Lifestyle self-management experiences of South Asians post myocardial infarction

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"The Woman Whom even God dreamed of before the world was made; The Woman of Who, though no priest, could yet on Calvary's Hill breathe, 'this is my Body; this is my Blood' – for none save her gave Him human life. The Woman Who guides my pen, which falters so with words in telling of the Word. The Woman Who, in a world of reds, shows forth the blue of hope. Accept these dried grapes of thoughts from this poor author, who has no wine; work a miracle and save a soul forgetting not my own."

Archbishop Fulton Sheen
(Dedication Poem in World's First Love)

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For all the errors that inevitably and inadvertently occur, the fault is mine alone.

Declaration

I hereby declare that except where specific reference is made to the work of others, the contents of this dissertation are original and have not been submitted in whole or in part for consideration for any other degree or qualification in this, or any other University.

Dilla Davis

Abstract

Background: Coronary heart disease is the biggest killer in this country. South Asians carry the burden of increased incidence and prevalence and have poorer outcomes after a MI than the general UK population. Reviews have shown lifestyle modification including physical activity, healthy diet and smoking cessation, alters the course of heart disease and reduces recurrences crystallising its significance as a cost-effective public health strategy to reduce the rising burden of this disease. There are lacunae of knowledge as to what constitutes to guarantee a therapeutic lifestyle modification for better health outcomes in the South Asian community.

Aim: To explore the self-management experience of South Asians after a heart attack.

Method: Pioneering of its kind, this study used a grounded theory approach to elucidate how South Asians navigate these lifestyle changes. Two phase interviews at 2 weeks and 8 weeks of discharge, were conducted with 14 participants who were newly diagnosed with heart attack- from 2015 to July 2016.

Results: Theoretical categories were developed through constant comparison and theoretical sampling – these were *patronage of the family, affinity towards one's group and conforming to the religious and health (causal) beliefs*.

Discussion: By providing a unique insight that choosing and prioritising lifestyle style changes is not an *individual act*, but a *shared act*, a case for '*shared efficacy*' is made. The concept of '*shared efficacy*' as an essential strategy to enhance an individual's ability to make meaningful choice, is showcased. The novel presentation of making and maintaining lifestyle choices as a *conflict resolution strategy* with the aim of '*maintaining harmony*' among South Asians calls for a 'harmony model' to deal with diagnosis of heart attack and subsequent lifestyle changes. This proposed harmony model homes in on a family centred approach, where there is an *awareness* of the family's needs, an *appreciation* of the cardiac patient's religious and causal beliefs as well as an *acknowledgement* of their cultural priorities, in self-management programmes.

Conclusion: Migrant South Asians across the globe have an increased propensity to this disease. The findings contribute to the development of supporting negotiating strategies by capturing concepts that crystallise the significance of lifestyle self-management. To alleviate the burden, there is a need for ethno-sensitivity rather than an ethnocentricity in the delivery of services. This calls for a move from cultural competence to cultural intelligence.

Dear Reader,

In my endeavour to explore the experiences of the South Asians after a heart attack, I was partly influenced by my nurse training in the 90's. "He shall live because of me" was the motto of the institution where I trained with a mission to reach out willingly to the medically unreached. In my choice of what is important to study, the methods, and the emergent analysis, I draw upon almost 20 years of experience working as a nurse in a multicultural mainstream health service. Perhaps I have always been subtly enticed by the narrations of the underprivileged, the minority. Perhaps this is why, though I have been 'pushed and pulled' around the differing ontological and epistemological turns of grounded theory, my research finally rested on a methodology that offered inroads to hear the stories and invoke the voices of participants, thus embracing subjectivity. This attractive proposition of privileging on the action of entering the world of the participants to view their circumstances and attending to the meaning they create, was crucial to this research. For as a health care professional it is imperative that I know how and why South Asians choose as they do so as to enter into a meaningful dialogue with them.

Critical debate surrounds questions on the existence and nature of truth and reality as well as the representation of knowledge. Under the mantle of a constructivist, I do not assume there is a reality awaiting discovery which can be exhumed, nor I have finally arrived at 'the truth'. This is not to say that I hold on to a nihilist belief that there is no material reality, no action or agency, empirical confirmation or social structure. For in art, music, books and works – for example in Beethoven's symphonies, missionary works of Mother Theresa - one is compelled to concede the exquisiteness of a reality that goes beyond the needs or expectation of one's ego. As a staunch Roman Catholic, I firmly cling on to an absolute truth thereby defining an epistemology of absolutism as opposed to relativism. Nonetheless, what I would like to emphasise is that between reality and its representation is a process of knowledge construction which is cultural, partial, complex and positioned within a labyrinthine social and historical context – akin to the differences in the gospels of Mathew, Mark, Luke and John, narrating the Truth of Christ.

As Bourdieu's notion of 'habitus' dictates, some of my ideas, expressions and actions may be partly shaped by my exposure to a western frame of reference, schooled in western theory and research methods; others from my South Indian middle class upbringing, parental values, peer influences and life experiences;

whilst others from the service/institution where one works, the research industry; the predisposition of the organisation from where the research originated and research is published. The historical space within which this knowledge is co-constructed is singularly poignant with welfare weariness, fiscal restraints, devolutions and integrations of health care along with Kings Fund review of the NHS (Quarterly report – March 2017) reminiscent of the statistics of a bygone era. Overhanging everything else is the anxiety and uncertainty of Brexit. Thus, the underlying philosophy, politics, history, and related power interests form a subtle but tangible link between our actions, the research and the pursuit for evidence.

This research has been exercise in self-interrogation, ensuring transparency regarding the construction of knowledge. Even so, in this research journey, I learned, in parts, about my own beliefs and why I believe the way I do. Researcher reflexivity, detailed here as confessional accounts, is hoped to portray how my own socio-biographical perspective might have had an impact on how I undertook the research and how it is presented. As such I would like to acknowledge the tensions inherent in writing up a grounded theory, for example, the deliberations on deviating from the well-trodden path of the prevailing ideas of structuring the thesis and unconventionally organising it as the methodology unravelled – delegating the chapter on literature review after the chapter on data analysis. And yet, I have chosen the conformist path and ordered the thesis in the traditional way with the aim not to deflect the reader, but to ease the perusal of the text.

However, it would be unwise to judge the book by the chapter for this is a substantive theory. The appreciation of convictions and distinctions comes only from undertaking the research – amidst struggles and sacrifices. For this research is not complete without further questions arising from it. As I draw my writing to a close, I do not make any claims of unlimited wisdom and epistemological perfection. As a social researcher, at the back of my mind is 'both how little the single scientist knows in relation to the total community of inquirers, and a respect for the complexity of reality' (Kalleberg 2007:141). Therefore, as a sign of epistemic humility and honesty, I pay homage to the Aristotelian conception of 'phronesis' - practical, limited wisdom and leave you with just one facet of the reality, a truth as I see it with the participants, tailor made for this context, for this community, a story we tell together... me as the researcher and the participants – South Asians with their diagnosis of heart attack.

Dilla

Chapter 1   Introduction

This opening chapter of the thesis, perhaps the shortest of all the thesis chapters, is where I build the case for my research. I provide the rationale for the choice of population and the disease condition. The main concepts involving the participants and the disease focus only deserve a cursory mention here, for they are extrapolated further on. After delineating the scope of this research, the aims and objectives are then presented, followed by the thesis structure and a short summary for the chapter.

1.1   Building the case for the study

From the chronicle of how a heart muscle contracts to the explication of a human genome, scientific achievements in heart disease have made phenomenal global impact. Spearheaded by empirical research, critical advances have paved way for early diagnosis and treatment of several abnormalities of the heart and circulatory system. Yet, as italicised above, the prediction of World Health Organisation (WHO) has materialised with the diseases of the heart and its blood vessels remaining the principal killer worldwide (WHO 2011). Accounting for more than 75,000 deaths per year, myocardial infarction remains the principal cause of mortality and morbidity rates in England (Townsend et al 2012), the treatment and care for which a substantial amount of the primary and health care budget is spent (Department of Health 2011). However, the disease burden shows no egalitarian pattern, with standardised comparisons among different ethnicities unmasking a disproportionately high prevalence particularly among migrant South Asians (Scarborough et al 2010).

Representing the largest ethnic minority in United Kingdom, South Asians (people who share a common ancestry of the Indian subcontinent) suffer a higher incidence of myocardial infarction than their Caucasian compatriots (Scarborough et al 2010). In a country hosting a multi-ethnic society with around 4.6 million ethnic migrants from around the world (Office for National Statistics 2012), South Asians' admittance rate to hospital with myocardial infarction is twice that of the general population. Moreover, prevalence and incidence reveal migrant South Asian communities, for example the Punjabi Sikhs, are at a 3-5-fold higher risk of premature death due to myocardial infarction (Shah et al 2015). Such disparity in incidence and prevalence is not limited to British South Asians, but is obvious in worldwide migrant South Asians, crystallising the fact that South Asians are very vulnerable groups within their host country health care systems.

Though several hypotheses have been put forward, to date, none has been able fully to explain this disparity. Modifiable contributing factors for this incongruent pattern are thought to be both physiological and socioeconomic in nature, comparative to the general populations of the host countries South Asians migrate to (Meadows et al 2011; Nair and Prabhakaran 2012). Significant contributors to this disparity include excessive prevalence of diabetes, language difficulties, distinct health beliefs, poor knowledge and understanding of the disease process (Lai and Surood 2012). With no acknowledged cure for the disease (the definition and pathology is explained in chapter 2), and with the survivors at an increased risk of repeated infarction (Mendis 2005), the only method known to slow down the disease progression is lifestyle modification along with concordance with cardio protective medicines.

Consequently, adopting a secondary preventive approach, of which self-management is an integral part, has the potential to avoid recurrent attacks or deaths thereby improving clinical outcome (British Association for Cardiovascular Prevention and Rehabilitation 2011) and to ease the escalating burdhen of myocardial infarction. Moreover, reviews by De Gucht et al (2013) and Cole et al (2011) have shown that improved physical activity, a healthy diet and smoking cessation can deter the progression or alter the course of the disease as well as reduce recurrences. Likewise, the national political agenda (for example National Institute for Clinical

Excellence Myocardial Infarction Secondary Prevention 2013) advocates the need to encourage lifestyle changes as a critical component of cardiac rehabilitation programs. Therefore, in the aftermath of often life changing events like acute myocardial infarction, a comprehensive healthy lifestyle change is advocated as first-line therapy along with cardio-protective pharmacotherapy for the long-term management of patients.

Nevertheless, the polarising corollary to this persuasive evidence surrounding the benefits of lifestyle changes is the bleak picture in clinical practice where the evidence based recommendations are not fully translated into improved clinical outcomes (Piepoli et al 2015). Many patients struggle to self-manage therapeutic lifestyles, and merely a third of individuals after a myocardial infarction join cardiac rehabilitation programs (National Audit of Cardiac Rehabilitation 2013). Furthermore, there is a seventy-five percent relapse in those who quit smoking with these people reverting to old habits within a year, after making successful lifestyle changes initially (Borland et al 2010). Contemporary data from large European studies such as EuroAspire provide the evidence for the poor management of risk factors and lack of lifestyle modification post myocardial infarction that exposes these patients to high risk of a future cardiac event or death (Kotseva et al 2016). Despite a strong aforementioned evidence base asserting its efficacy, the major limitations of secondary prevention programmes significantly limit their impact and raise questions about their appropriateness, particularly for niche groups such as South Asians (National Institute for Health and Care Excellence 2013).

Against the backdrop of fiscal constraints and a call for efficient monetary savings plaguing the NHS, effective self-management (further defined and explained in chapter 2) becomes a key priority (Wellard 2010; Challis 2010). The NHS Outcomes Framework 2013-14 (Department of Health 2013) includes a strategy for better secondary prevention in the community by improved disease management, particularly by self-management to reduce the rate of readmission to hospital. For this strategy to be effective, it is imperative to recognise patient accounts of recovery experiences which involve decisions on lifestyle changes, following a cardiac event such as myocardial infarction. Several reviews have been undertaken pertaining to different aspects of self-management, many of which target specific

conditions such as diabetes (Deakin et al 2005) or mental health conditions (Duncun et al 2010), types of intervention such as lay-led programmes (Foster et al 2007) or on specific outcomes such as medicines adherence (Haynes et al 2008).

These studies show people who engage in self-management tend to be predominantly white, male, well-educated with and have the ability to efficiently utilise available support networks (Blustein 2008). Few studies recruit South Asians with myocardial infarction and even those few self-management studies aiming at improving factors such as weight status and metabolic profile of South Asians have not shown promising results (Admiral et al 2013; Hawthorne et al 2008). In the United Kingdom, apart from very few qualitative studies, there has been no substantial scholarly research looking at the experience of South Asians, although they are biggest ethnic minority group which accounts for 4% of the total population (Office for National Statistics 2012). Even though several studies of ethnic minorities show lack of adherence and lack of continuity in self-management, there has been no substantial scholarly research looking at lifestyle self-management of South Asians per se. Often, such studies suffer from recruitment challenges or high participant drop-out, leaving behind major 'knowledge gaps', especially around the challenges faced in making lifestyle changes.

Regardless of highlighting certain specific themes in the literature affecting the self-management needs of cardiac patients (Galdas et al 2012), there is a paucity of appropriate support systems for self-management among the population in general and South Asians in particular. In addition, these patients are not consulted about what social and emotional support they would prefer to receive to guarantee a therapeutic lifestyle modification, thereby weakening their ability to choose and prioritise, maintain and sustain lifestyle changes for better health outcomes. As such, there is a need for better appreciation and understanding of the factors that affect the self-management, particularly lifestyle changes of South Asians, for the success and sustainability of lifestyle self-management among this group. The present study addresses this gap in current research.

One way to conceptualise the necessary knowledge and their reflective application for effective lifestyle change is to explore how South Asians self-manage and navigate lifestyle changes. Novel of its kind, this research used a constructivist grounded theory approach to elucidate how South

Asians navigate lifestyle changes, after an acute myocardial infarction. Alluding to the challenges they face, this research affords an insight into participant's perception of influencing factors, as well as their apparent social and emotional needs actively to self manage these lifestyle changes, by proposing a substantive explanation of how they choose and prioritise lifestyle changes. This research contributes to the relatively limited body of recent cross-cultural research on self-management of cardiovascular disease in the broader healthcare field in the United Kingdom. The findings, by capturing broad concepts of lifestyle self-management, crystallise the significance of cultural sensitivity and family centeredness in the provision of self-management support.

1.2   Aims and Objectives

The overarching aim is to explore the lifestyle self-management experience of South Asians post myocardial infarction. However, it would be beyond the scope of a single study to incorporate all scholarly discourse on self-management, therefore to afford depth to the main purpose, which is to provide a theoretical window into the world of South Asians experience of lifestyle self-management, I focus on the following main objectives:

➢ To explore South Asian groups' experience of choosing and prioritising lifestyle changes post myocardial infarction to develop an understanding of the contextual factors that influence their choice.

➢ To understand the perceived social and emotional support needs of South Asians in self-managing and sustaining lifestyle change.

➢ To establish what barriers and enablers influence the realisation of self-management of South Asians with cardiovascular disease.

➢ To conceptualise the influence and role of South Asian culture and ethnicity in lifestyle self-management and to contribute to the theory of self-management.

➢ To inform policy and make recommendation for support strategies to meet the South Asian self-management needs and implications for clinical practice based on their perspective.

1.3   Structure of the thesis

For easy navigation through the chapters, an outline of the overall thesis is given here. Chapters one, two and three form the first part focusing on the rationale for the research and providing a contextual background for the study. I have included a prelude and an epilogue as well. The prelude serves as part of the introduction, giving a foretaste of the reflective accounts threaded throughout the thesis, then the epilogue draws the thesis to a close whilst reiterating the purpose and the original contribution.

In the present chapter, chapter one (Introduction), I provide a succinct overview of the thesis in order to build up my case for the research and provide an explicit rationale. At the beginning of the next chapter, chapter two (Background), I consider the significance of coronary heart disease – globally as well as nationally - and homes in how the burden of the disease rests on the South Asian community. Critical summaries on associated concepts such as secondary prevention strategies like self-management and risk factor modification are also produced here. Chapter three (The Review) opens with the contentions surrounding literature search in grounded theory. The chapter concludes by apprising the reader of the sensitising concepts drawn out from the literature search.

Chapters four, five and six form part two which centres on practical aspects of conducting a constructive grounded theory and achieving the research objectives. Chapter four (Methodology) centres on research methodology. In here, after addressing the differing approaches to grounded theory and the philosophical issues which subtly distinguish each of the approaches, I have justified the use of the chosen approach. I have also ensured that I am not involved in a methodological pick and mix and therefore have examined the key issues and methodological concerns involved in undertaking a constructive grounded theory.

Towards the latter part of the chapter, I discuss the strategies used to ensure rigour in qualitative research generally and in this research in particular. Grounded theory in practice forms the essence of chapter five (The Study) which includes the study sample, participant profile and the recruitment process. In chapter six (The Analysis), I make sense of the data, scrutinising it for the information regarding South Asian experience of lifestyle changes after an acute myocardial infarction, their perceived views, challenges and needs, how they choose and prioritise the lifestyle choices. I discuss the coding undertaken and the categories constructed with the help of memos.

In part three I confer the results of the study in lieu with literature and policy to detail the implications and recommendations. Thus, chapters seven, eight, nine and ten form the final part of the thesis. In chapter seven (The Findings), I detail how the journey of data collection and analysis - conducted simultaneously and informing each other – was made, and how the categories were developed from the interview accounts, subsequently leading to a substantive theory being developed - 'to be in harmony'. I have adhered to the key principles of grounded theory such that one can be considered to be undertaking grounded theory as a distinct methodology and not another form of qualitative data analysis.

Whilst chapter eight (Conflict and Harmony) details the how and why lifestyle choices are made, chapter nine (The discussion) as an extension of chapters three and six, draws attention to extant literature surrounding beliefs, culture and family to demonstrate irrefutably where the research fits in and adds to the current body of knowledge. In the concluding chapter ten, (Denouement) I relate how these findings inform the current health care policy and practice. Recommendations interfacing culture and social support of South Asians effectively to self-manage their lifestyle is proposed. I have called upon the policy makers to rewrite the learned ethos of the health care system by providing family centred, culturally relevant cardiac rehabilitation programs and self-management support programmes. I conclude the thesis highlighting the milestones achieved and signposting the study's contribution to the body of knowledge, with a call to stimulate the dialogue of lifestyle self-management in the coronary care unit itself.

1.4   Chapter summary

Coronary heart disease remains the leading cardiovascular cause of mortality and morbidity globally, with South Asians carrying the burden of increased incidence and prevalence due to several modifiable risk factors. To counter this 'epidemic' are secondary prevention strategies at the heart of which lie lifestyle self-management of modifiable risk factors. Lifestyle self-management has the potential to provide good clinical outcome and prevent complications. Poor appreciation of patients' needs leads to unsystematic secondary prevention programmes and unchanged lifestyle behaviours. Towards this end, it is important to ensure that self-management support is based on what patients need and not what professionals consider to be significant. A necessary prelude to this is the necessity to understand patients' experiences and interpretations of their illness, for such interpretations may have a significant effect on their health and illness behaviour.

The experience of social adversity and opportunities for social support and network may differ from other sections of the population living in the United Kingdom. For the development of culturally appropriate services, it becomes important then, almost imperative, that any health services offered should be appropriate to the culture, religion, and languages of South Asian community. Nevertheless, there has been a lack of clarity about the main barriers and facilitators to lifestyle self-management after a myocardial infarction among the South Asian group. Thus, the experience of South Asians with heart attack needs to be considered alongside their interaction with, and access to health care provisions. As a primary step to meet this end it becomes essential to elucidate the South Asian lifestyle self-management experience after a myocardial infarction.

This study therefore is concerned with articulating the experience of South Asians after myocardial infarction. It aims to provide important new insight and evidence to healthcare experience within the current social and political context which will have significant implications for improving the quality, safety and appropriateness of cardiac services and rehabilitation among South Asians. As such, the results will have implications for developing has cultural relevancy and sensitivity in improving the cardiac health outcomes of the South Asian community. With an ageing population

coupled with current levels of chronic disease, improvements need to be made in secondary prevention. If not, past gains will not be sustained. The cost of inaction is clear and fuels a need for further research to resolve issues to produce healthier nation. To inform appropriate action now to prevent difficulties in the decades to come, efforts and resources will need to be mobilised effectively to improve lifestyle self-management experiences of patients.

In this chapter I have laid out the arguments for the research and outlined the importance of lifestyle changes as well as argued for undertaking research to effect positive behaviour change in the South Asian population. With this fore note for the necessity of the research study as well as detailing the overall outline of the thesis, I conclude the introduction chapter. In the next two chapters, I have set the scene and introduced the concepts central to the research, thus providing the background and context to the research.

Chapter two - Background

In this chapter, I introduce the two main players – the disease and the population to provide the necessary background and context to the study. With an aim to make it more amenable for reading, the chapter is divided into two parts; in part one, I explain the context of coronary heart disease and after a brief discourse on risk factors, conclude with highlighting the importance of lifestyle self-management. The terms briefly mentioned in chapter one, are further extrapolated here. In part two, I explicate the emergence of South Asians, the origins of their heterogeneity, their propensity towards higher incidence and prevalence of the disease homing in on the necessity to study this population. Herein, the historical elements are explored in order to provide needed context, to lay a foundation for understanding the emergence of the current issue. Thus chapters two and three taken together provide the essential information that identifies and describes the history and nature of the research problem, thereby setting the scene for the study.

Part one: coronary heart disease

With every heartbeat, blood is pumped out from the left chambers of the heart, transported through arteries of ever-decreasing size, finally reaching the capillaries in all the tissues, to oxygenate the body organs (Mackay et al 2004). Eventually, the blood laden with waste products, is brought back to the heart through a system of ever-enlarging veins (Mackay et al 2004). Unfortunately, this remarkable system is vulnerable to assault and breakdown leading to diseases of the heart and blood vessels, commonly called cardiovascular diseases. Accounting for one in five

deaths in Europe, cardiovascular disease remains the world's number one killer and is the costliest condition in terms of health expenditure. Whilst cardiovascular disease is the umbrella term enclosing all disease of the heart and its circulatory system, coronary heart disease is the term given for the disease of the 'coronary' arteries or the blood vessels that supply blood to the heart. Myocardial infarction (heart attacks), is a part of the spectrum of acute coronary syndromes ranging from unstable angina to transmural myocardial infarction (American Heart Association 2014).

Myocardial infarction is and remains a major cause of death and ill health (Mirzaei 2009). Whilst detailing it here, I have used both terms myocardial infarction and heart attack (as the term my participants used), interchangeably. Because of the underlying pathology, terms coronary heart disease and myocardial infarction is also interwoven in the discussion of the epidemiology of the disease.

2.1 Epidemiological transitions – history, incidence and prevalence

If thou examinest a man for illness in his cardia and he has pains in his arms, and in his breast and in one side of his cardia… it is death threatening him.

This is believed to be the first reported classical description of coronary ischaemia, noted in the Ebers Papyrus, dating back to 1550 BC (Boisaubin 1988). It took 3000 years more for an English physician named William Heberden to publish a clinical description of angina in 1768. However, within few years, in 1786, Edward Jenner published a report establishing the pathophysiologic correlations between anginas and coronary heart disease after witnessing the autopsies of angina patients (Feye et al 2005). In 1856, Rudolph Virchow proposed a theory of inflammation and plaque formation in the coronary blood vessels, a close version of contemporary theory (Conti et al 2005). Though many cholesterol lowering drugs such as nicotinic acid and plant steroid were introduced during the 1950s and 1960s, the lipid lowering

therapy became widespread only after the discovery of statins by the Japanese microbiologist Akira Endo (Reges et al 2011).

In addition to its effect on the lower density lipoproteins, the pleiotropic effect of the drug (such as plaque stabilisation, reduced inflammation) was found to be an added benefit (Rosenson 2001). The introduction of cardiac rehabilitation programmes by the New York State Employment Service was another landmark achievement in 1940s (Certo 1985). By the late 1950s, inpatient cardiac rehabilitation programme began with emphasis in the coronary care unit itself (Detrich 1948), and after another decade, extended to the outpatient settings to support patients in the community (Hellerstein 1968). Stem cell and regenerative medicine, molecular targeting, viral theory, genomics and pharmacogenomics all hold promise to ease the escalating burden of the disease (Nabel and Braunwald 2012).

The above synopsis of the history of myocardial infarction through the ages, signposts not just the exemplary advancements made, but also highlights the milestones still to be achieved. In 2009, WHO stated:

Mankind's greatest epidemic: Coronary heart disease has reached enormous proportions striking more and more at younger subjects. It will result in coming years in the greatest epidemic mankind has faced unless we are able to reverse the trend by concentrated research into its cause and prevention.

The above WHO statement does not differ much from the warning issued by its Executive Board in 1969:

Coronary heart disease is now the leading cause of death worldwide; it is on the rise and has become a true pandemic that respects no borders.

These remarks remain prophetic as mortality and morbidity rates of coronary heart disease escalate around the globe. Though known to be the main cause of death in the Western world, coronary heart disease is increasing in developing countries as well (Nichols et al. 2013; World Health Organisation 2013). The polarising corollary of the increased prevalence of coronary heart disease risk factors in the face of landmark achievements accentuates the pivotal role of secondary prevention and the timeliness of this research.

2.2 Global and national burden of the disease

Each year, over 31.9 million deaths are caused by coronary heart disease in the European Union (WHO - Global Health Observatory Data Repository 2014). European registries show myocardial infarction as the cause of 5% to 13% of all deaths (WHO 2012 mortality database), whereas in Australia it is 12% and in USA 8%. These figures are representative of the variations in death rates across continents and countries (WHO - Global Health Observatory Data Repository 2014).

As signposted in the introduction, coronary heart disease is the principal killer in the country (Myocardial Ischaemia National Audit Project 2013), responsible for nearly 70,000 deaths in the United Kingdom each year, an average of 190 people each day, or one death around every eight minutes. Worldwide, each year more than 7 million people experience myocardial infarction, in which one-year mortality rates are now in the range of 10%, but vary with patient characteristics.

The consequences are even more dramatic: among patients who survive, 20% suffer a second cardiovascular event in the first year and approximately 50% of major coronary events occur in those with a previous hospital discharge diagnosis of coronary heart disease (Piepoli et al 2017; Townsend et al 2012). Nearly half a million hospital episodes were attributed to coronary heart disease; this equates to 2.4% of all episodes in 2012/13 (Townsend et al 2014). Over 4200 people were admitted to hospital with a myocardial infarction in 2013/14, which equates to twelve people per day (Northern Ireland Chest Heart and Stroke 2014).

However, recent evidence from Europe suggests that in some countries cancer has overtaken cardiovascular disease as the leading cause of death. In 2012, for the first time since the middle of the twentieth century, cardiovascular disease went from being the main cause of

death to the second cause of death in the United Kingdom. Twenty-eight per cent of deaths were caused by cardiovascular disease in 2012 and 29% were caused by cancer (Office of National Statistics 2016). When analysed by sex, however, cardiovascular disease is still a larger cause of death than cancer for women. Though death rates from coronary heart disease in the United Kingdom have fallen, this fall is not as high as in Norway (54%) or in Australia (48%) (Townsend et al 2012). Of note, though mortality rates from coronary heart disease have halved since 2002 (Coronary Heart Disease Statistics British Heart Foundation 2010), morbidity appears to be rising accounting for approximately 33 percent of all hospital admissions in England.

In the United Kingdom, there are 188,000 hospital visits each year due to heart attacks: that is one every three minutes (British Heart Foundation Coronary Heart Disease Statistics 2015). Thus, though the mortality rate is declining, the prevalence of the disease in the United Kingdom remains high, which appears to have at least doubled from 1994 to 2006 in patients aged under 45 years, whilst categories over 55 years have stabilised or decreased in prevalence during the same time (Scarborough et al 2010). Among United Kingdom countries, death rates are highest in Scotland and lowest in England (British Heart Foundation 2012). The incidence and prevalence is greater in the North of England and Wales (Scotland 4.6%; Wales 4.3%) than in the South of England (3.5%) (British Heart Foundation 2012). Within England, the North West has the highest incidence rate (Manchester Alliance for Community Care – Cardiovascular disease briefing 2010). Nearly 20% of all deaths in Manchester are from coronary heart disease (British Heart Foundation 2012). There is an eighteen percent difference in life expectancy between men in Manchester and the national average (Manchester Alliance for Community Care – Cardiovascular Disease Briefing 2010).

Prevalence is higher in lower socioeconomic groups with unskilled working men three times more likely to die of coronary heart disease than men in managerial or professional occupations (Ibanez et al 2017). Throughout the United Kingdom, prevalence of myocardial

infarction in men was almost three times greater than for women and the prevalence increases with age (British Heart Foundation 2012). Mortality rates are lower in West Africans and people from the Caribbean. However, the mortality rate from coronary heart disease is 38% higher for South Asian men and 43% higher for South Asian women than rates for the population as a whole (Prasad et al 2010). This propensity towards coronary heart disease at a younger age in South Asians is primarily the rationale for choosing this group for the research.

2.3 Risk factors and pathology

Many risk factors that contribute to the development of endothelial dysfunction and atherosclerosis have been identified, in fact more than 300 different risk factors are said to be associated with the disease. Risk factors are classified as modifiable (abnormal ratio of blood lipids, stress, tobacco smoking, physical inactivity, insufficient consumption of fruits and vegetables, abdominal obesity) or non-modifiable (age and gender) (World Heart Federation 2014; Capewell et al 2008). However, it is interesting to note that about eighty per cent of the coronary heart disease cases is mainly a result of modifiable behavioural risk factors (Ibanez et al 2013). Other non-modifiable risk factors are social history, socioeconomic status, mental health status, family history and genetic disposition (The National Vascular Disease Prevention Alliance 2012). In addition to doubling the risk of coronary heart disease, it is also indirectly linked to other risk factors such as hypertension, diabetes and increased weight gain, which have a more direct effect on the atherosclerotic process (WHO 2009).

2.5 Long-term management: role of secondary prevention

Effective secondary prevention measures such as lifestyle modification outlined in clinical practice guidelines (Ibanez et al 2017) can significantly reduce the risk of a subsequent cardiovascular event. Current evidence suggests that the earlier the secondary prevention measures are implemented the better the results are (National Institute of Clinical Excellence 2013). In addition, these programmes focusing on non-pharmacological interventions consisting of

modifying lifestyles related to patient risk behaviours, such as stopping smoking, engaging in physical exercise, and a healthy diet, help reduce cardiovascular mortality in people with prior cardiac event (MacKay-Lyons et al 2010). EUROACTION (Wood et al 2008) and Global secondary prevention strategies to limit event recurrence after myocardial infarction (GOSPEL) interventions (Giannuzzi et al 2008) provide evidence for a beneficial long-term effect of community-based programmes. Cardiac rehabilitation, a model of a secondary prevention intervention is recommended to people following acute coronary events and coronary revascularisation.

Achieving such therapeutic lifestyle changes is of proven benefit (Ibanez et al 2017) and is a critical element (British Association for Cardiac Prevention and Rehabilitation (BACPR) 2013) (Fig 2:1) of cardiac rehabilitation.

Fig 2:1 Core components of cardiovascular prevention and rehabilitation (adapted from BACPR 2013).
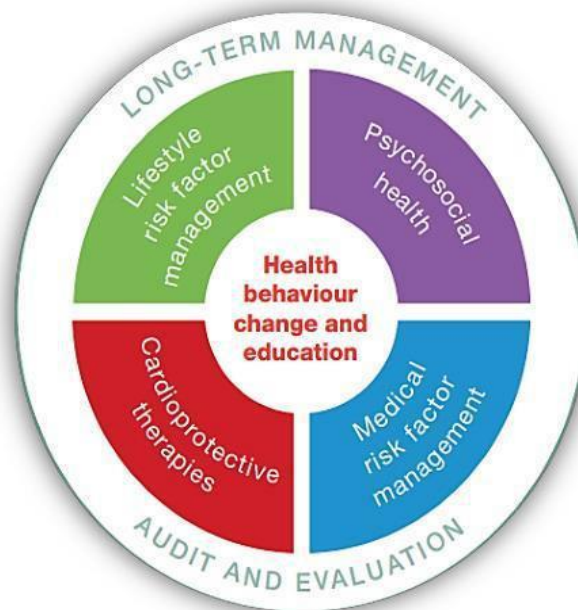
Cardiac rehabilitation as defined by the WHO in 1993 is inclusive and sensitive to the psychosocial, biomedical, professional expertise and service delivery mode and location elements required of a contemporary cardiac rehabilitation service:

..the sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible, physical, mental and social conditions, so that they (people) may, by their own efforts preserve or resume when lost, as normal a place as possible in the community. Rehabilitation cannot be regarded as an isolated form or stage of therapy but must be integrated within secondary prevention services of which it forms only one facet (WHO 1993).

Cardiac rehabilitation programmes are coordinated, multifaceted structured programme of care designed to optimise a cardiac patient's physical wellbeing and social functioning by reversing or slowing the progression of the underlying pathogenic atherosclerotic processes (British Heart Foundation - National Audit of Cardiac Rehabilitation 2013). The National Institute for Health and Care Excellence (NICE) (2013) recommends cardiac rehabilitation involving lifestyle changes and appropriate uses of medication as an essential intervention following a hospital admission for myocardial infarction by reiterating the standard 7 of the National Service Framework for Coronary Heart Disease (2000):

NHS Trusts should put in place agreed protocols/systems of care so that, prior to leaving hospital, people admitted to hospital suffering from coronary heart disease have been invited to participate in a multidisciplinary programme of secondary prevention and cardiac rehabilitation. The aim of the programme will be to reduce their risk of subsequent cardiac problems and to promote their return to a full and normal life (National Service Framework for Coronary Heart Disease 2000:4).

Meta regression analysis demonstrates lower mortality and lower incidence of recurrent MI (Lawler et al 2011), when such programmes are implemented. Furthermore, embedding cardiac rehabilitation within the work stream of cardiovascular networks has also been shown to be worthwhile (Shahid et al 2011) in addressing the main modifiable behavioural cardiovascular risk factors (Perk et al 2012; British National Audit for Cardiac Rehabilitation 2013) such as physical activity, smoking, diet. Cardiac rehabilitation programmes are usually based in hospitals or community settings, with patients commencing the program for 2-6 hours per week within a month of hospital discharge (Lawler et al 2011). In facilitating the patient to self-manage their

own condition, cardiac rehab services ideally need to provide each patient with the choice of program setting, typical choices being a hospital, community or home-based programme.

Though these cardiac rehabilitation programmes vary in length, content and the place of delivery, they set up realistic goals for any required lifestyle changes and provide comprehensive support education and monitoring of coronary heart disease patients (Heran et al 2011). In effect, cardiac rehabilitation programmes are meant to be seamless, taking a person through from diagnosis of the illness to long-term lifestyle changes. The prevention of future cardiac events through lifestyle changes is the cornerstone of cardiac rehabilitation, which provides a significant improvement in prognosis for patients and improves quality of life (Condon and McCarthy 2006; Knudsen et al 2014). Programme components of cardiac rehabilitation such as medicine management, encouraging physical activity and exercise, healthy eating, are all self-management activities. Cognitive intervention is based on self-management techniques such as self-efficacy enhancement, management of barriers and problem solving. It is suggested that those risk factors are modifiable by using lifestyle education and self-management techniques (World Health Organisation 2010).

Notwithstanding the physical, psychological and social benefits obtained from cardiac rehabilitation, only 50.7% had been advised to participate in a cardiac rehabilitation or secondary prevention programme (British Association for Cardiovascular Disease Prevention and Rehabilitation 2012; Clark et al 2005). Secondary care remains sub-optimal. Barriers such as time and resources are commonly cited by participants to attend face to face hospital or clinical setting leading to substantial underutilisation of existing programmes internationally (British Heart Foundation - National Audit Cardiac Rehabilitation 2013). Previous research on barriers to cardiac rehabilitation programme uptake suggest this is because cardiac rehabilitation services are traditionally delivered within a health facility environment, and are often seen by patients as exercise-focused and protocol directed (Aalto et al 2006; Kaiser et al 2013).

The EUROASPIRE IV study conducted in 78 centres in 24 European countries, demonstrated a high prevalence of unhealthy lifestyles (smoking, little or no physical activity), uncontrolled modifiable risk factors (obesity, diabetes, high blood pressure, dyslipidaemia) in coronary heart disease patients (Kotesva 2016). Such a position evidently indicates a deeper understanding of these issues is crucial. With the development of service commissioning guides released by the Department of Health, the value of cardiac rehabilitation is brought into much sharper focus. Equally important is to ascertain new ways to improve the quality, acceptability and focus of cardiac rehabilitation when dealing specifically vulnerable groups such as South Asians.

2.7 Self-management and lifestyle modification

Self-management is commonly defined as an individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (Barlow et al 2002:178). For this thesis, the definition of Richard and Shea (2011) is considered:

..the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions (Richard and Shea 2011:261).

Thus, it relates to the ability and process that individuals use in conscious attempts to gain control of the disease, rather than being controlled by it (Thorne et al 2003). These definitions, though they may capture the skills and tasks involved, do not wholly conceptualise the process involved in self-management. It involves the decision-making and behaviours performed by individuals to manage illness daily and promote health (Henderson et al 2014). Though self-management involves all the above strategies, for practical purpose only the lifestyle self-management is considered in this study (Fig 2:2).

Fig 2:2 Self-management dimensions adapted from (Richard and Shea 2011).

This conception that the underlying political beliefs and values exert a significant influence on public health promotion policy (Nutbeam and Boxall 2008), is in fact reinforced by the accompanied changes in the health promotion policies following the changes in the political orientation of governments such as in USA (Baum 2008), in United Kingdom (Nutbeam and Boxall 2008), in Australia and Canada (Bryant et al 2010).

In 2001, the Expert Patient Programme gathered momentum when the government brought out a key document – 'The Expert Patients: A New Approach to Chronic Disease Management of the 20th Century' (Department of Health 2001). It signposted to the untapped resource of patient knowledge and experience which could be drawn upon whilst managing the care for chronic conditions. Faced with demands of monetary savings by the NHS (Review of NHS productivity 2015), efficient self-management became a key priority. This drive reflected in the NHS Outcomes Framework 2012-2013 (Department of Health 2011) which highlights the need to ensure that patients feel supported to manage their condition effectively.

With the report conducted by the Health Foundation (De Silva 2011), policy makers have established that if people performed 'effective' self-management, they would need less health care help (Rogers et al 2009; Wellard 2010). Furthermore, literature confirms that patients more educated about their diseases have a better control of their care and are more readily engaged in managing diet, exercising regularly and quitting smoking (Blustein et al 2008). Consequently, despite a declining emphasis on expert patient programmes, the self-management drive continues to remain fundamental to health policies.

A plethora of government policies and initiatives such as annual national self-care week (Department of Health 2010), position paper on secondary prevention of coronary heart disease through cardiac rehabilitation (British Association for Cardiac Disease Prevention and Rehabilitation 2013) and Quality Innovation Productivity Prevention work-steam (Department of Health 2010), build on the World Health Organisation guidance on coronary heart disease prevention (World Health Organisation 2012) ascertain that self-management movement continue to be on top of the political agenda and is debated regularly.

The morbidity and mortality rates from myocardial infarction underscore the importance of secondary prevention and self-management. Within the domain of myocardial infarction self-management involves (i) attending regular check-ups, and (ii) adherence to a physician-prescribed, tailored medication, and lifestyle changes (Sol et al 2008). Nonetheless, though the guidelines for lifestyle changes are supported with evidence (Balady et al 2007), there is a significant gap between what is expected from published guidelines and the reality of clinical practice.People are living for many years with coronary heart disease and there has been some criticism that patients feel abandoned after receiving acute care (Department of Health 2013). Patients and their carers are reported to receive little help (Murray et al 2013) or adequate support to improve their lifestyles which impacts on mortality and general wellbeing of the individual. Self-management perspectives represented in government policies is insufficient to understand the ways people manage their chronic condition in general and make

and maintain lifestyle changes in particular. For better outcomes, the patient should find themselves empowered to self-manage their condition which calls for much more than the routine responsibility of the cardiologist and surgeon to recommend cardiac rehabilitation to all eligible patients.

Devoid of the experiential understandings of the ill person, how people manage and take care of their chronic conditions in daily life (Furler et al 2008), self-management is ill-conceived as being the 'mundane' reality of living with chronic disease. Again, the central concepts of tailoring the programme to the needs of the patient and understanding their preferences and priorities within the context of their own lives, if not duly acknowledged, can lead to inefficient programmes with insufficient participants (British Heart Foundation - National Audit for Cardiac Rehabilitation 2013). Therefore, understanding how the layperson self-manages the lifestyle changes is imperative, highlighting the need for current research.

2.8 Lifestyle self-management – risk factor modification

However, despite the known contribution of multiple lifestyle risk factors which produces a synergistic response, patients who had made lifestyle changes experienced a range of improvement, slowing the rate of coronary heart disease progression to regression of coronary lesions (Ornish 2013). Any failure to address the underlying biomedical and behavioural risk factors not merely places the patient at increased risk of restenosis (re-closure) of the revascularised artery, but leads to progression of atherosclerosis in other coronary arteries as well and ultimately to diminished quality of life.

· **Physical Activity**

Whilst Lavie et al (2009) showed that engaging in physical activity reduces the risk of recurrent myocardial infarction, Hambrecht et al (1993) found that even at five years of follow up, patients engaged in physical activity had a better event-free survival compared to patients with

less physical activity. Regular exercise reduces myocardial oxygen demand and enhances myocardial perfusion (Hambrecht 2004).

• Smoking

Patients who continue to smoke after a myocardial infarction have a fifty percent increase in the risk of non-fatal re-infarction (Rea et al 2002). In addition, cigarette smoking among patients with coronary heart disease increases the risk of plaque erosions and rupture (Shah et al 2013), which suggest that smoking promotes endothelial injury. Though the mechanisms of thrombosis are unclear, increased plaque thrombogenicity has been proposed for the higher incidence of thrombotic events in smokers (Matetzky 2004). Moreover, smokers also have a higher propensity to develop increased heart rate and increased blood pressure due to the high levels of circulating inflammatory risk markers (Hansson 2005). However, the most interesting fact is that all these adverse effects appear to reverse with smoking cessation (Rea et al 2002). Smoking cessation advice should be available for all people who smoke, in line with smoking cessation guidance, with referral to an intensive support service (NICE guideline for myocardial infarction 2013). If they are unwilling to accept a referral, they should be offered drug therapy according to the guidance on smoking cessation services.

• Diet

Until recently, it was hypothesised that by decreasing the level of serum cholesterol by limiting the intake of saturated fats and cholesterol, the progression of atheromatous plaques can be slowed down. However, though benefits of substitution of dietary polyunsaturated fat for saturated fat have been shown to lower coronary heart disease risk, the benefits of replacing saturated fat with carbohydrate are still to be proven with large epidemiological or clinical trials. Nonetheless dietary changes which consists of efforts to limit intake of refined carbohydrates and reduction of excess adiposity, have the potential benefit of reduced inflammation, improved endothelial function and decreased thrombotic tendency (Ibanez et al 2017). Associated lower blood pressure and weight reduction lowers the risk of atherogenic dyslipidaemia (Scrutinio et al 2010). Strategies to

promote healthier lifestyles-rather than invasive surgical or medical procedures-promise to reduce the use/overuse of medical services, help contain costs and moreover prevent recurrent heart attacks.

2.9 Part one - summary

The first part of the chapter provided a background for the research by describing the burden of coronary heart disease, specifically myocardial infarction and its long-term management. An overview of the pathophysiology of coronary heart disease was given and the risk factors impacting on the genesis and progression of the disease was discussed, as well as the implications for secondary prevention with emphasis on lifestyle self-management. With the shift in predominant disease patterns from acute to chronic disease, the promotion of self-management among people with long-term conditions is central to current NHS priorities.

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The associated costs resulting from physical and psychosocial disabilities of coronary heart disease places a significant burden on the patients and the community. One of the greatest challenges of delivering care to cardiac patients is to assimilate the risk factor modification strategies into clinical practice. Adjustment and lifestyle modifications following a myocardial infarction can sometimes be a long and arduous journey. The consequences of a myocardial infarction can be amplified in the context of vulnerable ethnic groups such as the South Asian community. For this, as briefly pointed out earlier on, it becomes necessary to delve into the history of South Asians to know who they are, why they carry this burden. Towards this end, the next part of the chapter moves into the discussion surrounding the South Asian diaspora and the essentiality of studying this population in the context of coronary heart disease.

Part two: South Asians

The South Asian population constitutes one of the largest ethnic groups in the world and refers to residents of Britain, whose ancestry is in the Indian sub-continent, meaning countries that include India, Pakistan, Bangladesh and Sri Lanka.

2.1 Emergence of South Asians in United Kingdom

Contrasting to the figure of 2,331,423 in the 2001 census there are now approximately 4,214,000 South Asians. This figure makes up of 5.5% of the total population of which 2.5% are of Indian origin, 2.0% of Pakistani origin and 0.75% of Bangladeshi origin (Office of National Statistics 2011), making South Asians the largest ethnic group in UK (ONS 2011). In certain parts of the country such as the North West (Manchester and Lancashire), this proportion has reached up to 12% - 22% of the local population. The rapid expansion of Britain's South Asian community at the turn of the millennium is indicative of the vital part this community plays in the social and economic fabric of modern multicultural Britain.

Initially men came on ships, worked as peddlers or took low paid work with the intention of working for a short period of time, alongside the educated East African South Asians who mainly did clerical jobs (Tinker 1977). The pattern of the South Asian migration to the United Kingdom has changed over time.

In her study of South Asian migration over the 19th and 20th centuries, Vizram (2002) categorises three key groups of sojourner, each inflow with its own unique and specific historical roots:

> ➢ servants and personal domestics of imperial administrators as well as adventurers who followed their employers on their return home. Among the Gujarati Hindu

tradesmen, a few returned to India, whilst a large majority took advantage of their status as British subject and moved towards the United Kingdom (Ballard 2004).

➢ sea men of British merchant ships and these ex-seamen included two further communities from Kashmir and Bangladesh – the Mirpuris (Kashmir) and Sylheti's (Bangladesh) (Ballard 2004). Whilst manual workers, mainly from Pakistan, were recruited to fulfil the labour shortage that resulted from World War II, workers from the Punjab region of India worked in the foundries of the English Midlands and at Heathrow Airport in West London.

➢ affluent travellers who came to Britain in academic pursuit or adventure, among these were the wealthy Gujareti Hindus and Punjabi Sikhs.

Thus, at present this community consists of: Pakistani Muslims (mainly from the Punjab, Jammu and Kashmir; Gujareti Hindus from Central India (Gujarat) and Bangladeshi Muslims (Sylhet) as well as Punjabi Sikhs from Northern India (Pereira 2011). According to Watson (1977), the East African Asians were the filling or the ingredients in the sandwich (colonial), on one side, they were 'superior' to the local population, however, they were still 'inferior' to the Europeans. They were well educated (men and women), and spoke English fluently.

Those that came to the United Kingdom initially worked in low paid jobs and became upwardly mobile once the opportunity arose (Robinson1993). Muslim communities from both Pakistan and Bangladesh as well as some Sikhs from India eventually settled within the inner regions and cities such as Bradford, Manchester, Glasgow, London and West Midlands (Khunti et al 2009). Modern day migration is different because people move for different reasons, including work-related ones, political turmoil (East African South Asians during the reign of Idi Amin) and as refugees (Sri Lankan Tamils).

Thus, the different points of migration in addition to the diverse strategies of adaptation followed by the members of each of these groups since their arrival in Britain have influenced their experience and have given rise to heterogeneity within this particular ethnic group. These communities had the experience of living in a new culture totally different to their own.

2.2 Heterogeneity and acculturation

Asian is not a meaningful identity, nor is it widely recognised by those to whom it is attributed. A pan-Asian identity is rare because of the many differences between Asian groups. Within each of these groups there is still more diversity, some of them based on regional differences, for example Indians include those who originated from Punjab and those who originated from Gujarat. There is also religious diversity among these groups, with Pakistanis and Bangladeshis being predominantly Muslim, but Indians including Muslims, Hindus, Sikhs and some Christians.

Heterogeneity partly arises from differences in the country of origin experience, the migration experience and the process of settlement, diverse ways individuals and communities react and adjust to these factors and cultural diversity within the group (Powles and Gifford 1990). Most evidently, the different South Asian groups settled in Britain had little in common apart from the fact that they had once been under the imperial rule (Smith and Eade 2008) in the same country prior to partition. Though similar in physical appearances, they differed in the language they spoke, clothes they wore, food they cooked and in the customs and religions they followed.

The diversity of these groups is also reflected on many measures of income, housing, health, education and employment. Whilst Bangladeshis were often poor and uneducated even before they migrated; others such as the Sikhs and Gujareti had been well educated and relatively prosperous (Ballard 2004). Meanwhile, though many Bangladeshis experienced social mobility, a majority still reside in deprived inner-city areas with low income jobs (National Equality Panel Report 2010). Thus, essentially there is essentially a two-way split, with the Gujareti/Sikh and Indian people in a similar position to Whites, with Pakistanis and Bangladeshis lagging (Kershen 2005). To further illustrate this diversity that flows through the subsequent generations of the South Asian diaspora there is at one end of the continuum there is the Indian investment in luxury properties in London whilst at the other end of the continuum, painting a rather bleak picture, are

the deprived areas of Tower Hamlets, home to 47% of Bangladeshi population, governed by social unrest, poor racial relations and persistent high levels of, crime and anti-social behaviour.

The migration of nurses holding work permit visa under the Blair government from 2000-2001 onwards is an example. In addition, many South Asians in the UK have also been born here or spent a large part of their life here, with a consequent degree of acculturation. Indeed, South Asian population living in the UK is heterogenous with different social and economic background. Thus in regard to the South Asian community, it can be argued they do not represent a homogeneous group but that there are differences among them which should be noted in research (Bhopal et al 1999). Diversities in the migratory history, patterns of settlement in United Kingdom and economic experience may explain one reason for the pattern of diversity in health.

However, exploration of such heterogeneity is missing from literature for the existing literature on South Asian community has grouped and labelled participants as 'South Asian' (Galdas 2012) and as implied by Ahmad (1989), the use of the term somehow denies rightful recognition of the diversity within the South Asian community in the UK. In realising that there is such diversity within the South Asian communities, researchers need to refrain from assigning them to groups with predetermined labels. Any future research investigating any facet of South Asian community, irrefutably should recognise that this is a heterogeneous plural community differing in lifestyle, language, religion as well as socioeconomic status (Gupta et al 2006), all potentially influencing the health outcomes.

2.3 South Asians and their burden of coronary heart disease

The concept of Hritshoola—literally heart pain—was known to Sushruta, the Indian surgeon (Dwivedi and Dwivedi 2007). According to him, angina is chest pain which is precordial, temporary, exertional, emotional, burning like and relieved by rest. It embodies all the essential components of present day definition, that is, site, nature, aggravating and relieving factors and referral. He also linked this kind of pain to obesity (medoroga) which is described separately in the 42nd Chapter of

Sushruta Uttara Tantra entitled Gulma pratishedadyaya (Chetan et al 2014). It is indeed ironic and would have been deemed comical if the situation was not so severe that South Asians coming from the land where the disease was first explained and the remedy advised such as corrections in hahar (diet) and vihar (activity), prior even to Hippocrates and William Harvey without resorting to any expensive investigations and powerful illustrations of modern day, shoulder the burden of the disease worldwide.

Persons of South Asian ancestry who originate from the Indian subcontinent contribute approximately one quarter of the world's population with the highest burden of cardiovascular disease (Scarborough 2010). As early as 1959, a study based on expatriate Indians in Singapore demonstrated the first published evidence of elevated coronary heart disease rates among South Asians (Yusuf et al 2004). Numerous subsequent standardised comparisons of the disease prevalence among different studies corroborated the findings (Bhopal 2004; Gupta et al 2006), unmasking a disproportionately high prevalence of the disease among South Asians in the Canada, South Africa, Trinidad, Fiji, Mauritius, United States and United Kingdom. People of South Asian origin living in developed countries have considerably greater risk, morbidity and mortality from coronary heart disease than European origin populations (Rana et al 2014), making it one of the most prevalent health problems facing South Asians today.

Regardless of location, South Asians exhibit the highest rates of cardiovascular disease among all ethnic groups (Patel et al 2012). They have a three to fivefold increase in cardiovascular disease compared to other racial ethnic groups (Joshi et al 2007).

South Asians have 1.5-2 times the prevalence of the disease compared with native population (Fernando et al 2015). For instance, the meta-analysis of Canadian studies by Rana et al (2014), demonstrated that South Asian men had 4.97 acute myocardial events per 1000 population per year compared with 3.29 events among Europid men. This is consistent with a meta-analysis of British South Asians which reported a higher incidence of coronary heart

disease among South Asians than among the general population (Zaman and Bhopal 2012)., showcasing the burden of the disease in this community.

Although coronary heart disease mortality rates declined for all migrants, the rates and ratios of coronary mortality continue to remain high for men and women of South Asian origin. Importantly, increasing mortality rate ratio figures for Indian Asians compared to Europeans suggest that the overall observed decline in coronary heart disease mortality is slower amongst UK Indian Asian populations (Tan et al 2014). With respect to coronary heart disease and mortality, South Asians are not all the same, with Bangladeshi faring the worst, followed by Pakistani and then Indians (National Obesity Observatory 2012).

In the United Kingdom, the rate of myocardial infarctions for men under the age of 40 in South Asians was four times that in Caucasians (Knowles et al 2006). Similarly, another study (Knowles et al 2006) from United Kingdom found the rate of first myocardial infarction among South Asian men under the age of 40 was 10 times that for Caucasians of a similar age.

Additionally, their admittance to hospital with myocardial infarction is twice as frequent compared to their White counterparts (Coronary Heart Statistics 2012). Among those South Asians who survive the myocardial infarction crisis and hospitalisation, the death rates are twice as high over the ensuing six months, compared to the other populations (Jose et al 2014). Thus, as opposed to the general population, people of South Asian ancestry experience myocardial infarction at significantly younger age (40- 60 years) and at a higher rate (Bansal et al 2013). Among those South Asians who survive the myocardial infarction and hospitalisation, the death rates are twice as high over the ensuing six months, compared to the other populations (Yusuf 2004). It is interesting to note that despite the fact South Asians are younger and smoked less than other heart attack patients and even had equal access to medical care and medical management to the Whites, still the outcome is fatal (White 2007).

2.4 Harbingers of South Asian disparity of coronary heart disease

To date, no hypothesis has been able fully to explain this disparity. Studies have put forward the migration/thrifty gene theory, effects of central obesity, use of ghee and oils in cooking 'proatherogenic diet', stress and racism, specific lipid abnormalities, enhanced plaque and systemic inflammation (Prasad et al 2010), as harbingers of this disparity. Because association between factors does not necessarily mean a causal relationship, any evidence of an association needs to be interpreted tentatively. As pointed out by Nazroo (1997), there are tensions between approaches used to study variations in health across ethnic groups and the evidence of association as absolute, given the limitations of abstraction concerning ethnic categories.

In addition, recent studies did not show excess visceral fat in South Asians but did show larger adipocytes and abnormal adipokines that were associated with increased insulin resistance compared with Caucasians matched for total and regional fat mass (Chandalia 2009). There is a shift in the thinking from excess fat mass—visceral or otherwise—to adipose tissue dysfunction being a cause of metabolic complications of obesity. Incorporation of novel 'genomic' approaches in prospective Indian Asian cohorts such as the London Life Sciences Population Study (LOLIPOP), started in 2002, provide an exciting opportunity for the identification of new risk factors underlying coronary heart disease in this high-risk population.

2.7 South Asians and cardiac rehabilitation

An integral part of providing health care in a multi-ethnic society such as in UK, is the accountability and liability of health care providers to cater to its diversity and effectively address their unique needs, in an attempt to dispel the prevailing disparity. Almost two decades ago 'creating a patient-led NHS-delivering the NHS Improvement Plan' (Department of Health 2005) called the NHS organisations to be, 'better at understanding patients and their needs, use new and different methodologies to do so'; reiterating the need to focus services around the patient – be it Caucasians or ethnic minorities. Almost into two decades of several health care policies and several strategies later, disparities across health care service and delivery is still prevalent – in all accounts more widespread among the South Asians in regards to the provision, uptake, adherence (Banerjee et al 2007) and utilisation of services (Jolly et al 2004; Galdas and Kang 2008).

Despite the empirical evidence of the use of cardiac rehabilitation, underuse of the program (attendance and completion), particularly among South Asian and other ethnic minority groups and culturally diverse populations have been reported in several English-speaking countries including the USA, Canada, the UK and Australia (Beswick et al 2004; Jolly et al 2004). Health disparities are commonly encountered both in referral to and uptake of cardiac services (Scott et al 2013), a disparity even more striking among South Asian women (Astin et al 2008, Vishram et al 2008, Chauhan et al 2010). Surprisingly contrary to the above findings, the Hospital Episode Statistics data (2012) showed startlingly different profile. The ethnic profile of people recorded as surviving a heart attack and taking part in cardiac rehabilitation in England and of those recorded in the full patient level NACR database were strikingly similar. However, this finding has to be treated with some caution as not all centres complete the ethnicity data. Most work has focused on developing interventions to increase programme referral, or examine determinates of initial referral and initial attendance.

2.8 Part two - summary

Part two of this chapter has provided a snapshot into South Asians – their migratory history into United Kingdom and their heterogeneity. There is indeed an inspiring need to optimise the reach and effectiveness of lifestyle self-management support for people with coronary heart disease, particularly in South Asians who carry the major percentage of this disease burden. Since South Asians represent a substantial proportion of these nations' populations, medical conditions that are prevalent among South Asians are increasingly important to their societies as well. It is important that the experience of South Asians after an acute myocardial infarction is considered, as their interaction with, and access to health care provisions, experience of social adversity and opportunities for social support and networks may differ from other sections of the population living in the United Kingdom. Most importantly, among South Asians, myocardial infarction often causes death or disability in the prime of life. A strategy of addressing social determinants of coronary heart disease and implementing high quality secondary prevention equitably to complement primary prevention is needed. Early recognition, aggressive treatment and efficient management of risk factors through lifestyle alteration is imperative among South Asians to reduce the devastating economic, emotional and social consequence to the individual and society.

2.9 Chapter summary

There are also many hospitalisations and operations which in conjunction with the improvements in survival mean that there is now a high prevalence of people living with the disease. The continued presence of premature coronary heart disease at disproportionate rates in South Asians. This study attempts to envisage ways to overcome these limitations and explore ways to bridge the gaps identified.

The discussion of the context and background aligned with the research approach, is purposely kept brief here, for later in chapter three this discussion attains a more analytical and critical depth. For this, as briefly pointed out earlier on (introduction), and to take this journey forward, chapter three provides the appropriate context of the problem in relation to research, practice and the extent to which previous studies have successfully investigated the problem, noting, in particular, where gaps exist that this study attempts to address. The following chapter focuses on the research performed in self-management of South Asians to isolate the gaps in research.

Chapter 3   The scoping review

I have sketched into the chapter the details of a scoping review conducted to explore the 'geography of the subject' as portrayed in the existing literature. Included in the introductory paragraphs of this chapter are the contentions surrounding the preliminary literature search in grounded theory and the rationale for this scoping review. As the final part of the background, the literature review includes summaries of important, relevant research studies, to showcase what is known about the specific research problem. This scoping review by enabling the emergence of the sensitising concepts – namely culture, ethnicity, self-management, behaviour change theories, provides a valuable insight into current knowledge within the field without imperilling the tenets of the research approach or the integrity of the research aims.

3.1   Contentions surrounding literature review

Broadly defined, literature review is an examination of the relevant research which has hitherto been conducted in the researcher's particular field of study (Hart 1998). It is integral to the success of academic research as it essentially ensures the researchability of the topic. Moreover, critical reflection on pertinent studies previously conducted in the proposed study field is an essential preliminary step of a research project, a milestone to be reached by the student researcher to be considered competent. Nonetheless, this creates a discord when the ontological and epistemological grounding of research approaches such as grounded theory, entail the restriction of a priori knowledge in order to restrict influence on theory formation (Elliot and Higgins 2012). Charmaz concedes that the issue of positioning the literature review in grounded theory approach has long been disputed, debated and misunderstood, where engagement with extant literature as formal review and synthesis of evidence is normally delayed (Charmaz 2006).

Thus, in the grounded theory approach many researchers intentionally elude having their "*grounded theorising being contaminated by existing and previously published theories*" (Carnwell and Daly 2001:57). However, later Strauss and Corbin (1998) relent saying it is not necessary to review all the literature prior to a grounded theory study, which then makes one wonder how much literature should be reviewed at the very beginning.

3.2   Scoping review for the 'geography of the subject'

With a constructivist paradigm, Charmaz (2006) acknowledges that the researcher can never be neutral in their interpretation of a phenomenon, as meaning is constructed through disciplinary emphases and perspectival proclivities (Charmaz 2006). Therefore, as a researcher, I enter the field with a wealth of information, and it is in within me as a reflexive researcher, to make explicit the processes of interpretation (Carolan 2003).

In this thesis, I have made use of scoping of the literature to facilitate what McMenamin (2006:134) calls the '*geography of a subject'* – identifying what works have been done and the knowledge gaps thereby providing a cogent rationale for the study. Furthermore, this scoping review is done to orient me as to how the phenomenon has been studied to date (McMenamin 2006), so it naturally affords a justification for the specific research approach I have taken (McGhee et al 2007). It is also done with a view so that it can help contextualise the study (McCann and Clark 2003) whilst simultaneously signposting to the lacunae in existing knowledge (Creswell 2008) and issues that are central to this field (sensitising concepts). These sensitising concepts, showcased here as the issues that are central to this field can explicate how meaning is co-constructed and be used as the starting point for interpretation and analysis (Charmaz 2003; 2006).

Reviewing the literature is an acknowledged requirement for research training in a PhD candidature, an essential criterion set by both examining boards and ethical committees. Charmaz (2006) asserts that reviewing literature can be done in such a way as to not influence

thinking with pre-existing concepts, but rather to provide a general awareness as a departure point for research and it serves so in this thesis. Therefore, this engagement with literature and the ensuing sensitising concepts assured me it could stimulate theoretical sensitivity, enhanced by researcher reflexivity as presented in chapter six.

3.3 Scoping review – definition, differences, merits and uses

The scoping review as it exists today may have first been named by Mays, Roberts and Popay - "*aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available…….*" (Mays, Roberts and Popay 2001:194). Nonetheless, most authors of scoping types of reviews claim that directly or indirectly their methodology is derived from a paper by Arksey and O'Malley (2005), though interestingly they do not use the term 'review', but 'study'. The term scoping review (study) is not clearly defined and is also applied to a systematic exploration of which concepts and terms are used in what manner in a particular domain, rather than to the creation of an inventory of research findings. Scoping reviews are similar to systematic reviews in that they are used methodically to organise and describe a body of literature, though several other aspects of scoping reviews distinguish them from traditional systematic reviews.

One such difference is that they do not aim to critique and review the quality of an evidence base, but rather to identify the breadth of evidence (Armstrong et al 2011), as was the intention here. A systematic review is an overview of primary research studies conducted according to an explicit and reproducible methodology (Davis 2016), whilst a scoping study tends to address broader topics where many different study designs might be applicable (Antman et al 1992). Arksey and O'Malley (2005) highlight these are useful as a rapid mapping exercise to chart the broad themes that exist within published literature, highlighting what previous research has covered and where knowledge gaps exist. I found this characteristic of a scoping review conducive and

appropriate in order to develop an awareness of concepts, which would help ease the entry into the field without imposing a pre-defined agenda or an in-depth critical appraisal.

Moreover, the highly iterative process embedded in the review approach with its aim to capture literature regardless of study design particularly suited my research methodological approach. The framework draws on systematic procedures to structure scoping activity across five stages which include (i) identifying the research question, (ii) identifying relevant studies, (iii) selecting appropriate studies, (iv) charting the data and (v) collating, summarising and reporting the results (Arksey and O' Malley 2005). There is (vi) an optional sixth stage, consultation of research stakeholders (this optional sixth stage was not used in this scoping review). I present below the scoping review using the Arksey and O'Malley (2005) framework, and the sensitising concepts that duly emerged from the review.

3.4　Scoping review – Stages of activity

As cited earlier, the aim of this scoping activity was two-fold: to produce a profile of the existing literature in a topic area which will help to narrow down the topic and set the study for my research, and secondly to identify the sensitising concepts in the topic area. Achieving the first aim was central to the justification for the research and helped in the formulation of the research aims and objectives. In addition, I used the review to identify any previous studies to avoid duplication which outweighs the 'risks' of conducting an initial literature review as espoused by Glaser (2009) importing and imposing prior knowledge and preconceived ideas or previously published theories onto the data.

- **Stage 1: Search questions**

1. What studies have been undertaken pertaining to lifestyle changes or self-management of South Asians with coronary heart disease?
2. What are the sensitising concepts/themes that can be derived from literature?

- **Stage 2: Finding relevant studies**

Adapting and using specified search terms and using an inclusion criteria (Table 3:1), the following databases were searched for relevant literature: The Academic Search Premier – CINAHL (1980–December 2016), MEDLINE (appendix 1), AMED (1985–December 2016), Ovid (1950–December 2016).

Table 3:1 Criteria for inclusion

eria for Inclusion
1. Be published since 1990
2. Population: Include participants aged 18 and older diagnosed with coronary artery disease.
3. Use a culturally adapted competency intervention.
4. Population: Ethnic minority population should include any group of South Asians.
5. Language: Be in any language, but English translation should be available.
6. Methodology: Quantitative and qualitative studies will be included.

One of its key strengths is redefining search terms (Table 3:2) as familiarity with the literature grows. Unlike a conventional systematic review, this iterative process allows for the inclusion criteria to be developed post hoc (Arksey and O'Malley 2005; Brien et al 2010).

Table 3:2: Search terms

Population Terms	ethnic* immigra* south asian indo* minorit* racial india* sikh* muslim*, moslim islam* pakistan* gujarat*, gujerat* sri lanka* bangladesh* ethno-cultural, ethno cultural panjabi*, punjabi* Indian sub-continent - Gujarat*, Bengal*, Asia, western; India; Bangladesh*; Gujaret*; Pakistan*; Asian*; south* Indian*; Punjab*; Urdu*; Hindi*; Hindu*; ethnic minorities; ethnic minority groups; human*black and ethnic minorities, BME communities.
Disease Terms	chronic disease, coronary ischemic* myocardi* infarct* "heart attack"; "myocardial infarction"; coronary heart disease; "cardiac infarction", CHD
	smok* tobacco us* barrier*cultural barrier* physical inactive*diet*exercise*activity*knowledge*attitude*lifestyle

Lifestyle/behaviour	* life style*
Intervention/Practice Terms	self-manag* promot* educat* policy interven*behaviour* behavior*empower* skill* community development community interven*self-care*selfcare* lifestyle modification*language and barrier*; communication barriers cardiac rehabilitation"; enablers; cardiac rehabilitation, secondary prevention.

Reference lists of key articles were perused for potentially pertinent articles. The search results were imported into a folder titled 'scoping review' to store citations and track the review process. Articles that discussed South Asian experience of self-management in coronary heart disease were deemed suitable. No limitations were set on study design, participant's age or type of coronary heart disease. However, a reason for the low retrieval rate maybe the paucity of studies in this field.

- **Stage 3: Selecting the studies**

Abstracts were retrieved and reviewed applying the above criteria. Any uncertainty from the abstract alone was dispelled by obtaining and scrutinising the full paper for its suitability. Using the iterative process for scoping reviews (Arksey and O'Malley 2005) and not restricting the review to myocardial infarction and including patients with angina led to the identification of four further studies that contributed to the overall number of included studies. Thirty-nine full text papers were obtained and read in full. From these, 8 papers describing 6 studies were eligible and included in the review. Two papers were duplicate publications. These two publications were scrutinised and were judged to add nothing further to their associated papers, and on that basis, the duplicate publications were excluded.

- **Stage 4: Mapping the data**

The fourth step in the review process involves reading and re-reading the text to identify and 'chart' key emerging themes from all the papers included in the review (Ritchie and Spencer 1994; Davis et al 2009). With the support of a member of the supervisory team, a simple data

extraction sheet – the template of which included descriptive characteristics (author, purpose, design, key findings) of collated studies, was developed and adapted to capture significant themes across all the papers included in the review (Table 3:3). The broad themes/concepts became my emerging sensitising concepts.

- **Stage 5: Collating the results**

To provide a cogent structure to the literature, the findings are reported in thematic components, so that it can be contextualised by the reader. However, unlike other scoping reviews (Brien et al 2010), this review did not reveal a large body of evidence despite the relatively comprehensive and broad search strategy used. It is likely that the dearth of evidence for this population resulted in the low number of papers retrieved. Other factors contributing to this may have been the inconsistent terminology of 'self-management' used in the literature and a lack of detailed definition. Such challenges aside, I have collated the results in terms of the aforementioned research questions (Table 3:3 – overleaf).

3.5   Studies conducted to date (1990 - 2016)

The few studies identified were from United Kingdom, Canada and Australia. Predominately the studies, focused on coronary heart disease (Astin et al 2008; Bedi et al 2008; Galdas et al 2012; Mir and Sheikh 2010; Darr et al 2008; Rodrigues 2014; Webster et al 2002; Jones et al 2007; Anthony et al 2012; Mohan et al 2008), were qualitative in nature using framework analysis (Darr et al 2008), ethnography (Mir and Sheikh 2010), descriptive/comparative (Rodrigues et al 2014) and interpretive design (Galdas et al 2012). Five studies (Astin et al 2008), (Darr et al 2008), (Galdas et al 2012), (Mir and Sheikh et al 2010), (Webster et al 2002) used either semi-structured or in-depth interviews whilst one used questionnaire (Rodrigues et al 2014). Two of the studies (Darr et al 2008), (Astin et al 2008), compared South Asians with Caucasians with coronary heart disease.

Table 3:3 Collated studies and data extracted

Author	Study purpose	Design/methods/sample	Findings
Anthony et al (2012)	Compare physical activity levels, body mass index, habitual diet, tobacco use and prevalence of non-communicable disease	Cross sectional survey of Asians of Indian descent and white British adults	Beliefs attitudes and knowledge were similar to whites
Astin et al (2008)	Explore the nature of family support among South Asian and white-European cardiac patients	Qualitative approach, semi structured interviews conducted with 45 south Asians patients and 37 carers and 20 white-European patients and 17 of their carers	Linguistic barriers evident among south Asian patients/lacked information regarding recovery
Bedi et al (2008)	Examine the influence of gender and ethnocultural affiliation on people's decisions about modifiable risk factors.	10 retired Sikh men who had had a previous myocardial infarction. Semi- Structured interviews.. Constant comparative approach.	Religious beliefs regarding destiny
Darr et al (2008)	Examine and compare the illness beliefs of South Asian and European patients with CHD about casual attributions and lifestyle change	Qualitative study using framework analysis to examine data gathered from in-depth interviews. 65 South Asian participants (20 Pakistani-Muslim, 13 Indian-Hindu, 12 Indian Sikh) and 20 European diagnosed with CHD	Found it difficult to make dietary changes
Galdas et al (2010)	Describe how culture underlies Canadian Punjabi Sikh men's experiences of adopting lifestyle changes following MI.	Qualitative interpretive design. In-depth, individual interviews with 27 Canadian Punjabi Sikh men post MI	Cultural influences and collectivist family and community contexts were identified related to self –care.
Jones et al (2007)	Explore patients reason for non-participation in or non-adherence to home or hospitable based CR	Individual semi-structured interviews Conducted with 48 patients (as part of BRUM study).	Some aspects of CR programme beneficial for lifestyle changes.
Mir and Sheikh (2010)	Explore the impact of religious identity and beliefs on self-management of long-term conditions within Pakistani Muslim communities	Ethnographic study involving in-depth interviews and participant observation.	Patients receive little or no support from professionals about decisions involving self-care. Religious identity influences the health beliefs and practices of many British Pakistani Muslim patients.
Mohan et al (2008)	Report lifestyle factors of Asian Indians in Australia in relation to coronary heart disease.	8 participants – 63% male semi structured in –depth interviews using a naturalistic approach. All post MI patients interviewed in a community setting.	The main themes were: diet, social and religious customs, exercise, stress, help-seeking behaviour, impact of migration. Knowledge of risk factors did not help participants to follow a healthy lifestyle.
Rodrigues et al (2014)	To examine knowledge, behaviours, and beliefs related to heart disease of Indo-Canadians.	A cross-sectional descriptive/comparative study, 102 Indian-born Indo-Canadians (ICs) and 102 Canadian-born Euro-Canadians (ECs) completed a standardized questionnaire on IHD knowledge and lifestyle-related behaviours and beliefs.	Resorted less to exercise for stress relief and more to religious/spiritual activities. Collectivist orientation was evident specifically in reliance on family support and religious faith.
Webster et al (2002)	Explore the needs and experiences of Gujarati Hindu patients and their partners in the first month after MI	Qualitative study. Semi structured interviews conducted with 35 Guajarati Hindu patients and their partners' post-MI.	Poor expectations after MI, Poor activity level and a strong belief in fate.

Though the importance of avoiding homogeneous generalisation about South Asians is highlighted in Galdas et al (2012), only Darr et al (2008) further classified participants based on religion and ethnicity.

Questionnaire studies (Rodrigues et al 2014) have limited validity because they are based on self-reported data. Though Darr et al (2008) offer significant insights for hospital care and cardiac rehabilitation of South Asians, their retrospective design, the small sample size of each ethnic group and the absence of the risk factor profiles may be viewed as limitations. Examination of coronary risk factor profile would have enriched the study's description of lifestyle changes. The studies often concentrated on diet and physical activity rather than on any other aspect of lifestyle changes. Webster et al (2002) used a qualitative approach to understand the experiences and needs of Gujarati Hindu patients and partners in the first month after a myocardial infarction. South Asians were less likely than other groups to be working towards the modification of traditional risk factors and their ability to change their lifestyle were limited by a lack of information and cultural barriers (Banerjee et al 2010). Astin et al (2008) and Darr et al (2008) identified a number of cultural differences between South Asian and White-European cardiac rehabilitation patients alongside similarities, which they described as representative of generic characteristics of recovery after a cardiac event.

These researchers (Webster 2002; Darr et al 2008; Galdas et al 2012) suggest that a lack of culturally appropriate information about coronary heart disease, its management and prognosis may influence South Asian patient's uptake and adherence to cardiac rehabilitation recommendations. Common issues, especially in South Asian populations for example, are those such as linguistic barriers and a need to address additional nutritional information. However, it should also be understood that not every difficulty a person encounters whilst engaging in cardiac rehabilitation can be attributed to ethnic differences (Astin et al 2008). Indeed, the problem has been highlighted, however, much more needs to be done. The explanatory utility of these various studies is questionable for although they vary in their emphases, the general health science discourse sustains an often subtle and vaguely conceptualised role of culture that invoke the cultural pathology notions of the past which seem to persevere even though

self-management support strategies as well as government health promotion activities has been under the watchful critique of sociology (Baum 2008).

I therefore assert there is place for more in-depth work to be undertaken on those aspects of the South Asian experience which involve biographical qualitative approaches in event of coronary artery disease diagnosis and subsequent decisions on lifestyle choices. No study has specifically examined individuals' experiences during early convalescence. Although they are at significantly higher risk of mortality, there remains a dearth of research examining the experiences of such patients (Webster et al 2002, Astin et al 2008). Information of this type is sorely needed if culturally and linguistically appropriate cardiac rehabilitation services are to be designed and used. These studies set a precedent in finding specific predictors for lifestyle self-management of South Asians after a diagnosis of coronary heart disease. The role of a critical assessment of health discourse in relation to South Asian and coronary heart disease as well as a comprehensive understanding of experiences that are culturally embedded, is therefore crucial to developing this area of research and practice.

As specified in the introduction to this chapter, whilst undertaking an initial review of literature for this study, it was not my intention to establish a preconceived conceptual framework, but to identify any studies with the same research focus so as to avoid duplication. An additional aim of the review was to identify the sensitising concepts. No preconceived theoretical perspective was adopted prior to the fieldwork, but instead an area of interest was pursued. In doing so, the relevance of a grounded theory is earned, rather than preconceived. In contrast to this the later analysis (chapter 6) will integrate the data collected with any relevant literature.

3.6   Sensitising concepts

Charmaz (2003) has referred to sensitising concepts as "*those background ideas that inform the overall research problem*" and stated further, "*sensitising concepts offer ways of seeing, organising, and understanding experience; we may use sensitising concepts only as points of departure from which to study the data*" (Charmaz 2003:259). Nonetheless, I had to remain cautious in the use of sensitising concepts for though sensitising concepts might alert researchers to some important aspects of research situations, they also might direct attention away from other

important aspects (Bowen 2006; Gilgun 2002). I have prudently used them to lay the foundation for the analysis of research data and so these concepts which formed the background discourse to the thesis will be further expounded after completion of data collection.

• Concept one - Culture and its impact on self-management

In everyday language, the word 'culture' holds and convey a wide range of subjective meanings and thus remain value laden. Since culture has been studied from the anthropological, sociological, and psychological perspectives, the term brings forth shared attributes across these disciplines.

One important dimension of culture is the extent of individualism or collectivism exhibited (Desai 2007). Cultural differences mean that people in different cultures have fundamentally different construal of the self and others (Wang 2004). Because the concept of 'self-management' depends on personal attributes such as self efficacy and self-reliance and personal goals this construct is expanded further on.

Evidence from these existing studies cannot be directly transferred to niche groups such as South Asians. The cultural context of any human phenomenon informs the meaning given to it and the cultural beliefs held by people are inextricably linked with their behavioural and emotional responses to what befalls them. Though several commendable self-management strategies were uncovered during the review, there was a lack of consensus in the literature about the optimal format and the best approach or strategies to self-managing lifestyle changes for this group of patients, after a heart attack.

• Concept two – Ethnic considerations in health and disease

Even though the term 'ethnicity' is yet to attain conceptual hygiene, it is important to explore briefly the concept of ethnicity to avoid any obfuscation of terms. The etymology of 'ethnicity' is from Greek word 'ethnos' meaning a nation. Since it is easier to think of these characteristics as fluid, this makes the above definition imprecise. However operationalised, ethnicity is a dynamic concept. Depending on the context in which one is being asked to identify one's ethnic origin, an individual may view his/her ethnicity differently over time as society evolves with the forces of social and political change, such as socio-economical patterns of migration, mixed

marriages and intergenerational shifts in defining self-identity. Senior and Bhopal (1994) and Bhopal (1996) have suggested ways to make use of 'ethnicity' in research more meaningful.

Participants recognised as being of `South Asian' ethnicity in this thesis are therefore people whose ancestry may be traced back by several centuries to the Indian subcontinent, when Pakistan, Sri Lanka, Bangladesh and parts of Burma, were an integral part of India (Laungani 1999). The choice of this term is because much of the literature that will be reviewed has used this term and its implicit use denotes the ancestry of the people within the framing of this study. However, I do acknowledge that the term 'Asian' is not without contentions Researchers, using the terms interchangeably without seriously challenging the derivations of concepts, reveal seriously flawed assumptions (Sheldon and Parker 1992) and run the risk of purporting homogeneity of populations and samples (Senior and Bhopal 1994).

The multidimensional view of ethnicity and culture resonates with the medical anthropological work of Manderson and Reid (1994) in which the complex interaction of ethnicity, culture, health embedded in a broader political, economic and social context is highlighted. They warn against 'over-reading' notions of culture based solely on ethnicity and the dangers of developing behavioural expectations and stereotypes based on research agendas and 'dated ethnographies' (Manderson and Reid 1994:13). The dilemma is referred to by Gunaratnam (2003) as the 'treacherous bind' of research in the area of ethnicity and she suggests –

"*We need to recognise and care about lived experience of ethnicity and we also need to resist and challenge the appetite for essentialism in research*" (Gunaratnam 2003:34).

However, such groupings have the danger of hiding the heterogeneity (mentioned in chapter 2) within subgroups thereby diminishing the value of ethnic categorisation. Such obscuring of group characteristics can make the delivery of culturally appropriate health care to ethnic groups more becomes complex and challenging than necessary.

Research needs to account for ethnicity's shifting nature and account for ways in which the aspects of ethnic identity are realised or politicised through the process of social negotiations. For this may be research should turn away from attempts offering prescriptive cultural descriptions, but offer a more general discussion that contextualises diversity and differences

without purporting to explain and manage ethnicity with simplistic explanation or with naïve solutions which has the risk of propagating disadvantage and discrimination.

Countless research articles are available which claim homogeneous knowledge about particular groups based on the narratives or experiences of some individuals. It is impractical at this point to delve deeper into this palpable complex interweaving of social, historical and institutional factors, but enough to make the qualification here that social processes are inherently different and complex.

In the past 40 years United Kingdom governments have shifted from egalitarian to more libertarian perspectives on healthcare as fiscal availability tightened whilst healthcare demand increased. In turn, the mainstream health policy agenda has shifted from a concern with access to an interest in efficiency, outcomes and effectiveness and to quality and patient safety (Eagar et al 2001). Negative stereotypical representations by political and media leaders is that these people are not deserving of services or resources and that rather than being people in 'need', they pose potential threats to English livelihoods, ways of life and even to personal safety.

Large scale surveys such as the Health Survey for England have shown that minority ethnic groups experience higher rates of disease and poorer health related outcomes than the White British population, for instance the British Heart Foundation (2009) found rates of cardiovascular disease have been falling among White Europeans in the United Kingdom since the 1970s, but the same rate of decline has not been seen within minority ethnic groups. It is often observed in the health care arena that either research related to minority ethnic populations is often marginalised as 'speciality' or considerations of ethnicity and minority ethnic populations are excluded from 'mainstream' studies (Hussain-Gambles 2003). This could be because of the added task of using interpreters and expense of translating materials. As such there is a need to apply ideas of culture and ethnicity to health and illness with great care.

Concept three – lifestyle: culture, chances and choice

The concept of lifestyle has been central in the development of a socially based model of health. Discussions of lifestyle and health largely ignoring systemic influences and focusing almost

exclusively upon individual responsibility draw together some combination of discrete behaviours with little reference to the social and cultural contexts in which they are embedded and given meaning (Beckett and Davison 1995). Coreil's comment (1985:428) is still pertinent: "*The failure of health promotion programmes to adequately deal with socio-cultural context of behaviour represents a major weakness of the lifestyle modification approach*".

Variation in health behaviours may be explained by the fact that many lifestyle behaviours are influenced by intuition, emotion and cognitions. Crossley (2000) describes mainstream health psychology's theoretical models as producing an image of the individual that is overly rational and thus inadequately psychological and social. Mainstream theories of health behaviour often assume erroneously that if you give people information they will act upon it. Such models fail to incorporate the structural dimensions of social action and may therefore be counter-productive (Naidoo and Wills 2009) particularly if they fail to take account of the sociocultural variations in health beliefs and practices. However, to emphasise these lifestyle factors in isolation from their social context is, given what we know about lay health beliefs, somewhat artificial (Korp 2010). In focusing on individuals' health related perceptions, none of the self-management models explicitly address important social, interpersonal and contextual issues. The reason why individuals do not follow healthy lifestyles, or are unable to make changes to their lifestyle behaviours is therefore an important area of research.

• Concept four - Self-management models and theories privileging individual action

Self-management approaches have drawn on theories of behavioural change originating from social psychology for example social cognitive theory (Bandura 2004), reasoned action and planned behaviour theory (Ajzen 1991) the health belief model (Becker 1974) and psychological models such as the common-sense illness model (Leventhal 1998), the trans-theoretical stages of change (Prochaska et al 1992) and Antonovsky's salutogensis (1987). These models help to understand the factors that influence an individual's adherence to a medical regime, such as secondary prevention of coronary heart disease. The main concept of the health belief model is that an individual has an expectation that changes will take place, and thus the probability of a person adapting to a health-related behaviour is based on how

much he or she believes that the treatment and recommended behaviour will personally affect them and reduce the threat (Rosenstock et al 1988).

Though used extensively, health belief models fall short of accounting for social, cultural and environmental influences on individual health beliefs. However, not all researchers are keen to use this model because of the difficulty in ensuring validity in maintaining and checking for consistency at different stages (Whitelaw et al 2000).

Generally, the main theories of behaviour change include a concept relating to confidence and motivation, formation of goals and intentions. The concept is variously called self efficacy in the health belief model (Rosenstock et al 1994) and social cognitive theory and perceived behavioural control in theory of planned behaviour. The concept of self efficacy is developed from social cognitive theory and emphasises the role of cognition in motivation. Defined as the belief in one's capabilities to organise and execute the courses of action required to manage prospective situations (Bandura 1977), the motivational principle of self efficacy concerns the idea of 'control of one's life'. The concept is linked with an individual's perception that they are in fact '*contributors*' to their life circumstances' and not 'just *products'* of them and as such indeed able to influence their motivation to make behavioural changes in a given social environment. This alludes to the importance of an individual's internal drive to make changes in their personal health.

Thus, though each one of them have unique features many of these models have significant similarities (Ong et al 2014). The prominence given to the influence of individual action and choice (Nutbeam and Harris 2004) as the basic mechanism for changing health behaviour, one of them. Indeed, there is a tendency for these models and theories to assume people are ready to receive lifestyle/risk factor modification messages. Though there is a logical appeal in the idea that providing sufficient knowledge to people will influence them to change their 'risk behaviour' (Montague et al 2001), this will only have a time limited effect on individual health. No single model (Self efficacy theory or theory of reasoned action) has universal applicability for all the changes in health beliefs and health behaviours, as all these models only attempt to predict the likelihood of change in any time.

Early contentions circled around the relative priority of person and the environment as essential and sufficient determinants of behaviour (Ong et al 2014), with less thought given to the influence of the 'social' environment. The equation B = f (P, E), captures the view that behaviour (B) is a function of the person (P) and their environment (E) (Lewin 1947). But the inevitable reality is that a wide range of factors not just limited to social and economic resources (Lindsay 2010) reflect on people's life and their abilities to respond and act upon these health behaviour messages. Many sociologists point to the self-management perspective represented in dominant policy, privileging individual rational action, thus omitting social context (Wilson et al 2007) leading to tensions between the lay model of self-management and biomedical models (Kendall et al 2011).

According to Nazroo (1997) structural factors outside individual control have an effect on one's health beliefs and behaviour such as effects of racism, employment prospects and acculturation. Therefore, a helpful sociological critique would be to enhance prevailing models with work that recognises sociocultural context which can impinge on the peoples' abilities to make lifestyle changes. Again, there can be a clash between the behaviour change priority and what priorities the individuals hold about managing a chronic condition. Therefore another critique would be to enhance prevailing models with work that recognises context and the everyday reality of individuals living with chronic illness (Taylor and Bury 2007). Moreover, behaviour change techniques and theories have been criticised for being constructed on a single unifying theory of motivation (Webb and Sheeran 2006) that is behavioural change techniques that influence the individual's intention to make behavioural changes towards their health.

3.8   Positioning the review in the research

The collated data of literature review encourages health professionals to pay close attention to South Asians in the community in order to improve their therapy and enhance their quality of life. The literature review deliberates the key sensitising concepts from collated literature and highlights the research implications. The study could not have been designed without a brief exploration and understanding of existing definitions and concept of lifestyle self management as well as ethnicity and what it means. A scoping review conducted to explore whether a study with such a focus and

aim was done before, and to identify broad sensitising concepts. As iterated in the beginning of the chapter, scoping reviews do not involve similar critical engagement with literature as with systematic reviews (Armstrong et al 2011), for they do not appraise the quality of evidence in the primary research reports in any formal sense. However, Daudt et al (2013) do suggest that scoping reviews should use some form of quality assessment. Nonetheless, in here to align with the approach chosen a quality assessment was not undertaken.

What is acknowledged in the literature (British Association of Cardiovascular Prevention and Rehabilitation 2013; NICE 2010) is that the practice of making lifestyle changes is irrefutably a very challenging and complex task for patients. What is missing from the literature, in general, is a body of knowledge from the South Asian community and in particular their perspectives of day-to day adjustment of attempting to make and maintain lifestyle change.

This review has demonstrated the scarcity of studies on this topic among South Asians which points to the clinical relevance and rationale for the study. It indicates the need to develop a theory of how and why South Asians undertake lifestyle changes after myocardial infarction to formulate effective self-management support. Despite the compelling evidence that lifestyle modification has the potential to improve health outcomes of people with coronary heart disease, few South Asians succeed in incorporating such changes. Elucidating their perspectives regarding lifestyle changes thus becomes imperative to gain a deeper understanding and develop a conceptual platform. Such conceptual frameworks emerging from a grounded theory inquiry can advance social policy and contribute to social change by anchoring "agendas for future action, practice, and policy" (Charmaz 2008:210). This is surprising and as Galdas (2012) points out - given the increased risk of coronary heart disease in this population and the significant benefit South Asian individuals stand to gain from these services.

3.9   Chapter summary

In this chapter, I have presented the scoping review done to characterise and catalogue the body of literature pertaining South Asians and their self-management. It considers theories in behavioural science that have contributed substantially to the understanding of behaviour, but which fall short of explicating the lifestyle changes in South Asians. I have discussed the place and purpose of sensitising concepts in relation to grounded theory research. The scoping review was used to gain an overview of the studies that set precedent to this study and to glean insight into key concepts without being prematurely immersed in literature. What the review do reveal is the need for an approach that can provide a more rounded and richer picture that can help reveal the various intersections between culture, health, and social experiences after a myocardial infarction.

With the end of this chapter, the background and literature review for the study is completed. Against this backdrop of sensitising concepts - ethnicity, culture, lifestyle and expectations of predominant society and policy makers of the ethnic minority behaviour, the next chapter progresses into a discussion of methodology, clarifying the rationale for the chosen method.

Chapter 4   Methodology

A journey begins before the travellers depart. The journey started when I started to gather information to foretaste what the journey entails and what to expect along the way. I scoped the terrain that the grounded theory covers and what I expected to traverse. Towards this end, after a brief overview of the research paradigms, the differing approaches of grounded theory espousing different philosophical stances is presented. Then, I have critically examined how and why an exploratory qualitative method (grounded theory) was adopted to address the research aim – to conceptualise how South Asians manage the lifestyle changes after myocardial infarction.

4.1   Preliminaries of establishing an approach - Ontology and Epistemology

We have ways of viewing and ways of interpreting the facts, ideas, and events which surround us. It is this 'paradigm' or 'worldview' containing particular epistemological and ontological premises that a researcher brings to the research (Denzin and Lincoln 2005). The centrality of ontology lies in the deliberations surrounding reality - should it be objective (external to social actors), or should it be subjective (constructed from the perceptions and action of social actors) (Bryman 2004:18). Epistemology, by discussing the established knowledge in a particular field of study, provides the philosophical underpinning, the credibility, which legitimises the framework (methodology) of the research process.

Major research paradigms

Ontologically speaking, the key idea of the positivist paradigm is that the social world exists externally, and that its properties should be measured through objective methods, rather than being inferred through sensations, reflections or intuition (Easterly–Smith et al 1991).   Interpretivism takes the opposite approach, positing a view of social reality as wholly constructed, subjective and social in nature.

The research approaches: quantitative and qualitative

In each of two main research paradigms or philosophies - positivism and the interpretivism there are issues pertaining to ontological, epistemological, axiological (assumptions about the role of values) as well as methodological consideration regarding the process of research (Creswell 2002). Approaches grounded in interpretivist epistemological positions centre on interpretation and creation of meaning (Holloway and Wheeler 1996). These approaches are broadly qualitative, wherein social reality is formed or produced in social interactions and relationships (Guba and Lincoln 1994). |Thus, whilst positivism is about measuring and quantifying and essentially about numbers and figures, an interpretivist seeks to makes sense of the behaviour and about meanings people assign to them (Denzin and Lincoln 2003).

I was astounded to find the profound statement from young Joseph Ratzinger: *the "objective mind" discoverable in finite reality is the consequence of the "subjective mind" that thought it into reality*. Methodology is the perspective taken for the enquiry process which is enmeshed in explicit ontological and epistemological perspectives. Therefore, my choice of methodology is not taken in isolation; indeed, deliberations of the underlying philosophical paradigms, my thoughts and perceptions form critical components of this decision.

4.2   Establishing the qualitative approach

Since the research problem shapes the choice of methodological approach (Hall 2003), a methodology focusing on the perspective of the South Asian patient diagnosed with myocardial infarction rather than the viewpoint of the health professional was deemed appropriate to bridge the gap in knowledge about lifestyle self-management. My underpinning philosophical thoughts of this research are based on the assumption that lifestyle changes and the patient needs arising for making and maintaining such changes are both contextual and subjective. Vital to this research is the value I give to South Asian participants to construct a deeper understanding of what they consider important to self-manage their lifestyle changes after myocardial infarction. Such a philosophy of thought favours qualitative approaches that provide in-depth, inductive, person-in-context data through methods such as interviews, diaries and observation. These types of data collection methods appear effective in drawing out the 'how and

why' of choosing and prioritising the lifestyle changes after myocardial infarction. As little was known about the topic (how South Asian choose and prioritise lifestyle changes), it allows for exploration of the perspectives of the participants themselves, a process termed as "*understanding from within*" (Hofstede and Hofstede 2005:4). Below I give a brief account of this understanding from within and how I position myself as a researcher within the study - excerpt #1 from the research journal.

'An understanding from within'

Excerpt from research journal #1

I am primarily a nurse, who came over from India to join the NHS workforce in 2001. As a South Asian I acknowledge and am aware of the entrenching rituals, rites and different practices across the different groups in my multi-faith, diverse community and can identify with the participants with regards to having an identity which is culturally and socially diverse since I also consider myself to be both British and Malayali Christian. Being South Asian myself, I could understand the strains they encountered and the cultural demands placed on them. Nevertheless, my role as a researcher also raises few methodological dilemmas such as, the manner in which to address elders as well as I, as a South Asian woman addressing 'men'. More worrying is how to present explicitly the subtle and implicit understandings of cultural issues embedded in the patient narratives However all these pale in comparison as I relate the experiences that I had in my life of how people I knew coped with adversity with the additional challenges of being Asian and living in the UK. Some of these were unspoken but I could easily identify and imagine what these may have been like.

In here, there is a scarcity of the theory underlying the phenomenon, therefore I chose a qualitative (grounded theory) approach which permits the sociocultural views and meaning to be contextually and demographically situated.

As a relative newcomer to the qualitative enquiry, the diverse terminologies, strategies and procedures were at first confusing, but I soon realised that currently there is no unanimity regarding classifying the qualitative approaches and even seasoned researchers like Miles and Huberman find it bewildering:

"*As comprehensive and clarifying as these catalogues and taxonomies may be, they turn out to be basically incommensurate, both in the way different qualitative strands are defined and in the criteria used to distinguish them*" (Miles and Huberman 1994:5).

Nonetheless it was easy to appreciate that the three main approaches commonly used in health research are ethnography, phenomenology and grounded theory (Denzin and Lincoln 2003). In ethnography, social conditions, attitudes and interpersonal relationships are explored in conjunction with fundamental cultural prescriptions wherein anthropological approaches to the study of culture underlie the method. In the context of my study ethnography would help describe the culture of the lifestyle changes and self-management as they are applicable to South Asians. However, I had to consider whether I had the needed time to invest for extended fieldwork which would ensure richer data. Moreover, ethnography runs the risk of 'lack of focus' and thereby accumulates bulk of data which is analysed towards the end of the field work. Phenomenology has its origin in applied philosophy. The idea of using phenomenology as a methodology was uncomfortable to me. Acknowledging the fact that it is used as a methodology for exploring a phenomenon and providing conceptual awareness, where the task at hand is to understand an experience as it is understood by those who are having it, I would still rather see it as a philosophy.

For me, I needed to move my study beyond mere description but to a conceptual awareness as to how do South Asians choose and prioritise their lifestyle changes. However, the epistemological assumptions of grounded theory stress the importance of understanding the main concerns of the participants and how they go about resolving their main concerns. I found this characteristic of giving emphasis to the context in which people function accentuated the suitability of adopting this approach for this research which is essentially about understanding South Asian patients' experiences of lifestyle changes.

4.3   Deciding on Grounded Theory

My research stemmed from a growing interest in South Asian lifestyle after a myocardial infarction. The aim was to study the self-management experiences of South Asians – from the perspective of South Asians themselves. Much research in this area is about diabetes and lifestyle changes in context of this disease. Researchers in this area focused on making a case that lifestyle changes are difficult to sustain and maintain by this community. As such, there is the need to develop a sound theoretical platform of how South Asians manage and sustain lifestyle changes and again, grounded theory is considered as an appropriate methodology (Skeat and Perry 2008).

As a methodology that originates from sociology, grounded theory illustrates how social circumstances account for the experiences, interactions and behaviours of the people being studied; at its best it enables the construction of theory about issues pertinent to people's lives by eliciting and comprehending the way meaning is derived in social situations (Charmaz 2000). Instead of a cursory '*what's going on here*?', grounded theory propounds a systematic explanation – a theory – *for both 'why and how' it goes on, through a set of systematic procedures* (Locke et al 2001:192). Thus, the theory so produced is context specific, shaped by the views of participants and is grounded in the social process (Corbin and Strauss 1998) and emerges because the researcher is immersed in the data.

Consequently, instead of using the existing general theories in literature as a starting point and testing them out, grounded theory starts with the narratives and stories of people who are the core of the phenomena of interest. As opposed to setting out to prove or disapprove a theory, it allows me as a researcher to capitalise on 1) obtaining detailed accounts of individual experiences; 2) learning the 'how' and 'why' South Asians choose as they do 3) generating a substantive theory based on participant perspectives. All these aspects of grounded theory that aligned with the research aim helped in the choice of the methodology.

The aim of the method is to describe social process and synthesise the data to formulate theory and the aim of the research is to understand how South Asians choose and prioritise lifestyle changes after a myocardial infarction (Charmaz 2006). Grounded theory employs a systematic set of procedures to inductively develop theory that is "grounded" in the data from which it was derived. As such, I found this approach is ideally suited to explore the needs South Asians ascribe to their self-management during recovery post myocardial infarction. Moreover, I held the view because theory and practice are pragmatically linked, highlighting the practical value of the grounded theory, the finding of such an approach which generates knowledge from data 'grounded in the field' can inform healthcare practice and policy (Creswell 2007).

4.4   Grounded Theory: origins and contentions

Sociologists, Barney Galland Glaser and Anselm Leonard Strauss have been named as the founding fathers of grounded theory. Since the 1960s, their research and subsequent discovery of a 'theory of awareness contexts in death and dying' which captured the interaction around

terminal illness in the structural setting of a hospital remains one of bedrock examples of grounded theory. Leading the way for a qualitative revolution, Glaser and Strauss' s "The Discovery of grounded theory" became the key source for students of grounded theory (Denzin and Lincoln 2003). Provoking much discussion and lengthy debates, differing researchers with philosophical perspectives have taken grounded theory in divergent directions. Several adaptations or models such as situational analysis (Clarke 2005), post modernism (Macdonald 2001) and constructivism (Charmaz 2006) are reflective of the various philosophical perspectives or ontological and epistemological positions that guided grounded theory since its original version (Fernandez 2012).

In Glaser's approach to grounded theory, reality or true meaning exist in the data waiting to be discovered whilst Strauss and Corbin (1990) espouse a reality based on an enacted truth, that is reality can only be interpreted and not known (Macann and Clark 2003). Moving further along the continuum, the version which Charmaz (2000) espouses is 'constructive reality' – an interpretive depiction of the study's world, not an exact picture of it (Charmaz 2010:10). Despite this evolution, Glaser remain faithful to the original version of grounded theory (Glaser 1978; 1992) whilst Strauss and Corbin (1998) remodelled the original version by adding on analytic techniques to guide and direct researchers. Grounded theory has relocated from a positivist approach to remodel itself to sit in differing epistemological and ontological position (Mills et al 2006).

What differentiates these models or versions is not the ontological position they embrace, but rather the source of divergence lies in the methods they have remodelled it into (Heath and Cowley 2004). Thus, as remarked by Annells (1997) the deviation in grounded theory must not be construed as one being superior to another, but rather as a signal that grounded theory is maturing and branching with merits and arguments put forward for each approach. Moving away from its ontological specification debates, the basic method of grounded theory is designed with the epistemological idea that the participant is the expert (because of the knowledge of the phenomena) (Milliken and Schreiber 2001) and the exploration is so intended as to uncover the socially constructed meanings of the participant's own reality.

However, novice researchers undertaking the approach for the first time, can be perplexed at the outset by the historical debates and discourse surrounding this methodology. I was akin to a novice researcher entering the previously unchartered waters of grounded theory unwittingly, and almost immediately required to engage critical deliberations as to provide the best fit for my research. Though useful to me as a PhD student researcher to be cognizant with the ontological underpinnings of grounded theory methodology, there is an inherent need to match the philosophy of the method, philosophy of the research as well as the world view of the researcher. An efficient way would be to view the different approaches to grounded theory and choose that which best fits in with all three. In the below excerpt #2 I show how the philosophy of the method and the research resonates with my philosophy (world view) as a researcher.

'research philosophy'

Excerpt from the research journal #2

I come alive when I interpret experiences of others, for I value individual storytelling. What is vital to me is the participant's story, rich detailed narrative, conversations. I am unconvinced when a classic grounded theorist states things like 'emptying oneself of preconceived ideas'. Rather I am attracted to the idea of embracing subjectivity. I believe as a research instrument; I will be a 'catalyst' co-constructing knowledge with my participants and this embracing of 'subjectivity' keeps with my value system. 'What's the main concern? they ask. I believe individuals may easily have more than main concern. Charmaz's argument that there are multiple realities in the world strikes a familiar cord. I am not after 'a core category' or after an abstract account of an experience. I am definitely drawn towards the liberty to situate my participants under the banner of constructivism. I cannot prescribe to the classic grounded theorists who are simultaneous inductive-deductive thinkers –nor to Strauss or Corbin who are strong prescriptive thinkers. I am without doubt gravitating towards Charmaz's constructivism........

As depicted by an excerpt from my research journal #2, coming to terms with one's own research philosophy is often the pivotal factor in choosing a research approach. Moreover, one can cogently rationalise one's choice only by exploring the differences inherent in each methodology. Howell highlights this clearly:

"When we undertake a research project we approach the world with preconceptions about the relationship between mind and external reality; such will affect the methodological approach, research programme and methods of data collection" (Howell 2013:4).

Therefore, it became vital for me to utilise the best approach that resonates with my world view and cognitive style whilst it still matches the goal of the research. Instead of engaging in a methodological pick and mix and thereby muddying the waters, this portrayal of distinction between the original and constructivist approaches to grounded theory will help me to be clear and consistent in my choice of methodology, that is, to adhere to one particular form of grounded theory. Towards this end, Charmaz's constructivist approach to grounded theory is compared and contrasted against Glaser and Strauss' versions.

4.5   Choosing the constructivist approach

A student of the pioneering fathers of grounded theory – Glaser and Strauss, Kathleen Charmaz has proposed since the mid-1990s that a constructivist approach to grounded theory is both possible and appropriate because "*data do not provide a window on reality*", rather, the "*discovered reality arises from the interactive process and its temporal, cultural, and structural contexts*" (Charmaz 2000:524). As opposed to the emergent or discovered principles of knowledge acquisition, knowledge about the underlying process, is constructed by the researcher and the research participant (Charmaz 2006), where the onus is on the experiences that emanate from the participants' stories. Charmaz through her constructivist approach endeavours to decipher the meaning that '*shape individuals attitude and actions*" (Charmaz 2009:144).

Both phenomenological and ethnographic aspects are reflected in her approach – phenomenological as she contrives to capture reality as it is apparent by the experience of the participant and ethnographic as she deploys participant observation techniques in addition to in-depth interviewing (Hammersley 2008). For Charmaz, grounded theory is a *set of principles and practices* emphasising *flexible guidelines* and not *prescription or packages with its emphasis on methodological rules and requirements* (Charmaz 2006:11).

Thus, as opposed to Glaser's approach which begins with no preconceived questions, but only with a desire to know more about a substantive area, the constructivist approach begins with specific questions on a particular substantive area (Evans 2013). Again, like Strauss and Corbin but unlike Glaser, Charmaz's approach begins with a review of literature to determine what has been done before in the area of interest. Both these aspects of constructivism are useful to me as a research student.

The aspects of constructivism which drew me were the 'multiple reality' view and that literature review could be viewed as another aspect of the data. Walker and Myrick, in their detailed analysis on coding and process, concluded that "m*aybe it is more about the researcher and less about the method*" (Walker and Myrick 2006: 558), a sentiment shared by Bryant (2009), and Fernandez (2012). For me, as the researcher it is not about which method is superior, it is more which one fits both my data and me as the researcher.

4.6   Core features of constructive grounded theory

The core features that makes Charmaz's approach distinct from other versions of grounded theory are: embracing subjectivity, co-construction of data, the notion of multiple realities.

Towards multiple realities

Charmaz's perspective emphasis "*diverse local worlds, multiple realities and the complexities of particular worlds, views and actions*" (Creswell 2007:65). Charmaz considers reality as constructed "*interpretive portrayal of the studied world, not an exact picture*" (Charmaz 2000:10). According to Glaser, where Charmaz attempts to interpret how participants construct their realities and present multiple perspectives, she has remodelled the original purpose of grounded theory, which is to conceptualise a latent pattern of behaviour (Glaser 2011).

Charmaz's argument that there are multiple realities in the world and "*generalisation are partial, conditional and situated in time and space*" (Charmaz 2006:141) has been a core of the debate between Charmaz and Glaser (Charmaz 2000; Glaser 2002, 2012). The argument that constructivist grounded theory compensates for the single-minded view is unjustified to classic grounded theorist advocates who highlight that classic grounded theorist focuses on a single concern of study (Evans 2013). According to them, the value of grounded theory is not on producing and verifying facts, but is in generating concepts that will have different meanings to different people, and that the final theory is open to modification and new data (Breckenridge and Jones 2012).

The notion of co-construction

This idea that the researcher helping the dialogue in the interview is at odds with Glaser's view of true grounded theory. Glaser regards analytical development as emergent, whilst Charmaz' approach is based on co-construction (Glaser 2002). Glaser (1992) criticises Strauss and Corbin's (1990) structural approach to analysis which he sees as a method of 'forcing the data resulting in a full conceptual description and therefore falling short of a true grounded theory. Likewise, Charmaz (2000) also argued that Strauss and Corbin's set of rules do not allow for an understanding of the underlying assumption, for their method is didactic and prescriptive rather emergent and interactive. Charmaz recognises that analysis reaches theoretical level from the researcher's interactions within the field "*each is a rendering of one interpretation among multiple interpretation*" (Charmaz 2000:523). Therefore, for Charmaz (2000), rather than using systematic guidelines and obtaining data on acts and fact of situations and structure, the researcher should immerse in a creative process of coding wherein an understanding of participants' beliefs and meanings are sought.

Embracing subjectivity

Glaser tends to view the researcher as an objective onlooker of what is being explored and regards bias a distinct and tangible variable - a variable which can and must be controlled (Glaser 2002), for he advocates the passive interview-observation through which the bias of the researcher is contained. Accordingly, the truth in the interviews will be revealed through constant comparative method. Similarly, Strauss and Corbin by offering comparison of one's own assumption against the data through the systematic method of microanalysis, safeguards against assumption-driven data (Strauss and Corbin 1998:68).

Conversely, Charmaz' constructivist approach suggests comfort with the researcher's subjectivity (or biography), a factor that should be acknowledged and analysed, for she says what the researcher sees and hears is influenced by their previous experiences, their interpretive frames, interests, research context and their relationships with research participants (Charmaz 2006). Thus, clearly Charmaz does not assume that researchers are 'impartial observers' able to ignore background assumption and disciplinary perspectives. However, presumably this has led Glaser (2012) to state that the use of such methodologies completely subverted all the principles of grounded theory. However, I give below another excerpt from the research journal #3 to present my resonance and comfortability with such an approach.

'Embracing subjectivity and multiple realities'
Excerpt from the research journal #3

I bring a constructivist worldview to the study through my belief that in seeking an understanding of the world in which individuals live and work and develop diverse and multiple subjective meanings of their experiences. My role as the researcher in this process was to address the complexity of these multiple perspectives by listening to the views of the participants and the meanings they assigned to them within the context of their own lived experience. Charmaz's view 'neither the observer nor the observed come to a scene untouched by the world' (Charmaz 2006:15) has resonance with me (a research student) who must provide a rationale and background to the research problem.

As a nurse, I love the stories my patients tell. I was more able to listen to their accounts intently as I was free from intervening as a nurse. Reading from literature and hearing the live accounts of the same were totally different. Some accounts of family shock and coping was so rich that I had to come back to those thoughts later after the recordings. I believe the experience of storytelling may have given my participants an opportunity to make sense of their recovery. There were parts within the interviews where they would stop to reflect on their thoughts and experiences. I wonder if they have had the opportunity to do this with anyone else.

4.7 An attempt at introspection – an exercise on reflexivity

Charmaz suggests that a constructivist grounded theorist position's themselves within a reflexive framework paying close attention to how participants render their own reality – and subsequently, the researcher's position within those realities (Charmaz 2005). Assuming it is even possible to pin down something of my intersubjective understandings, which I found invariably difficult to unfold, a brief overview of my background and my thoughts are presented below – excerpt #4

'Personal reflexivity'

Excerpt from the research journal #4

In my endeavour to explore the experiences of the South Asians after a heart attack, I was partly influenced by my nurse training in the 90's. "He shall live because of me" was the motto of the institution where I trained with a mission to reach out willingly to the medically unreached. In my choice of what is important to study, the methods, and the emergent analysis, I draw upon almost 20 years of experience working as a nurse in a multicultural mainstream health service. Perhaps I have always been subtly enticed by the narrations of the underprivileged, the minority. Perhaps this is why, though I have been 'pushed and pulled' around the differing ontological and epistemological turns of grounded theory, my research finally rested on a methodology that offered inroads to hear the stories and invoke the voices of participants, thus embracing subjectivity. This attractive proposition of privileging on the action of entering the world of the participants to view their circumstances and attending to the meaning they create, was crucial to this research. For as a health care professional it is imperative that I know how and why South Asians choose as they do so as to enter into a meaningful dialogue with them.

Critical debate surrounds questions such as the nature and existence of truth and reality and the representation of knowledge. Under the mantle of a constructivist, I do not assume there is a reality awaiting discovery which can be excavated (by minimising

the effects of the researcher) nor I have finally arrived at 'the truth'. This is not to say that I hold on to a nihilist belief that there is no material reality, no action or agency, empirical confirmation or social structure. For in art, music, books and works – for example in Beethoven's symphonies, missionary works of Mother Theresa - one is compelled to concede the exquisiteness of a reality that goes beyond the needs or expectation of one's ego. As a staunch Roman Catholic, I firmly cling on to an absolute truth thereby defining an epistemology of absolutism as opposed to relativism. Nonetheless, what I would like to emphasise is that between reality and its representation is a process of knowledge construction which is cultural, partial, complex and positioned within a social and historical context – akin to the differences in the gospels of Mathew, Mark, Luke and John, narrating the Truth of Christ.

As Bourdieu's notion of 'habitus' dictates, some of my ideas, expressions and actions may be partly shaped by my exposure to a western frame of reference, schooled in western theory and research methods; others from my South Indian middle class upbringing, parental values, peer influences and life experiences; whilst others from the service/institution where one works, the research industry; the predisposition of the organisation from where the research originated and research is published.

Moreover, the historical space within which this knowledge is co-constructed is singularly poignant with welfare weariness, fiscal restraints, devolutions and integrations of health care along with Kings Fund review of the NHS (Quarterly report – March 2017) reminiscent of the statistics of a bygone era. Overhanging everything else is the anxiety and uncertainty of Brexit. Thus, I duly acknowledge, the underlying philosophy, politics, history, and related power interests form a subtle but tangible link between my actions and decisions, the research and the pursuit for evidence.

My research is only ethnographic for using methods such as interviewing the participant at their homes. It is a challenge to navigate the path of this complicated landscape, avoiding the mire of the infinite regress of excessive self-analysis, while confessing to methodological inadequacies. Yet I must note that though it would seem to Glaser (2012) that Charmaz's approach to grounded theory completely subverts all its principles, I see an inherent attraction to Charmaz's constructivist approach, positioning grounded theory as being fluid, interactive and open ended. Charmaz explicitly disavows the notion of objectivity and maintains that constructivist approach presupposes the researcher strives for a cautious and interpretive understanding and that all, 'even the mundane', is an interpretation. Thus, although Charmaz' approach is philosophically coherent, her use of 'flexibility' is a thorny issue for some critics. For some, this flexibility can be seen limiting the aspects of good science – rigour, clarity and a systematic approach – clearly from the viewpoint of an objectivist (Murphy et at 1997).

Hence, Ruane and Ramcharan (2006) criticise Charmaz' approach for failing to demonstrate a robust method for arriving at meaning (Ruane and Ramcharan 2006). Such looseness and lack of verification have been the basis for the main criticism of the grounded theory approach since its conception (Stern 2007). On the other hand, at a glance, Strauss and Corbin's (1990) structured framework would have been beneficial for me as a novice researcher, instead of deploying the 'vague and loose creative' approach of Charmaz (2000). Their structured approach would have minimised the risk of 'lack of transparency' in undertaking the method. However, I feared, a sincere and rigid adherence to analytic protocols and procedure (specifically the paradigm model and axial coding) would have me searching for occurrences in the data as an objectivist as opposed to searching for meaning as a constructivist.

The social constructivist perspective is dependent on the context of the teller and the listener: all '*narratives sit at the intersection of history, biography, and society*' (Liamputtong and Ezzy 2005:132). I am also drawn to the new attention across disciplines to narrative knowing-the impulse to tell a story. *Scholars now see the story in the study, the tale in the theory, the parable in the principle, and the drama in the life.* This conceptualisation of human beings as narrators involve the sociocultural constraints against which individuals labour to impart information about themselves to other individuals who, in turn, labour to listen, and, most pointedly (and interestingly) leading to the inherent paradox of making something scientific out of something entirely biographical (Geertz 1988).

I believe there is an inherent tension in Charmaz's constructivist approach – the tension created because of the demand to maintain flexibility within a process. Coupled with the urge to seek direction, there is also the necessity to endure ambiguity. Thus, the imperative to immerse oneself in the data is the biggest challenge, a frustrating and chaotic experience. However, I believe orienting oneself to what this methodology asks of you prior to the start of your research journey helps the researcher to tolerate the ambiguity, trust and surrender to the analytical process. I would affirm constructive grounded theory is a powerful research methodology, not just because of its inherent capacity to socially construct the meaning and experience of participants, but for its power to transform the researcher for I learned to tolerate the lack of clarity, I learned to explore the details

of the various versions of grounded theory and be constantly aware of signs of cherry picking or method slurring and most of all not to give up. I learned to believe in the epiphany moment that did come. For the journey through grounded theory is to deal with uncertainty, the experience of which can become a truly transformative one for the researcher.

In setting out these links as explicitly as possible, I envisage the reader is guided effortlessly as to the choices I have made, as well as the philosophical and theoretical thinking which guided the methodological framework of this research. Star (2007) described grounded theory as an emotional challenge and as a call for 'methodological maturity', and I think this project called for both a methodological and emotional maturity. Moreover, in the pragmatic words of Bryant (2009:32) "*The epistemological issues that separate different strands, or branches of the grounded theory family, can then be set to one side provided that people's research writings do not seek to make strong epistemological claims: the ultimate criterion of good research should be that it makes a difference*". Thus, this exercise in reflexivity has enabled me to avoid in Steve Woolgar's (1998) the arrogance of certainty and self-sufficient/self-immunising knowledge or, in general, "*dangers of complacency*".

4.8   Chapter summary

I have outlined the various approaches to grounded theory evolving over the last five decades which have aligned themselves with evolutions in epistemological and ontological trends. My central research aim was therefore to examine the experiences and roles of these patients and the ways in which they navigated the lifestyle changes. Towards this end a constructed grounded theory to the study design was deemed appropriate. Firmly locating the research within this school of thought has helped this research to evolve and position itself within the broader context of the health sciences, and not within just nursing as I originally expected.

Chapter 5 The study

This chapter is all about the research process in practice. As such it depicts the journey made of constructing a grounded theory, by traversing basic grounded theory steps. A path is forged to expand the vista by the stories my participants were keen to tell me, and which, as a researcher, I was keen to retell. In here, I point out to the obstacles and opportunities I traversed with, those participants who shared my journey and indicate the routes, the methods, I took to recruit, to sample, to interview. I conclude the chapter, reflecting on the concerns and honours of the journey.

5.1 Setting – participant identification sites

During the early stages of recruiting, I emailed a list of NHS organisations (10) across North West by providing them with details about my research, and asking if they were happy to be involved. One of them did not respond, another agreed initially but later did not respond to further correspondence. Three NHS hospitals supported participant recruitment. The two university hospitals are major providers of cardiac care to the population of Greater Manchester, South Manchester as well as wider North-West region. The host NHS hospital is a major provider of cardiac care to over 10,000 new patients a year, covering patients from local communities as well as patients from Greater Manchester and the wider North-West region. Specifically, it is the centre for adult congenital heart disease, undertakes blackout clinics, believed to be the first in the world, as well as multidisciplinary genetic clinic. The rationale for using a district hospital along with two university hospitals was to ensure that an adequate number of participants was recruited within the time frame and resources available.

5.2 Sample and sampling

5.2.1 Sample

Qualitative data should be suited for the exploration and uncovering of interpretations of phenomena that are not clearly understood (Denzin and Lincoln 2005). Therefore, sample suggestions for grounded theory include people who are familiar with the area of investigation and who possess knowledge pertaining to the subject (Milliken and Schreiber 2001). As such participants who can shed information on around the topic are selected. The importance of the chosen sampling strategy becomes more relevant, seeking to identify rich textual narratives (Vickers 2017). Furthermore, qualitative research is not dictated by terms such as generalisability, detracting it from the interpretive nature of the paradigm and the insight that it can shed on phenomena (Robson 1993; Robson 2002).

5.2.2 Sampling

Initially purposive sampling drove the recruitment phase of this research. Hood (2007) describes this initial sampling as 'a priori' purposeful sampling. Purposive sampling identifies a suitable selection of a population that meet the study aims and who are best able to articulate experiences relevant to the study's research questions (Pope and Mays 2008). the sampling becomes more directed – moving from purposive to theoretical sampling - as the research progresses. However, contrary to purposive sampling it is not possible to plan for theoretical sampling since it is a process which occurs in response to emerging ideas (Charmaz 2006).

The aim here was to explore the South Asian experience of self-managing lifestyle changes after an acute myocardial infarction and so South Asians were recruited. Accordingly, attempts were made to sample the participants based on who self-identified Punjabi Sikh, Indian Hindu, Guajarati Hindu or Indian-Christian, Pakistani Muslim, Kashmiri Muslim.

Participants were included in the study sample if they were over the age of 18 years, had recent myocardial infarction and were of South Asian origin. This tactic is used because experience and life-situation influence an individual's self-management experience (Radley and Billing 1999). Patients who have had repeat heart attack will be excluded as their needs will be different from those facing the crisis first time. Selection bias was reduced by enrolling incident cases of first myocardial infarction, thereby minimising any biases resulting from changes in lifestyle adopted by individuals with previous coronary artery disease. Contingency sampling plans such as snowball sampling and consultations with communities to enhance participation at religious venues, were made if recruitment strategies resulted in inadequate enrolment.

5.2.3 Participant Profile

A defining feature that differentiates constructivist grounded theory from other approaches is the attention it pays to give voice to the participants within the study (Charmaz 2009). To ensure that I do not just 'neutrally' to report facts, but give 'voice to my participants', I find it useful to provide a succinct, but cohesive account for the situation, the interaction, and perspectives of the participants (Charmaz 1995). This, in addition to the table provided with the participant data will provide a better insight into participants' profile. Pseudonyms are used to protect their identity and preserve confidentiality. In the following sections, I will let them introduce themselves.

1.

Mohammed
67 yrs old, male Pakistani
Muslim

Mohammed was the first person I interviewed. A doctor by profession from Pakistan, he did not pursue the career here, rather worked in a grocery store he owned along with his cousin. From Pakistan, he had migrated to Germany and from Germany, after his first wife died, came to England. Here he had married another Pakistani Muslim. As soon as I had sat down, he said: I know why I had this, its too much cola. He said he was expecting it as he had known his diet was not 'going the right way'. 'What to do', he said mischievously, 'I enjoy eating and my wife enjoy cooking'. He was clearly impressed with the health service and he said it was one of the reason why he responded to my letter 'to do something of his own in return for the kindness received'. He had received his cardiac rehabilitation appointment letter and he was looking forward to it – though he was a bit apprehensive as it was in Trafford, and he was living in Longsight. It was Ramadan when I visited their house and I remember turning down their offer for coffee/tea since I knew they would not have broken their fast at 5pm, the time of my interview. I was welcomed to join them to break the fast at 6.30, a time when the interview ended.

With the buoyancy felt with the success of the first interview, I interviewed Patel. He was a Sikh who liked to quote from the Path – the holy book. He was happy with the prognosis given to him by the doctors. He lived with his son and his family. He was sure the medicines and the prayers will get

2.

Patel
70 yrs old, male Sikh
- initially from
Birmingham

him back on his feet soon. He was less sure of the diet as it was not his domain. He was also not sure whether he could 'self-manage' his lifestyle on his own, as 'you don't live on your own, the decisions you make impact on others, isn't? 'how do I decide this is what I am going to do – when you live with others? He believed self-managing your life is for the young when you are young and free, not tied down with family and worries. He also informed me of the difference between a Birmingham Sikh and Manchester Sikh.

3.

Raju
54 yrs old, male Gujareti Hindu

Raju was a Gujarati Hindu – a taxi driver, he was very reflective and poignant of the fact that he did 'at the end get the attack'. He had gone to the doctors a week before for an ECG – routine check-up and apparently, it was all clear. But while he was in the midst of his taxi fare, he developed the chest pain. However, he did not tell the passenger. He dropped the passenger at the place and then he went to the hospital by his own taxi. He was admitted. Only after he was admitted and booked for surgery did he call his family as – 'because of his taxi/car' (which he had parked on a known road), he smiled and said. He was following a 'healthy' diet. He offered me a bowl of fresh fruit. He did not want to start exercising in the gym at his age/but he went for walks with his daughters. He had come to settle in England from Denmark. After an hour and half, he ventured to tell me, it was better 'if I had stayed in Denmark, I wouldn't have had this heart attack' and I asked why – 'Its so stressful here – the people…' The material he gave me then would suffice another thesis.

4.

Philip
(Thommachan)
50yrs old, male
Malayalee
Christian

5.

Padma
71 yrs old, female Hindu -
Indian

Thommachan was a Malayalee Christian, a social worker who had been in the country for 13 years. His wife had initially migrated to England on NHS work permit, married him and thereby he came to England. Two young children. He knew this disease would come knocking so he had gone to his GP for regular check-up. However, he didn't expect it when he was so young. He was worried about his son's grammar school admission, which tuition centre he had to enrol his son. 'So maybe that could be the reason', he said. He was more worried for his son getting through the grammar school entrance exam, than his son. Seeing his son not worrying about his forthcoming exam, made him even more tensed up, he said. But now he exercises, and controls his diet as well – 'though going to India, messes up his diet'. Even after saying goodbye, we had another door step chat for another half an hour in which he voiced his opinion regarding cardiac rehab and the idea of self-management.

Padma lived in Sale, not too far away from where I live. I found her looking after her grandson in her flat. She said she came from India, North and she was a Hindu. Her son is a doctor, and her daughter in law also works in the hospital. Prior to being taken ill, she was 'feeling very tired' and then 2 days later, she had 'this awful pain' and her son called the ambulance and she was taken to the hospital. She felt the doctors did not speak to her, but to her son, 'but this is ok as her son knows better'. But she would have loved if they had indeed 'talked to her!' She said she thought her weight was the problem, but the doctors said 'it was not, her pipes to her heart is all blocked up'. She did not smoke or drink. She loved cooking and she always cooked the way her mother cooked. She did not want to go to the programme for which the letter came, but her son thinks it would be good for her, 'so she will go'. She was a school teacher in India, now retired.

In Sabu's house, I met a whole clan of people, aunties and uncles, neighbours, nieces and nephews all who had come to see 'how he was faring'. Everyone had bought in food

6.

Sabu
45 yrs old, male
Christian

and the smell rafted in tantalising as the interview progressed. He was in accounts section of a manufacturing company and he did accounts in his spare time. He said he was too young to be struck down by this, he cannot waste time. He had 'lots of work to do', he wants to return to work as soon as possible. Will this cardia rehab help? Then he will go, otherwise it will be 'a waste of time'. He was quite anxious and 'worked up' when I met him for the first interview but at the final interview he was much more restful. He said everything 'has worked out fine'. He found a way 'where and how everything fitted' and so life can go on.

7.

Das
43 yrs old, male
Hindu -

Das was an engineer, initially from India, but now called himself 'British'. He was worried he had passed on this 'gene of heart attack' to his girls. He was worried his wife will not cope with his illness and with the children – taking them to school 'she cannot drive, you see'. So she has to rely on the bus. 'I feel helpless if I am not helping her'. He has a project which he must finish and this had him worried. He was due for promotion and this also worried him. He cannot let this disease ruin his 'chances for the promotion'. He was happy with all the things the doctor did, but he wished everything was quick and clear. No 'waiting and waiting'. He did not truly believe in self-managing. He wondered 'when everything is all connected together how can you manage on your own? Your one decision touches the other you are living with.'

8.

Kamal
45 yrs old, male
Pakistani Muslim

Kamal was another Pakistani Muslim and he was very upset, he had not taken a sick leave in his entire 45 years of life and now he has taken 3 weeks off. He ran a restaurant and he came home late at night at 11.30 at which time he had supper. He attributed his lifestyle to the cause of the disease. But this did not deter him from going back to work in his restaurant because 'he cannot be idle'. 'God

gave you this life to work and you have to work. The rest will come and go'. Yes, he has toned down his work and his timings, but the priority is his work. His wife and his only son is 'on his case' and they can manage. He did not think he can go for 'this cardiac rehab' and if it is in the way of his working at the restaurant he doubts it, but 'he will see'. He did go for cardiac rehabilitation when I went to see him the next time around and said he was pleased he had done so.

9.
Devi
50 yrs old, female
Malayalee Hindu

Devi was a good cook and this she said was the reason for her disease. She had a dimpled smile and she lived near Chorlton. She said 'her arteries too would have liked her food and ate too much of it' and laughed. She had an elderly father to look after and she was glad the heart attack caught her and not her father. She worked as a carer in a nursing home and now she is thinking of taking a year off just to be back on her feet. She thought she was capable enough to self-manage her condition, however it would depend on her father. He was her priority. She did not receive the letter after her discharge from the hospital, but she had a phone call to ask her how things were.

10.
Fatima
29 yrs old, female
Pakistani Muslim

Fatima was the youngest. Her mother is extremely religious and she said 'she has decided to take up her religion'. She has gone to stay back with her mother. She has two lovely daughters. One was 6 months old the day I went to interview her the first time. She said she will take up aerobic dancing as way of physical activity. 'And it was a good thing somebody is finding out why it is happening to young girls like her for she thought it really happened to old people'. In the week, she was discharged, she had another visit to her GP. She is now very tired with all the medications and it 'is drugging her'. She must look after the babies and it is a 'handful job'. She completed the cardiac rehab.

11.

Sayed
84 yrs old, male
Bangladeshi Muslim

12.

Abdulla
56 yrs old, male
Pakistani Muslim

13.

Miriam
63 yrs old, female
Kashmir/(Indian part)
Muslim

Sayed was a Bangladeshi Muslim. The oldest. He thought he had completed/achieved all he had set out to do in his lifetime. 'Married off his daughters, seen his grandchildren'. 'Now he is ready to go'. Whatever programme is offered to him; it 'will not prolong his life'. He is ready to 'break the ties'. He offered me cream biscuits and coke. He lives with his wife, but his son and daughter in law lives next daughter and looks after him, but he likes his wife to look after him. And to cook for him. He does not want to potter around in the streets walking and fall dead.no thank you, he will fall dead in his home. He did not go for cardiac rehab. He was in the same jovial spirits when I met him the second time. 'Happy to go when God called him'.

I met Abdulla on the street near to his house and we walked back to his house. He had gone for a very short stroll after his dinner. It was his 'usual habit'. A 56-year-old man, he reminded me of my father. He felt very very tired and he couldn't think of doing anything. He owned a stall in the market and he used to get up very early and go to the market, but now he feels he 'don't have any energy at all'. His wife is putting up with him. His children come and help him, but he wants to 'feel the same way he did before'. 'Will cardiac rehab help?

Miriam – was the silent of all, a woman of few words. Interviewing her helped me realise how changed I was. After a few silences and few yes and no answers to my questions, I realised I had to change my tactic. So, next time she offered me a cup of coffee, I got up with her to the kitchen and from there we had a chat about the spices/ and spicy food. How she hated her vegetables, how she liked her Korma, the dietician made no sense cooking without oil or little oil. How to sauté the onion. She used to work, but now retired. She came from Kashmir/ she is used to this

weather cold. Her friends and family lived near her and helps her out.

14.

Satti
51 yrs old,
female
Punjab/Sikh

Satti was self-employed, helped her husband in his business, active in social clubs. She had a lovely sense of humour. Proud of her heritage – 'she had married into a rich family', she said. 'But richness can come and go, but richness in behaviour is more important'. She it must be had no idea why the heart attack came to visit her, written in her fate. She will not fight it, she will flow with it'. Her family 'is important and this diagnosis will not interfere with her family routine'. She had help of her family and friends.

Table 5:1 Participant profile

Sl. No.	Participant	Age	Sex	Religion	Country	Marital status	Education status	Occupation status
1	Mohammed	67	Male	Muslim	Pakistan	Married	Doctor	Helping his brother - business
2	Patel	70	Male	Sikh	Pakistan	Married	Elementary	Retired – was working in a clothes mill
3	Raju	54	Male	Hindu	Gujaret/India	Married	Undergraduate	Taxi driver
4	Philip	50	Male	Christian	India	Married	MA social Work	Carer
5	Padma	71	Female	Hindu	India	Married	Old Baccalaureate	Retired school teacher
6	Sabu	45	Male	Christian	India	Married	Graduate	Works in Accounts section
7	Das	43	Male	Hindu	India	Married	graduate	Works in IT department
8	Kamal	45	Male	Muslim	Pakistan	Married	graduate	Runs a restaurant
9	Devi	50	Female	Hindu	India	Married	Undergraduate	Carer in nursing home
10	Fatima	29	Female	Muslim	Pakistan	Married	Graduate	House wife
11	Sayed	84	Male	Muslim	Bangladesh	Married	Old Baccalaureate	Retired
12	Abdulla	56	Male	Muslim	Bangladesh	Married	Graduate	Shopkeeper
13	Miriam	63	Female	Muslim	Kashmir	Married	Graduate	Retired
14	Satti	51	Female	Sikh	Punjab	Married	Graduate	Self-employed business woman

Fourteen South Asians participated in the project, from different subgroups of South Asian ethnicity, as well as different socioe conomic groups and different professions. All participants were over the age of 18, with 29 and 84 being the youngest and oldest participants respectively.. Of the 14 participants interviewed nine were male and five were female. All of them were married, living with their family. Five participants were employed, four ran their own businesses, two of the women were retired. None of the participants smoked.

5.3 Patient and Public involvement

An informal advisory group was formed which consisted of two NHS research nurses, South Asian mother involved in business and a South Asian myocardial infarction patient. They acted as members of an informal advisory group to provide a practitioner/service provider perspective. They also provided me with valuable feedback that helped to initially come up with research questions, develop a topic guide for interview and proposed dissemination strategy. They continued to act in as informal consultative/advisory roles to provide guidance at key stages of the project (for example during theoretical sampling). In addition to this informal advisory group, I had the support of the cardiac rehabilitation lead nurses, clinical audit co-ordinators and research governance panel members of the Trust where I worked. Such partnerships helped to develop and ensure appropriate outputs and knowledge mobilisation that would have an impact/benefit for individual service-users.

5.4 Ethical approval – considerations and challenges

Ethical Approval and Good Practice: I obtained ethical approval for this study from several different research bodies (Appendix A): University of Salford Research, Innovation and Academic Engagement Ethical Approval Panel (Reference: HSCR15/02), NRES Committee South West - Cornwall & Plymouth (REC) REC reference: 15/SW/0042 IRAS project ID: 156365; NHS permission from the Research and Development Department Central

Manchester University Hospitals (PIN: R03937). NHS permission from the Research and Development Department South Manchester University Hospitals NHS permission from the Research and Development department Pennine Acute Foundation Trust Hospitals.

I sought to be guided by the following principles (Beauchamp and Childress 2013).

I.   The right to Fair Treatment – There would be no discrimination, no judgements if participant withdrew at any point during the study. Promises were kept for example with regards to time commitment. I made sure I was available and accessible to ask questions and clear doubts, for debriefing, if necessary to resolve issues or to give information. Each of the participant was treated with respect and courtesy.

II.   Right to Privacy – this will be given its due priority with no information shared without permission. As mentioned above, anonymity and confidentiality will be adhered to by getting only necessary identifying information, using ID numbers, locking information in file, password protection, destroying personal information if not used/needed, making sure all associated with study pledge confidentiality, disguising data as well as reporting data as a whole.

III. Informed Consent -Informed consent is normally central to ethical practice as such it was obtained from all the participants of the research. This was obtained after they were fully informed of the research aims and potential benefits and harms, giving their consent voluntarily. At no time were the participants coerced to participate or unduly persuaded by the promise of a reward. The language used in the informed consent sheet was transparent and simple, devoid of jargon or abbreviations. Information was reinforced with verbal clarification and sufficient time provided for the participant to consider their involvement in the study and to ask questions. I undertook research training (Introduction to Good Clinical Practice) as necessitated for the NHS research governance boards (Appendix B).

5.5 Data management and storage

I approached data management in a more traditional manner. I transcribed the interviews and the data were stored securely. Written accounts such as journal notes, memos, and diagrams were both in hard copy and electronic copy. All electronic data were kept on a password protected computer. All paper based copies of completed information sheets/interview notes were research coded and stored in a locked filing cabinet, in a number locked postgraduate room, the key accessible only to me. The names of participants were removed from all paper documents and pseudonyms given to preserve anonymity. I also engaged in open discussion and dialogue with thesis supervisors regarding the ethical issues encountered during all phases of data collection. All information obtained and secured during the research was managed according to the Data Protection Act (1998) and the Research Governance Framework for Health and Social Care.

5.6 Recruitment: access and process

5.6.1 Gaining access

As mentioned in the settings, the sites were participation identification sites and not research sites. However, written organisational consent was gained from the research and governance department as though the sites were research sites, even though no research activity involving consent was conducted on site.

Once suitable sites were selected, (and whilst waiting for the research governance approval), I met with the cardiac rehabilitation nurses of each site. I sat with them and went through the research proposal and had a full discussion of the implications of research. My position as that of a staff nurse in the host hospital was seen as an advantage to meet and build relationship with gatekeepers. Over a total period of 5 months, I shadowed cardiac rehabilitation nurses, attended cardiac rehabilitation meetings and sessions and coupled these with ad hoc interviews.

5.6.2 Process of recruitment

Fig: 5:1 Process of recruitment
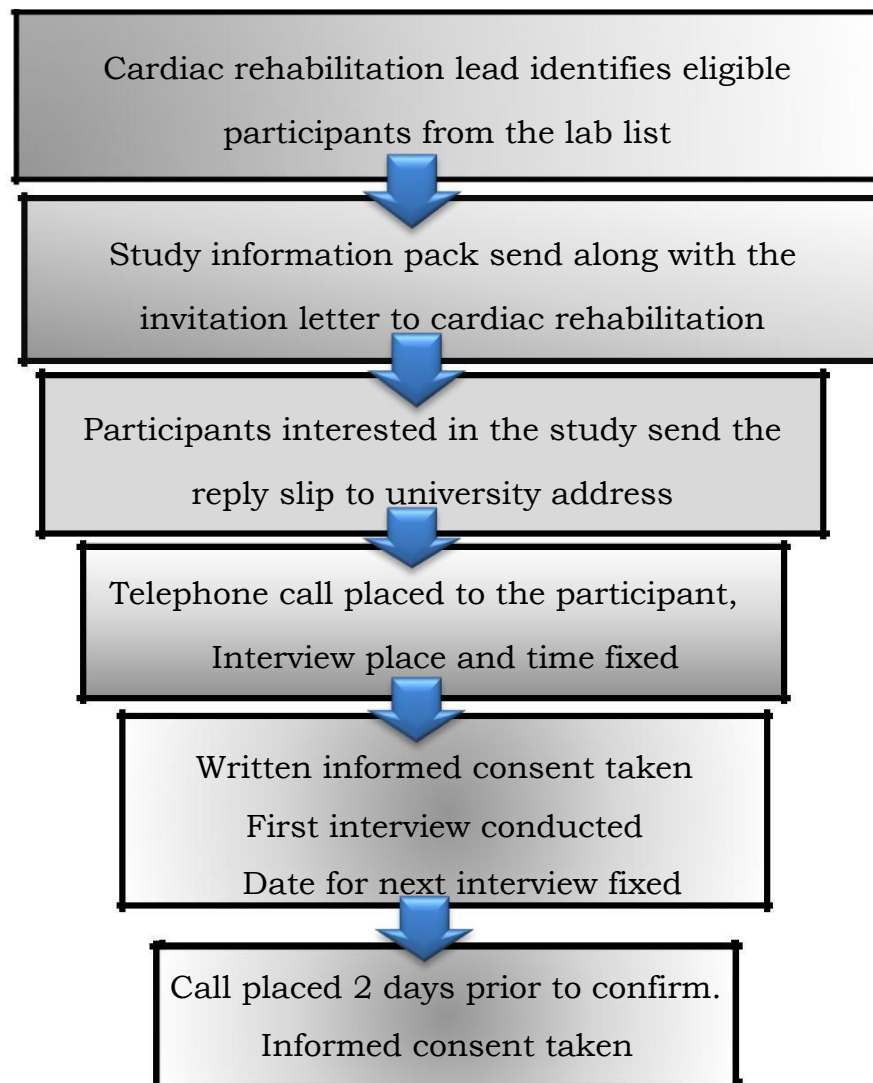
Initially the participants were identified by the hospital cardiac rehabilitation team. Cardiac rehabilitation lead identified the potential participants from the lab list (Fig 5:1).

Usually within three days of discharge from hospital, the cardiac rehabilitation team send out an invite for an outpatient programme to the discharged patients. For the study, a pack containing the patient information leaflet, invitation letter (which provided background information about me) to participants and the reply slip was also kept ready with the rehabilitation team for them to send the pack along with their invite. Patients who volunteered to take part in the study replied with their contact details in the reply slip provided, to the university address where I had a personalised mail

tray. If the reply slip was not returned within 14 days, another letter was sent out by the cardiac rehabilitation team. The returned reply slips were followed up by a telephone call to arrange an interview at a time and place convenient to the patient, at which point the purpose of the study was reiterated, further explained and any questions answered - something which I felt was an important step in attempting to form a reciprocal relationship with participants; a key part of constructivist grounded theory. Recruitment lasted for a year, although this was not a predetermined timeframe, merely a result of finding participants and then reaching the point where I began to encounter repetition in the categories I had constructed. Retrospectively, I could have also added a poster of the research at each of these participation identification sites with my contact details, to allow volunteers the opportunity to contact me to gain further information to decide whether to participate in the study. This would have also enabled the participants to approach the researcher on their own terms.

5.7 Data collection: interviews

The popularity of interviews as a data collection tool across different health settings is clear from the initial scoping review of literature (Farooqi et al 2000, Darr et al 2008, Oli et al 2014) and these are clearly a useful way of collecting data in grounded theory approaches. Interviews offer an opportunity to develop a greater understanding of the identified need, or make sense of individual experiences within the context of their lives and personal perspectives (Attfield et al 2006) (Julien and Michels 2004). Such an understanding can be used to develop or extend theories (McCaughan and McKenna 2006). Charmaz's in-depth approach facilitates a co-created articulated experience less likely to be articulated in everyday life (Charmaz 2008). For Charmaz (2006) emotions speak louder than words for the meaning of incidents which is shown in the emotions participants express when they 'retell the story' more than the words they chose to tell the story (Charmaz 2006: 34) and interviews make visible such 'emotions'.Therefore, interviews were an appropriate form of data collection and suitable talk-based method (Squires 2009; Sidhu 2012) to use in this community.

5.7.1 Location

Oberhauser (1997) explains that interviews in participants' homes have the potential of disrupting power hierarchies between researcher and participant. The degree of familiarity and comfort participants have within their homes would be difficult to replicate in other locations. My main consideration with regards to location were to go along with the participant's choice - as this is one way of limiting the possibility of developing a hierarchal relationship between participants and myself. I felt participants' homes were appropriate because it is the location where the majority of self-management occurs; diet, medication adherence, to name a few areas. On the other hand, some participants may not like a researcher, someone they hardly knew, in their homes. As a result, giving them the option to choose the place of interview was a facilitator to encourage participants to take part in this study. The University of Salford lone researcher policy was adhered to always to ensure safety.

5.7.2 Preparation

As the initiator of the interview, I had an active role in making certain decisions about the progress of the interview for which I need to be prepared. Apparently, preparing for the interview starts when the researcher selects the participants according to the sampling criteria. In selecting interviewees for qualitative interviews, interviewers should enter the world of interviewees (De Vos 2002:292). For this I reviewed the literature to see how the interviews and interviewers worked out in the past in similar studies (Astin et al 2008). In addition, the presentation on 'interviews and interpreters – conundrums' for the new Masters students which had a profound impact in my confidence and enthusiasm (excerpt #5 given overleaf). I anticipated 'emotional stances' perhaps when they recalled 'the heart attack experience'. I approached this with an empathetic understanding (Holloway and Wheeler 1996) as far as possible, showing sensitivity to the uniqueness of each participant throughout the interview.

'getting back my confidence'

Excerpt from the research journal #5

I write in my journal: burnt out and lost in the labyrinth of methodology I have to find a way, I have searched to find what gives me confidence and I know its to talk aloud, aided by a power-point. Was it luck or is it fate that I saw the opportunity in my mail? Any way I have asked for a slot. Let's see....... few hiccups but I am doing it.... Strangely when I look at those burning faces before me I cannot but be brave and say I failed openly. But this failure has taught me these things and here I am going through one of the issues I have failed. And saying I failed openly has liberated me, emptied me of the distress........ I am now in the interviewees' home, looking at them through the words of another....

5.7.3 Development of topic guide

Usually topic guides are used to provide structure to the interview process and ensure similar issues are covered across participants. However, in here it contained very broad questions and was developed primarily to meet ethical approval guidelines. The development of the topic guide was informed first, by the available research literature and second, from the input of an advisory group consisting of South Asian service users and professionals. The questions were guided by Charmaz' approach, particularly her chapter on how to phrase interview questions to allow respondents to express their views without constraints (Charmaz 2006). So in here most of the questions start off with...'how or what?' I ventured to ask a range of questions about their experiences including; their understanding of their condition, anticipated lifestyle modification, their perceived challenges and provision of emotional and social support. Interview questions become more focused as data collection progressed which is considered consistent with grounded theory (Duffy et al 2004) and subsequent questions were then developed in response to the issues identified by participants (an example of topic guide appendix B5).

5.7.4 Becoming acquainted

To build a 'spontaneous relationship' so as to elicit information (data) from a person you are meeting for the first is quite challenging. I also believe in the first few minutes the decision is made by the interviewee whether to talk and what to talk from the first impression given by the interviewer. So, as a South Asian meeting another (excerpt #6):

'the first interview'

Excerpt from the research journal #6

I knock on the door and wait patiently. I am wearing a contemporary styled cotton 'salwar' and I check the dupatta is properly draped across the shoulders. The door opens... I smile and say 'hello'... with a beaming smile the gentleman leads me to the lounge.... I remove my shoes, walk across.... a lady enters through another door wiping her hands on her dupatta, and she embraces me and calls beti.... we sit down and then the lady asks chai? I say no thank you.... Coffee? I refuse... and we sit and smile at each other... and I begin.......

This dress code was smart enough to follow the university dress code and but informal enough to meet the interviewees in their homes. I do not greet in our traditional Namaste (folded hands) because it will be a put on. Removing my shoes does not take any effort on my part for as a South Asian entering another house, this is my practice. What I have not done here is 'touching the feet of my elders'; instead I go for the embrace and to the lady only. And so I began, thanking them for the invite, and the small talk involved why they replied, how far I live from them. After few moments (in which their son came in and offer coffee/tea), I began explaining the practical aspects of the research such as the use of the recorder, recording of the interview, how it would be later transcribed by me and the consent form, where to sign. In such a non-threatening and non-judgemental process, a cordial atmosphere was established so that the interviewees would feel secure and have the confidence to speak freely.

5.7.5 Conducting the interview

Interviews are usually initiated with a broad or general question. After the interview began, I encouraged them to continue talking, using techniques such as nodding the head or making sounds that indicate interest. In some cases, the participants may be encouraged to elaborate further on a particular dimension of a topic of discussion (Burns and Grove 2003) by using probes. This interview involved open questions to guide the patient to think about and describe topic areas in which they need support in self-managing during the recovery phase. The interviews on an average lasted 40-50 minute. Prior to any interview written consent was obtained from each participant. I chose an approach to interviewing which is called one to one focused conversation akin to what Charmaz (2006) describes as 'intensive interviewing' (excerpt #7). These focused conversations also have a series of questions, which the interviewer is seeking.

One to one Conversations – the ultimate dialogue

Excerpt from the research journal #7

A beautiful picture or a piece of music, flash on our 'mind's eye' time after time. So, does these focused conversations. It is the ultimate art of conversing. Art in its uniqueness, makes us perturbed to go back and wonder at it again. So, does these focused conversations. The perfection of these conversations itself tells the story of the longing to have this conversation to go on and on and to ponder on the words spoken once you come away from it. It is to go beyond the 'what' to the 'why' that is risky, where there is a fine line between the prying and probing. Going beyond the 'Hi & Bye' acquaintships, such focused conversations identify the spiritual, social areas often left unexplored in our usual dialogues. In essence it is the epiphany of what makes this person tick? What makes this person angry? Whether the person has any social activities? On reflection to make conversations easy flowing and effortless, one needs to have a comfortable, trusting relationship with the other. Actually, this works both ways – relationships are forged with conversations. Few of us might feel vulnerable to access the emotional spectrum of our lives during our conversations. But the non-judgemental nature these focused conversation takes relieves such susceptibility and vulnerability. One person said: I feel 'unlocked' whilst another remarked 'I feel free'. On a more personal note, I feel it takes courage to lead a one to one conversation, but it takes a more courageous person to be the focus of the conversation.

In this research, I endeavoured to make the interviews with participants a lot like conversations with acquaintances - not utterly friendly, not utterly formal. I wanted to be open and approachable, and I wanted the participant to feel like they had power and the right to share what they wanted, in the way they wanted to. Usually I had the cup of coffee in my hand the microphone was switched on and discretely kept away, I used my phone as the primary recorder and the microphone as the secondary recorder, knowing that the phone is a nonthreatening device even when visible. I did not take any notes during the conversation, however spent few minutes in the bus/car whilst returning from the interview to jot down my feeling, the pauses and the facial expressions and the disruptions during the conversations which helped to develop early memos. I thanked them at the end of each interview (where usually another cup would be offered) for their time and knowledge and willingness to share their stories with me (excerpt #8).

'the trinity concept'

Excerpt from the research journal #8

Often I felt I embodied the 'trinity concept' – The researcher, the South Asian (normal), the nurse and each in itself an entity of its own. Therefore each time when I felt they looked up at me for elaboration or clarification or verification as a nurse, I found the easy way out, smile enigmatically and hmm softly. However, there were no situations which I would call an ethical clash - or when in my clinical judgement my participants were at risk. However, it is more than what you wear or say that matters to them, it is how you spontaneously behave in their 'territory'. For instance, in Mr Patel's house, whilst the interview was in progress, his daughter came out of the kitchen and went upstairs and did not close the kitchen door. Mr Patel immediately called out to her, and started to get up to go and close the kitchen door saying 'smell'. I immediately said, its ok, it's the smell reminds me of my home in India. He sat back (the daughter eventually came back into the kitchen and closed the door). Was it my tactic for him not to get up and so as not to break the flow or was that a genuine reaction?

Each of the homes I visited, I felt a part of me visiting my parents' home in India. They received me with such generosity - often I was welcomed into the kitchen - where I saw Punjabi dishes, Kashmiri dishes alongside South–Indian dishes, as well as Norwegian! – and the welcome I received at their homes, which I perhaps would not have offered to a researcher at my doorstep. And this makes me ashamed.

5.7.6 Multiple visits

Charmaz (2004) suggests multiple visits foster deeper understandings for participants' experiences. Multiple visits consider information on temporality and changes that could occur over time (Saldana 2003). Moreover, researchers (Russell and Gregory 2000) suggest multiple visits are well suited for the studies in chronic illness where adaptations and adjustment to the disease occur overtime. Here, a longitudinal approach was chosen because the aim was to explore how South Asians self-manage lifestyle changes overtime and by collecting data on two separate occasions.

Interviews at stage one: These interviews took place within one to two weeks of discharge from hospital. I chose this time when they are discharged home and before the cardiac rehabilitation programme begins. This early post discharge period is said to be isolating and stressful for the patients (Scottish Intercollegiate Guidelines Network secondary prevention 2004). Demographic data such as: age, gender and date of diagnosis was collected at this initial interview. Here the interview aim was to explore individual's perceived challenges in facing and incorporating lifestyle changes and therefore focused on exploring the individual's views of any perceived needs. At this stage, the material was as broad as possible to contain variations in self-management practices. Additional questions were used to obtain more detail and depth (How did you feel then? Could you give me an example?). I also elicited information regarding whether they received their cardiac rehabilitation letter and their anticipations regarding the programme. I also fixed the date for subsequent stage two interview as well.

Interviews at Stage two: These interviews occurred 16 weeks after their discharge from hospital, a stage at which the cardiac rehabilitation programme was completed. Here the interview aim was to explore individuals' perceptions of any need for their self-management practices and so the interviews focused on the individual's current situation and previously identified self-management strategies. The follow-up interviews began with the question 'How are you and how have you been doing since we last met?' In preparation for every follow-up interview, audio recording of the participant's last interview was listened to (for example, previously we talked about your work situation, how is it today?).

5.8 Recording and transcribing

I was responsible for transcribing all the interviews, which I did the day after each interview. I titled each transcript with a pseudonym which I appointed to that interview. Each transcript took approximately 3-4 hours to transcribe (I remember thinking the one year course doing medical transcription back in India 2000 which allowed me to become a touch typist helped me very much in this). Therefore, as my fingers flew, I was transported back to the space and time when we had the conversation. Though I had to rewind and listen sometime two or three times to a particular word in Urdu or Malayalam, I could do so without a pause in the typing. I remembered not just the emotions, but the interruptions, the pauses, the pivotal points in the interviews as well as my own trigger points. This wonderful immersion of data created a sense of interviewing twice over, which would have been lost had I allowed another person to transcribe on my behalf. Only during one interview did I became very uncomfortable and whilst writing the after notes in the bus, missed the stop I had to climb down.

However, whilst in-depth interviewing can obtain some insightful data with high degree of introspection, it is through the 'pragmatic tools of grounded theory' such as comparing inferences and analysing across interviews, across situations and across fragments of experience that meaning comes out. Charmaz stresses the importance of finding out the '*taken for granted aspects of life'* by which she implies that the meanings which are taken for granted will not be clearly visible even from a thorough scrutiny of an isolated interview transcript (Charmaz 2006:34). That is, instead of one in-depth interview providing the epistemological validation, the researcher travels across all the interviews - moving across data sets - comparing and refining categories, to postulate the underlying process.

5.9 Power balance and trigger points

Charmaz suggests that in order to discover participant's meanings, researchers need to be reflexive about their own. My initial empathic distance decreased, when my father suffered a heart attack. On the one hand, my presence was noted and I as a researcher in some respects did feel like an intruder, but on the other hand being of South Asian origin, fluent in Hindi and

dressing in the traditional 'churidar', I felt as though I 'mingled in' with my respondents and did not stand out in any way (Bhopal et al 1999). My physical identity immediately created a sense of empathy and belonging – indeed a spontaneous relationship - with the participants I was interviewing, in a way I do not believe 'white' researchers would intrinsically have been able to do.

Part of me was thrilled my interview reflected Scott's study (1998) exploring lay beliefs and the management of diabetes among West Indians suggested that rapport developed spontaneously because of shared ethnic identity: "We traded stories about how we ended up in England, what part of India we are from……..". However, on a deeper note, the professional in me cautioned that in fact studies have shown that the participants find it easier to work with white researchers, as they know that whatever is said will neither be questioned nor challenged, as they presume that most of them do not have an in-depth understanding of the South Asian culture and norms. Moreover, as part of the research process, researchers intrude into others' lives, no matter who is conducting research on whom. As such, qualities of a good interviewer include listening ability, enthusiasm, sensitivity and compassion (Sandelowski 1991; Payne 2000). These are the building blocks of any relationship which demands honesty, reciprocity, and trust. As a nurse, I am called upon to present these attributes as required by my profession and these may have worked rather than the 'magic pill' of ethnic matching.

5.10 Chapter summary

This research aimed to examine how this community self-manage the advised lifestyle changes after myocardial infarction. To achieve my aim, I used a grounded theory approach to interview the participants who has had a first myocardial infarction to acquire context based knowledge by going into the "field" (homes) and interacting with clients in their own milieus. This chapter shows how the research was explorative in nature, attempting to conceptualise how South Asian community choose and prioritise life style changes after an acute myocardial infarction. This chapter captures my thoughts on carrying out the research that formed my PhD learning journey so as to provide a context within which the reader can appreciate the journey undertaken.

As such, in here I have unravelled the recruitment process and the data collection method. I have also endeavoured to from coherent word structures from the research diary and blog entries I used throughout these three years of research. The interspersed reflexive accounts such as interviewing the members of same ethnicity, the adrenaline rush of listening to stories provide the necessary transparency to the research process and reflects how the constructive approach was adhered to.

Chapter 6 The analysis

This chapter follows my journey as a novice researcher, reflecting on the challenges faced and choices made at each stage of the analysis. A tripartite relationship, between the researcher, the participants and the data is generated during the challenging and creative process of data analysis. I filter the data through the lens of my personal philosophy and perceptions making the process unique and 'as I understand'. This forms part of my theoretical sensitivity and assists me in the collection and analysis of data. I use narrative excerpts and quotes to represent the views of the participants, so that their voice is heard and not too muffled by the authoritarian nature of the thesis. My role in this 'co-construction of data' is accounted for and declared throughout the chapter as I recount my struggles with the analysis and researcher role. This open and reflective approach is intentional, serving a dual purpose to convince the reader to trust the research decisions made (and thus the credibility of this constructive tale), as well as to defend the ethical integrity of myself as a researcher.

6.1 Selection of coding approach

Whichever version of grounded theory one uses, the grounded theory operates on cardinal analytic premises: theoretical sampling driven by constant comparative analysis (simultaneous data collection and analysis), conceptual understanding of data developed into theoretical categories, and finally formulated into a substantive theory (Charmaz 2003). A range of approaches to coding are outlined in grounded theory based on different interpretations of the method. Strauss and Corbin's version of grounded theory has been recommended to novice researchers as it provides direction and structure. However, for me it explicated an unhelpful layer of complexity and conceptualisation as Charmaz (2006) warns of axial coding that it 'applies a too rigid and formal frame'. I wondered

(sharing Charmaz's concerns) whether imposing a predefined structure moved away from a data-driven process, and whether this in fact resembled a more abstract *framework analysis* with its prescriptive procedures and graphic representation (Benoliel 1996).Viewed from this perspective, a constructivist grounded theory, values my engagement and acknowledges 'that I will leave *my footprint'* on the analysis and outcomes.

6.2 Encountering the coding in constructivist approach

Whilst Charmaz's writings seemed logical and understandable, for a novice researcher it is difficult to move from line by line coding to 'codes that create order' or to concepts or defend the line of decision made. This apparent loss of connection between the phases has compelled novice research students who followed Charmaz's method to add on other techniques for example – Clarke's situational mapping (Clarke 2005). Though this is allowed, I essentially regard this as a 'pick and mix attempt' which can potentially muddy the waters and so I have attempted to hold on to the tenets of the constructive grounded theory to carry out the analysis. Therefore, though I followed the data analysis of Charmaz (2006), a diagram (Figure 6:1) was developed to enhance logical flow for category development.

The diagrams are used in this thesis to make sense of the steps used and tentatively to form categories – that is to build the analysis. Whilst reflecting on the open coding process and the formation of concepts, it was also suggested diagramming/mind mapping would be beneficial. This proved to be an iterative process which I continued throughout the analysis. The use of such diagrams helped me not to be lost in between major steps. It also aided in providing enough structure and guidance so as to defend the 'co-construction of data' and to defend the emerging substantive theory. Moreover, it helped to limit methodological mistakes (Wilson and Hutchinson 1996), such as being `overly generic' (selecting names for conceptual processes that are not `situation specific') or importing concepts (adapt preconceived notions).

Fig 6:1 – Grounded theory Process

1. Initial coding (Beginning of conceptualisation).

2. Focused coding – separating/ sorting and synthesising large amount of data.

3. Categories – similar concepts grouped together.

4. Subcategories -Subcategories are characteristics and properties of categories along a continuum or dimensional range (Charmaz 1983)

5. Constant comparison - Linkages were made among categories to allow for some conceptual order to be placed on the data by using constant comparison, a method of comparing for similarities and relationships that exist among codes and categories asking questions about relationships in the data. Using the literature to outline and compare relationships among the categories (Charmaz 1983) and by using memos to argue the relationships.

6. Core categories – central story, key process around which all other categories can be subsumed.

Though I attended study sessions on the use of NVivo software for data mining, I was reluctant to use this approach for my coding process for three reasons: there could be a chance quite a number of codes could be assigned from interview accounts even those that had been used once or twice – which makes it look like some codes being forced upon the data and grounded theory has long accused of building analyses on skimpy data (Lofland and Lofland 1984), there is also a chance that these codes may resemble themes from the literature and may not explicitly be mentioned by the participants in the interviews and finally I wanted to immerse myself in these stories for I believed they would tell what they intended to say and not a 'machine'.

6.4 The coding journey – leaving my footprints

In order to give an insight into this process, I will present the exemplar codes and memos to illustrate the analytic process. Charmaz (2006) advocates to code for actions and meanings and do so in gerunds (noun forms of verbs) as much as possible for then it allows me to see processes that otherwise might remain invisible and to continue line by line coding 'until you have codes that you want to explore' (Charmaz 2006). These codes are taken and explored for how they account for further data – the questions are then reformed, literature is scrutinised to learn more about these codes.

6.4.1 Open coding

I began with a process of open coding of each interview transcript, using line by line coding (Charmaz 2006) to ensure that all relevant material was coded, and to break the text down into 'units of meaning'. I used an open coding method where I observed all of the participant's words. This line by line coding helped me not just merely focus on the points where the participants were emotional about, but on 'all the words and phrases' spoken by them. This was also one way of ensuring looking at the whole of the data instead of focusing on certain concepts at the initial stage (Fig:6:1 – overleaf)

Table 6:1 open coding/line by line coding

Line	Transcript passage	initial codes
1.1	My dad and my granddad both died in young age. Then both my aunties and	death
1.2	uncles they all have been diagnosed and get bypass done. So it's really bad	diagnosis
1.3	in the family and my younger brother, he is about 2 years younger to me. 3	family
1.4	years ago he had angiogram and a stent put in. His heart was stopped when	treatment
1.5	he reached the hospital. And it was luck for him there was somebody with	luck
1.6	him to drove him in their car to the hospital while he was having the attack.	help
1.7	So he reached the hospital in time so that they could revive him. So that	In time
1.8	was why I was worried and get a special appointment with the doctor and	worry
1.9	get my heart checked that year. Following year, this year, I went again for a	Heart check
1.10	recheck. Doctor booked me for another treadmill running, but before that	recheck
1.11	they send me what do you call it? Heart rest check it was in two parts, both	Heart check
1.12	parts was done. The week they done the second part, I was working that day.	Working
1.13	I felt my chest hurt badly. Normally that's ok, heart rate goes high and I	Normal
1.14	take deep breath and drink water. But that day it didn't, it lasted for more	Not normal
1.15	than hour. So that I went to the hospital myself. While I was there they did	myself
1.16	ECG and when the result came the doctor came. He asked for another ECG.	result
1.17	Normally it does not happen. They done another ECG, when that result	normal
1.18	came the doctor came into the ward. Before that they do another blood test. I	tests
1.19	had to wait for 12 hours. And that's what happened. And I told him I was	wait
1.20	Not expecting that and another so that we	Not expecting

The units of similar meaning were colour coded to 'group together' as seen below in Table 6.2. These words reflected the issues of ideas that the participants said were important to them. This routine helped to identify early concepts from which I could then shape subsequent interviews and therefore guide the data collection from early on. I also noted a "meaning of description" so that the differences and similarities could be easily identified and corrected (for easier theoretical sensitivity).

Table 6.2 units of similar meaning colour coded to 'group together'

Line by line coding and sorting		Focused coding	Constant comparison
death	Death	Worry of death/waiting	Constant comparison with another set of focused coding derived from sorted line by line coding
diagnosis	Worry	Timely support/self and family	
family	wait	Diagnosis and treatment	
treatment	In time	Normal and not normal	
luck	Help	Not expecting/expecting	
help	Luck		
In time	Myself		
worry	family		
Heart check	Heart check		
recheck	Recheck		
Heart check	Treatment		
	Result		
	Tests		
	diagnosis		
working			
Not normal			
Not normal	Not normal		
myself	Not		
result	expecting		
normal	Working		
tests			
wait			
Not expecting			

It was hard and tedious work, but as suggested by Charmaz, at this stage I did not worry about the 'sophistication of the codes'. I asked myself what is happening here, what is the story? This group of early codes later led to some early concepts as depicted in figure 6.2. Using open codes as a starting point, the process of focused coding helped to verify the adequacy of the initial concepts developed.

Fig 6:2 Some initial concepts from focused codes of first interviews

First
Interviews

Religion
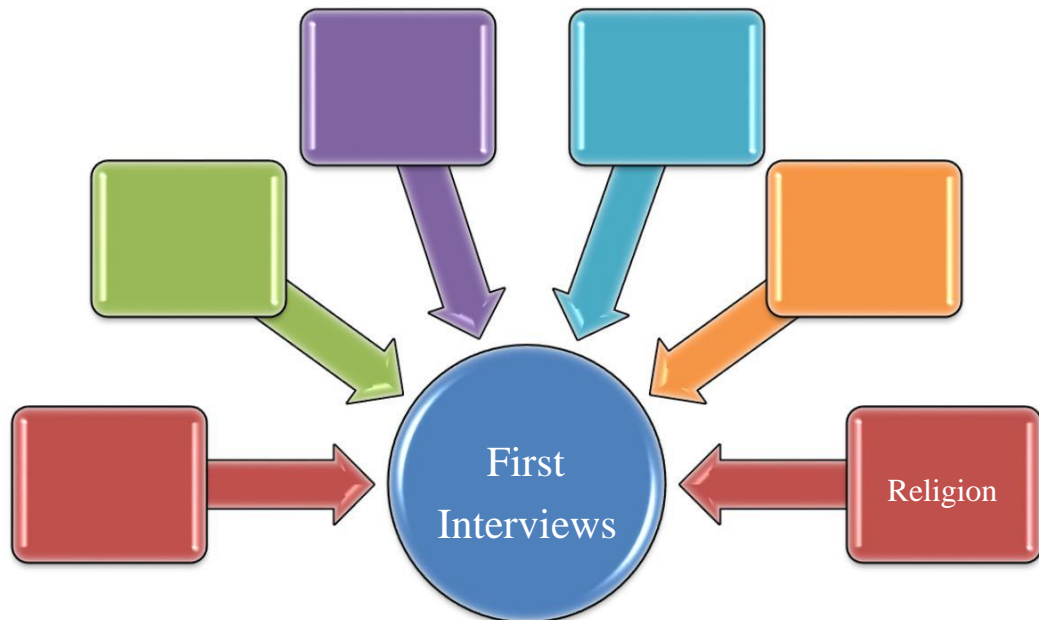
6.4.2 Focused coding

Focused codes require the researcher to choose the most telling codes to represent the interviewee's voice. This focused coding phase was more directed and selective than the initial phase of open coding. Therefore, they were not meticulously assigned to every single line of interview transcript but were used to develop initial concepts which later helped me to focus on. I comprehensively reviewed the existing memos, combining those covering similar areas example. Once the focus codes for each individual interview transcript had been established I began to write early memos to myself about each focus code. I found it helped to see where I am 'grounded' and where I am making 'conjectures'. This then allowed me to go back to the field to check the conjecture.

'Friends and family' was identified very early as key category. Figure 6.3 shows the focused codes developing into the category of family and friends. This was also followed for each interview, as each interview was a venue for a new story but as I was cognisant of the concepts emerging from the data, I was also able to see each new interview to add onto the emerging concepts as well as creating new ones. This allowed me to establish the relationships between the codes and helped me to select the appropriate concepts during the selective coding process.

Fig: 6:3 An early category formation of family and friends from initial quotes (blue speech bubbles forming initial codes clustered into similar groups (purple, pink and blue and forming focused codes/concepts green) and an early category (in yellow).
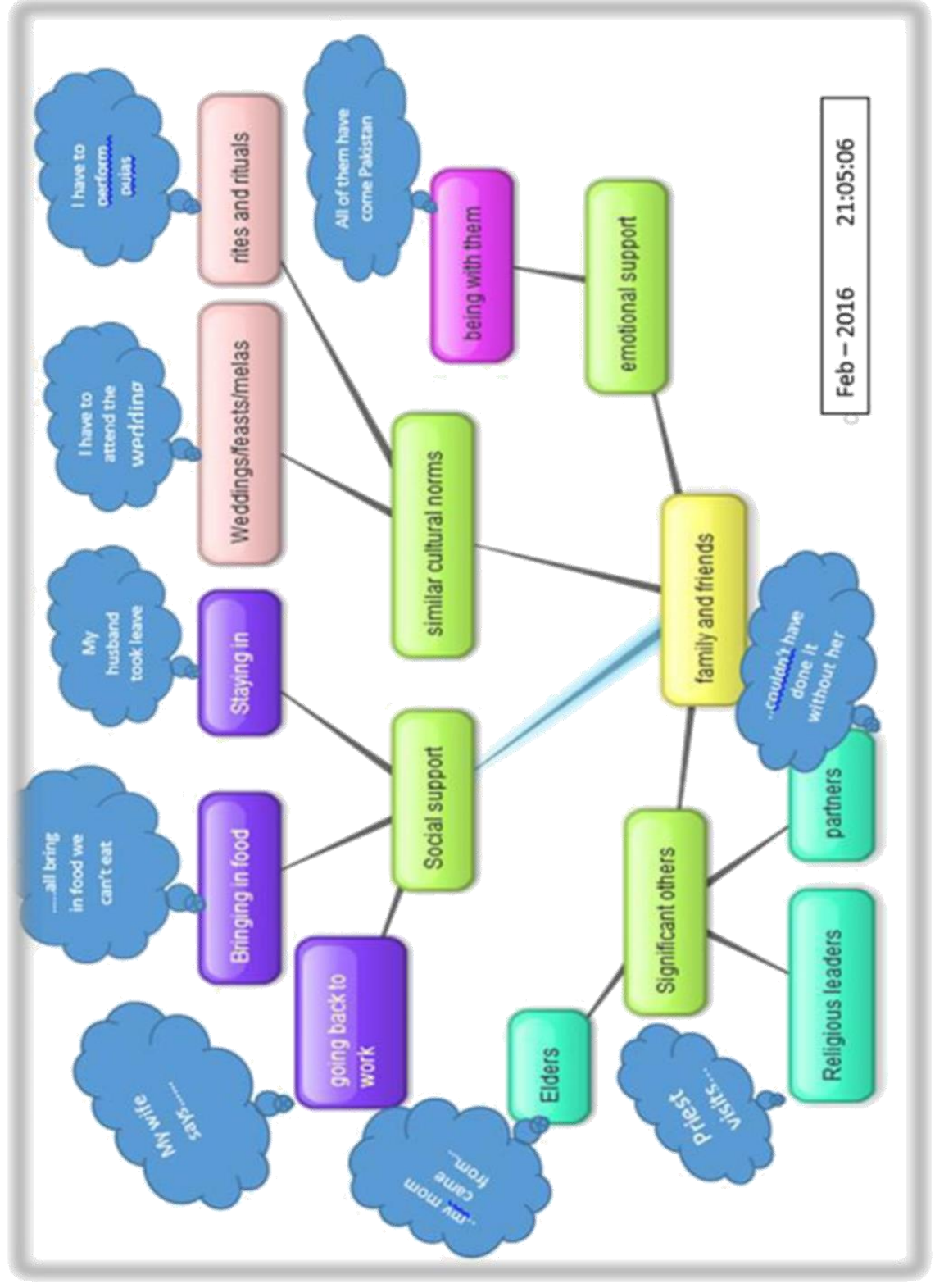
Charmaz indicates a comprehensive list of items which make up the constant comparison including: a) comparing diverse views b) comparing data from the same individual across various time frames c) comparing incident by incident d) comparing data categories e) comparing category with other categories (Charmaz 2010). Categories attain the theoretical level because of their '*theoretical reach, incisiveness, generic power, and relation to other categories*' (Charmaz 2006:11). By comparing the data from the same individual across two time frames, I could progress the emergence of conceptual ideas.

6.6 Use of memos

It is a process for recording the thoughts and ideas of the researcher as they occur throughout the study and are vital as they provide ideas that map the emerging theory. Memos can shed light on the direction of the analysis of data, help with the formation of new ideas for a code and identify and elaborate the relationships between categories or identify gaps for integrative discussion (Charmaz 1999). I attempted to use excerpts of my reflective journal and memos (Figure 6:4) to show the path of theory construction and to think early about the practical implications.

Figure 6:4: Memo on starting the coding
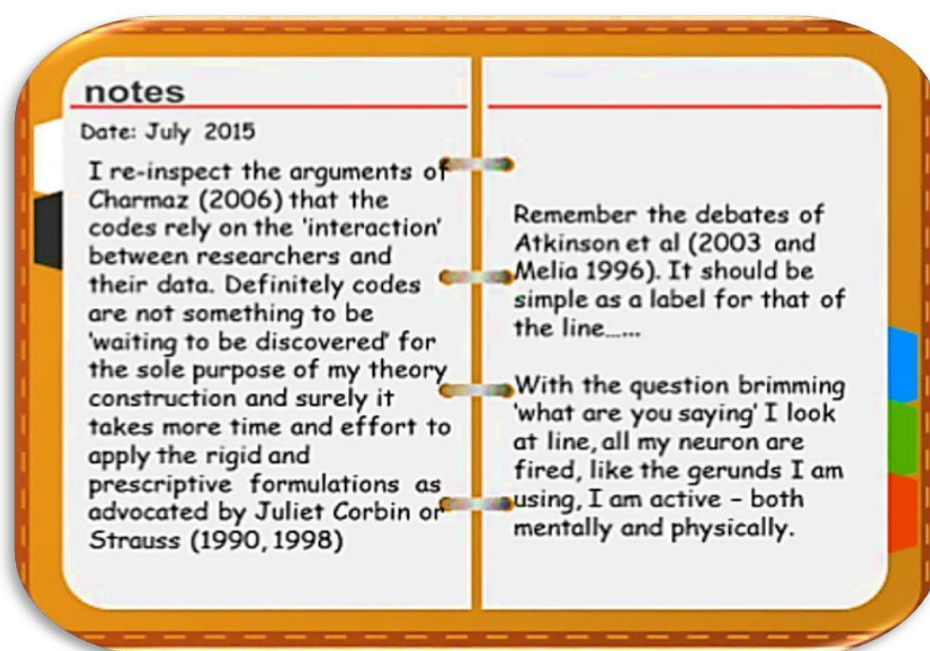
These 'conversations to myself' varied from post it notes to multiple A4 pages to blog posts. These memos helped the analysis in: facilitating reflexivity and reflection on data collection methods (as annotated in previous chapter), interpreting the interview accounts, clarifying the relationships among codes and categories, developing final categories and more importantly interface wider academic literature into the analysis. It also enabled me to reflect on my own experiences and how these informed the research process. On other occasions memos became the sounding board to raise my concerns, hesitancy, doubt and lack of confidence (prequel to the imposter syndrome usually felt by PhD students), always wondering whether I chose the codes and labelled the concepts and categories that reflects the data or whether they were preconceived labels.

Moreover, decisions and pivotal moments are explicated in the memos and they serve as analytical texts to expound what is found. As such memos form the records of analysis related to the development of the theory. The nuances, silences and pauses captured during an interview that are also noted in the memo can add detail thereby enriching the data analysis.

6.7 The review adding to theoretical sensitivity

Lifestyle changes and self-management literature is located across a number of disciplines, including psychology, sociology, anthropology and not just in the health sciences (Thorne et al 2002). Some were read as a snowballing technique – one argument leading to counter argument. Thus the literature was used to stimulate theoretical sensitivity by providing concepts and relationships that are checked out against actual data.

From my journal: regarding the reading

Excerpt from the journal #9

I could equate this reading experience to Anton Chekov's short story 'The Bet' where the young lawyer reads for 15 years in solitary confinement. Immanuel Kant transported me to the land of 'duty' whilst Antonovsky's salutogensis led me to a sense of coherence. I was mesmerised by theological arguments of 'burden of proof' by Bill Nye. I was astounded to find the profound statement from young Joseph Ratzinger: the "objective mind" discoverable in finite reality is the consequence of the "subjective mind" that thought it into

reality. I covered Richard Schweder 'thinking through cultures', the cultural matrix of social psychology (Hazel Rose Markus, Shinabu Kitamaya) and presentation of self by Erving Goffman before I had the 'epiphany' of the distinction between 'constructionism' and constructivism'. I also accidently read Margaret Mead, instead of George Herbert Mead (hearing the name Mead endorsed by Charmaz in her interview with Graham Gibbs). I travelled with John Dewey's pragmatism (rather 'instrumentalism'). I entered the tribe with anthropologist Malinowski's 'sexual life of savages'. In the British psychologist Elizabeth Stokoe's patterns of talk studies, I saw the difference a mere word in a sentence can make. I argued with my husband – proficient in German, about Martin Heidegger's 'Das Ein'. I read through the 12 laws of Karma and Dharma I understood fatalism has a mathematical equation. I was struck by Pablo's 'tragedy' (1903 portrait of the family). I was enthralled by crime movies that raced against time (behavioural psychologist and crime investigators competing to solve it first). In Sherlock Holmes, I saw the canons for both inductive and deductive reasoning. In each of these readings, I encountered parts of my participants. However, though I savoured these intellectual delights, what immersed me was the works of Michael Gruber which in turn led me to Jung's conflict theory.

6.8 Sensitising concepts: from the knowns to the unknowns

As mentioned as in chapter three, sensitising concepts captured through the review added to theoretical sensitivity and aided in data analysis. Charmaz (2003) has referred to sensitising concepts as "*those background ideas that inform the overall research problem*" and stated further, sensitising concepts offer ways of *seeing, organising, and understanding experience; they are embedded in our disciplinary emphases and perspectival proclivities* (Charmaz 2003:259). Blumer who originally developed the term distinguishes it from a definitive concept (Blumer 1954) and Charmaz clarifies that such general sense of reference and awareness will alert the researcher to search for certain possibilities and processes in their data (Charmaz 2006:16). Here the sensitising concepts were used not to lay the foundation for the analysis of interview data, but they formed the background discourse to the thesis. The divergence from the sensitising concepts is further explicated in the discussion chapter.

6.9 Theoretical sampling

The theoretical sampling started off and completed the theoretical coding. Major focused codes were fleshed out, examining the situations in which they appeared, when they changed and the relationship among them.

Table 6:3: from initial codes to category

Text	Initial codes	Focused codes	Theoretical sampling	category
We looked at what we eat, what we had done in the past that could have caused it. My wife tells me its me drinking coke and I know that it is and all the meat I had. But the difficult thing is I enjoy eating. I always enjoyed eating and my wife is a very good cook, she enjoying cooking and seeing me eat. Now we need to make some adjustments. But how far and how much I do not know. It depends you know. It depends on a lot of things. It depends when someone is coming to visit you, or you are going to your relative's place, we have a lot of relatives around you know. She (wife) too has a lot of relatives. She loves entertaining. So always there is someone coming in or we are going to theirs house. So it depends. Like when we go to their house, I cannot say I have I cannot have this, I cannot have that. That's not polite. And when they all come here, I cannot say, we do not eat this, we are on diet, that's not really nice. Its not in our way. Our guests are next to God. So you do not give less things to God, so you do not give less things to the people that come to our house.	Eating Past habits Cause Relative Cook meat Cannot plan Not polite	Lay beliefs Eating habits Relationships Socialising Difficulty in planning Making Adjustments	Hospitality Maintaining the norms Cultural values Difficulty in planning adjusting	Affinity towards one's group

The purpose of the second interviews was primarily to explore changes in people's experiences, it being assumed that the length of time since attending cardiac rehabilitation would mean that patterns and perceptions were generally well-established. It provided another layer of challenge that my father too had a heart attack. It was an overwhelming, strange, confusing and guilt-ridden experience and at many levels it presented a variety of practical and emotional challenges - excerpt #10 – overleaf.

Maintaining the emotional distance

Excerpt from the journal #10

I believe that self disclosure can be a beneficial activity. This was particularly borne out in one interview within which a participant talked about 'how tired he was, with no energy to do anything'. This phrase acted as an emotional trigger as it was exactly what my father had said a week into his discharge from ICU after his first heart attack. I observed a distinct 'relaxing of his posture and language' when he realised I was coming from a similar background, and was not what: 'an outsider looking in'.

The research had an unexpected cathartic effect. Perhaps this would be by undertaking research in an area that I had personal experience. By listening to their stories, I could feel more deeply, about their own struggles, deepening and expanding my comprehension of the participants' stories, and to reflect more deeply upon my (father's) experiences via the similarities and differences to participants' experiences.

6.10 Achieving the saturation – coming to terms with the enigma of saturation

Charmaz argues that data saturation is "an elastic category that contracts and expands to suit the researcher's definitions rather than any consensual standard" (Charmaz 2001:690). However, the concept of 'saturation' can be argued to differ between varying qualitative methodologies. In a grounded theory study, theoretical saturation is sought in which all of the concepts in the substantive theory being developed are well understood and can be substantiated from the data (Fig: 6:5 overleaf)

As the interviews and analysis progressed and when the categories identified in the data become more substantial, clear and refined, it was deemed appropriate to stop the sampling. This was the saturation point - when the data gathered provided enough depth, diversity and detail to offer the potential for developing a "*comprehensive and convincing theory*" (Morse and Field 1995:148). I have been able to determine this in several ways. As I became increasingly certain about the central focused codes, I re-examined the data to find all available insights regarding those codes. Then diagrams were drawn, aided by the

memos. I endeavoured to look for events or accounts not explained by the emerging theory so as to develop it further to explain all of the data. A pivot point is when I presented the developing theory to specialist audience and have found that it was accepted by and resonated with these audiences.

Dey suggests that the longer researchers examine, familiarise themselves and analyse their data there will always be the potential for "the new to emerge". Instead, saturation should be more concerned with reaching the point where it becomes "counter-productive" and that "the new" is discovered does not necessarily add anything to the overall story, model, theory or framework (Dey:136). Towards this end, I am reminded of Bertrand Russel - probability is all we ought to seek:

Bertrand Russell and the problem of philosophy

The man who has fed the chicken every day throughout its life at last wrings its neck instead, showing that more refined views as to the uniformity of nature would have been useful to the chicken. But in spite of the misleadingness of such expectations, they nevertheless exist. The mere fact that something has happened a certain number of times causes animals and men to expect that it will happen again. Thus, our instincts certainly cause us to believe the sun will rise tomorrow, but we may be in no better a position than the chicken which unexpectedly has its neck wrung. It can never quite reach certainty, because we know that despite frequent repetitions there sometimes is a failure at the last, as in the case of the chicken whose neck is wrung. Thus, probability is all we ought to seek (Bertrand Russell The problem of Philosophy chapter 6).

6.11 Aligning researcher reflexivity and theoretical sensitivity

Theoretical sensitivity is the ability to recognise what is important in data and to give it meaning which in turn helps to formulate a theory that is faithful to the reality of the phenomena under study. Schreiber (2001:60) states that 'the personal background of the researcher is the filter of salience through which data are sieved"; the ongoing processes of constantly challenging the researcher's own biases and personal theories against participant data to ensure that emergent theory remains grounded in participant data. In here, I use the term theoretical sensitivity to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and capability to separate the pertinent from that which is not.

The sources of theoretical sensitivity in here were literature, professional experience and personal experience and the analytic process itself. By conducting the scoping review, I had some familiarity with the area which sensitised me with what is going on with the phenomenon and from being well grounded in the literature. Throughout years of my nursing practice, I had an inherent knowledge of how things work. By drawing upon the personal experience of my father's heart attack, I had another source for making comparisons. However, I was careful not to assume that my participant's experience has been similar to my father's heart attack event.

My insight and understanding increased as I interacted with the data, for example asking questions about the data, making comparisons. Often I found one idea or insight sparks another. This increases sensitivity to concepts, their meanings, and relationships and I found the concurrent data collection and data analysis speeded up the process, as each feed into the other thereby increasing insight and recognition of the emerging categories.

Researcher reflexivity, central to a constructivist perspective on grounded theory (Charmaz 2008), was not to undermine data or the generated theory, rather as reiterated in the prelude, rather it was a way in which the reader could understand the context in which the research took place and how the choices and decisions concerning the analysis were made.

6.12 Forging relationships - interview, coding and category emergence

During the theoretical coding, interviews were conducted using existing findings and codes to support this process, I followed Charmaz' (2006) advice to sample within the categories in order to develop theoretical coding and the categories. This was facilitated by two intertwined processes; *for one part the iterative process of focused coding*, and for the other part reflecting on the codes, facilitated by memos to establish links between codes and tentative categories.

And for this I was again aided by the memos. Moreover, I acknowledge I also brought in my particular field of knowledge and experience whilst co-constructing these categories. As such, in the coding, as well as in the construction of categories there is an unambiguous level of researcher's reflexivity enhancing theoretical sensitivity.

I felt the need for a third person to verify that these 'codes' were indeed correct. However, as I continued further into my coding journey I become more conversant with the perspective of there being no 'right' interpretation, that is no 'right code' – and this is rightly aligned to the 'multiple realities' perspective. As with all process, I expected the coding and analysis to move in a linear fashion, follow a neat pattern of one distinct stage to another, thus moving from open coding to focused coding. However, I found that it was not so and the analysis progressed in a much less 'neat' fashion. Though this concerned me, briefly I was reassured by Charmaz's (2001) description of the cyclical nature of the grounded theory coding process.

6.13 Chapter summary

In this chapter I have outlined how I explored data and the process of analysis took place in several stages, although many of these overlapped, as the nature of analysis in grounded theory. Theoretical sensitivity presented formed an important creative aspect of grounded theory and the research here, and I presented it here. The process of analysis, as delineated here, helped in the category formation. The description of development of theoretical categories is assigned to next chapter.

Chapter 7 Theoretical categories

I have crafted this chapter to represent the response to the research question that I pursued – and like the explorer have now come back to tell the tale. As such the three theoretical categories (Figure 7:1) constructed detailed in chapter six provide an insight into the processes about how South Asians choose and prioritise lifestyle changes after myocardial infarction. The three categories are - *affinity towards one's group, conforming to the religious and causal beliefs and patronage of the family*. It is important to note that although these factors will be discussed independently, they are not mutually exclusive and are, in fact, interwoven such that one may impact the other in an intricate and complicated manner. The chapter concludes by providing a brief discussion of how through the coalescing of these theoretical categories by the help of analytical memos, the theory is developed and advanced.

7.1 Constructing the theoretical categories

In a constructivist approach there is an attempt to understand the experience of the phenomenon through a theoretical rendering which "*describes, explicates, and synthesises multiple statements and observations*" (Charmaz and Mitchell 1996:295). A polarising corollary to this is the criticism of interpretive analysis and subsequent theoretical constructs as ambiguous, and questionable, weakening the credibility of ensuing theoretical assertions (Gasson 2004). To limit such a criticism, I have endeavoured to interweave memos as reflexive analyses into the account of these theoretical categories.

Early concepts of the interview transcripts – namely family and friends, religious beliefs, health beliefs and culture were initially categorised into collective attitudes, a relational orientation; relationship with the family, family duty and obligation and then later refined to following categories - affinity towards one's group, conforming to religious and health beliefs, and patronage of the family. Following the introduction of each category an explanation is given of how they emerged from the data, illustrated with quotations from the participants who took

part in the research. This is followed by a description and explanation of the categories, and how they converge or diverge from the existing literature. Thus, with the help of analytical memos, the section ends with a description of how the categories contributed towards the development and advancement of a theory.

7.2 First category - Patronage of the family

Support from family members was common and was the first descriptive theme to emerge. Family members come from far and wide to gather around the sick bed, they refrained from going to work to look after the sick person or the sick person (even married and with children) went to stay with their parents. Most of the participants were surrounded by either their immediate family, relatives or extended relatives. Spouses, children, daughters and sons-in-law, friends, neighbours and fellow-patients were judged as important for their recovery.

This category was constructed upon the following emergent initial concepts/focused such as– support, encouragement, with me all the way, couldn't have done it without her, aid, help, assistance, guide, influence, strengthens, motivating, staying positive. The recurring concepts were – family comes first, the naturalness of the helping process and a prioritising of family needs led into the development of the subcategories of influence and support which formed into the word – 'patronage' – which stands for influential support. Theoretical codes such as emotional incentive for lifestyle change helped into formulate the category. Thus the codes and concepts coalesced together to from the first theoretical category which recognised how families provided the influential support in the early stages of recovery.

7.2.1 Subcategory - support

Though the participants were upset whilst discussing their first heart attack, during interview, the overall tone of each interview was essentially not so negative. They had just been discharged from the hospital and they found the reality of what had happened very stark.

'I just feel the same ….… but at the back my mind is always the thought 'when will I have another one. But when I look at the family, and their help and support, I feel foolish to think like that. - Padma

Participant narrations suggest that through their survival, each of the 14 participants had emerged emotionally stronger and more determined to learn and move forward from their experiences. Family was an important motivating factor as participants recognised that their lifestyle changes were not solely for their own benefit. Family members exerted a positive emotional incentive for a healthier lifestyle. Family members exerted a positive emotional incentive for a healthier lifestyle.

My mother who lives in Sheffield comes and makes sure I take rest and eat the right food (88-year-old mother travelling to see her twice married son who is 67 years old). When she (her mother) comes to my house there will be fruits but when I go to my mom's house she gives me samosas (fried snack) (laugh). – Mohammed.

My sisters and brothers all encourage each other that you have really got to look after your diet and lose your weight. In myself I cannot say I have enough strength to go through the changes, but if it was my daughters, they said –amma you need to do start looking after yourself now. It's easy to talk to them you know they have been there they know what you go through. - Padma

She, my wife,.. she is a big support to me… She suffered with me actually we all did, changing. Its not easy to change for one, but all of us change rather than change for one - Kamal

My grandson, he says, 'Grandma, I'll help you – Devi.

My brother had it he told me what to do. "I found out more from more from my brother. Its easy to talk to him rather than to a doctor you know. He has gone through the same. So he knows - Raju

Of the fourteen participants in the study, all felt it easy to discuss their feelings and emotions with family members. It appeared that these had how much help they received in meeting the expectedness and unexpectedness of their condition.

7.2.2 Subcategory - incentive

Those who did not have their extended family, people who could have helped them in time of need to face the challenges heart attack made in their life. Usman reported:

It was a very difficult experience for me... I used to call them regularly and they used to call me as well. I used to cry for them like a small child. And I feel bad for crying when I shouldn't. This will upset my children all the more seeing me crying. So I try not to cry and this not trying to cry make it hard. But if they were here, it would be different.

Different?

Well. For one I can take break from taking decisions. For another, they can take the decisions what I need to do now… My wife she is only young…. she needs help as well. But our friends are there, you know. They do come. But they also have responsibilities. I feel bad if they come so often as well.

Usman clearly explains the need for family when in crisis. He does make a point when he says, he can take a break from making decisions. This is surprising, that decisions are not made by the individual, but by the family.

Readiness to make lifestyle changes was often prompted by family. For participants, most importantly this 'support' also influenced how they self- managed the dietary changes, started physical activities after the heart attack. Bringing in food Staying in Let them stay at parents' house.

For example, today its Friday she made poratta (a snack rich in carbohydrate) and instead of 3 tablespoons, used one teaspoon. Cannot see the shine and healthy of the oil (Wife made his favourite dish). I think you can eat curry or poratta once in a while the important thing is to balance it. After eating you need to go to gym or other exercise and wash it away. The thing is to keep it in balance. That is my philosophy. - Mohammed

History of heart attacks in the family prompted participants to purchase low fat foods, use healthier cooking oils and encourage their family members to do the same. They had received practical help by cleaning, gardening, repairs, shopping and transportation, and were no longer expected to look after the grandchildren as often as before. They talked to them about self-management.

We have friends that we see quite often...we talk about it...they are all supportive… Kamal

I have two cousins who had this, and they had the surgery and they say they are like new. So I am waiting to feel like that. It's a bit sore now. But I suppose it will go away after few weeks. -Devi

They seemed to rely on family members to provide them with information about their disease.

My son showed me what caused this block in my heart. In the youtube. He showed a picture of the heart and showed the whole thing as well as the surgery. It was amazing what you can do these days - Padma

Family played a significant role in recovery by supporting and enabling the participants to make lifestyle changes primarily by providing the incentive and motivation.

7.2.3 Subcategory - influence

Participants benefited from having family members with them and the subcategory of influence was developed by the codes - primacy and priority.

7.2.3.1 Primacy

According to the participants, family and friends were the first port for call of help, their primary source of support. For example, Fatima considered the presence of her mother a great support, especially while experiencing the hardships of the heart attack, as it offers "support" and "strengthens" her. She believed her challenges would be overcome through collaborative family support so she insisted her mother join her from Pakistan. Praising her family for the support she received, Fatima said:

…when in crisis we would first rely on our family first because Asians are family oriented. It does make a difference to have a family here because if your family is with you then you can support each other; otherwise, you will be depressed. It was an extremely painful experience which kept me depressed most of the time. It was difficult because I wanted to be upset, but I couldn't be more upset, because this will only upset my husband and my sons. But when my mother came from Pakistan it was like I could behave like my son (laughs).

We are used to receiving help from family, it's a duty and an obligation for the family to help you. - Satti

She is with me, she talks to me. We need to put family first.- Raju

Raju's whole family – wife and 5 children – was involved in supporting him. The children took turns to be off work to stay with their father, 2 of them had families of their own. He added to what Fatima said by highlighting how natural it is for him to turn to his family.

The help is natural, they are family members. If your brother or sister needing help, I do not think I'm losing my precious hours of sleep on this, you just help. You think, it's my people, they are family. We're a close-knit family in the sense that we're always there. He (brother) knows that I'd do the same for him, if he was in this situation. We are used to receiving help from family; it's our duty to help.- Raju

Complementing Raju's feelings was Philip's comment. Philips explained:

Its natural you know to turn to near and dear ones, they Understand better, its easy. My brother had a heart attack and he warned me you could get this as well. I know what he went through. I helped him when he had his and I turn to him when I had mine. Its like when our children were born, we had to help out each other when they were small and now we are babysitting each other… he laughs – Philip

The affinity of shared experience with immediate family members for example 'My brother knows because he has gone through this before' phrase highlights that family members were most likely to have come across comparable experiences and as such have resonating understanding of the plight of being diagnosed with myocardial infarction. The feeling of being supported by their family depended on the family understanding their condition. Thus, the family system provides access to 'familiar' people who have empathy with their experience.

7.2.3.2 Priority

Family versus 'individual' priorities – another characteristic was how they prioritised domestic duties over the lifestyle changes. For example making the school run was seen more important than going to gym. Importantly, domestic duties took the priority.

I think of them you know. After all they come first. At the end of the day they are only there for us. - Philip

Yes, this is a terrible disease, but it cannot interfere with our family pattern, the routine is set, they come first. – Sayed

There was evidence to suggest that this helped some participants to adopt more healthy behaviours.

It does make a difference to have a family here because if your family is with you then you can support each other; otherwise, you will be depressed. It was an extremely painful experience which kept me depressed most of the time. It was difficult because I wanted to be upset, but I couldn't be more upset, because this will only upset my husband and my sons. But when my mother came from Pakistan it was like I could behave like my son (laughs). - Fatima

I wouldn't be able to say no to what I was eating and drinking. In the programme I attended they said its your goal this is the target, and I come home sit down with others even my deaf mom, bless her soul, she will come and sit around and I will go through what I learned and we make it our target. Then its easy. I think of them you know. After all they come first. At the end of the day they are only there for us – Philip

The notion of "change" for oneself was given little priority as family were more important. The support and advice from friends when translated into social persuasions – shared efficacy seem to influence their choice on lifestyle changes. The notion of "change" for oneself was given little priority, as they tended to prioritise family goals and needs, conflicting over

individual interests and activities. When in conflict with family rites and rituals, family goal and needs took priority and the notion of family first was a key influence

I do not want to go out for a walk, my husband he cannot go out with me and I do not feel comfortable going outside without him. I know he will be worried if I go out without him and I cannot always ask my son who is so busy working to come for walks in the park with my old mother. What will people say? It is ok for the programme people and the doctor to say you have this and you have this, you need to do this and you need to do that. What do they know about us? But if the weather is fine and if it's a good day then my husband comes with me and we have a 10 minutes' walk. - Devi

Within Asian families, often family needs are given higher priority over the individual needs (Sue 1998). They tend to prioritise the family needs and priorities which conflicted over individual interests and activities.

7.3 Explicating the category in an analytical memo

Explicating the category in memo #1

from influential family support to patronage of the family

Family patronage as used in this thesis highlights loyalty, trust, and cooperative attitudes within the family group, which places the family wellbeing against the interest and necessities of each one its members through the development of a feeling of duty among its members. Social support means being able to access people that a person can rely upon if needed. The support offered for lifestyle management close by peers/family members demonstrate the considerable influence they have over lifestyle changes and choices. However, support strategies and tools for self-management are dependent on relationships based on obligation. From the inferences in the interviews I would suggest there was a 'social connection' that were helpful in supporting lifestyle changes.

I hear the comment "in our culture, we try to manage" and think this is because there are dimensions within the family system of support that bridges the gap/fulfils the aspects of care left unfilled by the formal health care system such as cardiac rehab programs. This finding can reveal the specific cultural situation of our society in which family play a vital role in meeting individuals' needs. Could this be because these supports have shared norms about the needs?

Because they are more stable than the 'systems formed by funding sources and so they do not need be compliant with the procedure of formal resources? That the system of help lies in interpersonal relationships which are sensitive to the individual needs and so can adapt based on knowledge obtained from these relationships? But how do we know how well these support systems meet their requirement? Is there any evidence of this in the literature? (I also note how uncomfortable I was when I was writing this memo. There was that feeling I was missing something here, the participants were trying to tell me something, but I was not able to capture this…maybe that's why I write my thoughts as questions).

Patronage of the family, developed from the codes – incentive, influence and support has helped to move my thinking towards shared norms. Whilst efficacy is termed as the 'ability of the individual to perform the task, meet a goal, I believe for South Asians, the ability lies not in the 'self' but in the family. The family providing the incentive, influence, and support and I wonder whether I can term it shared efficacy?

For South Asians families, a closely-knit group, provide the greatest social and emotional support for the patients. For most MI patients, good family and social support may be associated with better recovery with lifestyle changes.

7.4 Explicating the category in the literature

Modern living often demands the need to juggle both a career and family life; when normal daily living is upset by a myocardial infarction, the effects are felt by not only the patient, but also the wider family circle (Kettunen et al 1999; Arenhall et al 2011; SalminenTuomaala et al 2013). However, these family experiences include strength and solidarity (Jensen and Petersson 2003). The concept for family and friends support found in this study is consistent with existing research in which family and friends are sought in times of need (Ying 1990), reflective of the substitution framework (Scott and Roberto 1985). Thus, family support is

specifically influencing patient's behavioural characteristics as well as directly affecting selfcare.

7.5 Category summary

Participants relied on support from their family and friends to make and maintain lifestyle changes, family provided emotional support and give them information about coronary heart disease. The support and advice from friends when translated into social persuasions (shared efficacy) seem to influence their choice on lifestyle changes. When in conflict with family rites and rituals, then family took the priority.

7.6 Second category - conforming to the religious beliefs

The second theoretical category conforming to the beliefs captures the influences of the participants religious and health beliefs regarding their diagnosis of heart attack and the lifestyle changes they have to make, since their acute cardiac event.

7.6.1 Subcategory - faith as an adjunct to medical therapy

7.6.1.1 Complementing

Religious expressions often found their way into the interview centering on conversations about their recent heart attack and road to recovery, demonstrating close links between participants' health and religious beliefs. For participants, religious practices such as praying and trusting in God ran in parallel and more often than not trumped the advice and guidance provided by the health care professionals. For Muslim participants 5 Niskars* per day, for the Sikh participant following the teachings of the Gurbani*, for the 2 Christians going for mass and reading the bible and the Hindu participants, conducting pujas and reciting shlokas were seen to be just as vital as the medication for their recovery.

Sometimes I think…. I take the medicine but who decides it should work, Allah? Isn't? If I prayer and prayer I can become better, that is also going in my mind... after all who knows what is there in the medicines? All is polluted, God only has the power to make clean my soul and body……" Usman

of cos, you need to take the medicines, but the praying to your God is also important. Yes it is important. You take 5 pills a day, you pray 5 times a day.- Fatima

You know, my mom decides what pujas I have to take now It is important that I have to do that. it's all part of getting better you know." – Padma

I remember some of the religious teaching from my childhood. I used to recite prayers We needed to do that repeatedly. Even if we are going through a difficult time, we must rely on God, you know…… You need both prayer and medicine. Medicine works through prayer.- Satti

It was not just taking the medications prescribed that would aid their return to recovery but faith in their religion, rituals and practices as well. Faith and religion thus provided an additional resource for managing the illness. Thus, faith complemented rather than obscured efforts of secondary preventive measures.

7.6.1.2   Religious Rituals

The participants made use of religious rituals such as speaking to gurus (teachers), priests or Imam. Such visits from religious leaders such as Imam, gurus and priests were welcomed warmly as another source of support. Practices such as daily prayer, reading religious texts such as the Path* or reading the Qur'an and individual meditation helped to alleviate their fear and anxiety towards the changed future. Rituals, daily prayers, increased their ability to be more resilient with their condition.

Raju added: "*Yoga, I do yoga; it helps stress. Yoga will also help you to control… your thoughts...I think it will help me control my diet! (Laughs). My daughter does yoga and she says ji you should try!*

Such strategies were seen as possibly reducing or even stabilising the symptoms of heart attack and enabled them to cope with difficult experiences of changing their lifestyle. Participants expressed distinct conviction that such religious rituals were transcendental approaches helped their recovery journey added value to the other secondary prevention efforts prescribed by the doctors. Katsuno (2003) noted that participants believed religious practices such as ritualistic prayer enriched their lives and enhanced their capacity to recover from difficult situation.

We are religious you know, doing our bit of Puja. Actually I think I am here today alive and well talking to you, is because of my faith in my God - Devi

I go to church, and pray: please God help me because I cannot go through this alone - Philip

Participants repeatedly acknowledged their belief/faith enabled them to cope with the adversity. Fatima said she was too young to be religious. So was not that keen. But once she had the heart attack, she became once again religious in the paths of her mother.

I am basically non-religious person. I am too young to be so religious like my mother. But after this – this frightening blow-I have re-thought about my religion and faith. I am now obeying my mother and I have started once again to follow my mother. – Fatima

7.6.2 Subcategory - achieving acceptance through faith

7.6.2.1   It is the will of God

That what had happened was the will of God was a common finding. Patel thought that there was nothing he could have done to avoid developing the condition. (He was the one who offered me a can of coke along with cream biscuits).

I'm now 80 years old. There is only this much you people can do... I have to take what God brings to me. Dheko I am 84...ready... khatam ho Gaya. - Patel

He went to explain he had a fruitful life, everything is settled he is not afraid to die, he accepted his heart condition without fear because he has faith. However, Kamal said he was practical in his thinking. He said though he will die one, like everyone else, he will go down fighting. There was plenty he could do to fight this disease. He said:

If you are born you have to die one day and no one can do anything about that. Whether you drink or not, whether you smoke or not, whether you get u and walk or not you will die. But if you listen to what the doctors say, maybe you could die a better death. But you will still die…..

When you accept this is all from a higher power, then you will not be frightened and ask 'what is going to happen – Padma

Moreover, they accepted this 'God's will' with composure and tranquillity which helped them to adjust and accept their 'changed lives'

My friends console me and say 'please do not worry, these things happened don't worry, you will be better Allah knows, without him seeing nothing happens. Just leave it up to Allah'. Fatima

Though formulaic, such responses endorsed religious faith and helped to diminish the anger and frustrations the participants initially felt towards their condition and diagnosis. Achieving such emotional distance directed the individuals to respond with patience to the confirmation of diagnosis. Most participants believed that having faith was much better way of dealing with it.

It's easy if these things happen, if you have faith, and then you can accept it as God's command. You know no, big deal (smiles), cool, you know... Philip

The experience of a heart attack offered them an opportunity for spiritual reflection and a space to enrich their faith. For some their faith intensified.

I used to think I do not have time, but now I have time and I have found it helps me….me… this heart attack, the pain was too much to have gone through something big in in my life, my faith has just strengthened me so much - Parvati

This is reflective of this research which demonstrates individuals with greater religious commitment view religious and faith as a source of support.

7.6.3 Subcategory – fate

7.6.3.1 My decisions are my fate – 'Ente vidhi Ente Theerumanangallu'   (എന്റെ വിധി   എന്റെ തീരുമാനങ്ങൾ ആണ്)

Although participants held strong belief in God's involvement, they took responsibility for their own actions and outcome of their decisions citing 'my decisions are my fate'.

My brothers all had heart attack I was waiting for it. But I cannot sit here thinking oh I was born in heart attack family its my fate, so I went to my GP and said please check me up- Raju

The GP said with the things you are doing, I will write and give you in a paper that you will not get a heart attack… (laughs). me I've done what I could, Me I've done what I could, had check-up, did my exercise and still I've got it so it must be in the genes, in the DNA. I think that's what caused mine. - Philip

Participants perceived their heart attack as a confluence of their own actions as well as a genetic predisposition – family history of heart attack. They alluded to an inevitable risk for disease. But to most of these participants, personal initiative and was key to early detection.

You have to go when God calls you, but we can change many little things like exercising, changing your food. Everything Devi that happens is written in your fate. Devi

This notion of fate as an external locus of control has been identified as a key barrier in South Asian people's active self-management (Bedi et al 2008; Darr et al 2008).

7.6.3.2 Dual accountability (Davaim pathi than pathi) (ദൈവം പാതി താൻ പാതി)

Accounts of recovery in Webster's study exemplify a fatalistic attitude (recovery from myocardial infarction related to 'will of God' that signifies a pertinent impediment to adherence to recommended lifestyle changes. Contrary to these findings, in this research beliefs about fate were held alongside to individual responsibility. Fundamental to accepting the situation, there was a daivam pathi, than pathi attitude.

You cannot say it is God who has done, so I do not have to do anything. No it is daivam pathithan pathi, we too have responsibility. Devi

You know when you born you were clean – there is nothing dangerous To your health. God gave you good health. But I did not look after it.I ate what Was not good for me and made it like this. But it must be written in my Fate. But its my responsibility! Satti

Literature has identified that some were willing to adopt healthier lifestyles to prevent further recurrence (Darr et al 2008). However, it was explained in these studies that South Asians would take the onset of disease as a warning sign and take greater responsibility for maintaining health. But in here the narratives strike a deeper note and depth revealing a more abstract concept. Embedded in these narratives, it is interesting to note the duality of God both as an external force and a mechanism for managing.

7.6.4 Subcategory - Priority

Prescribed medication and marked exercises could clash with the religious activity, in particular mosque attendance and Niskars (ritual prayers). Negotiating these competing and conflicting demands often led to one activity being ignored or avoided and most often than not this was medical guidance. Again, they had to choose that advice which did not conflict with their religious duties and priorities.

You know …… if there are religious restrictions for example you ask me to go an exercise class where there is the mix, then I would not go, even if I really need to go. Religion comes even before myself. - Miriam

Thus, though religious beliefs and practice and lifestyle were entwined in an intricate and delicate mix and clearly directed their decision making and choices, participants were unwilling to verbalise this to the health care professional for they assumed the health care professional will misunderstand or will undermine their values of fasting and temple visits. Sentiments such as 'what do they know about it', thrown in the participant conversations indicate the lack of shared understanding of the health care professionals about how religious beliefs and practices influence lifestyle self-management among South Asians.

Yogurt and milk make my wind affliction worse… I just don't eat it. Fatima

I did not immediately connect the yogurt, the wind problem and mosque attendance. Further on in the conversation it was revealed that:

*because we pray regularly we need to be constantly in ablution. Making wind makes us not so. So I did not do what they asked me to do. No, I did not tell the doctors. They wouldn't understand. See.. What do they know about fasting? Being in the state of purification for prayer? No. first they do not have time, second they will not understand…..*Fatima

You know …… if there are religious restriction for example you ask me to go an exercise class where there are both men and women, I would not go, even if I wanted to go for the exercise but my first thought would be of my religion. Religion comes even before myself. Devi

We cannot follow dietary practices at religious gathering even though we can be careful at home, when we go there, we eat all sorts of things full of fat and sugar- Raju

Thus, though religious beliefs and practice and lifestyle were entwined in an intricate and delicate mix and clearly directed their decision making and choices, participants were unwilling to voice it out to the health care professional for they assumed the health care professional will misunderstand or will undermine their values of fasting and temple visits. Sentiments such as 'what do they know about it', indicate the lack of shared understanding of the health care

professionals about how religious beliefs and practices influence lifestyle self-management among South Asians. Thompson (2009) found that over 80% of Sikhs held views that health services and health providers to account for their religious beliefs.

7.7 Explicating faith in literature

Few studies have investigated how such religious beliefs sit with western models of illness with the dominance of biomedical explanation of illness. There is little research focus on its importance in dealing with heart attack and its subsequent lifestyle changes. Whilst Galdas et al (2012) identified the interplay of faith and religion in lifestyle self-management and their findings reflect the findings of Mir and Sheikh (2013) where religious values were highlighted as an important determinant of behaviour. Polzer and Miles (2007) investigated African Americans' relationship with God and self-management and found that some participants were supported by the spiritual relationship. However others (Naqvi 2003; Bedi et al 2008) have identified fatalism as a key factor in South Asian community's non-compliance with self-management and lifestyle risk modification.

7.8 Explicating the category in the memo

Memo#2

fatalism – cause and control – moving beyond fate

This category was formed from initial codes such as obeying, observing, complying with, hold onto, give priority, follow, keeping to, run in parallel, harmonise. My construction and exploration of the participant responses to fate suggests that studies that discussed fate and South Asians (in relation to heart attack) only served to measure the superficial aspects of the fate construct. This then challenges prior conventions regarding the impact of the belief in fate, for instead of the deficit model embodied in the concept of fate, this study illustrates a dual nature of concept of fate. Such misconceptions strewn in the literature concerning the concept of fate may be due to interpreter and translation issues which offer limited entry into 'the other world.

The sentiments verbalised during interviews force rethinking about the assumption about fate and showcase belief in fate as a complex construct, which may be rooted in sociological histories and trajectories. Participants were aware of the link between lifestyle and heart attack, acknowledged their own responsibility in making lifestyle changes. They however aligned them with their religious practices and faith. There was recognition of the importance of their own responsibility for self-management. To rely solely on God for recovery was seen as 'foolishness'.

The participant's interpretations distinguish between will of God and individual responsibility, further challenges simplistic notions of fate. South Asians concept of fate could be better understood as a comfortable confluence of inner and external forces which directs individual outcome. To better understand South Asians beliefs in 'fate', religious beliefs should be considered and contextualised. The decision about lifestyle choices may be predominantly salient among South Asians for whom religion is embedded in an all-encompassing belief or value system that helps individual to adapt to life's changes.

7.9 Conforming to beliefs – causal beliefs

An important aspect of this involved considering why they had developed heart disease. Respondents also identified behavioural factors, such as dietary habits and lifestyle habits – ('busy' and 'sedentary') as an important cause of heart attacks. Respondents spoke about diet and fatty foods specifically which can cause cholesterol. However, none of them identified smoking as a factor for heart attack. As these are related, they are presented under the theoretical category of explanatory models of illness.

7.9.1 Subcategory - psychosocial stress and stains

The majority of the participants reported stress as contributing to the development of their condition. For men, the cause of stress was often the anxiety s well as worries over raising children. Sayed talked about the stress brought about by losing his son:

I had a son when I came here, long back. He had diabetes. But at that time we did not know and he died. He was 3 years old. The pain is still in my heart and that was one reason I think I had this attack. It is in the heart still. The pain.

Many described experiences where a family member received bad news and then had a heart attack. Strains are related to traumatic accidents or violent events in the immediate family that might cause shock, serious illness or death of a spouse, marriage breakdown or financial state. Interestingly for Phillip, it was grammar school selection, as Philip explained:

you've got to see to your kids. You are worried about their education. You don't now where they will end up.

One of the younger participants, Sabu, found it difficult to come to terms with having a myocardial infarction. He said he was too young to be caught with heart attack:

My father was old when he died. So when this had happened Kamal to me at my father's age, I would not be so worried. But I am young and like all other young people I do my thing. if this has then I could have understood, but not at this age - Sabu

Fatima, could not comprehend how she could have had her myocardial infarction. A third-generation Muslim, she had started smoking when she was 12, but did not acknowledge the link between smoking and myocardial infarction.

*You know what my husband thinks? Hmm? I used to suck out my baby's snot from the nose. After that I used to feel tightness in the chest you know. And then now this happened -*Fatima

7.9.2 Subcategory – family history

Some of these individuals felt that because they were more prone to heart disease because it 'ran in the family' and they were expecting it. Philip knew heart 'trouble' ran in his family. However, he took precautions and went to the GP and had regular check-up.

I mean if its in your genes, its in your genes - Philip

7.9.3 Subcategory - habits

The participants attributed their heart attack to unhealthy eating habits.

I know its not good, but I like fried foods and I ask my wife to fry it. I love all the wrong kind of food.

I took this into theoretical sampling and asked few of my participants after cardiac rehabilitation that 'many people believe that stress or bad news cause heart attacks'. After going to cardiac rehabilitation, participants were unconvinced and confirmed the beliefs about stress causing coronary heart disease are widespread. For example, Mohammed said,

You are trying to address the myth here, but it is deeply rooted in people's mind. Just one sentence or with few classes this is not going to take it away – Mohammad

People also spoke about how these beliefs were rooted in their experiences and were reinforced by friends and family. Because these beliefs may impact perceived behavioural control related to coronary heart disease prevention.

It could be his lifestyle and. you know I come from the restaurant at 11pm ad then 12 we have our supper. The restaurant is my life. I have never taken sick in my entire life - Mohammad
I like to drink too much 'cola' have to cut down… Kamal

7.10 Explicating the category in a memo

Memo #3
Why believing in their beliefs is necessary

Many South Asians are immigrants and may have different explanations for what causes coronary heart disease, which could impact their willingness to change behaviour. This strategy can be used for addressing the disconnect that exists between lay casual beliefs and the biomedical model that underlies most cardiac rehabilitation programs.

7.11 Explicating the category in the literature

In a collectivistic world, other factors in addition to or different from the individual or biological ones (metaphysical beliefs) are an integral part of the world view (Landrine and Kolonoff 2001). The individual may hold beliefs that differ from the medical model of Western societies (Wade and Halligan 2003; Wang and Mathews 2010). These beliefs cannot be easily

delineated or explained like those of the world view of the western world which is situated and embedded in the physical and social world.

7.12 Category summary

Religious and cultural aspects play significant part in South Asian patients' acquiescence with lifestyle changes. In making sense of their diagnosis, all the participants stressed the importance of religious faith in their lives. The findings suggest that culturally targeted health communication must not only engage the biomedical model, but must also engage the lay belief models that facilitate or inhibit behaviour change in the target community.

7.13 The Third Category – affinity towards one's group

7.13.1 Subcategory – Customs - Hospitality

This strong hospitality culture and social norms of hospitality was pivotal and obligatory. In the first participant home, whilst the interview was going on, there was a flow of neighbours, community members with food. Philip explains this paradox:

This happens all the time, you know. Sometimes I eat, sometimes she (mother) says, no you cannot. And then I don't. but the thing is more than my body getting upset with the bad food, I don't want to upset them (those who bring in the food… we know how difficult it is to cook food and bring it. How can I throw them away like that? - Philip

It would have been very rude to refuse them and even though I know I should not eat these kind of food, its not health it was accepted as not to 'hurt their feelings'. Moreover, they would prepare the food the 'patient would have liked to eat' most often this would mean traditional Indian food 'fried fish, oil rich curry'. - Das

This happens all the time, you know. Sometimes I eat, sometimes she says, no you cannot. And then I don't. but the thing is more than my body getting upset with the bad food, I don't want to upset them (those who bring in the food… we know how difficult it is to cook food and bring it. How can I throw them away like that? And its not that bad. my brother he is diabetic. Sometimes he eats loads of food and then he increases the insulin. I do the same, if I eat more than my usual amount I go to the gym. the basic thing is you need to fix it.. you need to balance it… always balance. balance in the body, and in the house…(after a pause.. smiling) and outside the house. Balance? Yes balance. what the old books says is you need to bring it into focus/I don't the word… its madhyavedathata……its helps us..its not easy with our religion and with our culture and with our tradition, especially in this country. we need to be very careful. and ah yes, thankful too for the NHS. if it was not for my doctor I wouldn't be

here…. It would have been very rude to refuse them and even though I know I should not eat these kind of food… Sabu

In such instances, it was the priority was not individual health. Such unhealth food was was accepted as not to 'hurt their feelings'. Moreover, they would prepare the food the 'patient would have liked to eat' most often this would mean traditional Indian food 'fried fish, oil rich curry'.

Its said 'addhithi dhaivoo bhavaha! (Guest is God). So you cannot be miserly there. You need to give good food to them. Plus its our social standing you know. What will they say when they go out, that we gave only chappattis? - Padma

Food was cooked special for guests. Serving curries with reduced oil/ghee or food that were bland, was considered inhospitable: . .. we are in a group, we meet they come here, we go there. Its all about relationships. relationship with your family, relationship with your God – it can be Allah, Christian or Hindu.- and also relationship with your group. So we need to respect that. When he says he is coming to see me, I cannot say no you cannot, because we are not cooking extra or special because I had a heart attack, we cannot say that. Its not in our culture. Ok now we are here, we need to follow what they say (here he meant the doctors), but sometimes we cannot do that. We need to see. Who is important, which is important and then decide- Miriam

The best compliment I could get is I cook like my mother, even if that means loads of ghee and oil… Though now I am worried it wouldn't be health if I cook like that! - Radha

The conflictual nature of 'healthy behaviour' and social and religious norms added to the complexities of negotiating dietary changes.

7.13.2 Subcategory – Exercise

There was uncertainty over the type of exercise needed. Moreover exercise was seen as increasing physical weakness.

*He just says…you need to get out more. They do not forcefully say you need to do it for your health. Maybe that's what is required, writing it out in the prescription sheet – 10 minutes of walking. Yes that would certainly help. Smiles….*Sabu

I mean we don't exercise and you know we do all these kinds of things. We are too much engrossed with our family. We are family orientated and we concentrate on our family more than the exercise.- Das

They appreciated the monitoring process (cardiac monitoring) during the cardiac rehabilitation programmes learning how far and how much they could safely do. They participants indicated they welcomed the information of walking at the rehabilitation programme.

For me, I didn't know its ok to walk for me for 40 minutes … That's good. I had to ask again, 40 minutes? The programme was a great help.. Kamala

Some others mentioned the unease of using and sharing the gym facilities.

We wouldn't fit in there, at the gyms. Wearing our traditional clothes, our women wearing hijabs. Perhaps a dance class –for women or yoga classes. Then it would be more comfortable to be called exercises. 20 minutes of such exercises is worth a ton doing the rounds in the gym, you know. If you do it properly – Sayed.

The women participants felt it difficult to go for exercises, they would have preferred to stay in house and do 'more of the housework'. The youngest participant, she said she would have preferred dance exercises.

It is ok if we go to the hospital for exercise, other places …hmmmm no,…..no. I do not like to go for exercise wearing our traditional clothing. But I will try out some dancing classes. Definitely. – Fatima.

7.13.3 Subcategory – Be active, but not exercise

There was the general agreement that health is 'being without any ache or pain – without illness.

If there is not ache and pain that is enough. You don't need to build up your muscles or anything. You do your task in life and that should help you with good mind and health. Be at peace. That is my philosophy. You cannot go for walking after getting angry at someone. It is not going to be good for your health. Peace and less stress. That is what I say .. Das

I start early to work and come back late. I have already been away from the shop. How can I quit the shop and go to gym? I do not sit still in the shop. I walk around. It should be ok… Mohammed

Ritualised exercise regimen was not part of the ethos. For Muslim participants – prayer (that is, five times daily physical prostration) to be a form of exercise.

I do 5 niskars a day and there is bending and bowing. I think it can be exercise. Yes definitely its physical activity. I should mention it next time I meet the nurse.- Sayed.

7.14 Explicating the category in a memo

Memo #4

Maintaining Cultural Identity (the familiar becomes meaningful and the meaningful becomes important and is prioritised).

I used the word affinity to amalgamate codes such as shared norms, values, natural understanding of something, 'you know' empathy, rapport, sympathy, accord, harmony, like-mindedness. Hospitality was also used to 'show off' or display social status. There was a moral conflict between individualist goals and collectivist goals - the individual goal of healthy eating compared with the shame to the family of not

providing guests with specially prepared traditional food. The social significance of cooking for guests and of celebratory meals.

7.17 Drawing in the threads of the three categories together

Family, religious and cultural influences that accentuated family and community contexts and values subsumed the participants' experiences of adopting lifestyle changes following myocardial infarction. South Asians may hold multiple belief systems about coronary heart disease aetiology and prevention, combining a biomedical model with psychosocial and spiritual beliefs. Negotiating changes in diet and physical exercise were often intertwined with family practices, and collectivist ideals such as eating and privileging social connections during physical exercise. The communal nature afforded by social and religious norms added to the complexities of negotiating dietary changes.

7.18 Chapter summary

Themes, derived from the data, were identified as intertwining with the participant's lifestyle self-management. It seems then there is competing and often conflicting priorities in the self-management of lifestyle changes. For the participants, heart attack represented a significant life event – for some it was expected for others unexpected. The new diagnosis and with it the requirement for a 'lifestyle change' caused disruption in their family, cultural and religious spheres, such as domestic considerations, each of which had an impact on their decisions to choose and prioritise lifestyle changes. Familial, faith and folk beliefs and norms influenced their choices and often took precedence over the advice and information given by health professionals, despite acknowledged health implications. This thought of lifestyle changes seen as a conflict is given more attention in the next chapter which provides the model emerging from the categories.

Chapter 8   Conflict and harmony

Put simply, this chapter illustrates the search that was carried out within the analysis to find the category that could subsume all other categories. Indeed, compelling themes and categories emerged over the course of the study, some almost immediately whilst others at various points along the way. As such, in this chapter I have provided the challenges of sifting through the 'pretenders' and finally co-constructing the one that passed the test – that category that could integrate all other categories into a coherent framework – a framework that would provide the answer how South Asians choose and prioritise their lifestyle choices and why they do so.

8.1 An exercise of 'imaginative understanding'

Charmaz's constructive approach does not accentuate 'the core category' aspect of the grounded theory process (Charmaz 2006). Knowing one of the criticisms of grounded theory is early settling for a category I endeavoured to avoid what Wilson and Hutchinson (1996) describe as mistakes that novices make in using grounded theory, that is premature closure of the analysis. It was something of a revelation when during the writing up and through critical reflection that I could finally 'draw out' a coherent picture of what I had identified as the common thread and recognise where it fitted within the analysis.

The process of finding a common thread that synchronised all the categories was challenging and over a period of many months, several themes vied in my mind. For some time, compromising, negotiating, reconciling fought for the place for the basic underlying process. However, the complexity of the environments within which South Asians were making lifestyle changes and the ways in which their motivation and confidence were influenced was not clarified by just the process of compromising and negotiating. For the sifting process, I had to turn to what Holton (2007:275) suggests - "analytic competence" and "analytic temperament". Though I believed I achieved reasonable "analytic competence" by constant comparison and by explicating the categories from

the literature, what I needed was more of 'analytic temperament' (Holton 2007:275), which helps to tolerate the reversion in analysis and confusion. For this to happen, I had to transcend from wishing for a conceptual emergence merely by the method of constant comparison whereby one is able automatically to produce the final product.

Therefore, I turned to what Charmaz terms 'imaginative understanding'. Charmaz asserts that a set of interconnected categories are developed and the relationships between them are outlined (Charmaz 2006:126), a language that is proportionate to the constructivist ideals which I utilised in this research. It also helped me remain faithful to the approach (co-construction of data) that I adopted for this research. It was vital then to move beyond the descriptive mode of the transcripts to an interpretive and explanatory mode of theoretical categories to ultimately to produce a theory. For this 'imaginative understanding' I was guided in part by the analytic process, but more by the critical awareness – to use Holton's term analytic temperament – not to be bogged in by data but to let go. This also easily helped me to move away from the sensitising concepts and to construct, along with participant data, the concepts imperative to this research (for example shared efficacy).

At this point, I considered again the questions Charmaz (2006) suggests a researcher should ask; 'So what is the problem that my participants see?' How do they believe they address/resolve the problem they face? This helped me to find the basic social process that emerged in the data common to all my participants which underpinned all the other processes. I noticed there was a shift as my research impressions that gave way to an understanding of processes that took place over time, especially when I went back to the data. This re-reading of the interview accounts, after a period of letting it all go, helped me to identify the main concern running through all the narratives, the common thread, pulling in the categories. It is this degree of theoretical sensitivity exemplified in chapter 6, which led me to purport 'to be harmony'.

8.2 The problem – the inherent conflict of priorities

For the participants, heart attack represented a significant life event – for some it was expected for others unexpected. On diagnosis of myocardial infarction, they are advised to change their lifestyle either to stop smoking, start exercising or to consider a heart healthy diet. The new

diagnosis and with it the requirement for a 'lifestyle change' caused disruption in their family, cultural and religious spheres. Exploration of why and how they chose the lifestyle changes offers an understanding of the particular contextual influences operating within the South Asian communities. Managing lifestyle change was not always seen as priority. For instance, decisions related to lifestyle changes are influenced by the complex cultural and moral environment in which they lived. When they are given the advice, they then needed to prioritise the lifestyle changes based on those that made minimal disruption in the established family patterns.

They had to surrender to choices that did not conflict with their cultural norms and were there were clash/conflict of priorities, personal norms gave way to cultural norms. For example, unhealthy food was accepted. Again, they had to choose that advice which did not conflict with their religious duties and priorities – for example state of ablution before prayers in the mosque. Such patterns of behaviour help to understand why lifestyle change did not always take centre stage in life,

Thus one can see, lifestyle change was rooted within a larger and more encompassing milieu. Some participants could repeat accurately the basic recommendations and advice given at the course, but they said making changes was not a priority. From an outsider perspective, this brings out the discrepancy between the behaviour change priority (as seen/advised by the health professional) and what other priorities South Asians hold. The power of culture, religion, familial orientation, social values and norms to influence behaviour and lifestyle choices even when it supersedes professional advice and recommendations may be partly because such suggestions may appear familiar, meaningful, and aligned to the sociocultural milieu in which the lifestyle changes take place.

Analytical memo #5

A conflict appears between the patient's cultural expectations and his doctors' recommendations regarding lifestyle changes. Feeling so worthless or 'losing face' because he trying to do good for himself (eating healthy food, forsaking traditional cooking, doing exercise). In such cases, there is no point in trying to strengthen the autonomous ego/self efficacy because there is no autonomous ego.... Jung? We should restore harmony, work with the family. We should use quotations from the traditional scriptures...

Vedas, Quran and Bible. We don't probe the intimate details for family life because these patients think it is shameful to discuss such things. Instead we use the unusually rich life (role-models) we find among such people and make suggestions that will result in real change and alleviation of symptoms. Is there hint of cultural imperialism? West looks at east and sees oppression, where east sees stability and harmony. West sees corruption, where East sees ties of family, friend and mutual support and mutual responsibility. Gruber? What is important? To be in Harmony.

People pursued lifestyle changes that were not perceived to be an extra burden or which did not conflict with their everyday life. Collectivist cultural norms surpassed the restrictions that might arise from the recommendations for lifestyle changes. Thus, culturally situated influences on food choices and physical activity often took precedence over the advice and information given by health professionals despite acknowledged health implications.

Lack of time and domestic considerations, each and all of which had an impact on their decisions to choose and prioritise lifestyle changes. When engaging in health-related behaviours becomes a conflict, the individual avoids the behaviour altogether and this resolution is with the aim 'to maintain harmony'.

8.3 The resolution – to be in harmony

Understanding how and why they choose as they do, helps to contextualise the behaviour of South Asians towards lifestyle changes – that does not conflict with their cultural norms, that does not conflict with their religious beliefs. To avoid the conflict, their decision was based on which helped them to be in harmony. For South Asians, the influence of families and the community is even more significant. The hierarchy of cultural and practical influences is a complex web and sociocultural and religious norms were seen as part of their identify. There was a tendency to retain the harmony in the disrupted family routines, social norms and religious customs. For them getting back to normal, involved readjustment, in their terms maintaining the 'harmony', that is attempts were made to harmonise the lifestyle changes into their every family routine and social norms.

The level of lifestyle change reflects an individual's unique view of the balance needed to harmonise the lifestyle changes within a family, religious and cultural sphere. With an aim to

maintain harmony, sometimes the way they chose to adopt some lifestyle changes, the family and social needs and norms took precedence. Lifestyle changes that was in harmony with the family routines was welcomed and chosen. Thus, the final synthesis presents an interpretation of their lifestyles self-management experience which is nested within a much 'wider' illness experience of coronary heart disease.

8.4 Conflict and harmony

South Asian heart attack patient is caught between the conflict of 'choices and decision making'. On one side is the family, community and beliefs whilst on the other side is the health professional's advices on lifestyle changes. In here, conflict is an internal state that causes tension or anxiety when a person is unable to clearly decide between two opposing goals.

Popular dual-dimensional models of conflict management behaviours include intention to satisfy own needs and intention to satisfy other's needs (Blake and Mouton 1964), concern for relationship and concern for personal goals (Hall 1969), and concern for own outcome and concern for other's outcome (Pruitt 1983). Braithwaite (1997) showed that "pursuit of harmony" was a crucial value/attribute that maintained interpersonal relationships. This style is related to the phenomenon of conflict avoidance commonly observed in Chinese societies (Leung and Brew 2009) and among the Igbo. One form of harmony style of conflict resolution is to obey publicly and disobey privately described by Hwang (1997–8). This style could be termed superficial compliance, in which one appears to comply as required, but covertly does something else. In such instances, there is high emphasis on disintegration and to enhance harmony. This could be related to Whitmarsh's 'ascetic subject of compliance'.

Harmony is the absence of resistance to what is. Interestingly, the presence of harmony is not dependent upon a particular set of external circumstances and therefore harmony is not the mending of exterior forces, for they can never be totally 'fixed' (Hayley and Ratcliffe). This does not mean that health care professionals or patients should not try to do all that is possible to improve circumstances, but at the same time there is nothing more profoundly transformative than to 'be in harmony' (Hayley and Ratcliffe).

As Mol has argued, non-Western cultures have a more collective ethos within which such choices make far less sense (and in which it is much less possible to be 'compliant'). In individualistic cultures, such as the United Kingdom, the dominant model of the self is the independent self characterised by self-defining attributes such as self-reliance, independence, autonomy, personal achievement which serve to fulfil personal goals. They hold 'self' apart from the group and are responsible for their own decisions and actions.

However, with South Asian communities with collective orientations, the interdepended construal is the norm. Here the self is defined relative to others and is concerned with sense of belongingness, dependency, empathy and reciprocity.

This study provides insight into an interplay between individual health behaviour and collectivism is not new in literature – it has been highlighted, however what is now being added to is the theory/explanation of how and why this is played out – as part of conflict resolution – maintaining the harmony. For example, it has been recorded that experiences of making lifestyle changes following acute coronary syndrome were influenced by subjective life experiences and individual, sociocultural and environmental contexts (Davidson et al 2011; Galdas et al 2012; Guo and Harris 2016). What was focused in literature before was the South Asians way towards the desired (from the health professionals' view) behaviour, leaving out the context of what that behaviour involves. My research answers this context by providing the answer to what this behaviour means. Lifestyle changes is presented as a 'conflict' and the choices based on the 'conflict resolution' strategy of to be in harmony. What the current study adds to all the above literature is a substantive theorisation of how the multiple influences – religion, culture and family – meet and interact with the health professionals recommendations to produce a 'shared efficacy'.

It would reasonable to suggest this why family cohesion, solidarity and conformity are valued in the study. Such that they tend to avoid behaviours that cause social disruptions or disappoint significant others. For example, lifestyle modification may not be the priority whilst protecting valued societal roles maybe vital. The notion of family first was a key influencer over the decisions made to make and maintain lifestyle choices. Cultural norms often took precedence over personal norms (lifestyle changes).

8.5 Positioning the model within other self-management models

Historically, education-based interventions using information-based resources and training have been the most frequently implemented strategies to improve self-management practices (Newman 2004). Chronic disease self-management programs can be traced back to Kate Lorig's Stanford Model (Lorig et al 1994). This Stanford Model and other behaviour change interventions modelled upon this, aimed to enhance patients ability to self-manage their condition. Such models and interventions were used primarily educational strategies to develop the skills and impart necessary knowledge to promote health promotion activities (Lorig and Holman 2003). However an analysis of the EPP by Wilson (2001) critiqued both the notion of 'expert patients' and ability of interventions to transfer expertise. He questioned the apparent paradox of individuals being simultaneously self-reliant and compliant giving rise to conflicting expectations from the health professional as well as from the society. Moreover, Wilson et al (2007) argued the EPP The EPP had a 'Foucauldian potentiality' by medicalising self-care practices and bringing them into a person's home.

The Whole System Informing Self Management Engagement (WISE) approach (Kennedy et al 2007), placed a greater attention on a patient's social situation. Greenhalgh (2008) builds on this idea of a whole systems approach via the provision of personalised self-management plans. As well as further two models, the Personal Model and the Attitudes-Social support self-Efficacy (ASE) (Lanting et al 2008). However, I believe the model that emerged from this study resonates with Knott's cultural capital (Knott et al 2008) Fig 8:1 - overleaf. The essence of David Knott's argument for the cultural capital framework showcases the 'recursive process between individual behaviour and cultural norms, whereby the catalysis' of behaviour occur (Knott et al 2008).

As Charmaz (1999) elucidated living with chronic illness includes both 'good' days and 'bad days'. However, in my search for how South Asians choose and prioritise their lifestyle choices, I conclude that harmony is the central core equilibrium that they aim to reach. What this harmonic state looks like to the individual is influenced by the culture or world view of the individual, which colours the lens through which the strengths and stressors are perceived. Tapping into the fabric of interconnectedness – of family, religion and culture results in harmony, not getting rid of or avoiding stressors. This provides a framework for both theory and practice in that it reveals a dynamic process to assess the unique perspective of the participants in this context. In sum, the presented Harmony Model does not adequately explain the conflict management behaviours, it is proposed that it will serve as a stepping stone to understand and appreciate how South Asians choose their lifestyle changes after a heart attack. Below I present the diagram of the model:

8.6 From self efficacy to shared efficacy

Self-management is a concept emerging from Albert Bandura's social cognitive theory which is based on the principles of self-regulation, self-control, and self efficacy. Even though several behaviour change theories (such as the social cognitive theory) informing self-management approaches consider the wider social factors, the main emphasis lies on individual action and choice as the prime mechanism for changing health behaviour as mentioned in chapter three. Self efficacy is defined as one's confidence and will to control one's own health and has been known as the main predictor for complying with health promoting behaviours and one of the key determinants in choosing and maintaining health behaviours (Sheahan and Fields 2008). It refers to the extent to which an individual is capable of performing a particular task or behaviour, taking into account into account individuals' attitudes, perceptions, and emotions in relation to the behaviour. The basis of self efficacy theory is that cognition can affect behaviour.

Efficacy beliefs are typically "self"-beliefs (Neisser 1997:4). Therefore, self efficacy theory, with its emphasis on personal control "people guide their lives by their beliefs of personal efficacy". Such that "*Beliefs of personal efficacy constitutethe key factor of human agency*" (Bandura 1997:3) is firmly seated in a Western, independent, individualist context (Klassen 2004). Research has not demonstrated whether self efficacy plays the same role in self-management in non-European patient groups (Klassen 2004). Moreover, the small number of studies conducted

in nonEuropean groups have produced more mixed results (Ikeda et al 2003; Stewart et al 2000). These studies question the application of self efficacy into other non-European ethnic groupings.

However, Bandura (2002) rejecting the notion that self efficacy plays a lesser role in collectivist cultures, coined the term 'collective efficacy' (1997:477). Collective efficacy is not defined by Bandura as a collectivist substitute for self efficacy, but rather as a separate, group-oriented attribute that is "rooted in self efficacy". However, Bandura's interpretation and explanation of self-efficacy can de-emphasise the role social factors can play when implementing behaviour change (Klassen 2004; Biglan 1987).

I may I argue the 'others' belief in you to perform achieve tasks to achieve goals. Collectivist societies whose values are oriented to duty tend to follow shared norms and invest in relationships with other people (Cote and Levine 2002). Shared norms and practices influenced and help their confidence which I term shared efficacy in realising personal goals – for example going for exercises. The responses reflect not the lack of confidence in understanding their disease they are diagnosed with or the necessity of lifestyle change. What motivated them was the support they received from the environment – familial, cultural, religious – when the guidelines and advice of the health professional aligned it with this.

Bandura's claim that 'self-belief produces desired effects' does not resonate with the South Asian community. Self efficacy in self-management models where emphasis is placed on individuals may be not be readily applicable to South Asians whose priority is social norms and cultural values. From the South Asian perspective, it is challenging to modify or change habits shared with family and the immediate social environment, which have been in place for many decades. Thus, arguably | self- efficacy may be a Western construct that operates as an imposed etic in such non-Western cultural orientations. While external influences such as God, fate or destiny were often attributed to be the cause of disease, this research also highlights how religion and spirituality influences lifestyle changes. Thus, contrary to the literature findings that South Asian coronary heart patients often report low levels of self efficacy, this research showcases how family, culture and religion function to provide the efficacy and confidence to change lifestyle.

What I implicate here is that the role played by – what I term as a- 'shared' efficacy as opposed to self efficacy may be more relevant to communities such as South Asian with collectivist orientations. This is different to the collective efficacy where the group come together for a common goal, here the group rally around the individual such that the individual attains the goal. Confidence and motivation is rooted within the support received from family members or the community who provide social and cognitive scaffolding that is imperative in making and maintain lifestyle changes.

Prominence of family support to make lifestyle changes and high regard for peers and significant 'others' found in this research, overrides the self efficacy approach which advocates high patient initiative and autonomy in making lifestyle changes. What I claim and which Bandura rejects, then, is the idea that the self might vary in its fundamental composition in a different cultural setting. By claiming that a personal private and resilient self is a necessity for achieve, he tends to deny the 'we' consciousness or connectedness referred to by Kim and Lee (2000). What this showcase, is therefore, to focus on familial and other interpersonal relationships as well as acknowledging the existing family routines, alongside sociocultural expectations when making recommendations for a healthier lifestyle. This could provide members of the community with the internal motivation (shared efficacy) that is required to persevere with change.

This study found that patients' and their social network's (e.g., family, friends, and community) illness beliefs and attitudes are a crucial factor in determining successful self-management. When these beliefs are positively aligned with the professional advice, they create a supportive environment to initiate and/or maintain adherence. However, when patients and their social network were negatively aligned, then it impedes the patient's ability to engage in adherence activities. For instance, when considering a value system around food choice for South Asian families centred firstly on social benefits and secondly physical benefits, which may be real, imagined or vicarious rewards.

8.7 Making the model into practical wisdom: 'phronesis'

Glass and McAttee comment, human behaviour is "*sandwiched inextricably between ecology and biology*" (Glass and McAttee 2006:1656). Not eclipsing the importance genetics or molecular explanations, but I fear that there is an increasing '*desocialisation*' of scientific inquiry: a tendency to ask only biological questions about what are in fact '*biosocial phenomena*" (Famer et al 2006:1686). The findings of this study affirm previous work behaviour and lifestyle choices is mediated in a sociocultural milieu. It is within the trajectories of collectivisim that an understanding of the various factors influencing lifestyle changes and self-management.

For advice on lifestyle changes to be successful, however, we need to make explanations and interventions more meaningful. The choices they made, made sense to them and to their families – their choice was based on what the participant and their families thought was the as the right thing to do. Thus, to be effective, self-management interventions need to emulate these principles – that is, advice should reflect and be attuned to their familial needs, religious affiliation and cultural norms. Such a model would resonate with the wider chronic care model, which proposes that the prevention and management of chronic illness requires interaction between patients and proactive healthcare teams mindful of cultural traditions.

8.8 Chapter summary

This study has attempted to produce a theorisation of the sociocultural levels of influence in making and maintain lifestyle choices among South Asians. I always wondered whether there were any connections between the categories and whether it was possible to provide an explanation which made theoretical sense.

Eons later, after a 1001 sleepless nights, with baskets full of discarded drafts, I write:

'An original contribution'

Journal excerpt #12

I identify, eventually, what I had found out and position this with the existing literatures – a critical process of finding my own expert voice and a way of writing which foregrounds my research while still situating my research within the academic literature. I do not in any ways claim I have achieved closure, however step by step I am getting closer. I find the discussion enclosed in this chapter is a synthesis and interpretation of findings, a

venture not for recap and repeat but for a new theoretical insight, a presentation of a new reading of the research which links findings to literatures. For me, the writing up of this chapter was not merely a process of or writing, but a process of asserting my findings as original contribution.

Chapter 9   Discussion

This chapter was the most laborious of all to write, and yet once completed, it gave me a sigh of satisfaction. Finally, I undertake an evaluation of what my specific research has shown. In this chapter I consider the findings and position them in the light of existing research. As such the findings are interpreted, compared, explained. There is what I would like to call a 'dialogue' about the implications of the research for a specific theorisation. Most of the text is devoted to clarifying the theoretical worth of findings and further impact. The chapter starts with an autobiographical reflection on writing the chapter. The contribution of the work is highlighted as key inferences and the implications this research has for clinical practice, policy and future research and finally the chapter summary is provided.

9.1 An autobiographical reflection

Gripped with the paralysis from the venom of the imposter syndrome that turns blood to ice, I pen my memo: How many mornings more? October 2016 – 4.45am

<div align="center">

'Grappling with imposter syndrome'

Excerpt from the research journal #9

</div>

I go to sleep reminding myself every night for the past month that I have yet to complete my discussion chapter. I dream of expertly parrying all arguments in defence of my findings and yet now that I have woken up, I look blankly at the word I typed in – Discussion, at the sight of which I turn catatonic. For the thought gnaws on: 'it's all about making an original contribution to the body of knowledge. Although a PhD need only push the boundary of knowledge a tiny bit, it is an original contribution of knowledge. I look at the title I have just typed in and the empty space below– this is the space I must fill in. Not with just mere words of my findings, but with scholarly confidence, as an expert, assert my research as having an original and worthwhile contribution. I try to rewire my thinking – I pretend not to hear the cacophony of voices calling out: imposter, pretender; …. instead of writing what the literature says and then what I think, I try

to write how I interpret the findings, and then link it to the literature. However, this is uphill journey... a nightmare... for here are the 'real experts', my 'Gurus', leading veterans in my field, accomplished writers in peer reviewed journals.

I ask how can I not cling to the literature? I remember the story of Anton Chekhov the bet, how at the end of 30 years in prison – spent in reading and reading, he finally despises everything and forgoes the prize and 3 minutes before the stroke of the midnight hour, when his imprisonment ends, he goes out into the night. I also remember Johnathan Livingston – the seagull – who works tirelessly, passionately, lonely and relentlessly – to make the perfect most promising flight.... a feat no other seagull has attempted.

And this gives me courage, instead of sitting mute and frozen, I am asking myself: What do my findings mean (in relation to my research questions)? What established conventions/trends are affirmed or challenged by my study? Why am I surprised by my finding? Am I? What from my research is new in terms of, or absent from, the literatures in my area? I turn the pages for my research questions, used these as a frame for my discussion. Then I go back into my literature chapter and pull out the sensitising concepts related to those research questions, then I re-read the narratives of my participants, then I pull out the synthesis and interpretation paragraphs of my findings chapter and I bring all three into the blank in front of me. And I start my weaving, pulling the threads of literature and my data. Yet it was a start, a summary not a synthesis. A physiotherapy to get out of this catatonic state - writing, rewriting, annotating, iterating, building, breaking and re-building my discussion....

9.2 Key inferences from the findings

Research into South Asian health behaviours has mainly been driven by the increased rates of lifestyle related diseases in the older South Asian population. Yet, how they deal with lifestyle change once diagnosed and the processes of negotiation or concessions made to cultural values and beliefs to enable them to engage in a healthy lifestyle remained unexplored to date. By providing a novel insight into South Asian participants' lifestyle choices after

myocardial infarction, this qualitative research brings into forefront probable explanations why Asian perceptions and sociocultural attributes may be at odds with individualist motivations and with current models of self-management. Participant narratives uphold that health-related behaviour is the product of a complex interweaving of biographical, social and cultural threads. Therefore, their choice of lifestyle changes is situated in a framework with a unique blend of cultural norms, family values and religious beliefs. For example, only in such a framework is there the blend of familial responsibility ("I must prioritise my family, though I have had my heart attack"), affinity towards one group in maintaining group values and norms ("I must follow what 'they' say") and personally filtered spiritual and lay beliefs ("for the medicine to work, it has to go hand in hand with our prayers").

Central to the renewed thrust for secondary care commitments such as lifestyle self-management, is the exigent need to understand why people behave as they do with respect to the pathogenic and salutogenic processes. For without a working knowledge of the finer 'motors' that drive lifestyle choices and the conceptual structures within which they find meaning, it is highly unlikely that evidence based guidelines can meet with marked success or one-to-one communications can achieve their goal. My research, as reported here, reveals a relatively complex picture, albeit one that can be prudently expounded. What it brings to the foreground is the labyrinthine perspectives of South Asians that influence their choice of lifestyle changes – a labyrinth of ingrained health beliefs not veiled over by knowledge or education, an inbred nature to adhere to the group norms and religious customs, even at the risk of own health and mortality.

Adding to the gradually increasing body of research amongst South Asian communities, this research reveals considerable scope for adapting interventions by considering the multiple dimensions of individuals' self-management experiences. The findings showcase how people's experiences are underpinned not just by personal, but by biosocial and cultural complexities, which include heir cultural and religious beliefs and affiliation. The theoretical contribution to the to the field of lifestyle changes lies in revealing the underpinning rationale

for lifestyle modification, to provide closer match between different aspects of individuals' experiences and the complex web of social, cultural and familial milieu. Therefore, it is my argument that familial, cultural and religious patterning of South Asian behaviour should in turn structure the messages and conceptual content of any cardiac secondary prevention strategy *for it is through these 'agencies' the participants met their 'efficacy' to choose and prioritise their lifestyle changes.*

There is now some consensus that it is important within a health professional's role to be sensitive to patient motivations and cultural commonality. What this study adds is a systematic way of linking this knowledge and understanding to the delivery of services and to the interface these with the sociocultural and religious traits of the community. The model showcases the trait of belief in one's own ability to complete tasks and reach goals is developed not on its own but because of the support granted by the family, religion and culture.

When the choices were not entirely adverse and aligned with their family, religion and cultural and lay beliefs, they were likely to maximise health outcomes. What this essentially highlights is that the barriers can be bridges for the community who are willing to listen, learn, and adapt their behaviours if they are given opportunities to combine them with their sociocultural beliefs. These highlight the role of family members, advocates, and cultural or religious identification as pivotal factors, for initiating and maintaining change (Stolley and Fitzgibbon 1997; Greenhalgh et al 2005; Netto et al 2010; Kennedy et al 2007). An understanding of sociocultural and religious values, family dynamics and an acknowledgement that these concepts are valuable assets for service delivery can enhance the efficacy for South Asian people with coronary heart disease to maintain

their lifestyle changes. I lay out my inferences in the forthcoming passages, by citing each of the agencies on its own and how it affords a 'shared efficacy' to South Asians.

9.2.1 Towards a family oriented lifestyle self-management

Participants' narratives suggest myocardial infarction is a life altering, challenging experience for the whole family (Greenwood and Mackenzie 2010). A family oriented approach is highly relevant to self-care, and a recent framework published by Grey et al (2006) outlines the relationships among family factors, individual, and family self-management of chronic illness.

I believe it is imperative to distinguish what I term as 'family oriented' care as opposed to 'family-focused care. In family-focused care, there is a risk of health professionals providing care from the standpoint of an 'expert' – for example in family systems nursing – (Greenwood and Mackenzie 2010)– which denotes something is 'being done to and for the patient and family' by assessing,

recommending and maybe co-creating a plan for the whole family to follow. Family-centred care, by contrast is characterised by a 'collaborative approach to caring and decision-making.

The model developed from the findings affords a holistic view of families' ''circumstances, concerns, and resources''. The cornerstone of this collaborative family oriented care is what I term as 'honouring the family wisdom' which builds on family resourcefulness. Such a framework is embedded in an relational stance is very congruent with the values and principles of family-oriented practice, for it emphasises the person's and the family's well-being, considering spiritual and cultural traditions, social supports, and the person's engagement with her or his community. By acknowledging the individual in the biosocial and cultural context, the services can be tailored to needs, beliefs, and cultural values of patient and family.

A belief in families' strengths and decision-making capabilities by families and providers maximises family choice and their sense of competency. The identification of strengths and opportunities for choice are intertwined and resonates with what McWilliam et al (1998) called strengths based perspective of family oriented care: enhancing families' confidence and belief in their own abilities. Evidence highlights the importance of the whole family as the target for the intervention being particularly important in South Asian communities where extended family members frequently play a key role in feeding and shopping (Pallan et al 2012). Grewal et al (2005) identified the pivotal role of family among South Asians and participants in SAHELI study suggested that incorporating family members into group classes and targeting the whole family, especially with dietary advice, would improve the intervention. There is potential to harness this and, in collaboration with the family, use it to achieve better outcomes from cardiac rehabilitation, perhaps though a family-inclusive programme. Alongside the effectiveness of the health care team and cardiac rehabilitation, the family is another potentially positive resource (Wieslander et al 2005).

Successful secondary prevention models such as MyAction and EUROACTION have proven that family involvement is beneficial (Wood et al 2008; Gibson et al 2013) though these programmes were implemented in an older cohort of patients (Wood et al 2008; Gibson et al 2013), and not specifically for South Asians. It has been documented that family can be effective at assisting the recovering patient to make lifestyle change; however, there is little known about how the family can act as the incentive to change (Johansson et al 2010). The family is not only an incentive in the present study, but they have been engaged by the participants in their new lifestyle. There is evidence that the need to include family within all

cardiac rehabilitation programmes would benefit myocardial infarction patients' home life, whether by giving a fuller understanding of their condition to the family, or by providing an outlet for the family to ask questions candidly (Erikkson et al 2010; Salminen-Tuomaala et al 2013).

9.2.2 Towards cultural intelligence

Resnicow et al (1999) conceptualise cultural sensitivity as consisting of two dimensions, surface and deep structure. Therefore, pragmatic solutions such as providing information in linguistically appropriate forms; bilingual workers to enhance communication; working with community organisations to increase awareness of the service; gender specific exercise amenities that consider cultural and other tastes corresponds to this surface structure of cultural sensitivity. While peer advice was familiar, meaningful, and ethically resonant, health education advice from clinicians was usually unfamiliar and devoid of cultural meaning. This creates a social and knowledge vacuum. 'Behaviour change' interventions aimed at preventing and managing are likely to be ineffective if delivered in such a sociocultural vacuum. Hence, without addressing significant influences of the culture such as heritage, life experiences and cultural beliefs may act as a disincentive to make and maintain lifestyle changes.

Successful communication between healthcare providers and their patients from different cultural backgrounds depends on developing awareness of the normative cultural values of patients and how these differ from the cultural values of most Western medical professionals. Akin to the nurse interaction with family members, nurse interactions with patients of 'other' culture is fraught with its own inherent stress and tensions. For, different sociocultural or religious identities could have an impact on how lifestyle choice are made.

What I propose is the need to move towards cultural intelligence. Cultural intelligence refers to a person's capability to function effectively in culturally diverse contexts (Ang and Van Dyne 2008, Earley and Ang 2003). This definition of cultural intelligence as a capability emphasises a person's potential to be effective across a wide range of intercultural contexts. This is of

paramount importance to overcome the risk of 'essentialisation' and to face the challenges faced, as a health professional in a multicultural society. For, cultural intelligence differs from the capability to function effectively in a specific culture. Instead, cultural intelligence reflects a general set of capabilities that facilitate one's effectiveness across different cultural and in multicultural environments.

In this sense, cultural intelligence and culturally congruent nursing is when cultural care values, expressions are used appropriately and knowingly; when client beliefs and values are thoughtfully and skilfully incorporated into nursing care plans. Such culturally intelligent nurses can effect positive changes in healthcare practices for clients of designated cultures.

9.2.3 Towards providing a seat for faith and religion

Snippets of God's Will and fate can be seen in the lyrics of 'que sera sera'*, in the missile analogy*. The antiquity of the idea can also be seen echoed in the Prince of Denmark's reference to the slings and arrows*. However, such a lengthy discourse is not in the scope of this thesis. Suffice to say that in this study, discussion about illness they encountered and lifestyle changes they were advised to follow, highlighted a deep connection with God or a spiritual element.

Quite uniquely, this study depicts a complex aspect of religiosity – where the participants acknowledged the responsibility of man (mankind) alongside the responsibility of God –citing the dictum *daivam pathi, than pathi* (half responsibility is God's, the other half man's) shows participants did not endorse a passive or pessimistic stand after a heart attack. They rather initiated secondary prevention efforts with appropriate attention to medicine adherence and lifestyle change. Though in the interview narratives there is a thread of affirmation that this diagnosis was the will of God and as such predetermined, however, these excerpts illustrate their faith and religions provided a context in which they understood, accepted and made sense of their diagnoses.

Moreover, this did not preclude their engagement with efforts to manage their conditions. There is classic lack of hopelessness and bleak resignation inherent in the notion of fate of which literature cites several examples. Conversely these emic perspectives of 'faith', 'religious beliefs' support the multidimensional concept of fate. I can see the decisions of lifestyle changes are produced and maintained through a complex relationship that allows for both - religious belief (external forces) and individual effort (inner will). And this instead of creating a dichotomy between internal and external focuses, for the participants the will to change and the power of God merged comfortably into a single locus of control.

If religious beliefs centering on God as a partner can reflect acceptance of life-changing situations such as a diagnosis of heart attack, then this particular aspect of 'faith' can be harnessed which can actually serve as an adjunct to rehabilitation programmes. Though it may warrant further exploration, tentatively one could suggest that use of religious strategies may be a way to promote lifestyle changes among South Asians after a cardiac event.

In providing such a support, the health professional communicates their respect of the 'others belief'.

9.2.4 Towards embedding the lay narrative

The participant perspectives in this study highlight the ways in which a community's explanatory models, daily lived experiences, and socio-economic context can influence lifestyle changes. This study uncovered the tension that often exists between the biomedical model and a community's lay narratives. What the findings showcase, and what others suggest, is that culturally targeted health communication must not only engage the biomedical model, but must also engage the lay beliefs that facilitate or inhibit behaviour change in the target community. For example, Mr Philip – an educated masters graduate, working in the

health field, he explained his heart attack was due to the 'haemorrhoidectomy he had the previous year'.

Similarly, Fatima mentioned, she believed it is because of her practice of 'sucking out snot from the baby's mouth'. Mr Philip had a strong family history of myocardial infarction and in his narratives, he was waiting for it to happen, and he was proactive – careful of his diet and exercise. And yet his lay beliefs of the cause of heart attack were not as dictated by the biomedical model. Health beliefs of the South Asian diaspora can be defined as practices that are socially embedded and '*shaped by people's situations in the social structure, their cultural, personal biography, and social identity'* (Greenhalgh et al 2004:106).

Naturally as a health professional the first task is to 'correct this belief and attune it to the biomedical model. However, such an embedded belief first needs affirmation and inclusion in the dialogue between a health professional and the participant, prior to any attempts at correction of beliefs – attempting to connect to the deeper structures of culture. This also helps to showcase why knowledge provision in itself does not work for South Asians. Emphasis on clinical risk factors, downplaying or negating their lay narratives about coronary heart disease, the messages would be less credible. Incorporating South Asians' lay beliefs whilst also providing clear and actionable information about the importance of controlling clinical and lifestyle risk factors, can be used for addressing the disconnect that exists between lay beliefs and the biomedical model that underlies most secondary prevention strategies.

Others, building on anthropological and sociological theory, have suggested that health promotion interventions are more likely to impact behaviour change when interventions target the deeper structures of culture, such as the target groups' explanatory models about the causes of health and illness and their unique facilitators and barriers to behaviour change. Beliefs are deeply-ingrained and often reflect the psychosocial and experiential factors that influence health and behaviour change.

Towards this end, further formative research should be done to understand the lay beliefs that may be influencing health and disease prevention within a particular community; second, secondary prevention strategies can navigate the tensions that may exist between the community's lay beliefs and the biomedical model by incorporating the community's lay beliefs into targeted messages; third, communities and cultures are not monolithic, and messages must reflect the heterogeneity within a target community; and finally, it is hard to predict how communities will react to culturally targeted health messages, and thus, full engagement of the community in every phase of message design is critical and ideally, should be an iterative process.

9.3 Recommendations

No cure for cardiovascular disease has yet been found, which means that prevention is the mainstay of treatment and the efforts to slow down disease progression is now centre stage (Cardiovascular Disease Outcomes Strategy (Department of Health, 2013). Patients must manage a constellation of symptoms such as angina, shortness of breath and fatigue, combined with complex medication regimes (Astin 2013). This was a small, exploratory study however, the themes that have been identified in this study provide useful insights that may be applicable to other populations and may hold significance across all levels of health care, including professionals at policy and service level.

Implications for practice

1. Integrate BACPR standards and core-components such that all receive expert support, care and guidance in each of the components required to meet their individual needs. The final statement of the WHO definition of cardiac rehabilitation (as mentioned in chapter) highlights the importance of integrating with secondary prevention services. One underlying factor that needs to be ensured; that all the BACPR standards and core components should be provided, wherever the patient participates in the programme.

2. Good referral and re-referral systems in place between the cardiac rehabilitation team and the primary care services. There must be good communication between all sectors – primary, secondary and tertiary. Variations still occur in referring patients to cardiac rehabilitation (as some of the patients were still waiting for hospital appointment even after one month of discharge).

3. .Health professionals need to consider working with, rather than against, cultural norms, values, and individual perceptions. Health professionals need to re-think and re-engage with the cultural values and attitudes of the South Asian community. Strategies where there is due acknowledgement of the South Asian patients' cultural priorities need to be re-thought of.

4. .Early psychosocial support should ideally be provided immediately after discharge. Lifestyle modification programmes, such as cardiac rehabilitation, are effective in supporting behaviour change compared to routine care.

5. The provision of a family oriented care should be a key component of cardiac rehabilitation. This study confirms the importance of considering family responsibilities within the setting of cardiac rehabilitation and therefore a more family tailored approach is needed to improve uptake owing to their lifestyle and family commitments. Additionally, physicians and dieticians should discuss lifestyle factors and the lifestyle choices with the entire family. Family needs, priorities and goals should be incorporated whilst making individualised care plan during cardiac rehabilitation programs.

6. Move from enhancing self-efficacy to improving shared efficacy. Healthcare providers might better identify culturally appropriate heart health and rehabilitation messages considering the influences of collectivist cultures practices. Health care professionals must gain an understanding of the cultural importance of the South Asian diet. Instead of thinking cultural values as cultural barriers, it should be thought of bridges towards understanding the patients choices regarding making and maintain lifestyle choices.

7. Health professionals should be aware of the priorities of the individual which may clash with their treatment goal and so highlights the need for sensitivity to patient priorities. Self-management programs should also be based on patient need and planned and developed in consultation with patients and their families Health care professionals may need to invest additional time discussing the cultural and familial context of the South Asian patient.

8. Harness the social support system   There should be exploration of strategies already existing in the community that are accessible to the South Asian patient. Reinforce family-based eucational interventions that can build on beliefs, attitudes, and behaviours already existing in the community and is easily accessible to the patient. Ensure a culturally appropriate environment where there is "understanding of our ways." To mobilise this resource, health professionals involved in cardiac care play a pivotal role not only in signing off referrals to cardiac rehabilitation participation, but also being culturally intelligent in entering 'the other world', thus laying the groundwork for better adherence. As nurses, the priority is to foster collaborative partnerships with patients and their families, supporting them to 'self-manage' their lifestyle changes. The challenge whilst developing the policy and practice guidelines there is a need to recognise when ethnicity makes a difference and when it does not.

9.3 Chapter summary

The research suggests that in several instances people do not appear to view lifestyle changes in terms of a series of targets or goals, as is advocated in standards and guidance. Neither do they seem to accept uncritically the generalised advice about lifestyle changes provided in cardiac rehabilitation programs. Rather, people seem to relate recommendation regarding lifestyle changes to their own circumstances, which highlights the tension between approaches to coronary heart disease secondary prevention in the population at large and South Asian community perspectives. Research such as cited here, on the powerful effect of social norms on individual behaviour suggests raising awareness and information alone may be insufficient to effect change in behaviour. Therefore, to achieve more consistent and enduring improvements, researchers need to work with migrant South Asian communities. For only then could negotiating strategies where is an awareness of the South Asian cardiac patient's family needs, an acknowledgement of their cultural priorities and an appreciation of their religious and health beliefs.

This chapter has provided a discussion of the findings and the contribution to knowledge. The discussion was structured using the categories and its key inferences compared with

contemporary literature in the clinical practice. I find this discussion chapter is a synthesis and interpretation of findings, a venture not for recap and repeat but for a new theoretical insight, a presentation of a new reading of the research which links findings to literatures. A *scholarly place for interpretation and theorisation*. For me, this writing up of discussion is not merely a process of writing, but a *process of asserting*.

Chapter 10 Dénouement

By focusing on the outcome of the study and clarifying the theoretical worth of findings, I have attempted this chapter not to be the end, maybe the end of this study, but the beginning of further exploration of its impact. The below thesis dénouement draws the summarising of the study and study findings together. Initially, the quality of the study is discussed using specific criteria of credibility, originality, resonance, and usefulness (Charmaz 2006). Moving along, the strengths and limitations are of the research is then acknowledged, alongside the recommendations for future research is then presented. Finally, this chapter concludes with a reflexive account of the culmination of the study.

10.1 Quality

It is generally accepted that, within a qualitative paradigm, ontological positioning informs epistemic claims (Vickers 2017). As this research was conducted using a constructivist grounded theory a relativist stance is threaded throughout the thesis narrative. The following sections discuss the concepts of credibility, originality, resonance and usefulness that was used to appraise the quality of this study (Charmaz 2006), by providing examples of how each of these criteria were met.

10.1.1 Credibility

The narrative of the participants was made explicit throughout comparative analysis, whilst simultaneously ascertaining that the researcher's presence maintained. Throughout Chapters 5, 6,7, and 8, analysis was linked back to participant's accounts and narratives which bought depth and life to the theory, alongside credibility. The participants had a strong presence in this research, as was intended, and the narratives they proffered guided the study. Moreover, to maintain the presence of the participants

in the study, their narratives and biographies are interwoven into the discussion and findings chapters.

10.1.2 Resonance

The criterion of resonance relates to 'make sense' of narrative, providing insight the co-construction of meaning (Charmaz 2014). Participation in conferences (Salford Postgraduate Annual Research Conference in 2015 and 2016) for the presentation of findings and the feedback gained about the concepts meant that these concepts were being checked by experts in the field. Moreover, conference presentation slides uploaded onto social media sites drew feedback and comments from researchers across the globe. Memo writing was also especially important in this process, identifying how I interpreted the narratives and developed the codes and categories.

However, at this point in time has not yet been fed back to my participants. Plans are in place to produce a booklet 'Dhil Ki Kahani – Your story of harmonising life after myocardial infarction' which will be sent via post to the participants. Moreover, this can then aid in reaffirming the theoretical construction and theoretical rendering of the phenomenon. In the reflective accounts strewn throughout the thesis, I have articulated my personal views and insights as a researcher, as a South Asian and as a nurse about the phenomenon explored, how the literature review was positioned. I have also specified how and why the participants in the study were selected to ensure fittingness and delineated the scope of the research as well as contextualised the setting for the theory that was generated.

10.1.3 Originality

As identified in chapter 2, there is very little health science research that explores how South Asians choose and prioritise life style changes. This research adds new insights that may well stimulate further dialogue and debate. I believe the research is a valuable addition to the

literature, not just because it is grounded in the participant perspectives, but it crystallises the insights around the more focused issue of behavioural change, something that individual studies on the same subject have not achieved. The research adds to the hitherto limited research of making lifestyle changes following a myocardial infarction. Perspectives from the participants illuminated the realities of life to provide an insight into their experiences of making lifestyle changes. In particular, it showcases the integral part played by social norms and culture in lifestyle self-management among South Asians. Although literature was found which resonated with specific parts of the theoretical model, this research extends the knowledge by arguing that family, religion, culture and lay causal beliefs were all important and collectively influenced (shared efficacy) the lifestyle changes made by the South Asians. This was what made this research different and distinctive.

10.1.4 Usefulness

Charmaz summarises usefulness as follows: '*When born from reasoned reflections and principled convictions, a grounded theory that conceptualises and conveys what is meaningful about a substantive area can make a valuable contribution*' (Charmaz 2014:338). I explored the experiences and views of South Asian patients living in Northwest England and highlight the cultural expectations and challenges this community faces in terms of recovery from myocardial infarction and the support they need. I captured participant meaning, and described how the literature relates to each category which emerged in the theory.

Hopefully, I have achieved the aim of raising the awareness of the salient features of different groups of South Asians and in doing so, I believe, it will point towards some of the ingredients necessary for providing more culturally appropriate post myocardial infarction interventions for this vulnerable patient group. Since comparatively little data exist regarding the experiences of South Asians of North West, and in the landscape of developing interventions

within a wider context of competing theory based strategies, the study findings will be make a welcome contribution to the literature.

10.2 Strengths and limitations

As indicated in the preface, no research is complete without further questions arising from it. As a preliminary to this, the study strengths and limitations are properly identified to generate debate on the topic and stimulate further research. Such an exercise is important, for by placing the findings in context, potential errors borne from methods of data collection as well as the relevance of the work for other further research can be extrapolated. Further, the constructivist nature of this grounded theory allows me to acknowledge the limitations to demonstrate reflexivity. Therefore, whilst this study is original and innovative there are some limitations that should be acknowledged. By the virtue of using gatekeepers, I can only approximate the numbers. Although an effort was made to recruit South Asians based on their religion and ethnicity, such an effort was not possible as recruitment depended on how gatekeepers identified suitable participants. Moreover, it was reported that the ethnicity column in the database was often left blank, and often the cardiac rehabilitation lead had to guess the ethnicity based on the name. Therefore, it is plausible that South Asians with Anglicised names may have been unintentionally missed. I could have also added a poster of the research at each of these participation identification sites with my contact details, to allow volunteers the opportunity to contact me to gain further information to decide whether to participate in the study. The follow-up period of six months was rather short.

As previously noted, though there were many areas of resonance between the theoretical model and existing literature, what was most distinctive, however, was the way in which this research pooled in the categories to explain the basic underlying process. I have explored my participants' experiences before and after cardiac rehabilitation and this further advances the knowledge produced, contributing to the

evaluation of the existing rehabilitation programmes and identifying unmet rehabilitation needs. Again, as noted previously, this is the first qualitative research to present the 'lifestyle changes' as conflict and the resolution in 'maintaining harmony' of the lifestyle self-management process which is contextualised within the wider illness experience of being diagnosed with myocardial infarction.

Deviant cases were included in the analysis. For example, Patel did not go for cardiac rehabilitation stating there is nothing "you could do for me, when its my time, I will go". Such a sentiment is given due merit in the analysis with the help of theoretical sampling. It has been evidenced in research, that when researchers tend to rely on written invitations, or questionnaires or letters of invitation to promote participation, this can limit recruitment of minority-ethnic participants due to issues surrounding literacy or comprehension of complex concepts when consenting to research (Hussain-Gambles et al 2004). Therefore, I used, instead of the usual information letter, a reader friendly booklet (inside pocket)

10.3 Future research

Longitudinal studies that examine the family and self-care trajectory over time and the reciprocal relationships between the self-care demands and changes in family functioning would be enlightening. However, because family structure, function, and roles are influenced by culture and influence self-care behaviours such as the family variables that can be relied upon to improve or discourage self-care can be explored. The concept of mixed/hybrid South Asian identities is another avenue to explore. Lifestyle changes are more difficult to uphold over periods longer than six months, and longer follow-up studies should therefore be investigated.

10.4 Concluding thoughts

To reiterate the first line of chapter one - the achievements of modern medicine over the last century are impressive, if not phenomenal. For this paradigm shift is needed that would be to tip the balance away from health services that are overly biomedical oriented, disease focused, technology driven and doctor dominated. Some of these matters are less likely to be a function of technical medical care but rather a function of healthcare professionals providing therapeutic and health-promoting support for people to manage the physical, mental, domestic, occupational and social aspects of their lives (Jahangiri 2011) – all of the goals at the heart of a good cardiac rehabilitation and chronic disease management and prevention programme.

If such is the case, then there is a need to rewrite some of the learned ethos of health care. For the model that is emerging in my study, contributing to the hub of knowledge is a family centric culturally empowered service provision where the family is at the centre; where there is acknowledgement of cultural, religious, and beliefs; where lay explanations are deliberated. For this, we may have to take a step forward from cultural competence to cultural intelligence where one is willing to enter another's world to apply the cultural knowledge and skill. For the participants belong to a plural community. They are a repository of multiplicity, a grand synthesis of diverse social, religious, language and caste and creed, a panorama of its own type without a parallel in other communities, which has upheld its unity and cohesiveness despite migrations and acculturation.

10.5 Epilogue

On reflection, at the beginning of the study, there was a prevailing view that migrant issues were discussed and addressed eons ago, and that there was no new knowledge to be gleaned, with no possibility of a new insight within this field. I worried that perchance by the concerted efforts of government guidelines, alongside an unprecedented advent of rapid communication via social media, the exoticness of

this niche group has vanished. This led to the 'failure' I mentioned in journal excerpt 8 (page 10). Despite such challenging 'feelings', a few months into my study, I was able to recognise the culture of apathy that nurture the futile notion that all is fair and just and make us increasingly immune to differences.

Such negativity at the onset of the study, at the end became its strength. It helped me steer clear of research methods and questions that could lead to the danger of developing behavioural expectation and stereotypes based on research agendas. The more the study took shape with interviews conducted at participant homes, the more the data shifted to reflect the depth and influence of social, cultural, religious and familial fabric that surround lifestyle self-management.

This study defines the participants as South Asians after their first heart attack, recently discharged from the hospital. After making concessions that the analysis is spatially and temporally located and the knowledge is the product of the interaction between those participants and the researcher, it is indeed possible to essentialise the experience of people after a heart attack. And yet I have to concede the knowledge produced about lifestyle self-management of South Asians is inherently partial. For undoubtedly, the participants would define themselves very differently if the study was based on their family relationships or their identify within their social community. After all, the substance of everyday experience refers always to a 'where and when' (a 'here and now' or a 'there and then'). Therefore, it would be wise not to judge the story based on the chapter you walked into.

*In conclusion, I have sought to integrate the philosophy, policy, history, research and evidence of self-management alongside the story of emergence of South Asians as an integral part of the multicultural contemporary fabric of British society. The importance of lifestyle self-management in the changing landscape of health and disease is reiterated throughout the study. Interlacing the narration by journal excerpts, I have sought to retain the conviction that this research is real, that it can advance progress and promote positive change in our society. As a sign of epistemic humility and honesty, I pay homage to the Aristotelian conception of 'phronesis' - practical, limited wisdom - that for South Asians in this study lifestyle choices made after a heart attack was **not an individual act but a shared act**. The study has achieved much more than it set out to do as evidenced by the enthusiastic approval of its findings at internationally recognised conferences and*

invitation for workshops by clinical psychologists – accolades that makes all the hard work worthwhile. Therein, by claiming my findings as original contribution and marking my imprint in the field, I signoff as a research

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Approvals

A.1 Approval from University of Salford

A.2 Approval from Reginal Ethics committee

A.3 Approval from South Manchester University Hospitals

A.4 Approval from Pennine Acute Care Trust

A.5 Approval from Central Manchester University Hospitals

University of Salford
MANCHESTER

6 March 2015

Dear Dilla,

RE: ETHICS APPLICATION HSCR15/02 – **Lifestyle self-management experience of South Asians post myocardial infarction**

Based on the information you provided, I am pleased to inform you that application HSCR15/02 has been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible.

Yours sincerely,

Sarah Starkey

Sarah Starkey
Engagement & Innovation Assistant

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25 February 2015

Ms Dilla Davis
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Central Manchester University Hospitals - Manchester Royal Infirmary
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Oxford Road
Manchester
M13 9WL

Dear Ms Davis

Study title:	**Lifestyle Self-Management experience of South Asians after a heart attack**
REC reference:	**15/SW/0042**
IRAS project ID:	**156365**

Thank you for your letter of 25th February 2015, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Kirsten Peck, nrescommittee.southwest-cornwall-plymouth@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation

as revised.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering letter on headed paper [Covering letter]	1	10 February 2015
Covering letter on headed paper [covering letter]	2	25 February 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Interview schedules or topic guides for participants [Topic guide]	3	02 February 2015
Letters of invitation to participant [participant invitation letter]	2	02 February 2015
Other [support letter from CMFT (Participant Identification centre)]		
Other [Participant Identification Center - Wythenshawe Hospital]		
Other [Participant Identification Center - Pennine Trust]		
Other [Lone worker Policy]		
Other [use of interpreters]		
Other [internal panel feedback on research]		
Other [C.V. Martin Johnson]	1	10 February 2015
Participant consent form [Consent sheet]	2	02 February 2015
Participant information sheet (PIS) [information sheet]	4	25 February 2015
REC Application Form [REC_Form_06022015]		06 February 2015
Research protocol or project proposal	1	05 February 2015
Research protocol or project proposal	2	25 February 2015
Summary CV for Chief Investigator (CI) [C.V.]	1	05 February 2015
Summary CV for supervisor (student research) [Supervisor CV]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

<u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

15/SW/0042	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Canon Ian Ainsworth-Smith
Chair

Email: nrescommittee.southwest-cornwall-plymouth@nhs.net

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Professor Tony Warne*
                           Lynne Webster, Manchester Biomedical Research Centre

University Hospital of South Manchester **NHS**

NHS Foundation Trust

Research & Development Directorate
1st Floor, NIHR Building
Wythenshawe Hospital
Southmoor Road
Manchester
M23 9QZ

20 October 2014

Dilla Davis
PhD – GTS student
School of Nursing, Midwifery, Social Work & Social Sciences
Mary Seacole Building
University of Salford
Salford
M6 6PU

Dear Dilla

Re: <u>Life-style self-management experience of South Asians after an acute myocardial infarction</u>

This is to confirm that the University Hospital of South Manchester NHS Foundation Trust will support the above study as a 'Participant Identification Centre' (PIC) site.

Yours sincerely

███████████████

Karen Rhodes
Research Governance Manager

Research and Development Department
Trust Headquarters, 1st Floor,
Room 137 North
Manchester General
Hospital
Delaunays Road
Crumpsall
Manchester
M8 5RB
T: 0161 604 5233

Dr. Steve Woby – Head of R&D
Manager Steve.Woby@pat.nhs.uk

Charlotte Lever – Quality & Performance
Charlotte.Lever@pat.nhs.uk

Katie Doyle – Research Operations Manager
Katie.Doyle@pat.nhs.uk

Dilla Davis
PhD – GTS student
School of Nursing, Midwifery, Social Work
& Social Sciences
Mary Seacole Building
University of Salford,
Salford,
M6 6PU

21 October 2014

Dear Dilla

Re: Life-style self-management experience of South Asians after an acute myocardial infarction

Thank you for providing the Research & Development (R&D) department with your research project information.   I can confirm that The Pennine Acute Hospitals NHS Trust will support your study and act as a Participant Identification Centre (PIC).

We look forward to starting the governance process for your study, once you have submitted your Ethics forms.

Yours sincerely

Katie Doyle
Research Operations Manager
The Pennine Acute Hospitals NHS Trust

cc: Simon.kaye@pat.nhs.uk – Senior Research Nurse

Central Manchester University Hospitals NHS

NHS Foundation Trust

Research Team – Manchester Heart Centre
Manchester Royal Infirmary
Oxford Road
Manchester
M13 9WL

Dilla Davis
PhD – GTS student
School of Nursing, Midwifery, Social Work & Social Sciences
Mary Seacole Building, Rm 1.10
University of Salford,
Salford, M6 6PU

Dear Dillia,

Thank you for submitting your study for consideration at the Manchester Heart Centre Research Meeting on the 5th August 2014. At the meeting your study titled;

"Life-style self-management experience of South Asians after an acute myocardial infarction?"

At the meeting Sarah Evans explained that you have approached and coordinated the study with the clinical team regarding the identification of patients (Jean Brett – Cardiac Rehab) and the research team (Elly Owen-Jones and Sarah Evans) regarding the submission for the study.

I pleased to inform you that the Manchester Heart Centre will be happy to support the above research project.

If you have any queries in the meantime please do not hesitate to contact a member of the team

Yours sincerely
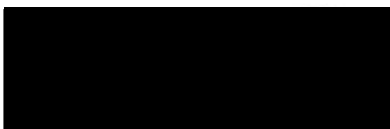
Sarah Evans
Clinical Trial Coordinator
Manchester Heart Centre

B   Research Activities

B.1 Participant invitation letter

B.2 Participant reply slip

B.3 Participant information booklet

B.4 Consent sheet

B.5 Interview Topic guides

University of Salford
MANCHESTER

Dilla Davis
PhD – GTS student
School of Nursing,
Mary Seacole Building
University of Salford
Salford, M6 6PU

M: █████████
Email:d.davis1@edu.salford.ac.uk

Dear Participant,

I am a PhD student undertaking a research study to explore the lifestyle self-management experience of South Asians, supervised by Dr Ian Jones, University of Salford.

I am exploring the experience of South Asians in managing their lifestyle changes after a heart attack. To do this, I need to talk to South Asian people who were recently admitted to hospital with a heart attack about the challenges they may be facing and their perceived emotional and social support needs arising from these changes. You have been identified as someone who was recently diagnosed with a heart attack.

Enclosed is an information sheet explaining all about the study. If after reading the information sheet you would like to participate then please return the reply slip, attached, in the prepaid addressed envelope. I will then contact you, answer any questions you may have and explain the study further. If I do not receive the reply slip within 14 days you will receive another letter. If you do not respond after this second letter, it will be assumed you do not wish to participate. Your participation is completely voluntary. **If you are interested in being involved please return this reply slip in the envelope provided within 14 days.**

Thank you for taking the time to read the information.

Dilla Davis

Patient Information Leaflet

This leaflet provides information about the study you are invited to take part

People of South Asian descent are more likely to develop and suffer from heart disease than any other ethnic group in the U.K. There has been limited research carried out within this community explaining how lifestyle changes in diet, smoking and exercise are managed by people of South Asian heritage.

I want to find out more about your experiences after a heart attack. I want to know how you manage the lifestyle changes – dietary, smoking, exercise – you make (or don't), what challenges you face in making these changes.

I would like to invite you to take part in the study.

➢ You do not have to say yes.
➢ If you decide to say no, then you don't need to give me a reason.
➢ Please read this information carefully before you decide what to do.
➢ I will give you time to think about taking part and ask other people for advice.

Why is the study useful?

The information you provide in the interviews will give me a deeper understanding of South Asian experience of heart attacks. I will also be able to know your specific emotional and social support needs in making and maintaining any of these changes. The study may highlight better ways of coping with changes in diet, smoking and exercise. This information can be used to design better ways for people in this community with heart problems to make and sustain a healthy lifestyle change.

Why have you been asked to take part?

You have been invited to take part in this research study because you have recently been admitted with a cardiac condition in one of the hospitals – Royal Manchester Infirmary, Pennine Acute Trust Hospitals or Wythenshawe Hospital. I have invited you to participate in the study, so I can gather your views on your experience of recovery from heart attack, how you manage your diet, exercise and your smoking (if any) and your emotional and social needs in managing these changes.

What will you have to do if you take part?

You have received this information sheet and a letter which has a reply slip. If you want to be involved in the research study, you will need to send back the reply slip with your contact details on, in the envelope provided, within the next 14 days. Once I receive your reply slip, I will telephone you to answer any questions you may have and if you still want to be involved will arrange an interview with you. This interview will be with me. *If you need an interpreter, you can state the request on the reply slip and an interpreter will be available at the time of telephone call (provided free of charge).*

The interview will take place at a time and place which is convenient to you and probably take 40-50 minutes of your time. You will be requested to take part in two interviews. In the first interview within the first three weeks of discharge, you will be asked to describe and discuss your experience of the heart attack, the lifestyle changes you are managing or expecting to make. The second interview will occur approximately 16 weeks following your discharge from hospital and will centre on questions regarding the

challenges you may face whilst self-managing lifestyle changes and what emotional and social support you require. Both the interviews will be tape recorded, if you agree.

How will this information be used?

The information gathered from all the patient interviews will be used to gain a deeper understanding of South Asian experience of heart attacks and whether they have specific emotional and social support needs specific. It will inform strategies to support lifestyle self-management among South Asians in secondary prevention programs such as cardiac rehabilitation

What are the possible disadvantages of taking part?

Taking part in this research project will not change your treatment in anyway. However, it will take up to 2 hours of your time in total.

Will your taking part in the study be kept confidential?

All data will be stored in accordance with the data protection act of 1998. The database at the university will be password protected, known only to the primary researcher. Recorded interviews will be digitally uploaded to this password protected computer in the University accessed only by the primary researcher, who will be responsible for the complete transcribing of the data.

Data stored on this study data base will be anonymised and have a research code and be encrypted. The main file with names and addresses of patients and their subsequent research codes will be stored separately, electronically accessible only to the primary researcher. Any data that is shared between the researcher and her supervisor will be transferred using encrypted email or an encrypted USB. No agency outside to the research will be used to transcribe the interviews.

The data from the study may be used in academic papers but anonymity will be maintained, by removing any identifiers. No one will know you have been involved in the study unless you choose to tell them.

All paper based copies of completed information sheets/interview notes will be research coded and stored in a locked filing cabinet, in a number locked postgraduate room of the University, the key accessible only to the primary researcher.

All data will be stored till the end of the study period that is 3 years. However, this data will be anonymous and stored securely until of a time when it can be shredded and disposed of appropriately. Recordings from interviews will be destroyed when the study is complete and the data is available transcribed on both hard and electronic copy, accessible only to the researcher.

What if you don't want to be involved?

It is up to you to decide whether or not to take part. Your participation in the study is voluntary. If you prefer not to take part you do not have to give a reason, your care and treatment will not be affected in any way.

Participation in this research will be based around your commitments, whereby times for interviews can be arranged for your convenience. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive from the NHS.

What if you have a complaint about this study?

If you have a complaint about this study you can request to speak to my supervisor Dr Ian Jones at the University of Salford or the usual NHS complaints procedure is available to you. Moreover, if you would like to take it up any further, you could also email Mr Anish Kurien, Research and Innovation Manager, at University of Salford. Both their contact details are given below:

Dr Ian Jones RN, PhD, Senior Lecturer in Cardiovascular Nursing, School of Nursing, Midwifery, Social Work & Social Sciences, Room MS230, Mary Seacole Building, University of Salford, Salford M5 4WT t: +44 (0) 1612957278 | m: +44 (0)7725910761 Email: i.jones@salford.ac.uk

Anish Kurien MBA, PRINCE2, MSP, Research and Innovation Manager | College of Health and Social Care AD101, Allerton Building, University of Salford, Salford, M6 6PU t: +44 (0) 161 295 5276 | e: a.kurien@salford.ac.uk

What happens now?

If you wish to take part in this study, please complete the reply slip and send it back in the envelope provided to the researcher Dilla Davis. If you have any questions please do not hesitate to telephone **Dilla Davis – 07525377995**

Thank you

If you are interested in being involved please return this reply slip in the envelope provided within 14 days.

Please indicate the time of the day you would like me to call you.

I am happy to be contacted by telephone to discuss my possible participation in the research study described in the letter to explore the lifestyle self-management needs of South Asians after a heart attack. My contact details are:

Name_____

Address_____

_____

_____

_____

First Language _____

Telephone No: _____

The best day to call is _____

The best time of day to call is _____

Dilla Davis

PhD – GTS student

School of Nursing, Midwifery, Social Work & Social Science

Mary Seacole Building

University of Salford, Salford,

M6 6PU

Ph: 07525377995

University of Salford MANCHESTER

Consent Form

Title of Research: Lifestyle Self-management experience of South Asians post Myocardial Infarction

Project: PhD

IRAS number: 156365 15/SW/0042

Researcher(s): Student Researcher: Dilla Davis

Supervisor: Dr Ian Jones.

Please Initial

1. I confirm that I have read and have understood the information sheet for the above study dated 2/2/2015 version #3.

2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason why and without my rights being affected.

4. I understand that under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.

5. I understand how the researcher will use my responses, who will see them and how the data will be stored.

6. I agree to the interview to be recorded.

7. I agree for an interpreter to be used

8. **I agree to take part in the above study**

Participant Name   Date   Signature

_____

Researcher   Date   Signature

_____

Contact Details:

Researcher: Dilla Davis
Post Graduate Research Student

Mary Seacole (Room1.10)
School of Nursing, Midwifery, Social Work
& Social Sciences
College of Health and Social Care
University of Salford, Salford, M6 6PU
Email:d.davis1@edu.salford.ac.uk

Supervisor: Dr Ian Jones
Senior Lecturer in
Cardiovascular Nursing
Mary Seacole (Room 2.10)
School of Nursing, Midwifery,
Social Work & Social Sciences
College of Health & Social Care
University of Salford, M6 6PU
Email: I.jones@salford.ac.uk

Appendix 7: Semi-structured interview Guides a) stage one & b) stage two: version 3 (2-2-2015)

a) Patient Interview stage one:

Patient Research Code:	
Date:	
Interview Start Time:	
Interview Finish Time:	

Demographic Details:

Dob		
Gender	**M**	**F**
Ethnicity (*as stated by the patient)*		
Religion		

Educational Level:

Qualification

Myocardial Infarction:

Diagnosis	
Date of Discharge	
Date of Phone call by cardiac team	
Date of commencement of CR	

a) Stage One Interview guide

- Experiences

  - How are you getting on since your heart attack?

  - How do you feel about having a heart attack?

  - Why do you think it happened to you?

- Expectations

  - What do you expect to happen over the next few weeks/months?

  - What do you want to happen? (What's important?)

  - Have you made any plans? (What are they?)

  - Have you made/do you intend to make any changes in your life?

- Needs

  - What things would help you now/what do you think you need?

  - Were you advised to make changes to your life? By whom?

  - What kind of advice have you been given? Exercise, diet, smoking

  - Were you happy with the way in which you were provided with this information?

  - Were you invited to attend rehabilitation programme?

  - Did you have contact with any other health professionals after you were discharged

- Social Support - Partner/family relationships

  - How have you and your partner/family been managing?

  - Has the heart attack made any difference to the roles within your family?

  - What support have you had? (Social, emotional, spiritual, financial?)

  - What/who has been of helpful/unhelpful? Who do you turn to for help?)

- Lifestyle:

  - Did you think you were healthy why?

  - For people with your condition can you tell me what you think you need to do in order to regain good health? smoking, alcohol, diet, exercise, stress, other

  - What plan do you have in order to regain good health? Smoking, diet, exercise

b) Stage two: Interview Topic Guide version #3 (2-2-2015)

- Experiences

  - How are you getting on since we last met? (What's been happening to you? What have you been doing? Have you any worries/problems?)

- Lifestyle changes

  - Were you able make the necessary changes? What/who has been of helpful/unhelpful? Who do you turn to for help?)
  - What have you done to be healthy?
  - What do you find most difficult? Why?
  - Are you happy with the way you are managing the change?
  - Is there anything you are continuing to do, knowing it is not good for you?
  - What helped you to choose the change/prioritise the change?
  - Has your family done anything to help you regain good health? Ask them to identify who does what and why - Medication-prescribed/other, smoking, alcohol, diet, exercise, stress, other

- Social/emotional Support - Partner/family relationships

  - How have you and your partner/family been managing?
  - Has the heart attack made any difference to the roles within your family?
  - Are you happy with the support of your friends/family?
  - How do you see the future?

- Cardiac Rehabilitation

  - Have you been for the cardiac rehab?
  - How useful/helpful in making the lifestyle changes?
  - What are the things you liked/disliked about the program?

Thank you very much

Lone Working & Working in Hazardous Areas – Code of Practice

The University recognises that there are a number of workplace situations that potentially may present a higher risk to employee safety, these include:

1)   Lone working.
2)   Work undertaken in hazardous areas i.e. laboratories, workshops and out of office/off site visits.

The above situations MUST be risk assessed and the following controls considered:

Lone working / Working in hazardous area

There is a need to ensure that all persons working alone do not come to any harm. Therefore all tasks where persons are required to work alone must be subject to a risk assessment. Wherever there is a significant risk that work tasks might result in injury the University has adopted a "Two person working rule". The general interpretation of this rule is that there are two people present in the area where the task is undertaken.
The sole purpose of this rule is to provide immediate assistance or to summon help in case of accident or illness.
Certain locations within the University have been identified as High Hazard
Areas, for individuals working in these areas; further advice is available on the Health, Safety & Wellbeing Department website "Laboratory Cleaning & Maintenance by non-laboratory Personnel".

Lone working outside normal working hours; 8.00am-8.00pm (Mon-Fri) The School or Division must provide the worker with the appropriate authority and notify Security of the intended visit.
All lone workers must check **in** and **out** with Security at Maxwell reception.

Unattended equipment/experiments running overnight

The Health & Safety Co-ordinator must give approval for any experiment to run overnight unattended. A notice which indicates the location of any equipment and provides emergency contact details including instructions for an emergency shutdown must be clearly identified and placed at the entrance of the laboratory concerned and a copy should be given to Security staff.

In circumstances where working in a different location is unavoidable the School or Division must undertake a risk assessment and put procedures in place to ensure an employee's safety. The following controls should be considered:
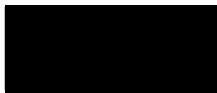
    1)   The full address details and phone number of the premises/location should be left with a named contact / buddy person prior to the visit.

    2)   The staff members undertaking the visit should leave their mobile phone numbers and should maintain contact with the named person.

    3)   If staff members fail to make contact the named person should initiate contact, if unable to do so they must inform a senior member of staff immediately for advice on further action.

    4)   Documentation relating to the visit should be filed / stored in line with local procedures.

NB The above list is for guidance only and should be amended to reflect any additional risks identified in the risk assessment.

_____

Read the Lone worker Policy on 14/06/2014
Signed:

Dilla Davis

C Publications, Presentations and Posters

C.1 Publications

C.2 Presentations

C.3 Poster

Presentation at academic conferences

Davis D (2017) Lifestyle self-management experiences of South Asians after a heart attack. Royal College of Nursing International Research Conference at University of Oxford, 5th May Oral Presentation (1.7.2 Lifestyle self-management experience of South Asians after a heart attack. Dilla Davis)

Davis D (2017) Lifestyle self-management experiences of South Asians after a heart attack – Central Manchester University Hospitals Inaugural Annual Nursing, Midwifery and Allied Health Professional Research Conference. 'Clinically Relevant Research - Imagining Possibilities' May 12th. Poster presentation.

Davis D. (2016) 'Researching your own community', British Sociological Association Postgraduate research conference Poster Presentation), London School of Economics and Political Science.

Published articles and articles under review

Davis D. (2016). A practical overview of how to conduct a systematic review. Nursing Standard, 31(12), pp.60-71.

Eldose S., Davis D. (2017) Home dialysis: overcoming barriers and encouraging independence Journal of Kidney Care 2017 2:3, 154-159

Davis D. Jones I. (2017) Barriers and facilitators of self-management of South Asians with Coronary heart disease, Journal of Transcultural Nursing, (under revision)

Davis D. 2015. A review protocol. http://www.crd.york.ac.uk/PROSPEROFILES/22095_PROTOCOL_20150502.pdf

Davis D. (2017) Stories of recovery and recuperating among South Asians after myocardial infarction – Journal of Immigrant and Minority Health (under review).

Davis D. (2017) The M word – navigating the methodological maze during a PhD journey (nearing completion).

Knowledge (gained from research activities) transfer sessions:

Davis D. Family and cultural issues in long-term conditions: cardiac disease as a case study – Guest lecture and 3-hour workshop for CBT and Physical Health module, (MSc Applied Psychology (Therapies) programme), University of Salford, Manchester (booked in for summer 2018).

Davis D (2017) The research Journey to date, Post Graduate Research Seminar, University of Salford, Manchester (Presentation).

Davis D. (2016) Findings of the PhD research for MSc Student, University of Salford, Manchester. Presentation (Dr Michelle Howarth).

Davis D. (2015) Defending your choice of methodology. Post-graduate Research Seminar, University of Salford, Manchester, May (oral presentation)

Davis D. (2014) Lifestyle self-management experiences of South Asians post myocardial infarction. Post-graduate Research Seminar, University of Salford, Manchester, November (Presentation)

Davis D. (2014) Interpreters in Interviews – challenges and conundrums. MSc student cohort, University of Salford, Manchester- Presentation (Professor Tony Long)

Awards and Honours:

Davis D. (2017) Lifestyle self-management experiences of South Asians post myocardial infarction. 3 minutes' thesis presentation heat winner from School of Nursing, Midwifery, Social sciences and Social work.

Davis D. (2016) Stories of Recovery and Recuperating among South Asians post myocardial infarction, Salford Postgraduate Academic Research Conference, Pecha Kucha best session award People's choice award.

Davis D. (2015) Lifestyle self-management experiences of South Asians post myocardial infarction. Salford Postgraduate Academic Research Conference June 3 minutes thesis competition. People's choice award.

Lifestyle Self-management experiences of South Asians post myocardial infarction

Introduction

Every 6 minutes someone dies of a heart attack. Globally as well as in UK, coronary heart disease, that is diseases of the heart and its blood vessels (Fig:1), is the forerunner in the list of common cause of death[1]. **South Asians -** people whose ancestry lies in the Indian subcontinent - carry the burden of increased incidence and prevalence due to several modifiable risk factors.[2] Their admittance rate to hospital with myocardial infarction is twice that of the general population.[3]

Survivors of heart attack are at an increased risk of **repeated infarction** Adopting a secondary preventive approach has the potential to avoid recurrent attacks.[4] At the centre of secondary preventive approach lies **self-management**. Literature iterates that lifestyle changes can delay cardiac disease progression.[5] As such in the aftermath of events like myocardial infarction, patients are often advised to make and maintain their **lifestyle changes**.[5]

Yet, lifestyle changes, central to the control and management of coronary heart disease, are not easy to achieve as they are often embedded in **ethno-cultural practices**. Irrefutably, the receptivity and the capacity to make and maintain lifestyle choices are predisposed by a patient's beliefs and culture.[6] Therefore, despite the persuasive evidence surrounding the clinical outcomes of managing lifestyle modifications for people with coronary heart disease, South Asians struggle to take up and self-manage therapeutic lifestyles.

Methods

One way to conceptualise the necessary knowledge and their reflective application is to understand the South Asian experience of managing these lifestyle changes. **Using a constructivist grounded theory** approach, this study aimed to explore **how South Asians choose, prioritise and navigate these lifestyle changes**.

Three participant identification sites were selected of which one was CMFT. Eligible participants were invited by the cardiac rehabilitation team by sending the participant information packs. **14 in-depth** interviews were conducted at patients' homes. Data collection and analysis was **performed simultaneously** to inform each other. Interview transcripts were analysed by **constant comparison**, initially of data with data, progressing to comparisons between their interpretations translated into codes and categories. Memos aided the analysis (Fig 2).

Results

Three theoretical categories were developed through constant comparison and theoretical sampling – patronage of the family, affinity towards the group and conforming to the religious and health beliefs. A harmony model to deal with diagnosis of heart attack and subsequent lifestyle changes is proposed (Fig 3). The model homes in a family oriented approach, with an appreciation of the cardiac patient's religious beliefs and cultural priorities, in self-management programmes such as in cardiac rehabilitation.

Figure: 1 Heart and blood vessels – pencil sketch

notes

Date: August 2015

traditional cooking, doing exercise). In such cases there is no point in trying to strengthen the autonomous ego/self efficacy because there is no autonomous ego..... Jung? Instead we should restore harmony, work with the family. Increase the shared efficacy... families'............ Most prominently, the family system of support is able to fulfil elements of care left unfilled in the health professional system.

Participants felt family members, due to their background would be able to understand the context of their needs and issues such as with lifestyle changes/and cultural obligations they were expected to fulfil; a shared understanding based on common causes of emotional distress: 'there is always something happening in our families.....

Figure: 2 Excerpt from memo

Figure: 3 Harmony model

Family centred care — Religion — Health beliefs — Culture

Discussion

South Asians make their decision and choices aligning it with their family, cultural and religious needs and priorities, for their goal is to maintain harmony in these spheres of life. Since their lifestyle choices is *not an individual act,* but *a shared act*, this calls for *enhancing the shared efficacy* of South Asians and *not self efficacy.*

Conclusion

Migrant South Asians across the globe have increased propensity of this disease. To alleviate the burden, there is a need for *ethno-sensitivity* rather than *ethnocentricity* in the delivery of services. Where there is a family-oriented approach instead of person-centred approach where there is collaborative approach involving the patient and the health professional and influencing cultural factors, and where there is embedding of practical aspects of cultural beliefs and social norms in self-management programmes such as cardiac rehabilitation. This calls for a move from cultural competence to cultural intelligence.

Practical Wisdom

Provision of family oriented and culturally empowered care:

➤ Acknowledgement of family needs
➤ Awareness of religious and cultural priorities
➤ Appreciation of health beliefs
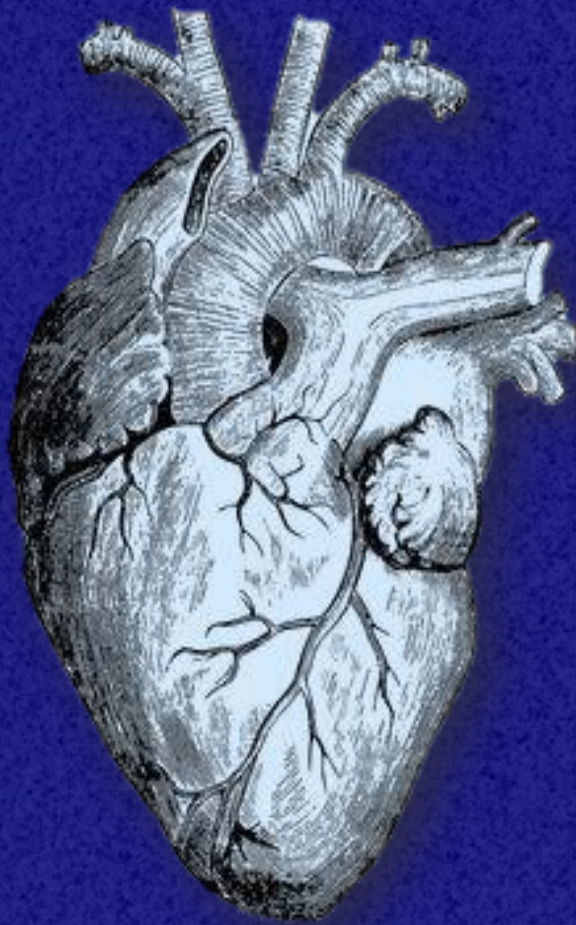
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