women: A Mixed-	USA	This study was undertaken to explore how various sources and types of health information influence	Cervical cancer Pre diagnosis	Mixed methods	167 African immigrants	Health care providers (78%), women friends (46%), and internet (45%) were the most common sources of health information used by

Methods Study. HLRP: Health Literacy Research and Practice, 5(2), e96-e108.		information sharing and health literacy in the context of cervical cancer screening among African immigrant women				African immigrant women, followed by women relatives (32%), television (22%), social media (17%), and church (16%). Content analysis revealed that the health care provider was rated as the most credible source; personal experiences of family and friends made health information more relatable; and church was the least endorsed source

Oliveira Pinto, S. M., Alves Caldeira Berenguer, S. M., & Martins, J. C. A. (2013). Cancer, health literacy, and happiness: perspectives from patients under chemotherapy. Nursing research and practice, 2013.	Portugal	To analyze the following topics the perception: the Portuguese cancer patients have about their health status while undergoing chemotherapy, the satisfactionwith the information relating to their health, their level of happiness, and their vision of the future.	Diverse cancers On treatment (chemotherapy)	Quantitative	92 men and women	The results indicate that, despite this life-threatening disease, patients consider themselves fairly happy and have an optimistic view of the future. Information about their health condition and religious beliefs was important coping mechanisms to help dealing with the suffering caused by the disease. The study highlights the importance of providing care in a holistic way. Nurses

						must be alert and available to listen, answer questions, provide supporting structures, or refer to other professionals when needed.
Ciria-Suarez, L., Jiménez-Fonseca, P., Palacín-Lois, M., Antoñanzas-Basa, M., Férnández-Montes, A., Manzano-Fernández, A., . . . Calderon, C. (2020). Ascertaining breast cancer patient experiences through a journey map: A qualitative study protocol. PLoS One, 15(12), e0244355.	Spain	This study seeks to describe breast cancer patients' experience over the course of the various stages of illness by means of a journey model.	Breast On treatment and post treatment	Qualitative-semistructured interviews	Prospective study	Prospective study

Berens, E. M., Vogt, D., Ganahl, K., Weishaar, H., Pelikan, J., & Schaeffer, D. (2018). Health literacy and health service use in Germany. HLRP: Health Literacy Research and Practice, 2(2), e115-e122.	Germany	This study investigated the relationship between HL and the use of different types of health services in a sample of the general German population, as we expected that the effect of HL on the frequency of use differs by type of health service	Did not have cancer	Quantitative survey	2000 people	Respondents with lower HL scores reported more frequent use of all four included types of curative health services

Schmidt, E., Schöpf, A. C., & Farin, E. (2017). What is competent communication behaviour of patients in physician consultations? – Chronically-ill patients answer in focus groups. Psychology, health & medicine, 22(8), 987-1000.	Germany	To inquire: how do the chronically ill characterise competent patient communication behaviour during physician-patient consultations.	Did not have cancer	Qualitative Focussed group discussions	Patients with chronic low back pain, chronic ischemic heart disease and breast cancer.	Overall communication style (upper category 1): the participants considered generally-accepted communication qualities to be important to ensure a successful dialog with a physician. These include being open and honest ('I think it is extremely important to … give the doctor the impression that I am being honest, so that he can react in the right way as it

						must be and it is also important not to conceal anything and try to play the hero’), to trust the physician (‘that one has a positive attitude and especially trust in the doctor (…)’.) or to only speak about what is genuinely important (‘I’d say that one should limit the conversation about me to only what is absolutely essential’

Gatimu, W. (2018). Constraints facing promotion of health literacy among women in Kenya. East African Journal of Information Science.	Kenya	The paper seeks to look into four objectives in an aim to bring out the constraints facing the promotion of health literacy among women in Kenya, which are: Identify the sources of consumer health information for women in Kenya · · Establish the constraints facing promotion of health literacy to women in Kenya. Identify the	Did not have cancer	Desk research approach	18 papers	Women gain great deal of health information from informal networks particularly female family members and friends, co-workers, peer-networks and women-groups. Other sources of information include seminars and workshops, church and religious organizations, community barazas, and social workers.

		possible interventions in promotion of health literacy to women in Kenya. .				
Gakunga, R., Kinyanjui, A., Ali, Z., Ochieng, E., Gikaara, N., Maluni, F., . . . Subramanian, S. (2019). Identifying barriers and facilitators to breast cancer early detection and subsequent treatment engagement in Kenya: A Qualitative Approach. The oncologist, 24(12), 1549.	Kenya	To identify barriers and facilitators to breast cancer care from the knowledge, perceptions, and lived experiences of women with and without a diagnosis of	Breast After treatment	Hermeneutic phenomenological Focussed Group discussions	Women with breast cancer and some without	The key barriers were costs, inadequate knowledge, distance to health facilities, communication with health providers, medicines stockouts, long waiting periods,

		breast cancer in Kenya.				limited or no counseling at diagnosis, patient vulnerability, and limited access to rehabilitation items. Facilitators were dependable social support, periodical access to subsidized awareness, and early detection services and friendly caregivers. We found no marked differences in perceptions between groups by socioeconomic status.

Samoil, D., Kim, J., Fox, C., & Papadakos, J. K. (2021). The importance of health literacy on clinical cancer outcomes: a scoping review. ace, 20, 30.		This review provides a detailed account of the associations between health literacy and cancer in the literature.	All cancers No specific stage	Scoping review	146 studies, most were cross-sectional	on diet and nutrition … not just medication and surgeries,” “people do not know about palliative care” (HSES). “The process from screening to treatment should be clear to the patient, explanation of risks of treatment especially on fertility to be done” (BCa-HSES), “patients need to have information, what is the road map, i.e., possible outcomes; risks;

						childbirth" (BCa-HSES), "who should do it (give information)? at what point? should it be a counselor, oncologist? this should be clear … before chemo, [the patient] should be called together with her husband to be explained to that sex life suffers" (BCa-HSES), and "fertility risks to be explained to young women" (BCa-HSES).

Ciria-Suarez, L., Jiménez-Fonseca, P., Palacín-Lois, M., Antoñanzas-Basa, M., Férnández-Montes, A., Manzano-Fernández, A., . . . Calderon, C. (2020). Ascertaining breast cancer patient experiences through a journey map: A qualitative study protocol. PLoS One, 15(12), e0244355.	Spain	This study seeks to describe breast cancer patients' experience over the course of the various stages of illness by means of a journey model.	Breast cancer On treatment and post treatment	Qualitative using semistructured interviews	Wome will be sampled from nine hospitals	Prospective study
Ormandy, P. (2008). Chronic kidney disease: Patient information needs, preferences and priorities: University of Salford (United Kingdom).	UK	To identify, from the patients perspective, the key information needs of a group of CKD patients and to develop an understanding of the contextual factors that	Did not have cancer	Mixed methods	Quali-20 patients Quantitative-89	The study has shown that it is not only possible to identify the information needs but also the preferences and priorities for information, of CKD patients. They

		influence the manifestation of information need				exist on an individual level but as a group there is consensus about what is most important. Perceived to be a high priority for the majority of patients is information on self-care and given that this corresponds with national priorities, it bodes well for future service development.

Muthoni, A., & Miller, A. N. (2010). An exploration of rural and urban Kenyan women's knowledge and attitudes regarding breast cancer and breast cancer early detection measures. Health Care for Women International, 31(9), 801-816.	Kenya	To explore Kenya women's knowledge, attitudes and behaviors concerning breast cancer and its early detection measures.	Breast cancer Screening	Qualitative- Focussed group discussions	Urban and rural set up women	The women had some knowledge about screening, but many did not practice it. BC diagnosis crippled people emotionally, and jeopardised falily finances. They knew that BC is a dangerous disease that had no cure, and that surgery promoted its spread, if discovered early, it prepared the family. Did not know how to perform BSE Barriers to early detection included:

						responsibilities in the home, lack of money, husbands, and lack of access to health information, and educational resources. They suggested churches, women groups and counselling centres as avenues for disseminating BC knowledge.
Chen, X., Hay, J. L., Waters, E. A., Kiviniemi, M. T., Biddle, C., Schofield, E., . . . Orom, H. (2018). Health literacy and use and trust in health information. Journal of health communication, 23(8), 724-734.	USA	The goal of the present research is to better understand the patterns of information source use and	Did not have cancer	? Mixed method	600	Participants with low HL commonly sought information from social media, television, celebrity blogs and websites in which the quality

		trust among people with different levels of health literacy.				of information is less likely to be assured.
Rust, C., & Davis, C. (2013). Chemobrain in underserved African American breast cancer survivors: a qualitative study. Clinical Journal of Oncology Nursing, 17(2).	USA	To explore the issues faced among underserved African American breast cancer survivors, their experiences with cognitive impairment from chemobrain, and the impact of chemobrain on their quality of life.	Breast cancer Post treatment	Qualitative-Focussed group discussions	24 women	Four themes were identified: (a) the concept of chemobrain,(b) variability of chemobrain among individuals, (c) the stigma of chemobrain, and (d) methods of coping. Women had to think harder,they forgot wherethey had put their phones,where to turn on the road

						when driving, and reasons they went to a certain room. Chemobrain was worse after chemotherapy, it was experienced differently by the women (worse in some patients). The forgetting was frustrating and devastating, and disrupted their normal lives. There was stigma and fear of being labelled mad.Humor, social support, spirituality, and self-efficacy

						were coping strategies

Rust, C. F., Davis, C., & Moore, M. R. (2015). Medication adherence skills training for African-American breast cancer survivors: the effects on health literacy, medication adherence, and self-efficacy. Soc Work Health Care, 54(1), 33-46. doi:10.1080/00981389.2014.964447	USA	What was the level and role of health literacy, with respect to medication adherence and self-efficacy among African-American breast cancer survivors? 2. What impact did skills intervention have on medication adherence, health literacy, and self-efficacy among African-American breast cancer survivors?	Breast cancer Post treatment within one year of treatment	Randomized, experimental design	24-Intervention group 24-Control group	Statistically significant relationship was detected between initial health literacy and medication adherence, as well as initial health literacy and self-efficacy. These findings indicated that individuals with higher health literacy were more likely to have higher levels of self-efficacy and were more likely to adhere to medication

						instructions. Analysis of the intervention and treatment groups did not show a statistically significant effect on health literacy, medication adherence, or self-efficacy from pre-test to post-test.Common barriers reported included: lack of breast cancer information and meetings that would help patients discuss health issues ,no

						opportunities to meet the pharmacists, frustration on the inconsistency and access to information, inability to afford the cost of health services and medication, difficult to understand medication labels, no information on drug interactions and side effects

Schmidt, A., Kowalski, C., Pfaff, H., Wesselmann, S., Wirtz, M., & Ernstmann, N. (2015). The Influence of Health Literacy on Information Needs Among Women Newly Diagnosed with Breast Cancer, With Special Reference to Employment Status. J Health Commun, 20(10), 1177-1184. doi:10.1080/10810730.2015.1018626	Germany	To identify information needs and aspects of health literacy in women of working age newly diagnosed with breast cancer.	Breast cancer Treatment (surgery)	Prospective multicentre cohort study	1344	Most frequently mentioned unmet information needs relate to supplementary naturopathy, nutrition, health-promoting measures, and working during breast cancer
Brabers, A. E., Rademakers, J. J., Groenewegen, P. P., van Dijk, L., & de Jong, J. D. (2017). What role does health literacy play in patients' involvement in medical decision-making? PLoS One, 12(3), e0173316.	Netherlands	To examine the relationship between health literacy and patient involvement in medical decision-making	Did not have cancer	Quantitative	974	Our results did not show a relationship between health literacy and self-reported involvement. We did find a positive significant association between

doi:10.1371/journal.pone.0173316						the health literacy scale appraisal of health information and self-reported involvement.critical health literacy, in particular, are important in reporting involvement in medical decision-making
Reid, J., McKenna, H., Fitzsimons, D., & McCance, T. (2009). The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. International journal of nursing studies, 46(5), 606-616.	Ireland	The aim of this paper is to describe the lived experience of cachexia from the perspective of patients with cancer and their family members	Diverse cancers After diagnosis	Qualitative-Phenomenology	15 patients and 12 family member	Six superordinate themes that reflected the complex dynamics of the cachexia experience. Themes were: physiological changes in appetite; visuality of

						cachexia; weight loss interpreted as a bad sign; response from health care professionals; conflict over food; and coping responses.

Appendix 7: Participant Information Sheet (PIS) and informed consent form for health literacy study

This informed consent form is for women with cancers of the breast or cervix who we are inviting to participate in research titled, "Cancer related health literacy status, information and educational needs of patients diagnosed with breast cancer in Kenya."

Name of Principle Investigator:	Dinah Kassaman
Name of Organization:	University of Salford
Contact Information:	D.Kassaman@edu.salford.ac.uk
Telephone	:254722408019

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Consent form (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Study title

Cancer related health literacy: a qualitative research study of the information and educational needs of patients diagnosed with breast cancer in Kenya

Patient Information Sheet (PIS)

Study title: Cancer related health literacy status, information and educational needs of patients diagnosed with breast cancer in Kenya

Introduction

My name is Dinah Kassaman and I am a lecturer at the Aga Khan University School of Nursing and Midwifery in Nairobi. I would like to invite you to take part in a research study. Before you decide, I need you to understand why the research is being done and how you will be involved. Before you decide, you can talk to anyone you feel comfortable with about the research. If there are any words on this form that you do not understand, please ask us and we will be happy to help. We are doing research to identify the type of information that is given to women with cancer and how the women understand this information. If you have questions later, you can ask me or anyone on my team. My contact information is provided above.

Purpose of the research

The number of women with breast cancer is increasing in Kenya and the government is concerned about it. We want to understand how women with cancer understand the information that is given to them about their illness and treatment. This knowledge will help us to improve the information provided from health care professionals.

Participant Selection

You are being invited to take part in this research because you have been diagnosed with cancer of the breast and you are on treatment. Your experiences and how information was given to you are what this study seeks to hear. We feel that by sharing your experience, you can help us to better understand the type of information that is helpful for patients with cancer.

Voluntary Participation

Taking part in this research is completely voluntary. We will describe the study and go through the information sheet which we will give you. We will then ask you to sign a consent form to show that you have agreed to take part. If you decided to take part in the study, you are free to withdraw at any time without giving a reason; this will not affect your treatment in anyway. However, we will use the data collected up until your withdrawal.

What will happen to you if you take part?

I will explain to you about the study in the cancer clinic, then I will give you an information sheet which is detailed and a consent form. You will go home with the documents, and after reading and agreeing to participate in the study, you will sign the consent form and return it to the clinic on your next visit. If you agree to participate, the research assistant will call you so that the time and venue of the interview can be planned and agreed upon. The research will take place over 18 months in total. During that time, we will visit you three times for interviewing. If you accept, you will be invited to participate in three (3) separate interviews which will last approximately 30 to 60 minutes. The first interview will be decided by you, followed by two more interviews of six weeks' interval. During the interview, I or another interviewer will sit down with you in a comfortable place either at the hospital or if it is better for you, we can also do the interview at your home. We will ask you a series of questions which we have prepared. If you do not wish to answer a particular question during the interview, you can tell the interviewer and they will move to the next question. No one else but the interviewer will be present unless you would like someone else to be there. We will tape record the information so that we can listen to it later and transfer it to text format. No one else except the research team will be able to see this information. No one will be identified by name on the tape. The recording will be kept in a locked cupboard and will be destroyed after the research is finished.

Risks

There are no risks to you if you participate in this research but, if we ask you a question that makes you feel uncomfortable, you can choose not to answer the question. In case you get distressed as you recall the events surrounding the cancer diagnosis and treatment, there will be counselling services available and we will appropriately refer you for psychological support if you agree.

Details of psychological support service can be found at the end of this information sheet.

Possible benefits

We cannot promise that the study will be of direct benefit to you, but the information from this research will help to increase the understanding of the type of health information to be given to women with cancer.

Will my taking part in the study be kept confidential?

All information which is collected from you during the course of the research will be anonymised, and any information about you which leaves the university will have your name and address removed so that you cannot be recognised. If, however you would prefer to be credited for your contribution, I will be happy to ensure that you are clearly named and referenced.

Further to this:

- Your data will be stored safely, specifically:
    a. Individual participant research data, such as questionnaires/interview scripts will be anonymous and given a research code, known only to the researcher
    b. A master list identifying participants to the research codes data will be held on a password protected computer accessed only by the researcher
    c. Hard paper/taped data will be stored in a locked cabinet, within locked office, accessed only by researcher
    d. Electronic data will be stored on a password protected computer known only by researcher
- Your data will be used solely for the purposes of this study.
- Your data will be accessible only by authorized persons such as researchers within the team, supervisors, and regulatory authorities (Kenya Ethics committees and the Kenya National Council of Science and Technology (NACOSTI).

- Your data will be retained for a maximum of 3 years (after the hand in date) before being disposed of in a controlled manner.

Also note that any information about you which leaves the university will have your personal details removed so that you cannot be recognized. Results would be published in research journals or presented in conferences or elsewhere without disclosing participants' names.

'I am aware that if I reveal anything that is harmful to self or others, the researcher will have to share that information with the appropriate authorities'.

What if there is a problem?

In case you have a concern about any aspect of the study, you should ask to speak to the researcher (Dinah Kassaman 0722408019 or Tayreez Mushani 0733400474) who will do their best to answer your questions. If your issue is not sorted out and you wish to complain formally, you can do this by contacting the Research Supervisor (Prof. Allison Brettle, Telephone number: 0161 295 0447) or the chairperson of Research committee Aga Khan University, Nairobi (Prof. William Macharia 020 3 740000 EXT 2148/1136).

What will happen if I do not carry on with the study?

If you withdraw from the study, we will use the data collected up until your withdrawal.

What will happen to the results of the research study?

The study findings will be reported through publications in journals – one in the field of cancer nursing and another in an education journal. In addition, the Aga Khan University has links with national news reporters and newspapers and an article will be drafted for press release. Study investigators will also share findings by making formal presentations at Cancer nursing conferences. Results will also be shared with local health care professionals through the weekly seminar series on ongoing faculty research activities. You will not be identified in any report or publication.

Who is organizing or sponsoring the research?

This research has been funded by CRDFGLOBAL under the Beginning Investigator Grant (BIG CAT) initiative.

For Psychological support, call:
Ms. Mary Gitau
Telephone: +254722753473/731888066

For further information or to ask questions contact:
Prof. Alison Brettle
Professor in Health Information and Evidence Based Practice|
School of Health and Society, University of Salford,
Mary Seacole Building, Frederick Road, Salford, M6 6PU
Tel: 0161 295 0447, Email: a.brettle@salford.ac.uk

Appendix 6- Consent Form for health literacy study

Please tick the appropriate boxes

Taking Part	**Yes**	**No**
I have read and understood the project information sheet dated 01/12/2017.	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in the project. Taking part in the project will include being interviewed and audio recorded.	☐	☐
I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part.	☐	☐
Use of the information I provide for this project only		
I understand my personal details such as phone number and address will not be revealed to people outside the project.	☐	☐
I understand that my words may be quoted in publications, reports, web pages, and other research outputs.	☐	☐
Please choose one of the following two options: I would like my real name used in the above I would not like my real name to be used in the above.	 ☐ ☐	
Use of the information I provide beyond this project		
I agree for the data I provide to be archived at the UK/Kenya Data Archive.	☐	☐
I understand that other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand that other authenticated researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
So we can use the information you provide legally		
I agree to assign the copyright I hold in any materials related to this project to [Dinah Makuba Kassaman]	☐	☐

________________________________ ___________________ ___________________________

Name of Participant Printed Signature Date

________________________________ ___________________ ___________________________

Name of Researcher Printed Signature Date

Appendix 8 a: Participant demographic data

Data Collection Form

1. Hospital where diagnosed ________
2. Diagnosis (Tick applicable): ________ BC _________ Cervical Cancer
3. Date of diagnosis: _________________ (Day/Month/Year)
4. Disease stage at diagnosis (if known): ______________________ (classification – 5 stages)

Demographics

5. Age (years): ___________
6. Religion: ____
7. Marital Status: ______________________________________
8. If married - Type of marriage (polygamy/monogamy): ___________________________
9. How many marriages vs Number of this marriage (1st, 2nd, 3rd, other________________)?
10. Number of children from all marriages, living and deceased, miscarriages: ____________
11. Currently sexually active: yes/no? use of contraceptive devices _____________________

Education and occupation

12. Education level (highest level of schooling or qualification): ________________________
13. Working status ((e.g. full-time, casual, seeking work, etc.): _________________________
14. If working or have ever worked - Occupation: ___________________________________
15. Self-rate of income (Ranges?) (Personal, family, household?)
    1. Low
    2. Middle
    3. High

Living conditions

16. Residence (rural/urban): ______________
17. Describe residence: ___________________ Options include the following depending on how they might be used.
    1. Building construction type – Brick, timber, metal, other
    2. Utilities – electricity, water, sewerage
    3. Overcrowding – number of rooms, number of residents,
18. County of residence: __________________

Other thoughts:
Family history of cancer, particularly female close relatives – may influence their knowledge levels

General literacy – can they read? What do they read? ________________________________
What channels of information do they access? TV, Facebook, twitter, newspapers, their church, women's groups

Appendix 8 b: Participant pseudonyms and information summarised

Participant pseudonym/code	Information	Treatment modalities	Date when diagnosed	Timeline when interviews took place		
				First	**Second**	**Third**
Connie AF01BC	47-year-old single business lady who attended all three interviews Recruited at private hospital Breast cancer stage 1 Education level: High school Form 4	Chemotherapy Radiotherapy Surgery	July,2017	Chemotherapy	Chemotherapy	Follow-up
Juliet AF02BC	58-year-old married business lady who attended all three interviews Recruited at private hospital Did not know the breast cancer stage Education level: High school Form 4	Chemotherapy Radiotherapy Surgery	November, 2017	Chemotherapy	Chemotherapy	Chemotherapy
Ruth AF03BC	41-year-old married teacher who attended all three interviews Recruited at private hospital Breast cancer stage 1 Education level: College	Chemotherapy Radiotherapy Surgery	April,2017	Chemotherapy	Chemotherapy	Follow-up
Lilly AF05BC	28-year-old married housewife who attended all the three interviews Recruited at private hospital (welfare patient) Breast cancer stage 2 Education level: Primary standard 8	Chemotherapy Radiotherapy Surgery	February,2018	Chemotherapy	Chemotherapy	Follow-up

Olive AF06BC	33-year-old casual labourer, separated from husband who attended all the three interviews Recruited at private hospital (welfare patient) Did not know the breast cancer stage Education level: High school Form 4	Chemotherapy Surgery	October ,2017	Chemotherapy	Follow-up
Rhoda AF07BC	57-year-old, married secondary school teacher who attended all the three interviews The only Muslim in the study Recruited at private hospital Breast cancer stage 2 Education level: University	Chemotherapy Radiotherapy Surgery	December,2017	Chemotherapy	Follow-up
Debora KF01BC	37-year-old, married (3rd wife) secretary who attended all the three interviews Recruited at public hospital Breast cancer stage 2 Education level: college	Chemotherapy Radiotherapy booked-to be called when space available.	Did not recall	Chemotherapy	Follow-up
Naomi KF02BC	34-year-old separated, unemployed woman who attended the first and second interviews only. Recruited at public hospital Breast cancer stage 3 Education level: High school Form 4 Education level: college	Chemotherapy Radiotherapy Surgery	Did not recall	Chemotherapy	Chemotherapy

Marion KF04BC	45-year-old, married housewife who attended all the three interviews Recruited at public hospital Breast cancer stage 2 Education level: High school Form 2	Chemotherapy Radiotherapy	Remembers January, but not the year	Chemotherapy	Chemotherapy
Abigail KF05BC	61-year-old, married, retired librarian who attended all the three interviews Recruited at public hospital Breast cancer stage 3 Education level: High school Form 4 Education level: High school Form 2	Chemotherapy Had metastasized radiotherapy could not be done	Novemeber,2017	Chemotherapy	Chemotherapy
Paula KF07BC	46-year-old, married, tailor at the export processing zone factories who attended the initial and second interviews only Recruited herself into the study at public hospital Breast cancer stage 2 Education level: High school Form 4	Chemotherapy Surgery	February,2018	Chemotherapy	Follow-up

Appendix 9: FIRST interview guide

Health literacy study-semi-structured interview guide

Interview Questions

Starter Question-How did you find yourself in the Oncology clinic?

1. Pre-diagnosis
   1. What and how did you know about breast and cervical cancer before you came to the hospital?
2. Personal information and events leading to diagnosis
   1. Who was the first person you went to for help and what did they tell you?
   2. What made you want to see the doctor?
   3. What did you think your problem was?
3. Health information from the doctor/nurse
   1. What did the doctor/nurse explain to you when you went to the hospital? / Tell me the instructions the cancer doctor/nurse gave you?
   2. Tell me what you understand/understood about what they said about what you were experiencing and what they said might be wrong?
   3. Can you tell me in your own words what you think is wrong?
4. Belief systems
   1. Apart from what the doctor said will help you, do you have any other beliefs about things or people that will help you get better?

5. Reflections
   1. What could the doctor/nurse have done differently to help you better understand your illness/medicines/instructions?
   2. Who taught/assisted you the most?

Post Interview Summary

ID: ____________________________________

Date: __________________________________

Interviewer: _____________________________

Length of Interview: ________________________

Location: ________________________________

Type of interview (circle one): Initial 1st follow up 2nd follow up

Detailed Questions (Interviewer to fill out notes):

1. How did the woman appear to present (comfortable uncomfortable)?

2. Who was present at the interview? (specific family members, care-givers, the woman was alone)

4. Was the woman ready to engage in a conversation? (Nervous at first, reluctant to engage, eager to engage)

6. Items that came up during the interview that should be followed up at the next interview.

Appendix 10: Health literacy study: second interview for Connie

Starter question: ***How have you been since I last saw you?*** Tell me how you felt after the interview, immediately and after going home.

1. Have you been getting your treatment as scheduled? If yes what would you say, has been helping you to do it? In addition, if not, what has been hindering you?
2. What instructions have you been given about your treatment?
   a. Probe about treatment adherence, prescriptions, lab investigations and follow-up appointments.
   b. Tell me how the instructions were given to you.
   c. Did you understand the instructions?
3. What do you understand by the word cancer?
4. What are you doing differently now after the diagnosis of cancer compared to before?
5. What are your beliefs about your cancer?
6. Tell me if there is any other information that can help you beside what the doctors and nurses told you?
7. What is the impact of the cancer diagnosis on your family, friends, relatives and other society members you interact with?
8. Who would you say has been of great help to you after the diagnosis?
9. What would you want to see being done by governments differently from what is being done?
10. In the last interview:
    - You said that the doctors and nurses had done their best in giving you information, what would you want to see the nurses/doctors doing it differently to patients diagnosed with cancer?
    - You said that they gave you a book about cancer.
      - Who gave you the book?
      - What was the book about?
      - Did you read it and what was your understanding of the content?
    - You stated that you had a deadly disease in your body. You felt that you were finished…Tell me more about this, how do you feel now?
    - You also mentioned that you would change your lifestyle (eating habits and exercising), tell me what you have changed.
      - What made you change?
      - How does that make you feel in relation to the cancer diagnosis?

Reflections

1. What could the doctor/nurse have done differently to help you had better understand your illness/medicines/instructions?
2. Who taught/assisted you the most?

Probing questions to be used:

"How is that?"; "anything else?"; "would you like to elaborate on that?"; "in what ways?"; "how did that happen"

Appendix 11: Health literacy study, second interview for Juliet

Starter question: Do you give me permission to proceed with the interview? Then….
How have you been since I last saw you? Tell me how you felt after the interview, immediately and after going home.

11. Have you been getting your treatment as scheduled? If yes what would you say, has been helping you to do it? In addition, if not, what has been hindering you?
12. What instructions have you been given about your treatment?
    a. Probe about treatment adherence, prescriptions, lab investigations and follow-up appointments.
    b. Tell me how the instructions were given to you.
    c. Did you understand the instructions?
13. Please tell me what you understand by having a cancer diagnosis
14. What are you doing differently now after the diagnosis of cancer compared to before?
15. What are your beliefs about your cancer?
16. Tell me if there is any other information that can help you beside what the doctors and nurses told you?
17. What is the impact of the cancer diagnosis on your family, friends, relatives and other society members you interact with? Alternatively, tell me what the people close to you feel about the cancer diagnosis?
18. Who would you say has been of great help to you after the diagnosis?
19. What would you want to see being done by politicians and governments differently from what is being done?
20. In the last interview:
    - You said that the doctor gave you notes after each consultation, did you read it and what was your understanding of the content?
    - You said that the doctors and nurses had done their best in giving you information, what would you want to see the nurses/doctors doing it differently to patients diagnosed with cancer?
    - Tell me what you feel about the language they used to give you information on-drugs, investigations and any other information.
    - You stated that you do a lot of juicing and fruits and vegetables. Tell me more about this, how do this help in the cancer treatment journey?
    - You also mentioned that you would ask the doctor about the method of using the needle in the chest. Tell me how it went.

Reflections

3. What could the doctor/nurse have done differently to help you had better understand your illness/medicines/instructions?
4. Who taught/assisted you the most?

Probing questions to be used:

“How is that?”; “anything else?”; “would you like to elaborate on that?”; “in what ways?”; “how did that happen”.

Appendix 12: Health literacy study, third interview for Connie

Starter question: Do you give me permission to proceed with the interview? Then…
How have you been since I last saw you? Tell me how you felt after the interview, immediately and after going home.

1. Have you been getting your treatment as scheduled? If yes what would you say, has been helping you to do it? In addition, if not, what has been hindering you?
2. What instructions were you given last time about your treatment?
    a. Probe about treatment adherence, prescriptions, lab investigations and follow-up appointments.
    b. Tell me how the instructions were given to you.
    c. Did you understand the instructions?
3. What do you understand by the word cancer?
4. What are you doing differently now after the diagnosis of cancer compared to before?
5. Tell me if there is any other information that can help you beside what the doctors and nurses told you?
6. Who would you say has been of great help to you after the diagnosis?
7. In the last interview:
    - You said that patients could be sharing information with each other on their experiences your opinion, how can this be implemented?
    - You said that you had fear when you first received chemo, how do you feel now?
    - You stated that you had a killer disease in your body. Can you tell me exactly what cancer does to the body and 2) how cancer treatment works?
    - You also mentioned that you were now happy with your eating, how is that going?
    - The doctor told you that the next drugs will cause internal change-has he explained about this?
    - Questions come after you have left, did you remember anything that we need to address?

Reflections

5. What could the doctor/nurse have done differently to help you had better understand your illness/medicines/instructions?
6. Who taught/assisted you the most?

Probing questions to be used:

"How is that?"; "anything else?"; "would you like to elaborate on that?"; "in what ways?"; "how did that happen".

Appendix 13: Health literacy study: third interview for Rhoda

Starter question: Do you give me permission to proceed with the interview? Then...
How have you been since I last saw you? Tell me how you felt after the interview, immediately and after going home.

1. Have you been getting your treatment as scheduled? If yes what would you say, has been helping you to do it? In addition, if not, what has been hindering you?
2. What instructions were you given last time about your treatment?
    a. Probe about treatment adherence, prescriptions, lab investigations and follow-up appointments.
    b. Tell me how the instructions were given to you.
    c. Did you understand the instructions?
3. What do you understand by the word cancer?
4. What are you doing differently now after the diagnosis of cancer compared to before?
5. Tell me if there is any other information that can help you beside what the doctors and nurses told you?
6. Who would you say has been of great help to you after the diagnosis?
7. In the last interview:
    - You said that patients could be sharing information with each other on their experiences your opinion, how can this be implemented?
    - You said that you had fear when you first received chemo, how do you feel now?
    - You stated that you had a killer disease in your body. Can you tell me exactly what cancer does to the body, and 2) how cancer treatment works?
    - You also mentioned that you were now happy with your eating, how is that going?
    - The doctor told you that the next drugs will cause internal change-has he explained about this?
    - Questions come after you have left, did you remember anything that we need to address?

Reflections

7. What could the doctor/nurse have done differently to help you better understand your illness/medicines/instructions?
8. Who taught/assisted you the most?

Probing questions to be used:

"How is that?"; "anything else?"; "would you like to elaborate on that?"; "in what ways?"; "how did that happen".

Appendix 14: Codebook

	Code	Interview stage	Recruitment site	Researcher Notes	Participant statement example
1.	Active information seeking	Third First	Public Private	Intentional search for information	Yes, I asked the doctor, and he told me that it is these chemo drugs that are causing that and the moment I will stop them it will just improve. (Abigail) Yes, so I have also been able to get my own information. I also know that knowledge is power. Whatever by sometime I do not understand I go back to the net. Yes. And read about it. (Rhoda)
2.	Anxiety caused by lack of information	First	Public	Worry about BC and the interventions	You ought to be explained when one gets out she finds herself with such things, so that it may not find you in surprise. Yes……… {participants phone rung} ………because there even sometime you will find the wound oozing water, but I saw my healed well and had no problem. I have had that some say that theirs stayed without getting healed and had water on the surface. (Paula)
3.	Awareness about screening and attendance of screening camps	First First	Public Private	Participant knowledge about screening	I come for screening because I had heard that cervical cancer has become rampant but on the side of the breast, I had not heard of it. It is only cervical I had heard it has increased. So when I heard that they were doing free screening I showed up. (Marion) I have been undergoing the medical check-ups every year in September since the year 2012. And no time it was discovered. Even during same year, in September I had been done the check-up. (Juliet)
4.	Belief in God	First First	Public Public	This is a value system where people	You know, he told me that disease is of God and there is no way we can do about. What is there is one is to get treated. (Paula)

		First First Second	Private Private Public	have faith in God a s a supreme being.	What I can tell someone who has been diagnosed with cancer not to see death, for cancer is like any other disease like malaria, if you have God and you have malaria……that's how I took it. It is like any other disease that can contract. (Naomi) …And let me say I thank God because I lack that fear. I have kind of placed it in the hands of what a God and I also believe that prayers do work. And when you have the right attitude and making sure that I also surround myself with people who have what a kind of a right attitude. (Rhoda) They have just been praying for me even the wife to our Bishop. Even our Bishop he has been praying for me and also the community members are coming to my home and we pray together. *(Olive, private hospital, second interview)* When I was told I have cancer I was praying that I may reach to the treatment and see what I can continue and how my body would respond to the treatment. *(Marion, public hospital, second interview)*
5.	Benefits of information	Second First	Public Public	These were the advantages of receiving information	Yes. Because there were results that were required so that they may know which drug they were to administer to me. That is what made to stay for all that before I got them ………. (Paula). On my side the information its self is not bad. I see the information is building me mentally and even giving me the strength to with stand the treatment. Yes. From my side that information to encourage I see as if it's beneficial to me. (Marion)

6.	Discovering the lump	First interview	Private	Symptoms that made the participant seek healthcare intervention	How I knew I have got a lump, I checked my breasts every month, so I decided to visit the clinic so that I can get more information when I felt a lump. *(Connie, private hospital, first interview)*
		First interview	Public		I just woke up and found myself with a lump, but I had a child I was breastfeeding. Then after that, I said it was milk, and took it rightly and I stayed for almost a year. But first, before I knew it was a disease, I started losing appetite, and after losing appetite started having back and legs pains. Then I started taking pain killers…later, I lost appetite and I could not walk. *(Lilly, public hospital, first interview)*
		First	Public		I had the lump but I did put it in my mind for I thought it was milk that had cloth in my breast. (Abigail)
7.	Emotions after diagnosis	First	Public		I was a bit stressed as I was going to the job. I was not able to work and I didn't tell anybody. So other workmate saw I am not the X that they used to know (Debora).
		First	Public		I felt I was finished and that was…. I thought that would be the end of me, but as time went on I just relaxed …. hum and asked God what to do. *(Connie, public hospital, first interview)*
		First	Private		When I was told I was positive, I was shocked and even cried. Because I thought I was dead. You know when we were schooling we were just saying, 'cancer is a killer disease'. At that hour I saw like I was dead! (Juliet)
		First	Private		I even I cried to the doctor. Then I will die. (Olive)

8.	Sources of information	First interview Second interview	Private	How participants accessed information about BC	I had heard about BC, but I had not gone for any check-up, but I had heard about it through TV *(Lilly, private hospital, first interview)* Now, doctor told me take everything. He told me like meat, it is good for your heart, I cannot remember whether he said heart, but for sugar, you can take because it is good for your brain. Take a lot of water to cleanse the kidneys so that they can work and not be affected by those drugs. (*Debora, public hospital, second interview)*
9.	Decision making	First	Private	Response when asked how treatment decision was reached.	For me I cannot comment on that. The doctor is the one who can decide for me. (Juliet)
10.	Diagnostic delays				
11.	Discovering the lump				
12.	Emotions after diagnosis	Third	Private		It took a lot courage, because that's first when the news was broken to me. I was like this is the end of everything, but then after that I have realized that, that is not the end of everything.
13.	Faith in God				
14.	Fatalism	First Second First	Public Public Private		Now, suffering with cancer you die! I thought am I going to die from this BC. (Lilly) I saw death because people say that when you are diagnosed with cancer you don't get healed, it is not treatable. (Naomi) I felt I was finished and that was…. I thought that would be the end of me, but as time went on I just relaxed …. uhmm and asked God what to do. (Connie).

		First	Private		Many, they believe when you have cancer you will die. It is a few who believe if you have cancer you will get cured. *(Abigail)*
15.	Finances	Third	Private		It would actually kind assist because the first time I applied for what a NHIF, they gave me what a 25 thousand shillings but it is because the doctor had not written the stage. So they give as per the stage. (Rhoda)
16.	Hope amidst fear	Second	Public		What normally come when I hear or read the word cancer, one can get cured of cancer, is curable if you follow the instructions and if you discover it at that early stage for like mine was at stage one.(Debora).
17.	How diagnosis was broken	First	Public		He just told me X do you know your results have come, then I asked him what have they reviewed. He told me that I have cancer. (Naomi).
18.	Impact of cancer diagnosis				
19.	Impact on the family				
20.	Incorrect information given	First First	Public Private	The information the patent received from the HC was incorrect	We were told if you seem as though you don't have any side effects, it is showing that the drug is not working in you. (Debora) Even it's the pineapples we are being encouraged to eat a lot, for it is its' sourness that kills the cancer cells. Even the lemons and these other bitter herbs. (Debora) I did not know if it would fall off. By the way, (.... cross talk ...).. I could have known but I was not explained to. It was the mistake of one of the nurse and i told her it was her mistake.... and... I asked her why she didn't tell me. She told me my hair fell off because I had plait. (Juliet)
21.	Information by counsellor	First	Public		Before I was administered the drugs, sections of counselling that a patient is taken through.

					Telling you that there are some things you are supposed to eat because the drugs are very strong and if you fail to follow what is instructed by the doctor you will hurt yourself. (Debora)
22.	Information by dietician				
23.	Information by doctor	Second Third Second	Private Private Private		What has helped me more is the information I have got from the doctors (Ruth) We opted for that because when we were being taken through after the. After the investigations, the doctor told us that we can do lumpectomy to remove the lump only or we can also remove the entire breast. So we discussed with my husband and we decided that we can do the entire breast. Instead of lumpectomy. We were taken through the advantages and disadvantages of the two. (Ruth) What the doctor told me is that aa..the side effects might get what, worse eee…. So that even when I experienced this it did what affected me much because I knew it what as side effects and I always tell myself they will not last for long. Yes. They are just what a short time. (Rhoda)
24.	Information by friends and relatives	Second	Private		The medical……ok. I had a friend who I used to stay with and she could tell me how I should go to the hospital she had an aunt who had BC and she could tell me she was treated and now she is ok. (Connie)
25.	Information by nurse	Third	Private		When you come from the hospital, the nurses they are trained to give you the information the way they are supposed to tell you but it can weigh you down. That it is as if you are putting your life at a stop, don’t mix with people, don’t do this don’t do that, although they have a point because of the immunity. (Rhoda)

		Second	Private		Because they told me about everything before I could take my first, my first chemo, they told me that my hair will disappear. Yeah. The medicine reacts my nails you can see. Yeah (Olive).
26.	Information by other patients	Second	Private		I thank God that I met her because she actually what told me something about what my hair and I felt what oooh… this is nice and she told me I think she was doing what the tenth one. And she told me, by the way, my doctor has told me that I might not have to continue, that there is something new that has come new on her *aceptin* that you do not have to do the eighteen that even if you do the half is just as the effect. And I thought oooh…ok that is what encouraging. (Abigael)
		Second	Public		There was another one who told me that she normally comes while she had not eaten anything and she never vomit when she comes she enters the vehicle and goes direct to her home. And if you don't eat, for me I said I can't do that, because I know for the drug I need to eat first well. For her advice, I said no.(Paula)
27.	Information by pharmacist	First	Private	Refers to information that Pharmacists gave.	The other one I asked questions is the one for the pharmacy, Pharmacist, I told her to explain to me how I will be administered the injectable drugs. There are some injections ………. yes, I asked her how I will be injected. (Juliet)
28.	Information given	First	Private		They told me that I should not take a lot of starch, like ugali I should just take a very little, then vegetables should be more than the ugali. Yes. And a lot of water. I take a lot of water. (Connie)
		First	Private		He was very good with information and explain all the things and also the nurses. Because when I started the first

					chemo they took me all through the information very well the side effects and everything, so I had the information.(Ruth).
29.	Information needs	First First First	Public Public Private		Now, when they say the grade or stage they need to explain to someone very well. So that you may not get scared much. (Naomi) I wanted to know the diet that I can take. (Paula) No. they never told me even how the operation will be. (Paula) I look older, while the face has turned out to be pale, these I had not been explained. First this one . . nails are black. Today. .and why has it been so? Nobody told me. (Juliet)
30.	Information seeking				
31.	Interview notes and memos				
32.	Knowledge and use of medical terms/jargon	Third	Private		I read but I couldn't understand and even now I can't remember. I move with it everywhere just in case I got to a place I show them so that they may read it. (Lilly)
33.	Lifestyle changes	Second Second Third	Public Public Private	The changes patient made after the BC diagnosis.	I feed the way I was feeding before but I have reduced taking processed things, meat and sugary drinks. I also take traditional chicken eggs only. (Abigail) Like now I make sure that I get the balanced diet but before I was not. (Naomi) At least I never used to do exercises. Yes, I never used to take at all of water, I never used to take fruits, yes. (Connie)

34.	Misconceptions about BC	Second	Private		Now how can they be what a helped, because the information out there, a-a-a can be misleading. Because some, there those that saying at a good percentage of it actually says you should even not do chemo.
35.	Non-verbal communication /cues				
36.	Preference for private vs public				
37.	Information seeking				
38.	Reaction to BC diagnosis				
39.	Side effects of treatment	First	Private	Refers to the undesired secondary effects other than the therapeutic effect.	After taking the chemo? It has changed me. I see the tongue has turned black then, my fingers have black I don't have hair but thank God that am a life and also my lump has disappeared. (Olive)
40.	Socio ecological model components/factors	First First Second Third	Private Private Private Private	Factors that participants referred to as important in their HL experiences.	The first day I talked with my daughter because I just received a call informing me that a lady hanged herself because she has found she has a lump in her breast. So that moment I just stood up in front of my daughter and removed my blouse so, since l knew how to check on my breast. I started doing the checking. (Connie) Let me say I had a sister with cancer …I had some information from her and during that time she passed away, I think it is about three years ago. (Ruth) It was. Then doctor XX - she sent me to another doctor outside the private hospital (Olive). My family…. first they became confused…lack of belief but I believed. But my husband brought them together our children… talked to them and told them now it is this way and I just want us to come together so that we can work together. I think we can sojourn on. (Lilly).

		First	Public		They just comforted me by telling me to persevere, for if cancer has not greatly extended it can be cured. Because there was even one of our neighbour who had it but passed on later for it had spread a lot, but the grade is what I can’t tell. But she had stayed long with it because from 1992 to now is when she has died (Naomi)
		First	Public		I was wondering (afraid) how people were going to take me when they look at me. But I said, I am the one who understands and you whatever you shall talk you do not see it. You will talk and mine I will just continue doing and it is a must I encourage myself. (Paula)
		Second	Public		I found out that one of our neighbours was sick at home and he explained to me how to feed what to avoid and to follow the treatment when I work and get tired I just relax first. I should not overload the body. (Abigail).
41.	Sociocultural beliefs and causes of cancer	Third	Public	What participants believed as the cause of cancer	For me, I have understood cancer to be, now I as X, that cancer is a disease that is caused by these things that we are using, feeding on. I have understood that is being caused by these things that we are feeding on.(Debora).
		First	Public		This cancer disease there in the upcountry is seen as though people…. are getting oppressed because they see it as though one way is witchcraft, sometimes others believe it is sorcery for those who are backward. Others thy see it as though one has been bewitched but for me, I have not believed that am bewitched but I see it just like any other disease. (Marion)

42.	Sources of information	First interview		How participants accessed information about BC	I had heard about BC, but I had not gone for any check-up, but I had heard about it through TV *(Lilly, private hospital, first interview)*
		Second interview			Now, doctor told me take everything. He told me like meat, it is good for your heart, I cannot remember whether he said heart, but for sugar, you can take because it is good for your brain. Take a lot of water to cleanse the kidneys so that they can work and not be affected by those drugs. (*Debora, public hospital, second interview)*
43.	Stage at diagnosis	First	Public	Stage at which BC was diagnosed, some participants were given the information.	They told me that mine is stage three. (Paula)
		Second	Public		Stage three (Naomi)
					Stage is stage one (Ruth)
		First	Private		I understood because he told me, because that is in stage one it be help well. (Olive)
		First	Private		
44.	Stigma experienced	First	Private	How participants disclosed the BC diagnosis to only few people for fear of stigma.	The ones am telling are those who are so close to me fully. So, I have decided when am through with the treatment and I see I have been cured, that is the time am going to tell people. But now I will not. (Juliet)
		First	Private		I only shared with my husband and we discussed it…. eeee… then after that we got to hospital, also shared with a few of colleagues at my workplace. (Ruth)

		Second	Private		There some even who could even meet me and ask why have you changed body wise, I tell them is …. because I am dieting. Just that coz I don’t want them to know. (Connie).
		Second	Private		As you know many when you tell them about this thing, they think you are raising funds. Because of that fear, that people may think, we want financial assistance. (Lilly)
		Third	Private		When you pass by people will talk and say you have a certain disease and it is a disease that has no cure. This one will die. (Juliet)
		Second	Public		That one, friends have reduced because when you have this disease people think that you need their help, now this has made the friends less because they think you need their money. Yes, they have minimized. Yes, they minimized including my brothers. People like my sisters, brothers and such kind of things. (Naomi)
		Second	Public		The difference is that since I got sick even those who were coming to my home stopped coming. (Marion)
		Third	Public		It has not yet changed even there are some of them that I usued to call them and when they receive after hearing that am the one they tell me that they will call me back even after that if I try to call them they cannot pick my calls and they won’t call me back. (Marion)

45.	Suggestions for improvement by participants	Third	Public		There is a need to have education for example at the village you come or plan with other partners and for example, let me use myself not because am selfish. (Marion)
46.	Support needed				
47.	Symptoms reported	First	Public		When I saw that the pimple was becoming bigger, I talked with a friend. With my, mum I never shared with her but told her when it became a wound. Because these small, small things I saw as though it will …… and it's not a wound she won't take it seriously. But when I saw it has become a big wound I decided to tell her. I sent someone to tell my mum am sick, let her come and see me, but she never came. …(Naomi)
48.	What patients need to know	First Third Third Third	Private Private Private Private	Interpreted as patient information needs after being diagnosed.	He told me I have to take treatment so that I may be healed, when I said that I just need not to leave my son to the wilderness. (Olive) There was something really I would have liked, after all this …there times, I would have liked to be checked whether those cells are over, but none I still have doubts whether I have the cells in my body. Yes, because there is no test I was done to prove they have done. Yes (Connie) I so this time because in that first time also she never told me that, I was going to get drugs to prevent vomiting. (Lilly)

		Second	Public		I cannot remember the drugs; you can look at the sheet of paper that I have…. like today I had a question to ask the doctor about what am expected to eat. (Juliet) I eat well and for two months now I am doing well and I am told that will take a few tests today. (Abigail).

Appendix 15: Summary of the emerging themes

#	Theme	Categories
1.	Despair and agony at diagnosis	• Breaking bad news • Cancer fatalism • Doctors and giving information
2.	Complexity of decision making	• Faith as a major coping strategy • Fear, hope amidst fear • Finances • Non-specific symptoms • Lack of knowledge
3.	Impact of BC diagnosis on self, family and others	• Side effects management • Stigma • Financial distress • Psychosocial Support
4.	Knowledge and information expectations of newly diagnosed BC patients	• Screening for BC • Breast Self-Examination (BSE) • Instructions on different types of treatment • Medication indication • Investigations • Post treatment instructions and follow-up • Patient as best teacher from experience
5.	Socioeconomic factors that influence HL across the cancer journey	• Faith • Finances • Support • Stigma

Appendix 16: Ethics approval documents

Research, Enterprise and Engagement
Ethical Approval Panel

Research Centres Support Team
G0.3 Joule House
University of Salford
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk/

9 February 2018

Dear Dinah,

RE: ETHICS APPLICATION–HSR1718-013–'Cancer related health literacy: a qualitative research study of the information and educational needs of patients diagnosed with cancers of the breast and/or cervix in Kenya.'

Based on the information that you have provided, I am pleased to inform you that ethics application HSR1718-013 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Sue McAndrew
Chair of the Research Ethics Panel

THE AGA KHAN UNIVERSITY

Ref: 2017/REC-07 (v2)
06th June 2017

Dr. Dinah Kassaman
Principal Investigator and faculty member
Aga Khan University, Kenya

Dear Dr Kassaman and team,

Re: Cancer related health literacy: a qualitative research study of the information and educational needs of patients diagnosed with cancers of the breast and/or cervix in Kenya

The Aga Khan University, Research Ethics Committee (REC) is in receipt of your revised proposal submitted to the Research Office on 04th May 2017. With reference to our communication Ref: 2017/REC-07 (v1) dated 28th February 2017, the committee has reviewed the revised proposal and conditionally approved this project (as per attached official stamped protocol), based on core ethical standards, which have been fully instituted in the protocol.

Prior to commencing the study, you will be expected to ensure compliance with relevant institutional administrative regulations. For further details of this regulations please contact Research Office. Besides, please obtain a research licence from the National Commission for Science, Technology and Innovation (NACOSTI) and site approvals from the proposed external site. Copies of these approvals should be submitted to the Research Office for records purpose. Subsequently, you are authorized to conduct this study from **07th June 2017**. This approval is valid until **06th June 2018.**

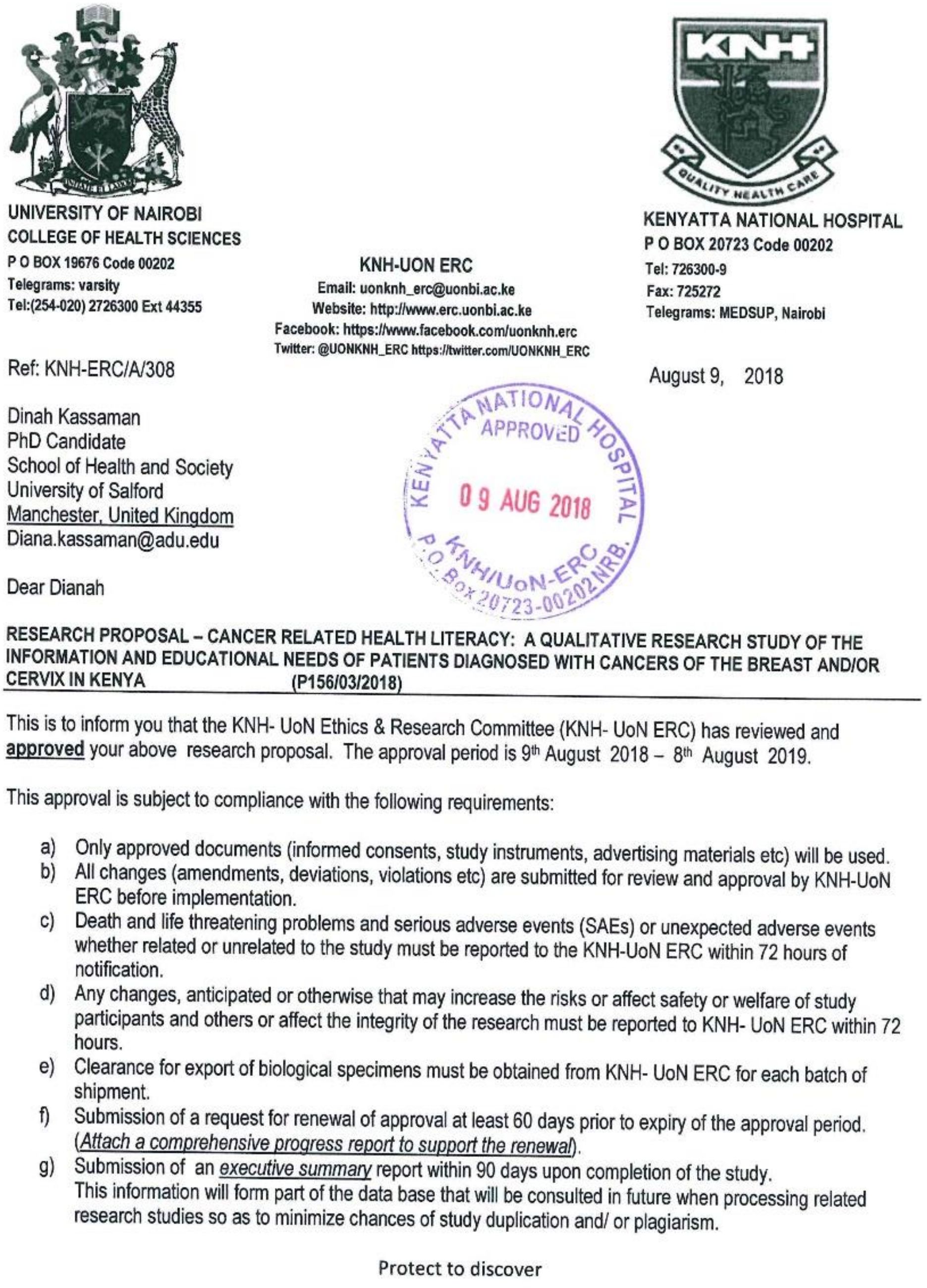
The study should be conducted in full accordance with all the applicable sections of the REC guidelines and you should notify the REC immediately of any changes that may affect your research project. You must immediately report any unanticipated problems involving risks to the participants to the REC. All consent forms must be filed in the study binder and for AKUH patients; a copy should also be filed in the patient's files. You must provide an interim report before expiration of the validity of this approval and request extension if additional time is required for study completion. As the principal investigator you must advise the REC when this study is finished or discontinued and a final report submitted to the Research Office.

If you have any questions and/or require assistance to obtain research permit from NACOSTI, please contact Research Office research.supportea@aku.edu or 020-366 2148/1136.

With best wishes,

Amyn Lakhani

Dr. Amyn Lakhani, Chairman
Research Ethics Committee, AKU (Kenya)



UNIVERSITY OF NAIROBI
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Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UON ERC
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Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/308

August 9, 2018

KENYATTA NATIONAL HOSPITAL
APPROVED
09 AUG 2018
KNH/UoN-ERC
P.O. Box 20723-00202 NRB.

Dinah Kassaman
PhD Candidate
School of Health and Society
University of Salford
Manchester, United Kingdom
Diana.kassaman@adu.edu

Dear Dianah

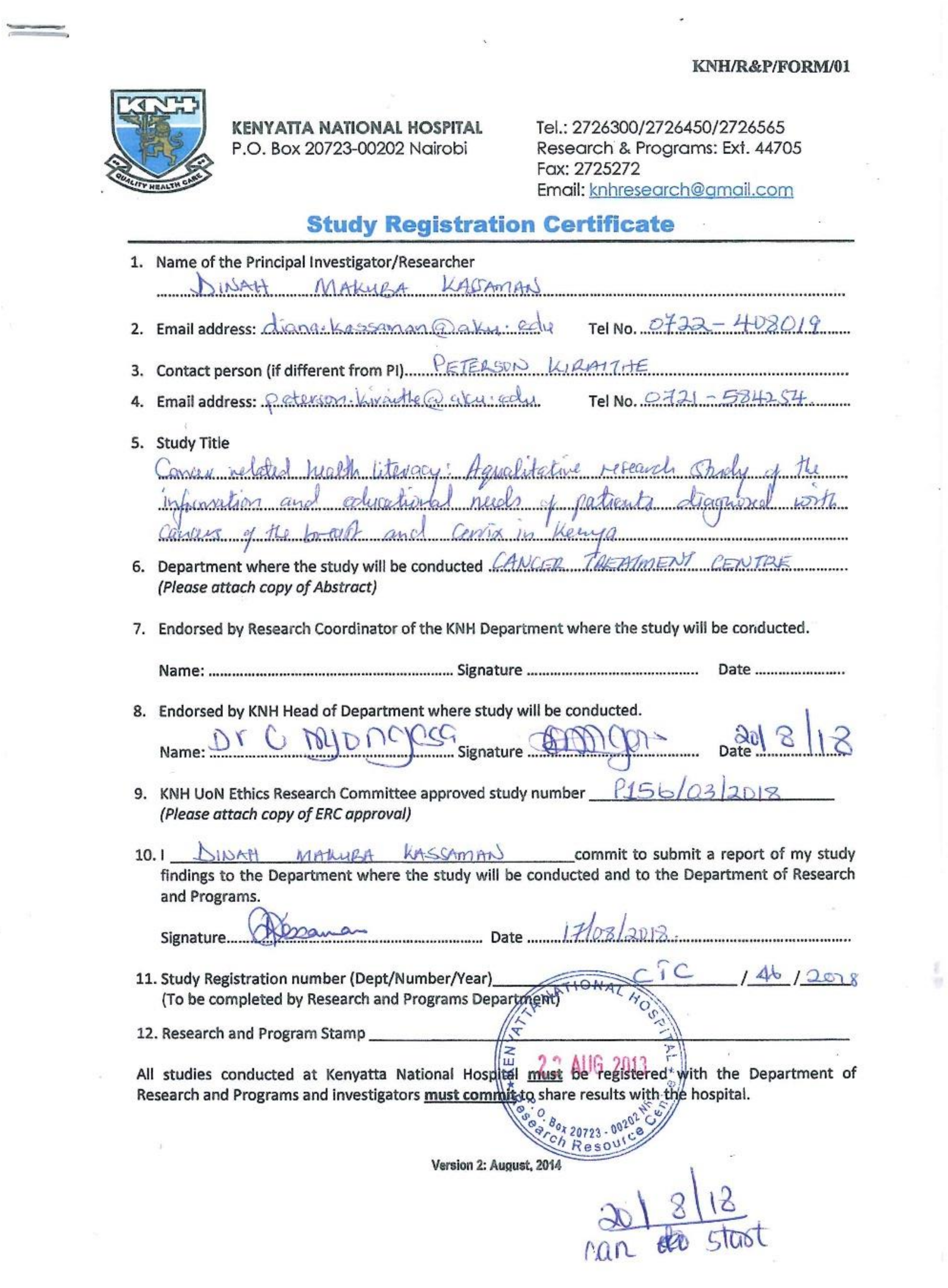
RESEARCH PROPOSAL – CANCER RELATED HEALTH LITERACY: A QUALITATIVE RESEARCH STUDY OF THE INFORMATION AND EDUCATIONAL NEEDS OF PATIENTS DIAGNOSED WITH CANCERS OF THE BREAST AND/OR CERVIX IN KENYA (P156/03/2018)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 9th August 2018 – 8th August 2019.

This approval is subject to compliance with the following requirements:

a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
c) Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e) Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
g) Submission of an *executive summary* report within 90 days upon completion of the study.
This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover



KNH/R&P/FORM/01

KENYATTA NATIONAL HOSPITAL
P.O. Box 20723-00202 Nairobi

Tel.: 2726300/2726450/2726565
Research & Programs: Ext. 44705
Fax: 2725272
Email: knhresearch@gmail.com

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
DINAH MAKUBA KASSAMAN

2. Email address: diana.kassaman@aku.edu Tel No. 0722-408019

3. Contact person (if different from PI) PETERSON KIRAITHE

4. Email address: peterson.kiraithe@aku.edu Tel No. 0721-584254

5. Study Title
Cancer related health literacy: A qualitative research study of the information and educational needs of patients diagnosed with cancers of the breast and cervix in Kenya

6. Department where the study will be conducted CANCER TREATMENT CENTRE
(Please attach copy of Abstract)

7. Endorsed by Research Coordinator of the KNH Department where the study will be conducted.

Name: .... Signature .... Date ....

8. Endorsed by KNH Head of Department where study will be conducted.

Name: Dr C Nyongesa Signature .... Date 20/8/18

9. KNH UoN Ethics Research Committee approved study number P156/03/2018
(Please attach copy of ERC approval)

10. I DINAH MAKUBA KASSAMAN commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.

Signature .... Date 17/08/2018.

11. Study Registration number (Dept/Number/Year) CTC / 46 / 2018
(To be completed by Research and Programs Department)

12. Research and Program Stamp ________________

2[illegible] AUG 2013

All studies conducted at Kenyatta National Hospital **must** be registered with the Department of Research and Programs and investigators **must commit** to share results with the hospital.

Version 2: August, 2014

20/8/18
can ~~do~~ start

THE AGA KHAN UNIVERSITY

Ref: 2017/REC-07 (v4)
22nd June 2018

Ms. Dinah Kassaman
Principal Investigator and faculty member
Aga Khan University, Kenya

Dear Ms. Kassaman and team,

Re: CANCER RELATED HEALTH LITERACY: A QUALITATIVE RESEARCH STUDY OF THE INFORMATION AND EDUCATIONAL NEEDS OF PATIENTS DIAGNOSED WITH CANCERS OF THE BREAST AND/OR CERVIX IN KENYA

The Research Office is in receipt of your progress report dated 18th June 2018. With reference to the Aga Khan University, Research Ethics Committee (REC) letter Ref: 2017/REC-07 (v1-v3) the committee records that during the reporting period:

- No changes have been made in the study objectives and methodology
- No adverse effects/events have been encountered.
- Initial approval expired on 07th June 2018
- Study implementation at AKUHN is ongoing. However, there has been delay in recruitment process at Kenyatta National Hospital (KNH).
- Additional time is requested to facilitate commencement/subject recruitment at KNH and continued recruitment at AKUHN.

Based on the above considerations, the committee has granted an approval of extension for a further one-year. This approval is valid until **06th June 2019**. As PI, you are further expected to observe all the guidelines as per the study approval letter Ref: 2017/REC-07 (v2) dated 06th June 2017 and subsequent versions. Additionally, for record purposes, you are reminded to file with the Research Office copies of your **NACOSTI permit and KNH Study site approval**.

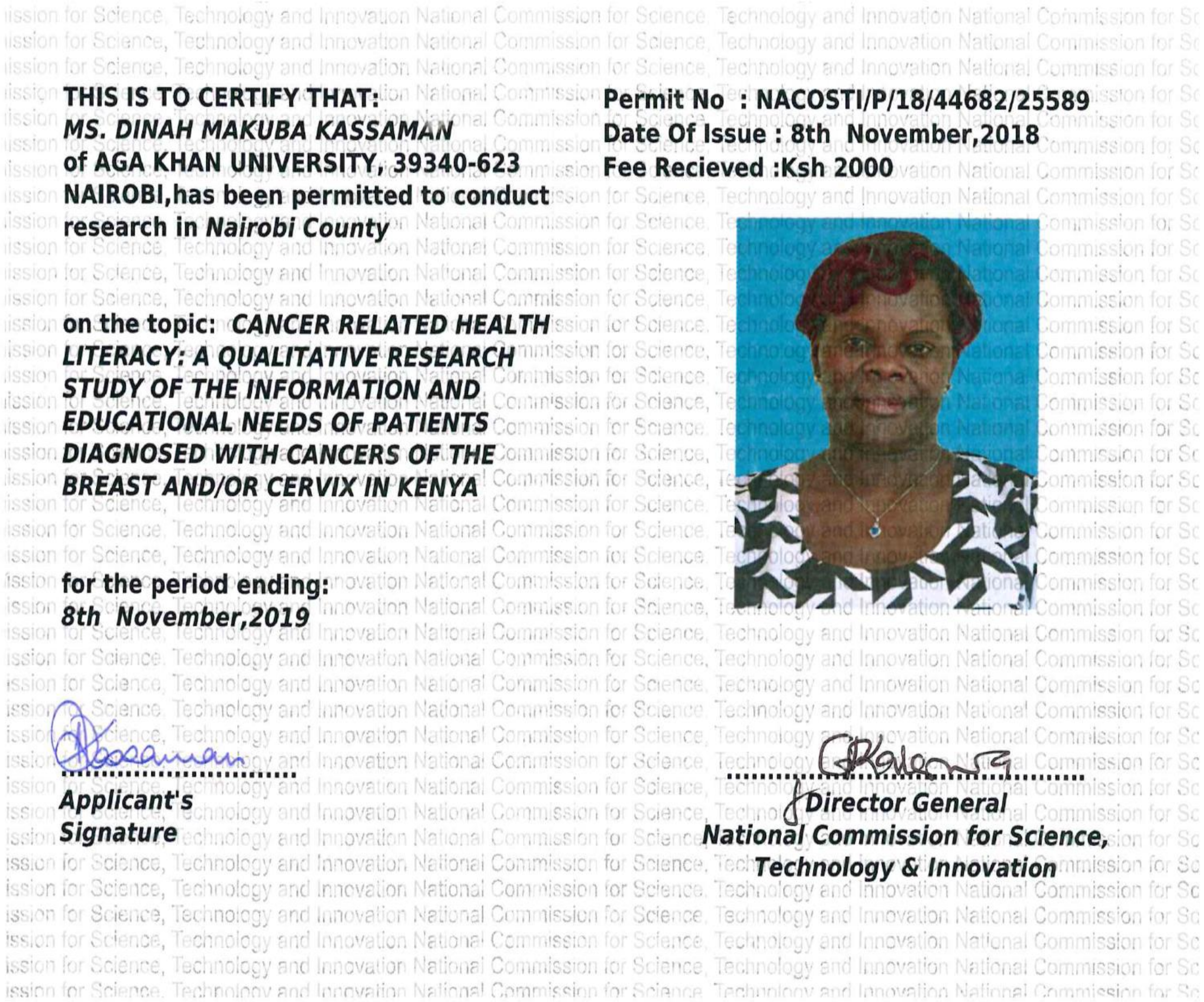
If you have any questions, please contact Research Office - research.supportea research.supportea@aku.edu or call 020-366 2148/1136.

With best wishes,

Amyn Lakhani

Dr. Amyn Lakhani, Chairman
Research Ethics Committee, AKU (Kenya)

Approval from National Commission for Science and Technology



THIS IS TO CERTIFY THAT:
MS. DINAH MAKUBA KASSAMAN
of AGA KHAN UNIVERSITY, 39340-623
NAIROBI,has been permitted to conduct
research in *Nairobi County*

on the topic: *CANCER RELATED HEALTH LITERACY: A QUALITATIVE RESEARCH STUDY OF THE INFORMATION AND EDUCATIONAL NEEDS OF PATIENTS DIAGNOSED WITH CANCERS OF THE BREAST AND/OR CERVIX IN KENYA*

for the period ending:
8th November,2019

Permit No : NACOSTI/P/18/44682/25589
Date Of Issue : 8th November,2018
Fee Recieved :Ksh 2000

Kassaman
....
Applicant's Signature

....
Director General
National Commission for Science, Technology & Innovation

THE AGA KHAN UNIVERSITY

Ref: 2017/REC-07 (v3)
January 8th, 2018

Ms. Dinah Kassaman
Principal Investigator and faculty member
Aga Khan University, Kenya

Dear Ms. Kassaman and team,

RE: CANCER RELATED HEALTH LITERACY: A QUALITATIVE RESEARCH STUDY OF THE INFORMATION AND EDUCATIONAL NEEDS OF PATIENTS DIAGNOSED WITH CANCERS OF THE BREAST AND/OR CERVIX IN KENYA

The Research Office is in receipt of your amended protocol and progress report submitted on 22nd December 2017. With reference to the Aga Khan University, Research Ethics Committee (REC) letter Ref: 2017/REC-07 (v1 & 2), the committee records that during the reporting period:

- No changes have been made to the study objectives and methods section
- No adverse effects/events have been encountered
- Study has been delayed due to pending approvals from Kenyatta National Hospital and Salford University.
- The team proposes to amend the inclusion criteria by including participants who cannot speak and write in English. Consequently, the interview guide, consent form and participant characters have been amended. These changes are aimed at averting biases.

The committee records that the modification is not likely to negatively impact on participant's safety. The rationale for amendment is valid and is bound to enhance the outcome of the study. Based on the above considerations, the REC has approved the proposed protocol amendments. As PI, you are further expected to observe all the guidelines as per the study approval letter Ref: 2017/REC-07 (v2) dated 06th June 2017. If you have any questions, please contact AKU Research Office at research.supportea@aku.edu or call 020 366 2148/1136.

With best wishes,

Amyn Lakhani

Dr. Amyn Lakhani, Chairman
Research Ethics Committee, **AKU (Kenya)**

Appendix 17: Participant biography

An introduction of the participants follows summarizing their background and reflections on experiences of getting cancer related information before and after the BC diagnosis. This will help my audience know whom I collected data from and help them to understand the findings and supporting evidence.

Connie

A jovial 50-year-old secretary, single mother of a teenage daughter in high school who was interviewed in English. She discovered the breast lump while doing her monthly breast exam that she learnt about in church. Her other sources of cancer information were television, radio, friends and other patients. The lump shocked her, and she called her friend to inform her. Unfortunately, the friend was attending the burial of her relative who died of BC and she told Connie that. The friend later came with her sister nurse who examined Connie's breasts and told her they were normal, but booked a clinic for her at ****, where the lump was felt and a biopsy was taken that confirmed BC stage one. Connie decries the way the doctor broke the cancer diagnosis. She felt that the doctor was 'beating about the bush', stating that he should have prepared her better to receive the bad news. She was shocked because she could not afford cancer treatment.

Connie seemed knowledgeable about her condition. The participant was very cooperative even though initially she appeared tense and nervous at the start of the interview. She was sensitive to any interruption, and seemed to be distracted by someone who was talking outside the room. I assured her that no one could hear her from outside, after which she relaxed, and openly relayed her experiences. In the second interview, Connie looked tired. At some point she became emotional, but fought it back; she kept quiet for some time, with her lips moving but saying nothing, and eventually resumed the conversation. In the third interview, she looked livelier than in the second interview. She was smartly dressed in a red cap, a black top and trouser; she looked lovely. She seemed to listen keenly and took more time to respond to questions than in previous interviews.

At one point, she considered committing suicide and got a rope to hang herself, but the daughter convinced her that she would be treated and get better. She was lucky to be taken in the ****welfare program where all the investigation and treatment costs were paid for by the hospital. Connie received lots of support from her friends, church and healthcare providers.

The first two interviews were conducted at the hospital, but the last interview posed challenges because she had travelled out of the city. She however created time and came back to my place of work for the interview, stating that it was healing to talk about her journey. All through her treatment, she did not experience any side effects, apart from occasional fatigue.

Juliet

A 58-year-old reknowned business lady, who is married to a senior government officer who accompanied her on all the visits. Juliet discovered the breast lump on her routine self-exam that she learnt from church. Her other sources of cancer information were health workers and the radio. Being socio-economically empowered, she also has private insurance and she goes for yearly health check-up at a high-cost private facility. Juliet was shocked when the cancer diagnosis was confirmed. She stated that cancer is a killer disease that had claimed her brother in law, and this increased her anxiety. She however had strong faith in God and believed this was a test that she would overcome.

In the first interview, Juliet appeared a bit withdrawn and not opening up. She expressed deep faith in a supernatural being and believed everything that was happening was pre destined. In the second interview, she appeared more tired than in the first interview. She had soup which she kept on taking during the interview. In the third interview, Juliet's face and skin looked brighter and livelier than in the second interview. She wore a short weave on her head and covered herself with a black *kikoi* (African shawl). She seemed to be more open and responded to questions faster than in the second interview. Juliet requested for more information about the right diet. This is because what was served at the clinic had a lot of oil and was not 'healthy food'. The tray of food served from the hospital kitchen had pancakes, *mandaazis and samosas (African pastry),* sausages, and tea with sugar. Juliet associated her good progress with her belief in a higher power When asked which drugs she was receiving, she stated that she had forgotten her document at home and would text the name when she went back home. She sent a text message that the name of the chemo drug was *Cytotoxic 6th cycle.*

Before consenting to participate in the study, she consulted the husband who granted permission but on condition that he sits in the interview room to hear what I was asking. In the first interview, he sat in quietly, but left after the first twenty minutes stating that the questions

I was asking were good for his wife. On subsequent interview dates, he would come and hand over the wife to me saying, “I have given her to you”. Though she was tolerating treatment well, she complained that the husband forced her to eat large portions of food that made her vomit. According to him, if the wife reduced in size, then people would say that he had neglected her, yet he was a renowned public figure in the country. On subsequent visits, Juliet was very happy because she told the husband what I had taught her after the interview; to eat small frequent meals and he was complying. Juliet had strong family support from her children who were adults and employed. During treatment she continued working and supervising her staff.

Ruth

A 41-year-old teacher who is married and lives in the outskirts of the city who was interviewed in english. Ruth discovered the breast lump on her routine self-exam. She learnt about BC from watching TV and attended a medical camp organized by the church. Since there are no diagnostic facilities in her hometown, she was given her biopsy specimen to bring to a different hospital??**** for histopathology. When she came to pick her results, she opened and read before taking to the doctor for further explanation. Ruth knew that cancer is genetically inherited and since no one in her family lineage had ever been diagnosed with cancer, she felt safe. She was therefore shocked and afraid when the doctor told her she had BC. The doctor explained that it was at stage one thus was curable. The doctor explained in detail the treatment required and the side effects of each treatment modality. She was very happy with the information that the healthcare providers gave her. She enjoyed the support of her husband, family and friends.

In the second interview, Ruth appeared a bit tired compared to the first interview. She took soup throughout the interview, and also had homemade food. Ruth pointed to the food she was carrying as evidence that she was well taken care of by her husband. She was concerned with her physical appearance for she looked a bit older than in last time. Ruth was well dressed, lively, and eager to participate in the interview. She stayed focused during the interview and shared her thoughts freely.

Abigail

A 61-year old former librarian with stage 3 BC who travelled to the city for treatment. Accompanied by her husband and two sons who were a great source of strength in the cancer journey. Abigail appeared relaxed and was comfortable to participate in the interviews. She portrayed a very strong faith in God, and she would close her eyes and talk slowly emphasizing a point. At times, she seemed to be in a trance and there would be long interludes of silence. She would then open her eyes and invite the next question. The interview seemed to take her mind to issues she had never shared with anyone since the cancer diagnosis. She was always accompanied by her husband, and two sons. During the interview, she was getting a lot of phone calls from friends wishing to know how she was fairing on and wishing her quick recovery. Abigail seemed to reflect deeply when asked about her journey to BC diagnosis, and the procedures she underwent. She was hesitant to respond to the question when asked if she was sexually active, and requested that we ignore that question. In the second interview, Abigail looked darker. She was accompanied by the husband who stayed in the room with her, but she was comfortable with his presence. In the third interview, Abigail's face and body looked swollen and different from her previous image. She was quite emotional as she discussed how the family (children and husband) reacted to the BC diagnosis, they were positive that she would be well after treatment and they support her all through.

Abigail's version of how she discovered the lump was not only interesting but unusual too. She fell in her bedroom and dislocated her ankle joint. During the fall, she also hit her breast on the edge of the bed. After one week, the breast started swelling and was painful. Her leg was put in a plaster cast, and for almost 6 weeks, she did not give much thought to the breast swelling until the plaster cast was removed. Her husband took her to a local hospital where the doctor requested for a breast ultrasound, then mammography followed by a biopsy. The biopsy revealed BC stage three.

Olive

A 33-year-old jovial woman who separated from her husband and lives with the son. She was having radiotherapy after completing her chemotherapy cycles. She does menial jobs for a living, mostly washing clothes for people and any other job that can earn her money e.g. working at a construction site. This in Kenya is called 'hustling'. She speaks amazingly good English. Olive discovered a lump in her breast in 2013 that was not painful. She discussed with her friends who told her it would disappear with time. In October 2017, four years later, a close friend recommended that she sees a doctor since the lump was neither increasing nor decreasing. Olive with stage 1 BC had no prior knowledge of cancer but heard a discussion about cancer in their women group, popularly called '*chama*'.

She went to ****, a public hospital where mammography was done, and she was advised to go to the private hospital for treatment. When she brought the X-rays to the private hospital, the doctor said they were of poor quality and she had to get others, straining further her financial situation. She explained her poor financial situation to the doctor who organized and got her enrolled in the patient welfare program. Olive was sent for what she called *myosy-meaning* biopsy, which confirmed a cancer diagnosis. When the doctor disclosed the diagnosis, Olive cried because she knew she would die. She was very disappointed because according to her; cancer was a disease for the 'rich' who could afford treatment. Her biggest worry was how she would afford treatment, because if not treated she would die and leave her son. The doctor explained that it was at stage one and if treated, she would be well.

Olive engaged easily, she was eager to talk and appeared comfortable. She spoke freely about her experience. She talked about God giving her strength and showed us her Bible which she carries with her and reads when she is on the bus, travelling to her appointments. She had a head scarf loosely covering her head during the interview. After the interview, she tightened her headscarf so that it was firmly covering her head before she left. Olive's second interview was conducted in the radiotherapy department and took place in a room that she complained that was too cold. We interrupted the interview to get the technician to adjust the air conditioner. The patient was once again engaging, friendly and readily shared information. This time, she wore a headscarf that was tightly wrapped around her head and stated that she needed to do this because her hair had fallen off. Olive seemed very happy and she verbalized the same. She thanked God for bringing her this far, and she appreciated being chosen to be part of the study. She stated that she was overwhelmed and stated "I am happy, happy, happy. I cannot even measure the happiness … thank you all".

Olive was very happy that physically, nobody could tell that she had cancer. She was interviewed in English.

Rhoda

A 57-year-old university graduate and high schoolteacher who lives in the city with her husband. The only Muslim participant. Rhoda is a mother of three grown up children and four grandchildren who I met during chemotherapy sessions. Rhoda looks young for her age;

she is 57 but looks like a 40-year-old. She reported a strong family history of cancer; her mother died from stomach cancer, her sister had BC and another sister died from colorectal cancer. She actively searches for cancer information from the newspapers and internet and expressed a concern for people who could not access the internet.

Rhoda appeared comfortable and was eager. to engage in the interview. She used many gestures when explaining her points. The last interview was conducted in her house. The participant's hair had started growing and she appeared stronger. Rhoda was taking some pauses before she responded to questions, and she seemed to have grown to the level of differentiating sound health advice from information that was not credible.

She disclosed her diagnosis to her colleagues, family and friends close to her; but they could not believe Rhoda had cancer since she appeared very healthy. Rhoda had immense support from her husband, sisters and children. Her last-born son deferred going overseas for a job placement when the mother was diagnosed with cancer, but she later convinced him to go so that he could send home money for treatment.

In all her sentences she inserts '*a what'* which may distort the sentence and the person reading the transcript may get confused. She referred to God all the time and requested for the other two interviews to be done in her house. She was interviewed in English.

Debora

A 37-year-old clerk at a coffee factory in one of the counties who started the interview in English but switched to Kiswahili later on. She is the third wife to her husband and has two teenage children. She discovered a lump while bathing but did not tell anyone because the breast is considered a private part. She later showed her husband who advised her to go to a private hospital for treatment. Debora however preferred a public hospital because according to her, private hospitals only focused on making profits. She argued with the husband about going to the private hospital but when she insisted on the public hospital, the husband agreed, but warned her that she would be blamed if anything bad happened. She gets information from the TV, church, health pamphlets, and the radio.

Debora went to the public hospital and the doctor upon examination confirmed the breast lump. He asked her to buy the needles and syringes to do a biopsy and return the following day. The syringe and needle costed her 59 USD, approximately half of her monthly wages. The biopsy was done the following day without any anaesthesia, but she persevered because she wanted to get well. She described the sample that was taken as looking like the small insects found in rotting beans. The husband took the specimen to the private hospital for histopathology and they were to wait for one week for the results. At this point, the husband reminded Debora that his preference for private hospital was because of faster processes.

She then asked for directions to the hospital and saw the doctor. When he saw the results, he called two other doctors and a nurse into the room. This was a major cause of anxiety especially when the doctor said, “she needs counselling”. Debora broke down and cried even as the nurse counselled her. The three doctors then came in, but no one wanted to start the conversation. All this time, her body was telling her something was very wrong, but she encouraged herself that God was on her side. The doctor asked her to call her husband who took a motorcycle taxi (*boda boda*) and arrived within 30 minutes. The doctors took family history from him and then disclosed that Debora had BC stage two and needed surgery to remove the breast and prevent spread of the cancer. She was booked for surgery the following day, but her blood pressure shot up to 220mmhg (systolic; normal is up to 120 mmhg). The doctors reassured her and she prayed the whole night telling God to preserve her life even if she lost her breast. On the day of surgery, the ‘whole’ village camped at the hospital praying and speaking in low tones as she awaited surgery.

At some point during the first interview, Debora became very emotional stifling tears, but she insisted on continuing with the story because she stated that something was *getting out* as she talked, and it made her feel better. She bargained with God as she walked to theatre (she refused to be wheeled on the trolley). She asked God to remember anything good she had done and bring her out of theatre alive. She was in the operating room from 9 AM to 3.15 PM and this caused panic amongst her relatives and villagers waiting outside since no one had explained to them what to expect. When she woke up, she had drains, which again shocked her since nobody had told her what to expect.

She however had a remarkably fast recovery and was discharged and referred to the city for chemotherapy treatment which was ongoing. Debora is now a BC champion in her village with lots of support from her husband, and educates women in church encouraging them to go for screening. She has improvised a breast prosthesis (she allowed me to see it) using a piece of cloth that works perfectly. Debora lives her life to the fullest thanking God for giving her a second chance in life.

During the second interview, Debora's level of concentration in the interview was lower compared to the initial interview. In the third interview her concentration was better and she was lively. Her hair had started growing back and she had left it open unlike in the other interviews when she used to cover it with a headscarf or hat. Her nails that had turned black were returning to their normal colour, and she was well pleased with that.

This is a participant who talked nonstop for one hour 26 minutes after the first question, *'How did you find yourself in the cancer clinic?* 'She gave every detail of her cancer journey from diagnosis up to the current chemotherapy cycle.

Naomi

A 34-year-old unemployed woman who separated with the husband due to the cancer diagnosis at stage three. She noticed two pimples on her breast when she was pregnant. Her friend thought they were boils but since they were not causing any pain, Naomi did not seek medical attention. In the health centre where she sought treatment, the doctors aspirated the fluid, but the swellings increased and actually looked like a second breast. They told her she could not be treated because of the pregnancy and they gave her Amoxil, an antibiotic. The swellings later became wounds which would bleed easily and had to be dressed weekly at the health Centre. When she developed the wounds, she sent for her mother to come and support her, but she did not come which saddened her. Naomi believed that the wound would heal after delivery. A biopsy taken later revealed stage three BC, and when the doctor disclosed this, Naomi wailed loudly because this meant death. The only information she had about cancer was that it kills, but she also had hope because she knew a cancer survivor who was diagnosed in 1992, but died in 2018.So amidst the fear, she was quite hopeful. When the doctor told her that she had stage three BC, she did not understand but did not ask for an explanation. She feels the cancer diagnosis was broken in a considerate manner, though she was never given any information about treatment options. In fact, the surgeon at the county hospital had booked her for surgery even before the biopsy results were received. After recovering from surgery, she was referred to the city for chemotherapy. In the referral hospital, she was given a lot of information about cancer treatment, but the doctor made all decisions for her. Naomi used a funny statement when referring to her fear of death, saying there is no 'dying squared', meaning you only die once. Nevertheless, she believed that God would heal her. Her husband abandoned her because of the financial implications for cancer treatment. She informed her neighbours, friends, mother and brother about the cancer diagnosis because they were supportive and would help with the baby. She was interviewed in Kiswahili.

Naomi was nervous at the start of the first interview. She had no hair and had not covered her head with anything. She participated well in the interviews.

Marion

A 45-year-old married woman of very low socioeconomic status whose story is very sad. She is the breadwinner in a family with two children where the husband is a drunkard and does not seek any employment. She had missed several chemotherapy sessions because she had not paid the five dollars required monthly for the government sponsored National Hospital Insurance Fund (NHIF). She had heard about BC in church but had never been screened. She however had seen a woman with BC who had wounds, so according to her, she never thought she would have cancer because there were no wounds.

When she discovered a lump in her breast, Marion informed her church women leader referred to as *Mama Assembly* a highly respected and coveted position, who advised her to apply *Robb*- an over the counter analgesic ointment popularly used for pain and swelling. After the cancer diagnosis, *Mama Assembly* expressed shock stating that she also did not know the signs of cancer.

Marion’s illness was affecting the son who was in high school and this worried her a lot. Her treatment was delayed for six weeks because of a countrywide doctor’s strike After the strike was called off, she was scheduled to start her chemotherapy, but she did not have the 11 USD needed for initial registration and six USD for consultation fee. She went home and came back after a week with the money. The doctor then prescribed chemotherapy but again she did not have money and her NHIF was not fully paid up. So she went home and took another three weeks before coming back after a friend referred her to the social worker who helped her get her first chemotherapy. Marion could not afford the diet advised in hospital because of her family needs and priorities.

Marion’s cancer journey is focused on the financial implications and her struggles to get money. During the interviews, she got very emotional, relieving how the cohort of patients she started treatment with had already finished their eight cycles, yet she had not done even three.

When we recruited her into this study, she was optimistic thinking there would be financial aid towards her treatment. All the same, she expressed lots of satisfaction and acceptance of her situation after the interviews. She claimed that it was therapeutic to tell her story, an opportunity she had never had before.

Since we kept contact with the participants even after the third interview, my research assistant (RA) on a follow up call discovered that Marion had defaulted treatment because of not paying for the NHIF for four months. She needed 40 USD to finish her treatment. My RA raised funds from friends and paid the 40 USD that Marion needed to complete her treatment.

Marion also gave a view of the beliefs her people in the village had about cancer. They believed witchcraft caused cancer and most of them would not go to hospital for treatment, but to traditional healers and medicine men.

Marion's situation portrayed the real picture of financial distress in a woman with no formal employment struggling to provide for her family and now faced with a life threatening disease. Her treatment journey revolved around the lack of money. Marion seemed to always wander off into deep thoughts during the interview. She faced enormous challenges since she also did not have strong family and friends' support. She was interviewed in Kiswahili.

Marion was always unaccompanied, and seemed to be desperate financially, and the way she expressed herself showed self-pity. She looked more depressed in the second interview, and was often emotional. Marion talked very softly, and when she mentioned family members she shed tears. Marion always seemed to be in pain and often touched her breast which seemed swollen. She stated that the swelling increased when she missed her scheduled chemotherapy treatment due to lack of finances.

Lilly

A 28-year-old married housewife, the youngest participant with stage two-BC. Lilly discovered a lump after she stopped breastfeeding and thought it was engorgement. She bought drugs over the counter, which seemed to reduce the swelling and she stopped thinking about the lump. For a whole year, she did not seek medical attention, after all, the lump was painless. Lilly developed back pain, chest pain and nausea, which made he stop working as a nanny. She went to the county hospital, had a stomach X-ray done, and she was given painkillers. The pains became unbearable, the doctors recommended a biopsy, which later revealed cancer stage two. The diagnosis shocked her because she knew young people do not get cancer.

Before the biopsy, the doctor had counselled her intensely therefore she was prepared and had hope that she would be cured. Her mother however was the most affected because she knew that Lilly, her only daughter would die of cancer. As she continued with treatment and improved, the mother became hopeful.

Her story paints another side of suffering where after long suffering without knowing what ails them, the cancer diagnosis comes as a relief; Lilly stated that at last she knew what ailed her. It is as if a solution to a complex puzzle was unravelled. She was interviewed in Kiswahili. Lilly engaged easily and participated well in all the interviews. She paid keen interest to the questions asked.

Paula

A 46-year-old married lady with stage two or three BC who recruited herself into the study after hearing others talk about it in the cancer clinic. She knew about cancer screening from church and practiced BSE. When she discovered a lump, she went to a nearby clinic and was given some drugs. When the lump kept increasing in size, she went to another hospital where mammography was done and it confirmed the lump. A biopsy done at the county hospital conformed BC stage three. The doctor explained to her that she would have what she called *masectomy* and meant mastectomy. She went and thought about it for two weeks and came back to the doctor. This first doctor was not explaining what the complex medical terms meant, so she asked another doctor friend to explain to her. There were however other things she wanted to experience for herself since nobody was giving her information; this included post-operative expectations e.g. presence of drains, effect of anaesthesia, staying nil by mouth and position in bed. Paula's strong belief in God helped her cope with the cancer diagnosis because she replaced the word cancer with *Jehovah heals*. Her husband also encouraged her saying that cancer belongs to God.

The only person she informed about her cancer diagnosis was her close friend who was tasked to pray ceaselessly as Paula went for surgery. After a series of chemotherapy cycles, Paula started feeling better and informed the other relatives about her cancer diagnosis. They got shocked but this did not bother her at all.

Paying for her treatment was not a problem because she had fully paid up for her NHIF and it catered for everything. She worried about her image after breast removal (mastectomy) and hair loss (alopecia) but found hope in God. She stated that God had replaced the prophets of old bible times with doctors who carry out His work of healing.

She took supplements, for example, organogold coffee to enhance nutrition and reduce side effects. These helped her a lot because she never vomited all through her treatment. She feels that patients who have undergone cancer treatment were the best to teach others, saying that doctors and nurses were very busy such that patients avoid asking questions. She expressed confusion where her cancer was staged at two at the county hospital and at three at the referral hospital in the city where she was receiving chemotherapy.

Her husband was very supportive and advised that they use condoms for family planning instead of hormonal methods. She was interviewed in Kiswahili but occasionally spoke some English.

Paula participated well in all the interviews She would get emotional at intervals, but she controlled her feelings. What seemed to worry her most was that she had the breast lump excised without having a biopsy first, something she learnt from the other women- that they had biopsies before the main surgery.

Appendix 18: Study timelines

Activity	**From**	**To**
Proposal development and writing	November 2017	January 2018
Submit and achieve ethics clearance (UoS,AKUH,N,KNH,NACOSTI)	January 2018	August 2018
Data collection	February 2018	January 2019
Full data analysis	February 2020	July 2021
Completion of literature review	July 2021	September 2021
Completion of methodology	January 2018	June 2018
Report writing	July 2018	May 2021
Submission of draft copy of complete thesis	July 2021	August 2021
Completion and final submission	May 2022	September 2022

Appendix 19: All supervision dates-from 2017 to 2022

Dates	Number	Dates	Number	Dates	Number
15/11/2017	1	26/04/2019	17	29/10/2020	34
22/11/2017	2	28/5/2019	18	1/10/2020	35
14/12/2017	3	4/06/2019	19	29/10/2020	36
11/01/2018	4	25/06/2019	20	26/11/2020	37
15/02/2018	5	11/07/2019	21	14/01/2021	38
18/04/2018	6	15/07/2019	22	18/02/2021	39
16/05/2018	7	17/07/2019	23	25/03/2021	40
21/06/2018	8	22/07/2019	24	29/04/2021	41
19/07/2018	9	12/08/2019	25	10/06/2021	42
29/08/2018	10	30/08/2019	26	22/07/2021	43
9/09/2018	I .A	17/09/2019	27	20/08/2021	44
31/10/2018	11	29/01/2020	28	22/09/2021	45
13/11/2018	12	26/02/2020	29	22/10/2021	46
18/12/2018	13	25/03/2020	30	24/11/2021	47
22/01/2019	14	2/07/2020	31	16/12/2021	48
26/02/2019	15	6/08/2020	32	27/01/2022	49
26/3/2019	16	1/10/2020	33	19/07/2022	50