'The Lived Experiences of People with Schizophrenia Prescribed Atypical Antipsychotic Medication'

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The candidate confirms that the work submitted is his/her own, except where work which has formed part of jointly-authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

Aspects of the work conducted in this thesis have been published in the
Journal of Psychiatric and Mental Health Nursing, 2010, 17, 242–250, entitled
'The experience and consequences of people with mental health problems, the impact of stigma upon people with schizophrenia: a way forward'
By J.Harrison & A.Gill

With regard to the publication there are two named authors - myself and Dr J. Harrison. Dr Harrison was the first author. I can confirm that her role in the development of the publication was mainly editorial. I carried out the majority of the literature searching, developing and editing of the paper to fit into the word count and requirements of the journal. Dr Harrison had very little input apart from suggesting minor editorial changes and remained a peripheral figure in the writing of the article.

I also confirm that sections of the journal publication are included in the thesis as the publication is a direct result of research undertaken as part of my PhD studies. The main aspects of the work presented in the published paper occur in chapter 2 of my thesis, which is the literature review and also in the results and discussion which is chapter 5 of my thesis.

Acknowledgements

Abstract

This thesis looks at the lived experiences of people with schizophrenia who are prescribed the newer atypical as opposed to the older forms of typical antipsychotic medication.

The older (typical) neuroleptic forms of medication have been shown to produce unpleasant side-effects that cause severe problems with everyday functioning and thus affect patients' quality of life.

Existing research has shown that people with a diagnosis of schizophrenia are excluded from society and are often labelled deviant and suffer from discrimination. A person with schizophrenia is often ridiculed and not listened to, with the media portraying them as dangerous and mad. There is no available evidence that has produced detailed, valid accounts of how patients themselves construct meaning in their lives, and in particular how medication has affected them.

A purposeful sample of 19 patients with a diagnosis of schizophrenia being prescribed atypical neuroleptic medication, were selected.

This study utilised a combination of data collection techniques, which included patient diary-keeping (for four weeks) and individual face-to-face interviews at the mid- and end-points of the diary-keeping period. The use of 19 diaries and 38 interviews gave a unique, original and a very detailed insight into the lived experiences of people with schizophrenia.

The data analysis was informed by a phenomenological approach, utilising the work of Erving Goffman. The emergent five core concepts from the data were analysed using Burnard's content analysis.

Patient accounts reported a loss of identity and a loss of control over their lives. Stigma from the public and the media continues to greatly affect their quality of life. Many patients felt disempowered by the mental health services and wanted to see changes made in order to allow them to develop a better quality of life and feel empowered and integrated fully into society.

The findings of the study give a unique and wonderful insight into how a person with schizophrenia lives their life, and it is clear that the stigma associated with schizophrenia has a negative impact on individual's lives. People with schizophrenia want and need to be listened to, in order for them to have an improved quality of life. It is clear that their lived experiences should be taken into consideration when implementing policy development in order to reduce the social isolation associated with schizophrenia.

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Chapter 1

1.0 Introduction

The aim is to give a brief overview of the various components that contribute to this study, (a more in-depth description is given in the literature review). The initial section consists of a description of schizophrenia and its impact on individuals and their families. Schizophrenia has many problems associated with it and these can make it difficult to treat and manage efficiently. This section describes how the illness can affect the individual and when it may manifest itself and the prevalence of schizophrenia. There then follows a description of the impact of schizophrenia and how the negative symptoms (withdrawal and apathy) are more difficult to treat as opposed to the more acute and vivid symptoms such as hallucinations and delusions. Following on from this is an historical overview of the medications used in the treatment of schizophrenia, the distress caused by side effects of the older typical antipsychotic medication. There then follows a description of how recent developments have led to a newer type of medication called atypical antipsychotic medication with the potential to reduce side effects.

It can then be argued that a person's quality of life is affected by the side effects of medication and a brief description of how individuals resent the side effects that this type of medication causes.

The quality of life of individuals with schizophrenia is then discussed by looking at the sociological work of Erving Goffman whose '*The Presentation of Self in Everyday Life'* is to 'consider the way in which the individual in ordinary work situations presents himself and his activity to others'. A review of Goffman's work is then undertaken and linked to the study itself following a detailed description of the sociological theories of mental illness. A review of the impact of deinstitutionalisation is looked at and how this has affected the daily lives of individuals. A review of how people struggle to become integrated into society is examined and the loss of identity explored. The final part of the literature review contains a look at the secondary impacts on individuals with schizophrenia and deals with stigma which can often lead to a loss of control and a loss of identity. The experiences of people with schizophrenia are dealt with in the literature review alongside the concept of disempowerment. Finally at the end of this chapter are the aims and objectives of the study

1.1 Schizophrenia

1.1.1   Prevalence

Goldner et al (2002) have indicated that schizophrenia affects approximately 1% of the UK population, (National Institute for Mental Health 2005) which equates to an incidence of 0.1 or 0.2 per 1,000, with a prevalence of 3 per 1,000. Interestingly studies have shown (Robins & Regier, 1991, Levav, Kohn, Dohrenwend, et al 1993; Kessler, 1999; and, Jablensky 2000, 2003) that the prevalence rates of schizophrenia can vary worldwide from 1 per 1000 to 10 per 1000, depending upon the diagnostic criteria applied.

However Saha, Chant, Welham, McGrath (2005) suggest that if the public were given a measure of the likelihood that individuals would develop schizophrenia during their lifetime, a more accurate estimate would be 7 to 8 individuals per 1000. Schizophrenia is a major mental illness, of which the two most commonly recognised symptoms are hallucinations (usually auditory) and delusions. Schizophrenia, as currently diagnosed, may be an umbrella term used for a number of different disorders.

1.1.2   Impact of schizophrenia

Schizophrenia is an important illness because of its high prevalence, the severity of the disability it can cause, its long duration, and the impact on the sufferer's family. Also the high economic costs of providing care and because it causes chronic long-term disability in over half of the people who suffer from it. In addition people with schizophrenia continue to live in an environment in which both the public and health professionals have low expectations for them (Jorm, Korten, Jacomb & Rodgers, 1997: Jorm, Korten, Jacomb, Rodgers, Pollit, et al 1997: Shera & Delva-Tauiliili, 1996).

In terms of the positive symptoms of schizophrenia, individuals will each have their own unique combination of symptoms and experiences, the precise pattern of which will be influenced by their particular circumstances.

The positive symptoms are often characterised by some deterioration in personal functioning. Difficulties may include memory and concentration problems, social withdrawal, unusual and uncharacteristic behaviour, disturbed communication and affect, bizarre ideas and perceptual experiences, poor personal hygiene, and reduced interest in and motivation for day-to-day activities. A person's relative or close friend may report that they have changed and are not themselves. These changes may well affect the person's ability to hold down a job, study, or relate to family and friends. This acute phase is characterised by symptoms of hallucinations, delusions, and behavioural disturbances, such as agitation and

distress. Following on from the acute phase is a situation whereby a person's health is often interrupted by acute exacerbations or 'relapses', which may need additional interventions. A person suffering with chronic schizophrenia or one who has not responded to treatment over a long period of time (referred to as a chronic patient) is often characterised as financially poor, dishevelled, unproductive, unkempt and dependent; an unemployable drain on people's taxes (Harding et al 1992). The negative symptoms are more commonly associated with the chronic condition, although they can occur alongside acute, positive symptoms as they represent a 'lack' of normal behaviour. Apathy and loss of motivation show themselves as aimlessness, lack of interest, and what some might label 'laziness'. The person can withdraw and become self-absorbed with slowed speech and emotional blunting. This may lead to social withdrawal, poor social functioning and poor contact with health care professionals. Although intellectual ability remains unchanged, performance may be affected through problems with memory and poor concentration. It is the negative symptoms, which are essentially seen as changing the personality, which may be more disturbing for the patient, family and friends than the more bizarre positive symptoms.

It has been estimated worldwide, that schizophrenia falls into the top ten medical disorders causing disability (WHO, 1990). Mortality among people with schizophrenia is approximately 50% above that of the general population, partly as a result of an increased incidence of suicide (about 10% die by suicide) and violent death, and partly as a result of an increased risk of a wide range of physical health problems.
These include those illnesses associated with cigarette smoking, obesity and diabetes, as recent research has shown.
Furthermore Thornicroft and colleagues (2004) found that 80% of people with a diagnosis of schizophrenia remained unemployed.

The impact of schizophrenia and the disabilities experienced by people with schizophrenia are not solely the result of recurrent episodes or continuing symptoms. Most likely the unpleasant side effects of medication treatment, social adversity and isolation, poverty and homelessness also play a huge part. As Sartorius, (2002) and Thornicroft, (2006) have indicated these difficulties are not made any easier by the continuing prejudice, stigma and social exclusion associated with the diagnosis.
Following on from these symptoms of schizophrenia is the profound physical impact on an individual from schizophrenia. Marder & Wirshing, (2003) have shown that the association between schizophrenia and poor physical health is well established and that according to Saha, Chant, & McGrath, (2008) poor health results in higher standardised mortality rates and increased morbidity for individuals with schizophrenia.
Reports on the mortality of people with schizophrenia indicate that there is an increased risk of death from circulatory conditions, infections and endocrine disorders.

Despite high reported rates of smoking in people with schizophrenia, rates of lung cancer do not appear to be raised (Gulbinat et al, 1992; Harris & Barraclough, 1998; Jeste et al, 1996; Osborn et al, 2007b). People with schizophrenia have higher rates of cardiovascular disease, including myocardial infarction, than the general population (Hennekens et al, 2005; Lawrence et al, 2003; Osborn et al, 2007b).

People with schizophrenia are also less likely to exercise and are more likely to have diets higher in fat and lower in fibre than the general population (Brown et al, 1999; Osborn et al, 2007a).

The fact that this excess mortality and morbidity has a range of causes – including dietary and behavioural ones – suggests that lifestyle factors have a significant part to play. It could be that some of the problems associated with the development of schizophrenia impair or otherwise affect people's ability to manage their own physical health effectively. It is also likely that socioeconomic factors, including social exclusion, have a significant role to play. Nevertheless, there is also convincing

evidence that psychiatrists and general practitioners (GPs) are poor at recognising and treating physical conditions, such as cardiovascular disorders in psychiatric patients. Osborn et al, (2003) have shown that people with schizophrenia are just as likely as others to attend their GP for cardiovascular screening as others without this diagnosis. In light of this it can be suggested that careful consideration should be given to the role of GPs in the management of physical health problems.

1.1.3 Quality of life

For people with a recurring or long term illness with continuing symptoms, the quality of life is likely to be low and social functioning poor. Mueser et al (1990) argues that symptom exacerbation, re-hospitalisation and future social adjustment play an important part in a person's social competence. Bellack et al (1990) also contend that impaired social functioning is widespread in schizophrenia and may be both a primary- as well as a secondary-disability, leading to deterioration in interpersonal relationships and withdrawal from social, personal and work roles.

Many people discontinue their use of anti-psychotic drugs because of adverse effects, thus leading to an exacerbation in their symptoms and eventual relapse; despite growing evidence to suggest that schizophrenia sufferers would be best served by the newer atypical antipsychotics. Funding for the newer drug treatments in schizophrenia has become a contentious issue with drug costs rising significantly in recent years. With increasing evidence that new drug treatments can improve clinical functioning sufficiently to allow

discharge from hospital in cases where treatment had previously failed, there would seem to be every justification for making such treatments available, when appropriate.

Not only can one see the importance of ensuring that the newer atypical neuroleptics are made available, but it is also paramount that the views of service users are taken into consideration.

When caring for people with schizophrenia in the community, a large reliance is placed on families to care. For example, Platt (1985) indicates the high burden, which includes subjective components such as stigma, guilt, blame and stress, and objective components such as housing and financial difficulties.

1.1.4 Stigma & Discrimination

Hargreaves (2003) states that people with schizophrenia often encounter stigmatisation and discrimination, not just within the NHS, but within society, which often leads to receiving substandard care. These stereotypes are not just reserved for the chronic long term patients but are being applied more broadly. They have even been used to describe people with only a few years of documented illness (Hoffman, Wyler & Kupper, 1995; Whitbourne & Sherry, 1991).

Evidence will show (within the literature review) that the problems associated with schizophrenia are largely manifested in the social domain. They include difficulties in relating to other people, problems pursuing employment or education, and problems functioning meaningfully in mainstream society. It is therefore vital that the lived experiences of patients are described in detail, which is something that research so far has failed to do highlighting the gap in knowledge which may influence how people are cared for with a diagnosis of schizophrenia.

1.2   Costs of schizophrenia and medication treatments

Murray & Lopez (1996) indicate that schizophrenia is one of the major contributors to the global burden of disease. They state that estimating the costs associated with schizophrenia is difficult because of the range of services used and the need to clarify which costs are to be included and excluded in calculations. NICE reports that schizophrenia costs more than any other mental illness, consuming 5% of the NHS budget. Knapp (1997) estimated the annual cost in the UK of schizophrenia at 2.6 billion pounds, but even this sum omits some indirect impacts that cannot be currently costed.

The indirect costs of schizophrenia (e.g. loss of employment, family caring) remain very high and often are several times larger than the direct health and social service costs (Knapp 1997).

NICE (2002) have recommended the more widespread use of atypical antipsychotic medication on the grounds that people who take them have fewer side effects than those taking typical antipsychotic medication, and the atypicals are as effective as the older typical antipsychotics.

To add further weight to the argument for prescribing newer atypical medication, the National Schizophrenia Fellowship (2002) said that "more than 80% of the 210,000 people with schizophrenia are currently denied access to antipsychotics on grounds of cost". Almond & Knapp (2004) reported that the cost of relapse in schizophrenia can be estimated at £8212 per individual, compared to £1899 for those who have no relapse during the first 6 months following discharge into community care. With increasing evidence to show that new drug treatments can improve clinical functioning, this will enable discharge from hospital in cases where treatment had previously failed, there would seem to be every justification for making such treatments available when appropriate to those with schizophrenia.

1.3   Government policy and legislation

There have been a number of Government initiatives and white papers aimed at improving and modernising health and social services, including the National Service Framework (NSF), which incorporates the role of NICE. Further initiatives from the Government include the white paper 'Modernising Mental Health Services' (1998), which suggests that "community care has failed" and blames amongst others underfunding, inadequate services, and overburdening of families. However, this paper acknowledges that the reduction in side effects offers the possibility of more effective drug treatment and the long-term benefits of improved tolerance for the patients and their family or carers.

Kisling (1994) has argued that, if patients taking antipsychotic medication were completely compliant, approximately 15% of patients would relapse each year. Currently, around 50% of patients relapse within a year of achieving a remission. The fact that atypical antipsychotics are better tolerated means that there are long term benefits for patients taking them. This can be evidenced further by the limited impact that typical neuroleptics have on the 'negative' symptoms and the neurocognitive deficits associated with schizophrenia. It can be deduced that, even if typical neuroleptics were effective in controlling positive symptoms of schizophrenia, it is likely that the impact on the ability of the patient to lead a productive life due to the continuing presence of negative symptoms will be negligible.

1.4   The impact of deinstitutionalisation on people with mental illness

This section will explore in detail the impact of deinstitutionalisation on an individual with schizophrenia which Goffman describes in his original 1962 work entitled Asylums. Subsequently Torrey (1997) has suggested that the stigma of mental illness has increased throughout the period of deinstitutionalisation as the majority of people with serious mental illness were moved into community settings.

It is the impact of this process that raises concerns about social integration as Barham concluded that patients following discharge from the asylums have been "neglected both as patients and as citizens" (1992: p 32). He also put forward the view that people with schizophrenia are by and large damaged individuals who appear unable to be integrated back into society. It is the intention to explore that concept further and examine the impact of stigma upon individuals with schizophrenia. Goffman (1970) has suggested that stigma is one of the main rationale for individuals with schizophrenia, who are disqualified from full social acceptance. The impact of deinstitutionalisation will be explored further in section 2.3.

1.5   Personal motivation

From the author's own experience as a qualified psychiatric nurse, an interest had developed into the medication used within psychiatry, and over recent years how this had influenced patients' quality of life. Within my clinical area there were often patients admitted, discharged and then re-admitted due to non-compliance. Some would stop taking the medication because the side effects were so distressing and, despite their complaints, were kept on the older typical neuroleptics. People with a diagnosis of schizophrenia were often prescribed an anticholinergic medicine to counteract the side effects. This in turn would cause patients to be more likely to be non-compliant and then repeat the cycle of discharge and re-admission.

It soon became apparent that the people who I cared for within the hospital I worked at, adopted a role assigned to them and were often disempowered by the psychiatric system which was something that I had been unaware of as a nurse.

I wanted to learn more of the process of how individuals became disempowered by the roles they assumed, by the way in which their personality was slowly stripped away from them, by the imbalance in power and the lack of choices they had. I wanted to see if I could make a difference and to empower people in some way to have better choices within their lives, and to try and enhance their quality of life is some small way. Having witnessed the

suffering those patients experienced due to the severe side effects and how professionals continued to administer these typical neuroleptics. I felt an interest had developed in the newer atypical neuroleptics, and how they were marketed, because of their ability of the newer atypical medication to have little or no side effects; surely these would benefit the patients more and enhance their life in some way.

As time progressed I became aware that I was in conflict within my own role and faced many dilemmas when giving prescribed medication. I struggled ethically and morally as we took a person's personality, character away and reduced them to severely medicated shells of their former self. The sadness and pain I inflicted caused much soul searching and conflict with prescribers, as I questioned the level of medication. More often than not the medical model was followed without question and without offering people any kind of choice.

Subsequently as part of a master's degree, I conducted a piece of research entitled 'An investigation into the distress caused by side-effects of atypical neuroleptic medication and the effects this may have upon the quality of life of patients' (Gill 2003). It is the intention of this doctoral study to see what the lived experiences are of people taking the typical and atypical antipsychotic medication.

1.6 The research problem

1.6.1 Quality of life of schizophrenic patients

There has been considerable research conducted on the quality of life of schizophrenic patients. Pinikahana et al (2002) conducted a review of available literature from 1995-2000 and found 47 studies carried out in English. Each of these studies utilised a quality of life (QOL) measurement scale that was either completed by a practitioner or the patients themselves. There are no published studies to date that have looked specifically at the lived experiences of schizophrenic patients and how these impact on their quality of life

1.6.2 Measuring Quality of life

The measurement of QOL in schizophrenia is profoundly affected by the instruments used to assess it, and the informants chosen to provide information. There is no evidence that has looked at the lived experiences of patients with schizophrenia on a day to day basis. It is the intention of this study to look at how patients live their lives, day by day, minute by minute in all aspects of their lives.

1.6.3 Social theory

Furnham & Bower (1992) discredits the theory that schizophrenia was created by families or society yet contends that psychosocial issues remain a priority in psychiatric research, as the problems of living with mental illness have not been fully addressed by biomedical treatment. Furthermore Estroff; S E, Patrick, D L; Zimmer, C R, et al (1997); Jeffries (1995) propose that efforts to help people with schizophrenia can create dependency on the system or on other people.

Corin, (1990); Corin & Lauzon, (1992); Gallo, (1994) identified that the social isolation of schizophrenia sufferers was linked to withdrawing and rejecting society as well as an overwhelming exposure to stigma. Williams (2002) suggests that the possibility that post hospital transitions create dysfunction remains an unexplored concept.

1.7.0 Aims and Objectives

The study objectives were to;

- Establish the difference in socialising for patients on atypical antipsychotic medication and to explore how schizophrenia may have an impact upon face to face interactions.

- Assess the nature of the relationships with health care professionals for patients on atypical antipsychotic medication and how patients' relationships with their family and social contacts affect their quality of life.

- Assess how a patients' perceived loss of control and loss of identity has an impact on activities of daily living (e.g. eating patterns, work, sleep and play).

- Investigate how the mood and motivation of a person with schizophrenia may be influenced by choice of medication and how this may impact on self-esteem.

- Explore how the views and opinions of others may affect the daily living of patients with schizophrenia, and to look at the consequences of side effects of atypical antipsychotic medication for patients with a diagnosis of schizophrenia.

In this chapter I have given an overview of some of the main topics relating to the study, many of these will be developed in chapter two. This study should generate evidence that

addresses how patients lived experiences affect their quality of life, as there is no evidence that looks at the meanings of patients' lives on the different types of medication. This study will enable highly valid accounts of patients' lives to be available which is not achievable from using survey methods, and to gain an understanding of their perceptions of how others see them.

The uniqueness of this study is its focus on lived experiences of patients on atypical neuroleptic medication, and the use of multiple data collection methods. This type of study has never before been conducted: to develop highly valid accounts of how patients themselves construct their lives to be meaningful and how medication affects this. It is hoped that the study will give an accurate meaning to what people do on a day to day basis, how they are perceived by others, and how this impacts on their daily lives and to see if the stigma associated with schizophrenia affects the daily lives of people. It is hoped that the confidence gained by people with schizophrenia on the newer atypicals can help them to become socially accepted in society and in some way reduce the stigma associated with schizophrenia.

Chapter 2 explores the literature associated with the negative impact of schizophrenia and how this influences how people are socially excluded. It examines how a person loses their identity, leading to a loss of control and low self- esteem. Finally this chapter looks at issues surrounding stigma and labelling and how this has a negative impact on individuals with schizophrenia.

Chapter 3 examines how the use of phenomenology enables us to gain a deep understanding into the unique world of someone with schizophrenia. This theoretical background enables individuals to use methods that describe how they are socially excluded, how they are seen and perceived by others and the devastating impact of the stigma of schizophrenia on their lives.

Chapter 4 establishes the way in which the data was gathered and analysed, looking at how people can freely write in their diaries and discuss in interviews the impact on their daily lives of schizophrenia.

Chapter 5 examines the concepts to emerge from the data collection, looking at the social isolation, stigma, confidence, quality of life and social networks of people with schizophrenia. Unique individual experiences are detailed in this chapter.

Chapter 6 looks at how people with schizophrenia want to be listened to, want to be included in society and examines some of the dilemmas facing Psychiatry in the future.

Chapter 2

2.0 Literature review

From an extensive review of the available literature, it was found that a number of major concepts had been identified that are associated with the lived experiences of people with schizophrenia and these concepts are to be explored further.

The review will discuss how the newer type of medication can reduce the chance of these side effects and their potential impact on quality of life. The review examines how patients' lives vary and how they have developed what they perceive as a normal existence of their own following the move from hospital to community care, looking at concepts that they see as important.

This chapter begins with an overview of what schizophrenia is and how it affects an individual and their family and then looks at the historical aspects of mental illness and how it impacts on the lived experiences of people with schizophrenia. A detailed look at the work of Erving Goffman highlights the rationale for why the study has been undertaken and how his concept of the moral career is still apparent and valid today. The chapter continues with an explanation of how deinstitutionalisation has impacted on people's lives and leads into the concept of how people with schizophrenia are not accepted into society. The review will also include an analysis of the social theories of mental illness including looking at deviance, the power of psychiatrists and how society accepts or rejects people with schizophrenia.

2.1 Schizophrenia

Schizophrenia according to Picchioni & Murray 2007 is a term used to describe a major psychotic disorder that alters an individual's perception, thought, affect and behaviour. Furthermore Ramsey & Fahy (1995) have suggested that it can be a debilitating illness; many patients with schizophrenia exhibit delusional beliefs, often with a paranoid theme, which can lead them to engage in irrational or destructive behaviour. Additionally schizophrenia is a complex condition that affects a person's ability to perceive, think and feel and translates to a personal cost that is often disastrous. Goldner et al (2002) have indicated that schizophrenia affects approximately 1% of the UK population, which equates to an incidence of 0.1 or 0.2 per 1,000, with a prevalence of 3 per 1,000. Interestingly studies have shown (Robins & Regier, 1991; Levav et al, 1993; Kessler et al, 1993; and Fryers & Woof, 1989) that the prevalence rates of schizophrenia can vary from 1 per 1000 to 10 per 1000, depending upon the diagnostic criteria applied.

However Saha et al (2005) suggest that if the public were given a measure of the likelihood that individuals would develop schizophrenia during their lifetime, a more accurate estimate would be 7 to 8 individuals per 1000, which would account for the short lasting episodes with no re-occurring symptoms.

McGrath et al (2004); Aleman et al (2005) have shown that males have an increased risk of developing schizophrenia than females, which has been estimated at a ratio of 1.4 to 1 male to female. Saha et al (2005) also indicate that the prevalence of schizophrenia is lower in developing nations than in developed nations.

Hallucinations and delusions must be present for this diagnosis to be made and supported by the Diagnostic Statistical Manual classification system (DSM-1V) (American Psychiatric Association (APA) (1994) and the International Classification of Disease-10 (ICD-10) (World Health Organisation 1992, Goldberg et al 2000).

Schizophrenia usually begins before the age of 25 years and persists throughout life and usually starts in late adolescence and early adulthood, many people recover from the first episode but subsequently experience further episodes that are evident due to the increased levels of dysfunction.

The peak age of onset for men is between the age of 15 and 25 years, and between 25 and 35 years for women (Kaplan & Sadock 1988) whilst Mendelson et al (1977) found that women as a group have a later onset of schizophrenia than men and they also tend to have better outcomes. Furthermore Alleback (1989) has indicated that an added complication of schizophrenia is that the mortality of men and women is twice that of the general population. Alleback goes on to state that the most common cause of death, being cardiovascular often linked to the adverse effects of the medication used in treatment of schizophrenia.

Andreasen (1995) suggests that schizophrenia is characterised by the positive symptoms of auditory hallucinations, delusions, and thought disorder, and by the negative symptoms of demotivation, self-neglect and reduced emotion. In addition to this Creer & Wing (1974), Lefley (1987) suggest that it is the acute socially disturbing behaviour, which is directly related to the illness which families find most difficult to cope with.

However despite the distress caused by the positive symptoms, it is the negative symptoms which result in social withdrawal, apathy and self-neglect which cause the long-term family conflicts and disruptions. The family may feel they have lost their natural relationship with the individual and may attribute negative symptoms to deficits within the person rather than the illness (Birchwood & Smith 1987).

According to the Department of Health (2000), modern antipsychotic medications greatly reduce both the severity of your symptoms and the amount of time you spend experiencing active symptoms.

Harrison & Gill (2010) discussed the alternative views of schizophrenia within their paper highlighting that Bentall (2003) proposed that hallucinations and delusions may be part of human variation and he questioned the scientific attribution of mental illness and the reality of the dichotomy or differentiation between insanity and sanity. He concluded that the origins of this dichotomy lie in faith in the Kraeplinian paradigm and the current DSM-1V (APA 1994).

Barker (1999) offered a view that the cause of schizophrenia may be explained by social factors for example in western societies the phenomenon of schizophrenia may be understood as being within or intrinsic to the person and there is limited capacity for change. Society has subscribed to the biomedical model and a narrow range of concepts or polar opposites (e.g. sane-insane) to identify people with the diagnosis of schizophrenia. Objective identification of the clinical features of schizophrenia is challenged by Barker (1999) and Bentall (2003).

Furthermore Armstrong (1994) argues that in objectification people lose their individual identity; hence people who are deemed to be mentally ill suffer from social objectification, through the use of panoptic power. Objectification means being treated as an object, not as a person (Fox 1993) it can therefore be argued that after objectification, people are treated differently and stigmatised.

Goffman (1970) has suggested that stigma is the situation of the individual who is disqualified from full social acceptance, which enables society to judge some people mad, or to mark out the deviant and perhaps the dangerous. Stigmatising involves projecting onto an individual or group judgement as to what is inferior, repugnant or disgraceful; consequently it could be argued that the stigma attached with schizophrenia implies that these individuals are mad, deviant or dangerous. Porter (2002) compounds the issue by asking, if civilised society is thus disordered, what right has it to pass judgement on the 'insane'?

Porter (2002) contends that the mentally ill have long been stigmatised as lunatics and 'village idiots' and often remained in domestic care but were neglected, locked away or hidden in a cellar, some were even sent away to wander the streets to beg for food, as families saw this as a stain on their good character, hence insanity was deeply shameful to a family due to the implications of being possessed or of bad stock, thus insanity often stigmatised the whole family and not just the individual.

2.2 Historical treatments and development of antipsychotic medication.

Historically there have been a myriad of attempts at physical or pharmacological treatment of schizophrenia (Lehmann and Ban 1997), and since the physiopathology of schizophrenia was completely unknown, all therapeutic efforts were launched on an almost random trial-and-error basis. Lehmann and Ban (1997) go on to describe some of the earlier treatments such as the prescription of cocaine, manganese, or castor oil, to the injection of animal blood. Whilst the Swiss psychiatrist Kläsi had some success with a prolonged sleep treatment caused by the injection of a barbiturate. However whilst some of his schizophrenic patients improved for longer periods of time, one of the major drawbacks was the development of pneumonia, often a fatal complication at a time when antibiotics were not available.

Sakel (1937) was one of the first to try physical treatments such as hypoglycaemic treatment, aimed at repeated, reversible comas induced by insulin and convulsive treatment, carried out first with intramuscular injections of camphor. These often gave reliable results and frequently led to full remission, however hypoglycaemic treatments were not without risk, as more often the insulin coma became irreversible.

Another method that was pioneered by Dr Von Meduna in Budapest was that of pharmacoconvulsive treatment, which involved inducing convulsions in patients. This showed some initial dramatic improvement but only lasted a few weeks. A drawback of this was that patients had seizures at unpredictable times, sometimes when the patient was walking in hazardous places such as stairways.

The problem that psychiatry faced was that all pharmacotherapeutic interventions in schizophrenia that had had any reproducible, significant effects were those which had resulted in major, often critical, alterations of psychophysiological functioning, that is, fever, sleep, coma, and convulsions.

Lehmann and Ban (1997) describe how a major breakthrough came in the second half of the 20th century with the seminal paper on Chlorpromazine by the French psychiatrists Delay, Deniker, and Harl in 1952. This represented a major step away from altering body states and targeted the elimination of psychotic symptoms.

The advent of Chlorpromazine, the first antipsychotic drug, was a phenothiazine. Historically the term neuroleptic has often been used instead of antipsychotic, whilst other terms like major tranquillizers, are no longer used within psychiatry. With the introduction of the first antipsychotic drugs, there appeared in the form of side effects, the first secondary extrapyramidal symptoms. It was only in the early 1960s, however, that the therapeutic effect of Chlorpromazine was established beyond reasonable doubt and it was only by the

end of the 1960s that it was determined that Chlorpromazine must be given in adequate dosage, that is, at least 500 mg a day, in order to attain therapeutic effects(Klein & Davis 1969). Following on from this development and the use of Chlorpromazine a surge of pharmacological screening for Chlorpromazine like drugs began without delay; and within the next 10 years over 20 antipsychotic phenothiazine's were developed each with their own structure and resulting side effects. They only differed from each other only in so far as side effects and effective dosage were concerned. Some of the problems included over sedation, extrapyramidal effects whilst it was noted by Goldberg, Klerman and Cole (1965) that the so called positive symptoms of schizophrenia, such as delusions, hallucinations, memory deficit, and feelings of irritability, as well as slow speech and movement, lack of self-care, and indifference to the environment, all responded to pharmacological treatment. However the residual negative effects received less attention at this time and concerns emerged because of the potentially destructive side effects.

Many patients responded to antipsychotic drugs, but some patients remained chronically deluded despite intensive use of pharmological interventions. Bebbington & Kuipers (1994) recognise the importance of psychosocial and family interventions in reducing the rate of relapse for schizophrenia, but they also suggest the importance of individual psychotherapy in helping patients with modification of their delusional beliefs, or help in coping with their delusional beliefs. Particular effort was given to try and educate the patient about their illness and to provide an acceptable explanation about the origin of their symptoms, (Ramsey & Fahy 1995).

Another drug that was soon to be implemented was that of Haloperidol, which was similar to that of Chlorpromazine but worked with smaller doses; however this new drug was eventually shown to induce irreversible side effects such as tardive dyskinesia and nowadays is very rarely prescribed. As research advanced, at least 6 other classes of antipsychotic drugs with therapeutic effect in schizophrenia were advanced each with their own side effects and potential problems in long term treatment of schizophrenia.

The use of the classical (or typical) neuroleptics produced a number of severe and unpleasant side effects such as, extrapyramidal symptoms (Parkinsonian- like syndrome, dystonia, akathisia, tardive dyskinesia), sexual dysfunction, orthostatic hypotension, neuroendocrine disturbances, excessive sedation and weight gain which had a limit on their therapeutic effect and thereby reduced the quality of life of patients.

Conley and Johnson (1991) have suggested that noncompliance is frequently the cause of apparent refractoriness to treatment. It is encountered in as high as 60% of schizophrenia outpatients within 6 weeks of starting treatment with an oral antipsychotic. This is compounded by the fact that according to Fishman (1992) approximately two-thirds (67%)

of patients with schizophrenia relapse within a year if their antipsychotic medication is withheld whilst Glazer (1991) suggests noncompliance is one of the most common findings in patients who responded to treatment initially but whose responsiveness to the antipsychotic seemed to wear off after a certain period of time. To counter act the non-compliance the primary solution appeared to be was to replace the oral medication with a long-acting, depot preparation. It was an effective measure in preventing relapse that resulted from noncompliance. One of the problems was the switching between antipsychotic medications in an attempt to reduce the side effects of the medication, during this time the prototype of the newer atypical antipsychotics clozapine fell into disgrace due to a report of some fatal cases of agranulocytosis in Finland which resulted in clozapine almost being withdrawn totally for a decade. It was resurrected in the mid-1980s, as the clinical problems of typical antipsychotics, especially of tardive dyskinesia, began to cast threatening shadows over the pharmacological treatment of schizophrenia. Whether this could have been prevented if clozapine's development had not been interrupted is impossible to know.

It is also worth noting that whilst the conventional (or typical) neuroleptics improved the positive symptoms of schizophrenia (such as delusions and hallucinations), the negative symptoms (such as blunted affect, and withdrawal) showed little improvement. It has been through the drawbacks of the conventional neuroleptics, reluctance of patients to comply with treatment and that some patients remained treatment resistive which led to a considerable amount of research to discover and develop novel agents that would treat both the positive and negative symptoms of schizophrenia, and also which produced fewer extrapyramidal side effects. (Gerlach and Peacock, 1995; Kinon and Lieberman, 1996; Remington and Kapur, 2000).

However by the end of the 1980's it was the general consensus that according to Meltzer (1991) clozapine had less extrapyramidal side effects in comparison to typical antipsychotics, less propensity of tardive dyskinesia, and had been shown to be more effective clinically than the other typical antipsychotics. Furthermore Kirkpatrick, Buchanan, McKenney et al (1989) had shown clozapine to be more effective in acting on negative symptoms.

Hence it can be surmised that s since the late 1960s, following the time of completion of the first clinical studies, there has been a considerable interest in clozapine, with some accepting it, while others questioned whether it should be referred to as an atypical antipsychotic; with some impressed by the low incidence of extrapyramidal signs. With the newly gained capability to characterize and classify antipsychotics on the basis of their receptor affinities, it became possible to channel the interest in clozapine into systematic research. During the 1980s, research focused on the design and development of antipsychotics with particular

profiles in terms of receptor affinities that are therapeutically effective in the treatment of schizophrenia, but, like clozapine, have a lower propensity for extrapyramidal side effects. Triggered by the shifting targets for developing new drugs for schizophrenia, a rapidly growing number of atypical antipsychotics were rendered accessible for clinical investigation and introduced into clinical use for example amisulpride. Following on from the numerous atypical antipsychotics, the first to follow clozapine were, risperidone, and olanzapine, while others were still in different stages of clinical development.

It has been shown that the introduction of the newer atypical neuroleptic medication seems to have significantly improved the treatment and quality of life of schizophrenic patients (Scatton & Sanger 2000). This is in large due to typical antipsychotics being effective at treating positive symptoms of psychosis, such as hallucinations and delusions. Typical antipsychotics do not, however, adequately alleviate many other common and important aspects of psychotic illness, such as negative symptoms (e.g., withdrawal, apathy, poverty of speech), cognitive impairment, and affective symptoms. Furthermore Barrett (2004) suggests that these typical antipsychotics can produce significant extrapyramidal side effects at clinically effective doses. These side effects, which include dystonic reactions, drug-induced Parkinsonism, akathisia, and tardive dyskinesia, can make treatment intolerable for some people, leading to subjective distress, diminished function, stigma, and non-adherence. Barrett (2204) then goes on to say that this led to the development of the find more effective atypical antipsychotics with fewer and less-severe side effects. These newer atypical antipsychotics were said to have fewer or no extrapyramidal side effects at clinically effective doses. Many of these newer medications are also more effective than the older agents at treating the negative, cognitive, and affective symptoms of psychotic illnesses.

Sartorius (2007) has reported that patients with schizophrenia suffer from increased rates of multiple medical problems, due to their lifestyle (high smoking prevalence, high-fat diet), inherent neglect of personal care, and barriers to treatment of physical illness. Sartorius (2007) has also indicated that after more than 15 years after the first atypical antipsychotic entered the market, psychiatrists have gradually come to realize that while extrapyramidal symptoms and tardive dyskinesia occur less frequently with atypical agents, these medications may present a different set of adverse effects. These include weight gain, diabetes mellitus (DM), hyperlipidemia, QTc interval prolongation, myocarditis, sexual side effects, extrapyramidal side effects and cataract in patients receiving atypical antipsychotics.

Haupt (2006) has suggested that 40 to 62% of people with schizophrenia are overweight or obese. Obesity increases these patients' risk for cardiovascular morbidity and mortality. In addition, excessive weight and obesity can have important effects on an individual's

adjustment in the community, adherence to prescribed medication, ability to participate in rehabilitation efforts, and self-image. Therefore it follows that clinicians have to take into account these differences when choosing an antipsychotic for an individual patient and when screening and monitoring for physical problems. It should be recommended that the full spectrum of marketed antipsychotics (including the typical drugs) should be kept available, and the correct medication should be prescribed for the right individual.

In a study by Browne (1996) involving 64 out patients with DSM-III-R diagnosis of schizophrenia, it was confirmed that these individuals had an impoverished quality of life characterised by negative symptom severity, duration of illness, cumulative duration of hospitalisation and the patient's age. This study also confirmed for the first time that tardive dyskinesia was associated with a poorer quality of life, which raise cause for concern due to its potentially irreversible condition, Browne concurs with Awad & Hogan (1994) who argue that quality of life is influenced by side effects of medication.

It therefore follows that atypical neuroleptics such as clozapine, risperidone, olanzapine that improve negative symptoms and quality of life and produce less tardive dyskinesia and will be of advantage in prescribing early in the treatment of schizophrenia.
In conclusion from a clinical perspective, the term 'atypical antipsychotic' is somewhat loosely defined as a drug that is therapeutically more effective in both positive and negative schizophrenia symptoms and causes no, or very few, acute and chronic extrapyramidal side effects.

2.3 Erving Goffman

Hammond (2008) suggests that the purpose of Goffman's *The Presentation of Self in Everyday Life* is to 'consider the way in which the individual in ordinary work situations presents himself and his activity to others' (1990a:9). Whilst she further states that Goffman believes that in every interaction that takes place, information about the individuals involved is both presented and absorbed (Goffman, 1990a:13). According to Hammond (2008) when an individual is interacting with others, Goffman suggests that two impressions are given; the first being the one the individual gives and the one that they give off (Goffman, 1990a:14).

Smith, (2006) suggests that it is how the individual achieves this which Goffman pursues, through providing a dramaturgical analysis of the components of an individual's expression, and the emphasis of this is very much on understanding how an individual attaches meaning to things. However Brissett and Edgley, (1975) contend that there is nothing fixed in these

meanings and they further suggest that 'what you do establishes who you are, not the other way round'

Goffman's work indicates that every individual is trying to persuade others to believe in their character (1990a:28), and an individual often see that the only way to achieve this is to carry out a performance which Goffman describes as 'all the activity of an individual which occurs during a period…before a set of observers and which has some influence on the observers' (1990a:32). This in turn Goffman suggests leads to the concept of an individual having a personal front (1990a.34) which can be divided into appearance and manner. Goffman further suggests that the individual's appearance will provide physical signs as to the social status and occupation of the individual in society, however he argues that an individual's manner is a sign of whether he will be more active or passive in the interaction (1990a:34-35). Goffman makes it clear that individuals impress upon others what they want to see in order to be valued and he argues that this can be very difficult depending on the role one is playing, and how much of the work appears visible to others (1990a:40-42).

Goffman debates that if agreements have had to be made between the individual and others as in the case say of mental illness then in order for the performance to take place (1990a:54), these must be kept hidden during the performance itself. Hammond goes on to suggest that Goffman's theory of the self involves a highly constructed performance, in which every element whether physical, verbal or mental has been developed so as to give the correct impression out to others. I would suggest that this is an on-going process in today's society, in order for people to gain what they want in terms of acceptance they adopt these performances so as to become socially acceptable.

Goffman would argue that one's face is the "positive social value a person effectively claims for himself by the line others assume he has taken during a particular contact" (1982:5). Furthermore Goffman suggests that in order to continually have face an impression must be maintained, which is done through the performance an individual gives (1982:6), one would argue then that it could be the impression that a patient gives to a doctor or psychiatrist in performing their role of a psychiatric patient.

In line with this patient role it appears that Goffman maybe suggesting that it is the individual who creates meanings in the world, as opposed to following a structure, however, this is not the case. Goffman states 'when the individual presents himself before others, his performance will tend to incorporate and exemplify the officially accredited values of the society' (1990:45).

The individual maybe effected immensely by the presentation of the values of society and Goffman would argue that the individual 'may privately maintain standards of behaviour which he does not personally believe in because of a lively belief that an unseen audience is present who will punish deviations from these standards' (1990:87). The stigma associated with schizophrenia ensures that people try and adopt and maintain a face that is acceptable within society.

Goffman has stated that society establishes the categorises and attributes that are needed for individuals to fit within normal roles (1990), and it therefore can be implied that when an individual does not meet a requirement of one of these categories, they are seen as deficient and thus attributed with a 'stigma' (1990b:12), and thereby socially excluding each individual.

It follows then that a stigma is based on social standards, something outside of the control of the individual. However, Goffman suggests that within the rules of social order there is some flexibility as these rules themselves does not produce social order (they do not compel us to act); but rather they are a way of exhibiting social order.

Manning, (1992) suggests that the rules of social order are open to interpretation and that any individual can choose to follow these rules and be predictable, but there is always a chance to go against the rules and still be considered free in choice thus maintaining the balance between the individual and social order.

The focus of Goffman's work was the organisation of observable, everyday behaviour within society as such he developed classifications of the different elements of everyday social interaction furthermore Manning (1992) argues that Goffman's work was an extension and integration of the perspective of symbolic interactionism. However, Hammond (2008) contends that one needs to understand that Goffman's work was a reaction against three dominant intellectual traditions of his time. The first is the grand theory of Talcott Parsons, the second is the psychoanalytic approach of Sigmund Freud and the third is the positivistic, quantitative trend of many social scientists of this era. Goffman's work is therefore a response to these three gravitational pulls, whilst his dissertation was a mixture of observations and classifications: part case study, part general theory which is similar to this study and which Goffman entitled 'The Interaction Order'.

Goffman's work was mainly based around investigating the concept of face-to-face interaction, primarily among people who do not know each other or who have never met before. Within this framework Goffman tried to classify the different elements of face-to-face interaction, and built upon this by developing an analysis of the role of reflexivity in sociological investigation, particularly as revealed by the framing of social life. This unique

approach is developed further within this study as we examine the everyday lives of people with schizophrenia.

Goffman's primary ambition was to establish the study of face-to-face interaction as a substantive concern in its own right; however this was in contrast to both grand theorists, such as Parsons, who wanted to absorb this and other fields into a larger theory whilst some sociologists judged Goffman's analyses to be as trivial as those of his intellectual predecessor, Georg Simmel.

Hammond (2008) argues that the intricacy of Goffman's observations was largely lost on Parsons as Goffman tried to show that the interaction order a conceptual map to each and every occasion of face-to-face interaction. It can be suggested that all face-to-face interaction requires the co-presence of participants; that is; people must sense that others are close enough to them to be able to register whatever it is that they are doing.

 Goffman's work entitled 'Behaviour in Public Places' (1963:13-22), distinguished three types of co-presence namely the 'gathering', the 'situation' and the 'social occasion', and within this Goffman states that a gathering is simply a coming together of two or more people. In contrast a situation occurs whenever there is 'mutual monitoring' but most importantly a social occasion is bounded by space and time. A good example of this is a social occasion such as a birthday party which becomes the background against which gatherings and situations can occur and which Goffman (1963:24) describes as a type of co-presence in which there are distinctive patterns of communication traffic order which Goffman called situational proprieties. Whenever a situation like this occurs Goffman describes how individuals focus their interaction to giving each other a special type of communication in order to sustain an individual type of activity (1963:83), and this involves a type of 'face-work' often relating to friends, acquaintances and, under special circumstances, the unacquainted. On the other hand an unfocused interaction predominates in other settings where people are unaccustomed with each other, and within this context individuals give impressions that either give a positive or a negative impression whilst Goffman (1959: 13-14) suggests that involvement refers to the attention we give – or fail to give – to the social situations in which we find ourselves. It is within this context that this research will look at how individuals live their lives on a daily basis. And that how others are perceived indicates an internal state through observable, behavioural markers.

Goffman has suggested that when people interact with others such as with a nurse or a psychiatrist they manage both a main and a side involvement at the same time, and the group and present situation determine what constitutes a dominant involvement. Contrastingly, Goffman suggests that a subordinate involvement is whatever the group endures once

appropriate respect is shown for the dominant focus of group attention and could be argued links to the moral career of a patient, because Goffman extended his work to the analysis of interactions in relationships in public settings.

Goffman's analysis of the interaction order presents a set of classifications with which to continue the investigation of face-to-face interaction, none more so when examining the moral career of the mental patient; as highlighted in his work entitled asylums a concept which is examined in more detail within this thesis and which has not been looked at in detail since his original work. In asylums Goffman describes how patients pass through a betrayal funnel prior to admission whereby the people they trust most – family and friends – conspire against them, reporting their questionable actions to doctors and others who often play a decisive role in the decision-making process. Once they become institutionalized, patients lose many of the freedoms that had taken for granted, and patients lose their 'self-identity' and the only way that they can progress through the ward system by good behaviour. This good behaviour is considered by the psychiatrists as symptomatic of improving mental health, thus adapting and beginning their role or career as a patient. This concept which Goffman describes in asylums has arguably continued into society nowadays as patients still act in a way that they believe doctors want them to.

As Goffman contends both phases of total institutional life demonstrate to inmates that they are less than they took themselves to be, and as Goffman put it, the total institution is a 'forcing house' for changing people. In the face of these overwhelming challenges, inmates must either accept a massively diminished sense of self or insulate themselves from the social psychological threat posed by the total institution itself.

Goffman (1961) stated that rules are underpinned by moral judgements and he argued that psychiatry projects ideals of ethical neutrality because this is a requirement of clinical judgement and practice. However, he observed that these aims could not be realised within mental institutions because patient management involves the promotion of acceptable standards of behaviour, and the application of sanctions for misdemeanours. In concluding he suggested that moral judgements are implicit during nurses patient interactions associated with rule enforcement.

 Goffman carried out his research based upon a large American asylum many years ago in the late 1950's and early 1960's, and as such the findings may not be generalisable to modern nursing situations within the UK. However Haralambos & Holborn (2000) contend that his work has had an influence on important developments within psychiatry since then. Goffman wrote about the institution from a symbolic interactionist perspective, and sought to define the social situation of patients rather than staff. Goffman referred to the large asylum as a total institution, and justified the use of this term as follows:

"A total institution may be defined as a place of residence and work where a large number of like situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life". Goffman (1961 p.11)

Goffman observed total institutions limited social contact with the outside world, and he observed that total institutions restricted all the activities of patient to the same place, and that they performed them with the same group of people. Consequently Goffman argued that outside the institution these activities would be carried out in various places with different groups for differing reasons.

Goffman described how the institutional system managed large numbers of people and that non-compliant patients were easily identified because they stood out from the rest of the group. Goffman observed a basic split between patients and staff who perceived each other negatively. Furthermore Goffman observed a restricted interaction between them, and noted that staff addressed patients in a particular tone of voice, whilst he also observed that they restricted patients' access to other members of the hierarchy, and excluded them from decision making about the plans that were made for their treatment.

Hammond (2008) commented that in Goffman's view, staff concealed care plans to prevent patients' adverse reactions, which might disrupt the smooth operation of the admission process. Furthermore Goffman observed that patients were routinely assigned to the sick role on admission to hospital, and he viewed this process as a basic aspect of institutional control. This perspective fits with concepts of stigma, in that other aspects of the self are invalidated by the diagnosis of mental illness and confinement to hospital. Goffman concludes that

"Having to control inmates and to defend the institution in the name of its avowed aims, the staff resort to the kind of all-embracing identification of the inmates that will make this possible" (p. 82).

Following on from this Goffman described how the process of admission to hospital caused changes in the patient's self-perception because the usual social activities that support a sense of self-identity were removed, whilst he further argued that people are usually admitted to mental institutions because their behaviour has breached social conventions. In conjunction with this Goffman observed that an important factor in the development of what he called a 'moral career' was that the patients' rights and relationships were mostly taken away during hospitalisation something that one could argue persists in today's society but in a more subtle way.

As Goffman observed within an institution people were thrown into contact with people that they might choose to avoid in the world outside and were made to share personal hygiene

facilities. They were generally treated as a group rather than as individuals and had to ask permission to carry out activities that they would have taken for granted if at home such as making a cup of tea, or going for a walk. In Goffman's opinion this constant exposure of the private self in public view erodes a person's self esteem

Furthermore Goffman goes on to suggest that patients were not allowed to speak freely about their own meaning of the situation which meant they tended to react in a way that was prescribed to them or more importantly in a way that further consigned them to the sick role by a display of anger. This resulted in an inability to maintain social distance from the staff, or preserve a sense of autonomy because this was destroyed during the interaction. Consequently this leads on to what Goffman describes as 'secondary adjustments' which patients make in order to preserve some kind of sense of self. However Goffman suggests that some of the activities that patients carried out were viewed as bizarre (by staff) and contributed to further evidence of illness as interpreted by the staff. In contrast as Goffman argues that if they were viewed from the patients' perspective, a different connotation would emerge; as this is how patients distanced themselves from the institution. An important aspect according to Goffman was that patients felt that these activities were important for the preservation of a self-identity within ordinary society and that a sense of autonomy is important for all.

Charon (1979) observed that institutions might constantly subject members of society whose capacity for self-determination (such as people with schizophrenia) is undermined by some form of impairment to humiliation and manipulation. This then leads to the view that their self-concept may be negatively influenced by these experiences, hence the individual is progressively redefined in a process that isolates them from groups and significant others outside the institution. Within this context the environment is completely controlled by a small, powerful group of people, and any interactions that a patient may have will be controlled by their collective social judgements, and their view of the self. Hence, as a result of this process each individual forms a new view of the self, one that is dependent on the behavioural expectations of others. Submission to authority is rewarded through approval and a positive view of the self becomes dependent on compliance with institutional rules, thus the moral career of an individual is set in motion with little or no regard for their views or opinions.

Hammond (2008) suggest that one could contend that Goffman's findings within his asylum work remains controversial, as Goffman suggested that psychiatrists may have weak clinical knowledge, and may lack a scientific understanding of mental illness and rely instead on lay interpretations (the scientific aspect is debated later in this chapter section 2.4). Consequently Goffman thought that psychiatrists routinely misunderstood the behaviour of their patients;

however his analysis of Saint Elizabeth's did contribute positively to the re-evaluation of psychiatry and the treatment of the mentally ill.

Goffman recognized that within an individual's make up, there consisted three major components that make up our identity; the 'personal', the 'social' and the 'ego' which would be affected by potentially damaging information. Our personal identity is what makes each of us unique; it consists of 'identity pegs' (such as fingerprints) and life histories (1963:57). Our social identity is what others understand about us by virtue of the groups to which we belong. Our ego identity refers to what we think about ourselves. Goffman give emphasis to reflexive aspects of social life – that is, the ways in which what we think about what we do affects the performance of the activity itself and can thus have an impact on how we view our experiences. Concurring with this Goffman defined a frame as a way of organizing experiences: we use frames to identify what is taking place. Thus frame analysis is the study of the 'organization of experience'. It is these most basic frameworks which Goffman calls 'primary frameworks' that reveal what is really happening in the natural or social world and that can only be investigated with a phenomenological approach to peoples lived experiences.

2.4 The impact of deinstitutionalisation on people with mental illness.

Throughout the period of deinstitutionalisation the stigma of mental illness increased (Torrey 1997) as the majority of people with serious mental illness were moved into community settings. It is in these social settings that people with mental illness are likely to have social interactions with a variety of persons from the public at large and these interactions may be affected by negative stereotyping and discrimination (Dickerson et al 2002).

Bott 1976 (cited in Barham 1992) suggests that the betrayal of mental hospitals is not because of a conspiracy but is in fact the product of social pressure put on the asylums and she goes on to remark that society tends to ostracize the mentally ill. Bott also contends that mentally ill people are treated as 'non-persons' and the chronic hospitalisation of patients has occurred due to the social process and not because of the illness an individual has. She goes on to argue that the social process is not that of the mental hospital but one of society. Barham (1992) takes Bott's arguments a step further when he contends that the 'asylum-made lunatic's' chronic disabilities could be prevented if they were returned to the community as quick as possible. He has also shown that in an evaluation of the closure of Cane Hill Hospital that patients had very little change in their social networks. However Barham suggests that the patients themselves are tarnished by the stigma of the mental hospital environment, whilst Barham (1992:p14), states "that psychiatrists have increasingly

abandoned the social view of psychiatry for a strictly medical stance" thus consolidating the view that mental illness is a product of a social process.

According to Skantze et al 1990, and Pinkney et al 1990, the effects of deinstitutionalisation and the quality of life upon individuals who were former patients and who now live in the community has mainly been studied using quantitative approaches. The majority of these studies have been follow ups by medical doctors and have focused on the clinical state of the patients and the needs of the health services (Johnstone et al 1984, Harding et al, 1987a,). However there are very few qualitative studies that look at the quality of life of deinstitutionalised patients (Dickey et al 1981, Gibbons & Butler 1987, Norman & Parker 1990) cited in Nikkonen (1996).

This social process also places restrictions on the patient's opportunities in education, employment and housing and thus the full integration back into society. Barham (1992) furthermore suggests a discrepancy between staff and residents assessments, as staff recommended that nearly two thirds of residents required twenty four hour care, thus limiting their choices and limiting their opportunities, as mentioned above. However Barham (1992) argues that the majority of them were capable of living independently and that the misconception of violent or dangerous behaviour is misinformed and that only a small minority posed problems. Nonetheless Barham concludes that patients following discharge from the asylums have been "neglected both as patients and as citizens" (1992: p 32). He also put forward the view that people with schizophrenia are by and large damaged individuals who appear unable to be integrated back into society. Barham states that "They are to be thought of as *in* the community but not as an integral part *of* the community" (1992:p37) and that they will be regarded as 'secondary sorts of people' in comparison to the vast majority of society.

Szasz (1961) contends that mental illness is not a disease but is fabricated by psychiatrists for their professional development and endorsed by society because it sanctions easy solutions for problem people. He alleges that over the centuries, by affixing psychiatric labels to people who are social pests, odd or challenging the medical profession has 'manufactured madness'. Foucault (1961) similarly argued that mental illness must be understood not as a natural fact but as a cultural construct. Hence Szasz and Foucault would contend that the history of madness would not be of disease but of freedom and control, knowledge and power. However Roth (1986) suggests that mental illness is no mere label or scapegoating device, but a real psychopathological entity, with an authentic organic basis, based on the stability of psychiatric symptoms over time.

Goffman (1970) suggests that stigma is the situation of the individual who is disqualified from full social acceptance, which enables society to judge some people as mad, or to mark

out the deviant and perhaps the dangerous. Stigmatising involves projecting onto an individual or group, a judgement as to what is inferior, repugnant or disgraceful; consequently, it could be argued that the stigma attached to schizophrenia implies that these individuals are mad, deviant or dangerous. Porter (2002) compounds the issue by asking, if civilised society is thus disordered, what right has it to pass judgement on the 'insane'?

The mentally ill have long been stigmatised the lunatics and 'village idiots' often remained in domestic care but were neglected, locked away or hidden in a cellar; some were even sent away to wander the streets to beg for food.

Insanity was deeply shameful to a family due to the implications of being possessed or of bad stock, thus insanity often stigmatised the whole family and not just the individual.

2.5 Social theories of mental illness

Scheff (1999) suggests that over the past 50 years there has been a considerable amount of research into mental illness which has looked at three main areas: first aetiology: which has focused on the biological causes of mental illness; secondly the classification of mental illness which looks at how types of illness are classified in line with the DSM-IV criteria; and, finally, treatments which Scheff contends can be treated effectively and safely with psychoactive drugs.

However Scheff also argues that these concepts are based on a large amount of clinical knowledge and that they lack scientific verification to substantiate its claims. Scheff thus raises questions about the validity of the biopsychiatric approach as much of the literature is unrealistically positive and assumes that all of the three above goals have been met. Tucker (1999) enhances this view by claiming that the system of classification (DSM-IV) does not fit many patients and in effect it takes away from the patient as a whole. Tucker also suggests that the syndromes outlined in the classification process still have no proven link to causes and cures and he postulates that the dominance of biological psychiatry may be coming to an end. This view is also supported by Lewis (1998) who suggested interpersonal causation as a major influence on mental illness.

Scheff furthermore argues that the classification of psychiatric disorders has been organised in such a way as to fit into current psychiatric practices as opposed to being validated by empirical studies. Strauss (1989,) concluded in his study that the clusters of *"the vast majority of patients fall between the syndromes"* and that this implies that the large majority of patients do not comply with the criteria as indicated in the DSM-IV and that the problems that psychiatrists treat do not fit into the medical model of the disease. This is a view echoed by Mirowsky (1990), thus further questioning the validity of the medical model and

providing a clear rationale for carrying out a phenomenological study of peoples lived experiences. Scheff (1999), questions the validity and effectiveness of randomised clinical trials (RCT's) due to the correction of biological deficiencies (such as adverse side effects caused by typical neuroleptic medication) and that these trials are not truly blind (Shapiro & Shapiro 2000;Healy 1997),thus raising the question of the validity of the entire method of research within psychiatry.

If, according to Scheff (1999), most of the doctors and patients know which medications are active (within RCT'-s) then one must raise the possibility that some or even most of the treatment effects seen are psychological or social (see Gill 2003). In challenging the role of the medical model and the possibility that improvement may be influenced partially or wholly by psychological or social circumstances, one must ask why the biological model has not been dismissed. Scheff (1999) contends that this is in part due to the economics associated with drug use and the issues of cost effectiveness of alternative approaches to treatment.

Scheff believes that 'Goffman was an incredibly perceptive observer of the microworld' (2006:15), something which no other theorists had undertaken, according to Hammond (2008).

Hammond (2008) comments that instead of just presenting a theory based on rational ideas, Scheff (2006) highlights that Goffman also took into account emotions, and the role they play in interactions.

Finally, Scheff argues that Goffman attacked 'the Western conception of the self as an isolated, self-contained individual. He offered an alternative conception: the self as an aspect of social and cultural arrangements' (2006:16), cited in Hammond (2008).

Smith (2006) has argued that Goffman was 'one of the twentieth century's most remarkable practitioners of social science and furthermore debated that Goffman's work created a distinctive style different to that of other sociological theorists, such as Marx, Durkheim and Weber.

One could contend however that one of the real achievements of Goffman's work is that it challenged sociology at the time, and provided a unique perspective on the idea of self and society.

Harrison & Gill (2010) contend that through differentiation and categorisation, medicine manages the lives of those deemed to be mentally ill and that those who are not perceived to be useful citizens are perceived to be a social problem and a sickness in the social body. Historically these processes occurred within the context of the Age of Reason (1657-1800) where an epistemology is created, and illness and disease are classified. They go on to suggest that any divergence from the norm is identified (Rose 1994), and it is this divergence from the norm that encourages stigma to be identified. Harrison & Gill (2010)

refer to Schlosberg (1993) who emphasises that psychiatrists, who are often oblivious to stigma have a clear choice of role: either to be stigmatisers or destigmatisers of their patients.

However as Byrne (2000) points out that psychiatry did not cause stigma but many of its former and current practices perpetuate it. It could be said that individuals are medicalised for as Armstrong (1994) would contend that medicine is oppressive and involves coercion, a view which is endorsed by Foucault.

Harrison & Gill (2010) suggest that diseases are created by medicine and individuals are objectified and perceived as less important than the disease. They go on to suggest that according to Foucault (1980, 1995, 1996) biopolitics where medical technologies interface with politics to define people, demands conformity, uncritical acceptance of medical knowledge, acceptance of treatment, and defining labels, compliance with treatment and insight. They conclude that with this comes acceptance of negative labelling and negative self-labelling.

Barham and Hayward (1995) asserts that a psychiatric diagnosis creates a stigmatised life for people with a mental health diagnosis. Furthermore it is implied therefore that with stigma comes isolation, discrimination, low self-esteem and feelings of worthlessness (Johnstone 1999). Sartorius (2002) proposes that labelling, mental health legislation and treatment of symptoms leads to stigma and proposed that the diagnostic labels, if used carelessly, cause stigma.

 Whilst a more complicated issue could be that psychoactive drugs give psychiatrists a competitive edge over other professionals as they are the only ones who can prescribe medication (Scheff 1999). Within the context of the medical model, it has been suggested (Scheff 1999) that doctors place patients in the 'sick role' who could have continued their life within a normal role. The subsequent diagnosis and labelling of a person can have far reaching consequences, as often this leads to questions about their social status and can then lead to irreversible damage within a social context. Psychiatrists argues Scheff, tend to make a diagnosis even when the person is healthy thus further raising questions about the validity of the medical model. This argues Parsons (2001) stems from the doctors determination to find symptoms to fit into a diagnosis and thus encouraging a person to enter the 'sick role' and proceed on a career of chronic mental illness. Durkheim (1963 cited in Scheff 1999, p116) describes how the reality that people live in is largely of their own construction and that as much of reality is a construction there maybe multiple realities. Furthermore it follows that what society construes as normal actions forms the way in which we take responsibility for our actions, thus in terms of a medical diagnosis the roles are often pre-determined and a career of mental illness is embarked upon. The power which is wielded by

the doctor often sets this course in motion; the desire of a doctor to find symptoms to fit into a diagnosis indicates that there is unequal power in the relationship, thus the need to investigate further the lived experiences of individuals with schizophrenia. The basic premise is that once the psychiatrist allocates a person a label then they fit into the roles allocated to them and adopt the sick role expected of them thus one could argue this then leads them into an existence pre-determined for them and one in which doesn't take into account the individuals own lived experiences. It furthers raises the question that individuals behaviour forms the basis of social structure and that any empirical research implies a model of social action, since as Scheff suggests this is dependent upon the observation of each individuals behaviour.

In line with this Goffman (1967 cited in Scheff 1999, p138) proposes *"that every sentence, its words, paralanguage, and gestures, imply an evaluation of the social and interpersonal status of the interactants"*

Goffman also argues that each interaction is dependent upon the amount of respect that individuals are rewarded, leading into the realms of feelings. Goffman goes onto suggest that within his analysis of social interaction the concept of communication and how we understand each other forms an important aspect of where we stand in the social order of things. Goffman (1967) identifies 'interpretive understanding' as how we read another's mind or how successful communication is likely to occur. Thus a successful communication would in principal lend itself to social acceptance however in the case of mental illness one would contend that a successful communication is unlikely due to the position of individuals within the social structure or their position in society. This concept of interpretive understanding was referred to by Mead (1934 cited in Scheff 1999, p142) as "role- taking" and in conjunction with Goffman's work on role analysis: suggests that individuals come close to sharing experiences with one another.

It has been suggested (Scheff 1999) that these ideas remain quite abstract and one may question their usefulness in scientific application: however Goffman's analysis of interaction suggests that embarrassment and anticipation of embarrassment are pervasive in social interaction and are fundamental in exchanges of feelings between interactants, and that emotional processes are both psychological and social processes. It can thus be argued that by sharing lived experiences (in a phenomenological context) we gain a much deeper and in depth comprehension of what an individual is thinking and experiencing as opposed to the more traditional quantitative approaches. The author therefore contends that in order to understand or gain an insight into the micro world that underlies all social interactions a phenomenological approach needs to be utilised within this study to examine the lived experiences of individuals with schizophrenia. This approach will enable the author to fully

understand what people do and why and how they interact with others and gain an insight into the social structure of society.

Scheff suggests that a basic failure in the deficiency of psychiatric formulations is the inability to include social processes within mental disorders. The formulation of mental disorder is based around the individual and their differences and does not include the impact of social and cultural issues experienced by individuals. Something that can only be explored further by using a phenomenological method to look at lived experiences. Scheff (1999) contends that the use of psychoanalytic theory is too narrow and it leaves out aspects of the social context and social control that are important in understanding mental disorder as it is based upon the medical or disease model.

Furthermore Scheff postulates that psychodynamic ideas which are built around individual systems are fashioned in a similar vein to Marxist analysis. These are both built around individual systems and exclude any influences of social context and that a Marxist theory was independent of the psychology of individuals, thus rendering it inappropriate for this type of study. It is more important within the context of this study that we adopt a theory that incorporates both the individual and social systems of behaviour, hence the use of the theories of Goffman who focuses on the individual that also incorporates social processes. In conjunction with what Scheff is proposing is the rejection of behaviour modification due to its focus on changing the behaviour of individuals to fit into society as opposed to the social system of which a patient is part. Hence it can be considered that the behavioural model is inappropriate for this study due to its isolating the symptoms from the context in which it occurs, similar to the medical model.

However the relationship of maladaptive behaviour (Ullmann & Krasner 1965 cited in Scheff 1999) to the social context is different in that this involves a concept called deviance which can be expressed as a violation of social norms and which leads to negative social sanctions. This concept of deviance was developed by Goffman (1964) who describes psychiatric symptoms as residual deviance due to the complexity of social norms that influences how a person behaves in the presence of others. Goffman postulates that psychiatric symptoms such as hallucinations and withdrawal, which negate involvement with others, can be deemed to be a violation of residual rules.

How one tends to avoid interactions' and involvement is a key aspect of Goffman's work, avoiding contact by having a preoccupied far-away look can be misinterpreted as possible hallucinations, thus lending itself to evidence of mental illness whereas withdrawal is not necessarily socially unacceptable.

One of the concepts that Goffman explored was the notion that someone who was a residual rule breaker within societal norms (i.e. someone with mental illness) could be termed as

deviant. This, Goffman argues, would lead to a deviant status and someone playing the role of being mentally ill; however Szasz (1961 cited in Scheff 1999) contends that these could be attributed to problems of living. It has been suggested that this deviant status that people adopt is a way of coping with the stress of everyday living within society and that patients apply a deviant label to themselves as a way of adjusting to everyday living.

2.6 Labelling and stereotyping

Haralambos et al (1993) proposed that being labelled and defined as deviant depended on the interaction between those in power, the labellers and the labelled. The status of deviant, (e.g. schizophrenic), overshadows other statuses (e.g. parent, worker). Labels are attached to the behaviour of the labelled by those in authority whilst Giddens (2001) states the categories of deviancy which are created by those in power reflect the power structures in society. Haralambos et al (1993) discussed how the labelled person perceived him/herself in terms of the label and acts accordingly therefore after public labelling as deviant; the person may be rejected or excluded by others.

Armstrong (1994) contends that the clinical gaze also leads to labelling and it could be argued that the external processes of labelling are carried out by health professionals who are perceived to be experts in society.

Harrison & Gill (2010) suggest that labelling involves individuals with a diagnosis of schizophrenia being identified as different and being assigned a lower value than others. They have no power to prevent this external social process. The accepted knowledge of mental illness supports the labelling process and expert knowledge and taxonomies of mental illness confirm the deviancy of individuals with schizophrenia (Goffman 1968, Giddens 2001), hence labelling can lead to social exclusion (Rabinow 1991, Barham and Hayward 1991).

Secondary deviancy occurs when individuals with schizophrenia accept their deviancy and lower social status and feel disempowered (Goffman 1968, Giddens 2001). This concept is similar to the concept of internal stigma proposed by Scambler (2004). This may lead to a negative self-concept in people with schizophrenia and failure to retain a positive self-concept may lead to further mental health problems and relapse.

An important aspect of the labelling of an individual with schizophrenia according to the original theory of Lemert (1951); was the fact that when an individual adopted the label they began to play the role of the mentally ill, sometimes inadvertently. However as their group of symptoms became stabilised and reaffirmed by others, they began a career of mental illness, a concept later developed further by Goffman. Goffman's (1963) work on labelling

and stigma has been suggested (Scheff 1999) to lack an emotional component to it in relation to societal reaction, thus there is a need to develop this further in a study of this type. Scheff further argues that Goffman and other stigma theorists were unable to show its central role in mental illness; hence a need to explore how emotions can cause extended conflict within schizophrenia.

Link et al (1989)) showed that a patient's quality of life has been affected by stigma and that patients tend to adopt strategies such as secrecy and withdrawal in order to avoid negative reactions. Furthermore it can be argued that the behaviours which are labelled as mental illnesses can be seen as social practice and social discourse, rather than forms of mental states (Green and Davis 1985). The labels of mental disorders can have a long-lasting negative consequence on employment, quality of life, and self-esteem of patients due to stigma resulting from the labels ((Wright, Gronfein and Owens 2000).

The concept of labelling is enhanced by psychiatrists who tend to look for symptoms, thus leading to concepts of shame and anger and their reaction to the label reaffirms the negative effect of their illness and then it spirals into a career of mental illness. Porter (1990) supports this theory when he claims that a person's morale is crushed under the weight of this labelling and thus the only option for individuals is to embark on a career of being mentally ill. In line with this one could contend that the symptoms of mental illness could be considered a violation of residual social norms. Thus leading the people who care for the so called deviants as dependent upon society's reaction and the role playing that occurs within a social structure for social acceptance. The impact that society has on labelling should not be underestimated in so as much that the weaker element within families could be labelled or scapegoated   and thus induced into the role of the deviant. This concept could be extended to psychiatric diagnosis as suggested by Lemert (1962) cited in Scheff (1999), where the absence of situational elements can lead to poor decision making and mis-diagnosis. The reliance upon symptom after symptom, without any reference to the context in which it occurs tends to suggest a flaw in the diagnosis and a more robust information gathering should be undertaken. Scheff (1999) further points out that the concept of disease refers to a process that occurs within the body of an individual. Psychiatric symptoms are therefore symptoms within an individual that are not part of the social context within which the 'symptoms' occur and Garfinkel (1964) enhances this notion showing that when you take symptoms in isolation the behaviour tends to lose its meaning. Therefore one would contend that the medical model, which is based on a physical understanding and not social events, has a bias towards so called deviant behaviour and one must question the negative bias of psychiatric diagnosis. Hence the unreliability of psychiatric diagnosis would indicate the need for a more detailed phenomenological study of the social factors that impact on

mental illness in order to give a more detailed and fuller meaning of a schizophrenic's day to day life.

The interaction between individuals actually reinforces the stereotypes of mental illness largely in part due to the negative portrayal by mass media that informs individual's' judgements. It is these negative stereotypes that inform individuals as to mental illness being incurable and that people with schizophrenia are violent, dangerous and unpredictable. The impression that we have of mental illness is often misleading due to the biased negative image portrayed and one can understand why people with schizophrenia respond in a certain way when interacting with others as suggested by Goffman. According to Scheff (1999) public stereotypes of mental illness are difficult to alter due to the continual negative portrayal by the mass media and any health promotion campaigns, he argues will be doomed to fail. However another rationale is that these negative stereotypes form part of society's natural order and they are integrated into the psychological makeup of members of society (Scheff 1999). These stereotypes are entrenched in our society and as Goffman (1959 cited in Scheff 1999) contends, people with mental illness are 'discredited' and according to societal rules, signs of abnormality or deviance are always looked for in a person's history to show that he was always a deviant. Hence Goffman would argue that people adapt to the role given to them within society and furthermore it can be reasoned that mental illness is a social role and that it reflects the status of the mentally ill within the structure of our society. Goffman further contends that playing the role of the deviant (or being mentally ill) gains rewards as in the relationship of doctor and patient, where the patient is rewarded for conforming to the stereotypes associated with deviant behaviour as identified by the doctor. There is a considerable amount of pressure according to Scheff (1999) for patients to accept the role of being mentally ill and they are often punished through discrimination when attempting to return to a normal role within society, a concept which will be explored later. According to Goffman the patient is sensitive to the cues of others when interacting and responds accordingly and begins to think of himself as mentally ill and organises his life around a career of chronic deviance. Within society 'normal' people can cope with stress and adapt, whereas people with schizophrenia are unable to cope and are deemed not normal. Hence the more a person is defined as mentally ill by others the more he is likely to enter into the role and thus begins a continuous cycle from which it is difficult to escape from. It can be argued then that a person withdraws from society and interactions with others in fear of being stigmatised and tends to withdraw from any of the social groups he was once part of.

2.7 Experiences of people with schizophrenia

Goffman (1959) has described the career of a mental patient in three distinct phases. Firstly the period prior to entering the hospital; secondly, the period in the hospital; and finally the period following discharge. Furthermore he contends that within everyday life there has to be some level of impairment in order to become a mental patient and that he contends that the social reaction to that person's behaviour is more important than the behaviour itself, which can result in a person becoming 'socially constructed as a deviant'. It is within this context that this study looks at the experiences of people.

Barham (1992) talks about the choices that people with a mental illness face when moving into the community following a period of hospitalisation and describes how despite having follow-up care by mental health teams, they often face a life of loneliness. This is enhanced by the inequalities they face with a constant moving in and out of hospital, living in hostels and community homes whilst as Barham (1992) states 'struggling to hold the line against the illness that threatened to destroy them'. In Barham's sociological study (Closing The Asylum 1992), he portrays how individuals have difficulties in developing relationships due to the stigma it leaves on them. As one stated "… they have a very strange attitude towards psychiatric … its taboo, you mustn't talk about it..." (Barham p44), whilst another describes how she felt a less of a person and how she was tainted by the illness.

The very fact that individuals describe how their lives are altered permanently once they have a diagnosis of schizophrenia and how they feel that they are flawed, would imply that they would be perceived as different within society. It raises a question as to how they could live a 'normal' life within society.

 Furthermore the issue of choices in relation to medication revolve around a complex relationship between the doctor and the patient where one 'appears' to have a superior role to the other and this creates a conflict and also has a negative impact on an individual's confidence, as noted in Barham (1992:p48) *"He's superior .....Between you and me, he's superior to me, I'm the patient and he's the doctor"*. This conflict manifests itself in the simple assumption that 'patients' feel that there is insufficient opportunity to talk through problems and that some state (Barham 1992:p49) that too much importance is given to drugs. Another (cited in Barham 1992: p 53) describes further the relationship as thus *"I have little regard for psychiatrists. I've had bad experiences with psychiatrists and nurses, so I don't get in touch with people. They really do give you a punch in the guts"*.

Allied to the above is the concept of lowered self-esteem, which has a devastating effect on individuals, who describe themselves as being 'an inferior person' and one who describes schizophrenia as thus *"With schizophrenia you are not living, you are just existing. There is not a lot of future for you, but you come to terms with the illness. I am labelled for the rest*

of my life….. I think schizophrenia will always make me a second class citizen." (Barham 1992:p58)

It is clear that individual's with a diagnosis of schizophrenia have difficulties in society accepting them as individuals and not as someone who is spoiled by the impact of mental illness, for it is society and its cultural forces that have turned individuals into people bereft of worth and prospects.

Barham (1992) would suggest that if we are not to exacerbate the demoralisation of people with mental illness and thus stigmatise them further, then society is in need of new psychiatric theories that look at what the service users themselves require, a further rationale to look at the lived experiences of people with schizophrenia and challenge traditional views. Barham (1992) infers that people with enduring mental illness such as schizophrenia were regarded as 'refugees, and who had no viable social place. He further contends that the society in which we function has no social order for them and that it has no place for them in its midst.

It has been mentioned above about the lack of choices faced by people with schizophrenia and how the relationship between a service user and a doctor was pivotal in the care given and how they would be integrated back into society. However the role of psychiatry was to remove a person's identity and declare them as incomprehensible and at the same time allocate them to a long term stay in a hospital or asylum. As psychiatry advances one could raise the question as to whether we have closed the asylums but created smaller asylums in the community. As more and more problematic behaviours (Walton 1985) are blamed on medical conditions and not on the deficiencies of society it is not hard to see how people with schizophrenia are seen to be suffering from 'a final and irrevocable loss of his mental existence'(Bleuler 1978a: p447, cited in Barham 1992). Allied to this concept is that of Baumann (1989) who argues that as the responsibility of one social group is eroded, it causes what he terms 'the process of social separation'.

Thus the impact of labelling, or the stigma associated with schizophrenia has led to a rejection of this group of people leading to social isolation, separation initiated and reinforced by society itself. Baumann elaborates on this concept by indicating that members of this group are then removed from their ordinary positions in life, in effect removing the group completely from sight: and one could argue that there life processes do not cross, there is no communication and ultimately they have no meaning in society itself. You could take this argument a step further by suggesting that if a group of people cease to exist within what we term society, then it becomes even more difficult to recognise them as people.

This idea of 'dehumanising' individuals argues Warner (1985), has been 'shaped and determined by the organisation of material conditions in a given society' (cited in Barham

1992: p 85), whilst Warner comments that *"The status afforded the mentally ill is the very lowest"* and, according to Barham (1992), the historical evidence will always point to the great majority of the mentally ill being among the poorest classes of society and despite improvements in many areas, this is unlikely to get any better. Barham (1992: p89) takes this historical aspect further when he indicates that once a label has been assigned to an individual, the insane were categorised as broken individuals. Furthermore he states that they were deemed to not have the qualities to become a successful individual in capitalist society. Warner (1989, cited in Barham 1992) argues that mental health professionals are likely to *'hold attitudes towards mental patients which are similar to those of the general public: they may be even more rejecting'* and he goes on to state that *'professional conceptions of mental illness may reinforce the popular tendency to dehumanise mental patients'*.

This dehumanising of individuals raises the issue of how schizophrenia impacts on an individual. Estroff (1989) describes how schizophrenia is not so much 'I have an illness' but how the individual becomes the illness, and that there is no 'after' with schizophrenia, only a before. Wing (1989) suggests that individuals become socially disabled due to the disabilities that persist over a long period of time. Wing also goes on to describe how the negative symptoms of schizophrenia can be termed as a 'primary' disability: arguing that these are part of a social consequence having been identified, labelled, and treated as such by medical experts and others within an individual's social network. Therefore the social isolation, labelling and loss of social skills may result in a person's ability to cope, leading to an assumption that the individual has a permanent illness of schizophrenia. It is interesting to note that individuals often see themselves 'as mentally ill and that this is an all-encompassing permanent view of self' (Lally 1989, p 95 cited in Barham). Whilst Lally proposes that the roles open to the mentally ill are restricted, in part due to the social and cultural context that give mental illness a negative meaning. This then raises the issue of people becoming a full-time mentally ill patient in self-concept, according to Lally (1989) something that has Goffman allured to himself.

Estroff (1989) remarks that as a society, we are partly responsible for the loss of an individual's identity with schizophrenia and that *'becoming a schizophrenic is essentially a social and interpersonal process, not an inevitable consequence of primary symptoms and neurochemical abnormality'* Estroff also suggests that people have to learn to live with schizophrenia, whereas Strauss et al (1989) suggest that by being told they will have the disease all their lives and that they will need life-long medication reinforces the stigma that patients feel, discourages 'therapeutic' messages, increases social dysfunction and makes engaging with the services difficult over a period of time. This view is endorsed by Warner (1989) who suggests that the features of chronic schizophrenia (depression, negativity,

social withdrawal, isolation, loneliness, loss of self-respect) could be socially induced and could be a reaction to the social control of psychiatry.

The rejection of people with mental illness by society causes problems when they have to be re- integrated, the very focus of psychiatry was about individuals whose identity as a patient was more important than that of an individual as a person. Society has taken away a person's identity on account of their psychiatric history and has labelled them as full time patients, a concept which is pointless and unwanted. According to Grimshaw (2001) patients can be transformed into ordinary citizens that fall within the structural constraints imposed by governments. However it can be argued that the lack of opportunities and inequalities faced by these individuals' means there is a basic flaw in the structuralism of society and that there is a basic flaw in this social theory that will always disempower people with schizophrenia.

 The experiences of people with mental illness in society has generally been one of disempowerment and a loss of control over their lives and, as Bennett (1983, cited in Barham 1992) suggests, we never hear from the patients themselves about their experiences.

This view is echoed by one service user who *states "One of the things that we service users have in common is this shared experience of total powerlessness. We learn to define ourselves by the roles and diagnoses given to us by psychiatrists, take them into ourselves and feel helpless to influence our own lives…. With our powerlessness goes poverty of an enduring and humiliating nature"* (Lindow 1990, p10).

The very concept of having a mental illness suggest Bott (1976, cited in Barham 1992), absolves an individual of all responsibility and entitles him to care, however the impact of the stigma associated with the label can alter one's sense of self forever. Whilst Bean (1986) implies that allowing an individual more rights and choices it enhances their perception of themselves, prevents intrusion and sets standards.

2.8 Socio-economic costs of Schizophrenia

Estimating the costs associated with schizophrenia is difficult because of the range of services used and the need to clarify which costs are included and excluded in calculations. The National Institute for Clinical Excellence (NICE), reports that schizophrenia costs more than any other mental illness, consuming 5% of the NHS budget.
Knapp (1997) estimated that the annual UK cost of schizophrenia at 2.6 billion pounds, but even this sum omits some indirect impacts that cannot be currently costed; there have been

no corresponding overall cost analysis since. However Almond et al (2004) analysed the costs, clinical outcomes and quality of life in terms of relapse in schizophrenia.

In terms of costs, the largest proportion is that of hospital costs, both of in-patient costs and the intensive community treatment, any potential relapse means that costs are very high as well as causing considerable personal distress.

It has been shown (Almond et al 2004) that patients who experienced a relapse within a 6 months period had mean service costs of £8212 compared with £1899 for those who had no relapse during this period. Furthermore Almond & O'Donnell, (2000) report that the methods for estimating the costs of relapse was based on expert opinion and assumed (rather than observed) service utilisation in a simulation model that compared three antipsychotic drugs. Almond et al (2004) have indicated that if new antipsychotic treatments in schizophrenia can improve efficacy and compliance rates compared with conventional neuroleptic therapy, and thereby reduce relapse rates, this might bring about reductions in the service costs of schizophrenia.

One of the major issues is that of drug costs, the actual direct costs of drugs to the NHS would be higher due to the availability of the more expensive atypical antipsychotic drugs. The NICE guidance, published in June 2002, suggested that the adoption of atypical antipsychotic drugs would reach a level of at least 65% atypicals, and within the UK the number of prescriptions for atypical antipsychotic drugs continues to increase steadily. In March 2007, atypicals had accounted for 67% of all prescriptions. The costs of atypical antipsychotic drugs in 2007 amounted to 4.02 million prescription items at a cost of £213.75 million. Typical antipsychotic drugs amounted to 1.99 million prescription items at a cost of £12.66 million.

The indirect costs of schizophrenia (e.g. loss of employment, family caring) remain very high and often are several times larger than the direct health and social service costs Knapp (2004).

Knapp has estimated that up to 80% of costs attributed to schizophrenia stems from in-patient costs, whilst the drug costs remains low at 4%, however due to the high costs associated with relapse there remains doubts as to whether the most appropriate choice of drug is used.

Drug treatments remain the mainstay of treatment for schizophrenia sufferers; psychological interventions such as family therapy, cognitive behavioural therapy are additions to drug treatment rather than replacements. It is the development of newer pharmacological therapies that are of greater interest to clinicians and to both carers and user groups. This can be recognised by the fact that the older typical antipsychotics have marked adverse side effects and that many sufferers experience long term disability, hence the need to value their opinions in order to attempt to improve their quality of life.

The question as to the effectiveness of antipsychotic drugs must be addressed, and the effectiveness of the newer atypical antipsychotics taken into consideration as a viable alternative for treatment.

The National Institute for Clinical Excellence (NICE) went on to say that any decisions about medication should be taken after discussion between the individual and the clinicians responsible for their care.

Professor Sharma (2002) from NICE commented that "Older antipsychotics dampen brain function, and these stable patients should be allowed the opportunity of newer medications as there is evidence that they could improve brain function"

To add further weight to the argument for prescribing newer atypical medication, the National Schizophrenia Fellowship said that 'more than 80% of the 210,000 people with schizophrenia are currently denied access to antipsychotics on grounds of cost'.

Vass (2002) reports that the yearly cost of maintenance of one patient on older type antipsychotics is £70, whereas on the newer atypical drugs it is £1220, and NICE estimate that the cost to the NHS of making these drugs readily available will be £70m. Conversely this cost will be offset by an expected shift away from inpatient hospital care to community care, which is less expensive, and ultimately may lead to an improvement in quality of life. Many people discontinue their use of anti-psychotic drugs because of adverse effects, thus leading to an exacerbation in their symptoms and eventual relapse, despite growing evidence to suggest that schizophrenia sufferers would be best served by the newer atypical antipsychotics.

2.9 Sociological aspects of mental illness

It has been argued that people with schizophrenia are among the most excluded in society (Sayce 2000) and that the diagnosis of mental illness comes with the additional burden of a negative label. It has been shown by Johansen, (1969), Rabkin, (1974) and Link et al (1987) that the community reacts adversely towards the mentally ill, and additionally that this stigmatisation affects employability, and social acceptability (Olshansky, Grob & Malmad 1958; Farina & Felner 1973; Link, 1982). The term stigma refers to any persistent trait of an individual or group which evokes negative or punitive responses (Lai, Hong & Chee 2000).

Goffman (1963) made the salient point that

"It is not the functional limitations of impairment which constitutes the greatest problem, but rather the perceptions of negative difference (deviance) and their evocation of adverse social responses (stigma)".

Goffman argues that a person is not a deviant until his acts or attributes are perceived as negatively different, however one fundamental problem is that 'disability' so often

overshadows personal identity. Thus this leads to 'normals' exaggerating the differences between themselves and disabled persons because disability symbolically represents that which 'normals' fear or dread themselves becoming (Stein, 1980). In addition Phillips et al (1990) and Philips (2000) says that society views disabled persons as damaged, defective and less socially marketable than non-disabled persons. Goffman contends that 'normals' experience ambivalent feelings towards stigmatised individuals and seek to avoid having stigma spread by avoiding close contact with the mentally ill.

Even when a schizophrenic patient is in complete remission, they may find themselves being shunned or derided, often finding themselves subjected to social discrimination and rejection.

It has been reported (Gibbons & Butler, 1987; Lehman et al, 1986; Oliver et al, 1997; Simpson et al 1989) that patients in community- based programmes of care have a better quality of life than long term hospital care patients. This is not always down to the setting itself but to other external factors, such as the hospital based patients perceived themselves to be more acutely ill and more susceptible.

This issue of stigma poses a threat to self-esteem, relationships and the job prospects of people with schizophrenia, and as the author has illustrated, it raises the question of whether people with schizophrenia do have different life choices or not. It can be seen from the literature reviewed that atypical antipsychotic medication has the potential to improve a patient's quality of life but it remains to be seen if society will accept these patients as normal, or if they will be forever labelled deviants.

As can be seen from the literature, schizophrenia sufferers have a difficult and complex time with their illness, but it has been shown that with the use of the newer atypical medication, a patient's quality of life can be greatly improved. Also due to the decrease in side-effects, patients are more compliant, there is an improvement in patient's relationships and social functioning. It is still unclear as to how patients on the different antipsychotics live their lives and if there is (if any) differences in their being accepted into society without being labelled deviant.

2.10 Stigma and lived experiences.

Schultz et al (2003) suggests that the experience of schizophrenia is not just limited to the symptoms of the illness, and in conjunction with Finzen (1996) contends that schizophrenia is accompanied by a 'second illness': the reactions of the social environment and the stigma associated with the disorder. The impact of stigmatisation upon schizophrenia sufferers has added a new dimension to the illness experience and has led to social isolation, limited life

chances and delayed help-seeking behaviour (Link 1982, 1987; Fink and Tasman, 1992; Rosenfield, 1997; Angermeyer, Matchinger and Riedel-Heller, 1999; Sirey et al 1999).

An important consequence of stigmatisation encountered by patients with schizophrenia is that of secrecy. Schultz, Mathias and Angermeyer (2003) found that patients described their contact with psychiatry as *"a stain on one's reputation"* and tried to conceal it from friends and relatives due to a desire to maintain a "normal life", which they perceived as compromised due to their schizophrenia.

The use of empirical research has shown that stigma reduces adaptive social functioning in people with schizophrenia (Perlick et al 2001) and that service users and their families feel devalued (Streuning et al 2001). In addition stigma creates barriers and was associated with reduced adherence to treatment (Sirey et al 2001). People with schizophrenia were perceived and constructed as disabled leading to devaluation, social isolation and rejection (Williams and Collins 2002) which in turn caused people with schizophrenia to not disclose their diagnosis because they were concerned about negative perceptions of themselves (Dickerson et al 2002).

Stigma has led to low self-esteem in people with mental health problems (Blankerz 2001, Knight 2003), and which in turn can lead to unemployment, poor quality of life and feeling demoralised (Graf et al 2004). Furthermore public prejudice leads to discrimination and stigma and people with schizophrenia suffer from negative self-concept, and social exclusion (Knight et al 2003).

Both internal and external stigma are harmful to people with mental health problems as both types of stigma lead to social withdrawal and loss of social support (Green et al 2003). The fear of stigma and discrimination leads to loss of confidence, or self-stigma whilst people suffer from social exclusion and negative attitudes in their community (ODPM 2004a), and carers also share the stigma and negative spoiled identity (Perring et al 1990). Carers are blamed and stigmatised for the patient's illness because of the popularity of theories of family pathogenesis. Poverty and poor living conditions are a consequence of stigma (Sartorius 2002).

Phelan et al (1998) established that parents and spouses of first admission patients attempted to conceal the illness from others and professionals were no different as they also attempted to hide the illness from others. Brugha et al (1993) cited in Harrison & Gill (2010) suggests that poorer outcomes are likely when a person's social networks are reduced.

 Harrison & Gill (2010) have implied that this secrecy leads to a negative cultural endorsement resulting in scapegoating in the wider community. Hence the reality of discriminatory practices lends itself to keeping mental health problems a secret and thus

social withdrawal by the person with schizophrenia, resulting in a more insular support network.

Goffman (1986) conceptualises stigma as an "attribute that is deeply discrediting…" and which makes the person carrying it "…different from others and of a less desirable kind" (p.3). Furthermore Goffman indicates that an awareness of the attribute then results in the belief that "….a person is not quite human" (p.5). This notion of stigma then affects the very identity of those the negative attribute is ascribed to, and complicates interaction with those that Goffman called "the normals" (p.13). In addition Lemert (1951) indicates that by having been ascribed a deviating characteristic by means of a label, individuals then follow a deviation from social norms. Thus it can be inferred that labelling is a prerequisite for the very existence of deviance that could justify stigmatisation, for as Becker (1963) points out, "the person with deviant behaviour is a person to whom this label has been successfully applied: deviant behaviour is behaviour that has been labelled as such by others" (p.9).

Stigma is a socially constructed phenomenon where there is evidence of an attribute that makes a person different from others. In stigma, there is acceptance of a devalued position leading to someone maintaining a negative identity (Goffman 1968), cited in Harrison & Gill (2010). In addition Hayward and Bright (1997) identified stigma as the negative effect of a label, whilst Schlosberg (1993) suggests it is the establishment of deviant identities. Corrigan and Penn (1999) however content that stigma is another term for prejudice based upon negative stereotyping. In addition having been ascribed a deviant characteristic by means of a label; individuals can follow a deviation from social norms. Furthermore those people, who are labelled, are then linked to undesirable characteristics due to our own cultural beliefs; thus it is important that we examine more closely the lived experiences of individuals by using a phenomenological approach.

Laurence (2002) questions the justification of forced treatment and hospitalisation of people with mental illness, thus leading the author to contend therefore that illness is a barrier to maintaining normal roles.

Discrimination is defined as "being treated unfairly or denied opportunities" (ODPM 2004a: 24). Stigma and discrimination are related and stigma leads to discrimination. The Office of the Deputy Prime Minister (2004a: 24) cited in Harrison & Gill (2010) maintains that "stigma arises from negative stereotypes associated with the symptoms of, or diagnosis of, mental health problems. Although stigma is often seen as the problem of   people with mental health problems they lack the power to change the way they are seen". Despite national action to tackle stigma and discrimination there has been a reduction in tolerance in public attitudes to people with mental health problems since 1993 (ODPM 2004a).

Manning and White (1995) reported that employers within the UK were reluctant to hire someone with mental illness though tended to be more tolerant of people with depression than of people with schizophrenia. Harrison & Gill (2010) conclude then that people with schizophrenia are more likely to be discriminated against possibly due to the label or the stigma attached to their illness.

It has been suggested that discrimination occurs across every aspect of social and economic existence (Fink and Tasman 1992, Heller et al 1996, Read and Reynolds 1997, Byrne 1997, Thompson and Thompson 1997). Discrimination is not just about how society treats its mentally ill but about the conditions in which they live, mental health budgets and the priority which we allow these services to achieve. Goffman (1963) remarked that the difference between a normal and a stigmatised person was a question of perspective, not reality.

There is a body of evidence (Philo 1996, Byrne 1997) cited in Harrison & Gill (2010) that supports the concept of stereotypes in mental illness; this makes it easier for society to dismiss people and in so doing maintain their social distance.   Harrison & Gill (2010) suggest that a further impact of discrimination can be seen in the deficits of quality of care provided due to the inequitable distribution of resources within the health care system. Patient's feel that the ranges of services are disadvantaged and limited to psychotropic medication. Mechanic (1994) pointed out that resources are always limited and priorities depend on values, attitudes and beliefs which influence resource allocation to the various needs of society.   Mechanic further suggests that the way in which resources are given to the mental health services affects not only patient's recovery but their quality of living as well.

Tsang et al (2003) identified that employment and financial burden also had a major impact on the quality of life of patients whilst many patients have their job terminated due to aspects of their illness.

It has been suggested that among persons with mental illness there is a high level of depression and demoralisation which correlates with stigmatisation (Link 1987, Link et al 1991, 1997, Rosenfield 1997, and Markowitz 1998), cited in Harrison & Gill (2010). It can be seen that the negative aspect of stigmatisation reflects not only unfavourable stereotypes but also encourages negative attitudes and adverse behaviour of those who stigmatise.

Byrne (2000) contends that any pessimism amongst health professionals may also have a negative effect upon a patient's perception of the health service for years to come allied with the fact that 50% of people with schizophrenia have significant social skills deficits and these further highlights the negative effects stigma has on an individual.

Scambler (2004) identifies two types of stigma: internal stigma, where shame and expectation of discrimination are likely to inhibit a person from disclosing a mental health problem, and external stigma, which is the experience of unfair treatment by others. Goffman (1968) and Giddens (2001) put forward that individuals with schizophrenia are assigned a spoiled identity and a lower value than others, which they accept; hence this also leads to external and internal stigma. Individuals accept and collude in the creation of mental health systems and structures (e.g. hospitals).These in turn create and shape individuals who accept and become dependent on these systems and structures (Giddens 2001), thus leading to internal stigma.

In cultural bias, a sociological concept, there is an accepted shared knowledge about mental illness (Bilton et al 1996) cited in Harrison & Gill (2010) . Individuals who are diagnosed as mentally ill accept the shared knowledge and internalise the cultural norms and rules. Harrison & Gill (2010) suggest that they accept the validity of the diagnosis of schizophrenia, their health status or the need for treatment, which may lead to accepting the negative identity assigned to them, which can be disputed leads to internal stigma.

Goffman's idea of conceptualising stigma highlights the fact that many people's knowledge of schizophrenia has been informed by studies of attitudes and beliefs (Angermeyer and Matschinger, 1995a), and general attitudes about mental illness (Nunnally, 1961: Taylor and Dear, 1981; Huxley, 1993; Wolff, 1997). These studies have shown that the public in general has a negative picture of people with schizophrenia, deeming them to be unpredictable, aggressive, dangerous, unreasonable, of little intelligence, frightening and lacking in self-control. Angermeyer and Matschinger (1995b) also show that many of the general public would reject entering into any kind of social relationship with someone with schizophrenia, and would not recommend anyone with schizophrenia for a job. Recent studies (Phelan et al, 1997; Phelan & Link, 1998) have also shown that despite recent educational campaigns, little has been done to alter the stigma associated with mental illness and schizophrenia.

 Harrison & Gill (2010) comment that the media perpetuate stigma as they give the public narrowly based stories based around stereotypes as evidenced by the 1998 survey by the Royal College of Psychiatrists who reported that 70% of people believed that people with schizophrenia were violent and unpredictable. Furthermore Byrne (1997) suggests that people with mental illness are frequently portrayed as victims, pathetic characters, or the deserving mad, emphasising the negative connotations associated with mental illness. According to Weiss (1994) these negative attitudes to people with mental illness start at playschool and endure into early adulthood, and continue throughout a person's life (Green et al 2005, Huxley 1993).

However, what these studies fail to take into consideration is the attitudes of people who have come into contact with sufferers of schizophrenia and their actual behaviour. Thus one would contend that we do not have a view of how schizophrenic patients see themselves, nor do we have a view of how they perceive that they are seen.

Link and Phelan (2001) dispute the findings of these studies and maintain that these theories and concepts are uninformed due to the lack of lived experience of the people studied.

It has also been shown (Link et al 1989) that a patient's quality of life is affected by this stigma and that they tend to adopt strategies such as secrecy and withdrawal in order to avoid negative reactions.

It can be argued (Green & Davis 2005) that the behaviours that are labelled as mental illness can be seen as social performances and social discourse, rather than forms of mental states. The labels of mental disorders can have a long-lasting negative consequence on employment, quality of life, and self-esteem of patients due to stigma resulting from the labels (Wright, Gronfein & Owens, 2000).

Hudson (1999) cited in Harrison & Gill (2010) put forward the concept that other people invalidate people who enter the mental health system, perceiving them as a failure and are often deemed as mad. Hence service users feel weak, stigmatised, negatively judged and treated differently from others. In conjunction with this Sayce (2000) puts forward the view that the focus should move away from the person who is stigmatised to those people or agencies causing the stigma.

Harrison & Gill (2010) suggest that iatrogenic stigmatisation starts with labelling but the use of medication which causes extrapyramidal side effects, increases the stigma as these side effects identify the person as someone with a mental illness more effectively than the original mental illness. Furthermore Sartorius (2002) suggests that health professionals are not sufficiently engaged in challenging stigma and discrimination, which are a barrier to a better quality of life for individuals with mental health problems.

Schulze, Matthias & Angermeyer, (2003); Link & Phelan (2001) have indicated that there exists an imprecise picture of stigma associated with schizophrenia, due to the way in which society perceives the illness. Goffman (1986) argues that those with schizophrenia first and foremost feel that their illness and the stereotypes associated with it often shapes people's perceptions of them, and thus imposes an illness identity upon them. This is regardless of whether or not they are experiencing acute symptoms of the illness, and is perceived as having a negative impact on their quality of life.

What is clear is that further exploration is needed of patients' lived experiences utilising a phenomenological approach, to identify individual incidences of how schizophrenic patients

carry out their daily lives. In order to combat the impact of stigma on schizophrenic patients it is essential that first-hand information is gained from the patients, and that they can make a difference to their social integration when faced with negative attributes associated with their illness.

2.11 Quality of life

Skantze et al (1992) define quality of life as 'a person's own subjective evaluation of his or her life situation' whereas Pinkney et al (1991) define it as the subjectively and objectively measured 'goodness of life'. The WHO (1994) defined quality of life as 'the perception that an individual has of his/her position in life, within the framework of the culture and system of values in which he/she is immersed and in function of his/her goals and concerns'.

A major concern within health care is that there is little consensus about what constitutes quality of life or how to measure it (Sainfort 1996),Campbell (1976),Ferrans (1992) & Andrews (2004), would contend that quality of life is defined in terms of subjective perceptions of life satisfaction, happiness, social relations, physical health and psychological well-being whereas Spilker (1990) would argue that more objective indicators such as income, quality of housing and physical function are determinants of quality of life. To compound this view, most of the instruments used to assess quality of life rely upon a single respondent, which is either the patient or the clinician but rarely both, in addition few quality of life instruments cover the broad range of domains that have been shown to be related to quality of life.

It is therefore of crucial importance to the patients themselves that a detailed study is undertaken to explore how schizophrenic patients actually live their lives, and to ensure that they do have a chance to improve their quality of life.

Following the implementation of de-institutionalization policies in many countries, the majority of individuals with severe mental illnesses returned to live in the community. Quality of life gradually became a worthwhile concept used to evaluate the outcomes of community mental healthcare programmes. The interest in outcomes and particularly quality of life (QoL) assessment in schizophrenia started as an extension of the increasing concern about the plight of the chronically mentally ill in the community following the institutionalization movement in the early 1960s and 70s (Lamb, 1979, Bachrach, 1976). Issues such as personal safety, poverty, and social isolation came to be identified as the personal concerns of patients discharged from psychiatric hospitals into the community (Lehman, 1982).

Sainfort (1996) explains that 'clinicians, clinical investigators and policy makers in the field of mental health have now recognized that quality of life is an important measure of

outcomes in patient management, cost-effectiveness evaluations, clinical trials, and treatment outcome studies', whilst Lamb (1981) & Lehman et al (1982) suggest that the major goal in the provision of mental health services is the improvement in quality of life.

Barry (1993) suggests that the concept of quality of life normally refers in some way to the sense of well-being and satisfaction experienced by a person with regard to their life and Baker (1982) indicates that this measurement of quality of life may be particularly appropriate for people with long term mental health problems, hence the importance for research linked to quality of life.

2.12 Patients' subjective and objective views of quality of life

Within psychiatry the initial focus was on 'objective' quality of life studies, which indicated that quality of life was low in most areas (Lamb & Goertzel, 1997; Rog & Raush, 1975; Segal & Aviram, 1978; Talbott 1978). However later studies have concentrated on the patient's satisfaction with their lives, hence the importance of the patient's 'subjective' view of quality of life (Browne et al 1996; Kemmler et al 1997; Lehman et al 1982; Skantze et al 1992). It has been argued by a number of authors (Van Putten 1978, Hogan et al 1983 and Davidhizar 1985) that patients' subjective feelings towards their medication are significant; in particular, Hogan et al. (1983) considered that patients' feelings about their medicine was the factor most closely associated with compliance behaviour.

There is strong evidence (Sullivan et al 1992) to suggest that positive family relations between psychiatric clients and their family enhance a client's perceived quality of life, whereas poor family relationships have been found to predict hospital return (Postrado & Lehman 1995). Clients with a better level of social functioning have reported a greater quality of life (Mercier and King, 1993; Corrigan and Buican, 1995), thus enhancing the viewpoint that a client's objective view is a vital component in improving quality of life.

Individuals with long-term mental health problems suffer from damaged self-esteem (Estroff, 1989), but Arns and Linney (1993) contend that psychosocial interventions that improve a client's self-esteem are also likely to raise their overall subjective well-being and quality of life.

There may be discordance between providers' and patients' views in relation to their quality of life; it is possible that some providers might implicitly formulate their own judgments of quality of life, which might differ from their patients' judgments. Greene et al (2005) suggests that concordance between providers and patients is the exception rather than the rule, and little is known about patients' values and preferences within mental health.

In support of this, two further studies by Van Putten (1974) and Van Putten et al (1984) established that patients' subjective reactions to treatment were often more reliable than that of an observers as they tended to recognise the more subtle extrapyramidal side-effects. Van Putten (1974) also reported that non-compliance was significantly associated with extrapyramidal side effects especially akasthesia and he emphasised the importance of taking this into account in evaluating the clinical effectiveness of any treatment.

There have been relatively few studies to examine the relationship between schizophrenia and quality of life in terms of clinical, sociodemographic and treatment factors, Awad (1992 & 1999) suggests that a lack of a satisfactory model for quality of life while on neuroleptic medication. Meltzer (1990), however used the total score of the Quality of Life Scale (Flannagan 1982) as an index of quality of life, and reported 'that negative symptoms may be more important than positive symptoms in determining the quality of life of treatment resistant schizophrenic patients'.

Meltzer also found that quality of life was inversely related to the number of previous hospitalizations, whereas Skantze et al (1992) found that quality of life was independent of gender, marital status, and standard of living (as defined by housing standards, access to public services and to educational/training opportunities).

In a study by Browne (1996) involving 64 out patients with DSM-III-R diagnosis of schizophrenia, it was confirmed that these individuals had an impoverished quality of life characterised by negative symptom severity, duration of illness, cumulative duration of hospitalisation and the patient's age. This study also confirmed for the first time that tardive dyskinesia was associated with a poorer quality of life, which raised a cause for concern due to its potentially irreversible condition, Browne concurs with Awad & Hogan (1999) who argue that quality of life is influenced by side effects of medication.

It therefore follows those atypical neuroleptics such as clozapine, risperidone and olanzapine that improve negative symptoms and quality of life and produce less tardive dyskinesia can be of advantage in prescribing early in the treatment of schizophrenia.

It can be clearly seen from the literature that numerous quantitative studies have looked at the quality of life of patients, producing similar results; however there is clearly a lack of evidence to identify what patients see as important in their everyday lived experiences. It is therefore an important development to establish what patients see as meaningful within the concept of their everyday lived experience. This study aims to explore these issues in greater detail.

2.13 Empowering individuals and prescribing issues

The impact of stigmatisation upon individuals has far reaching effects including discrimination however one of the most powerful aspects is that of disempowerment

It can be suggested that empowerment is positively related to quality of life and income and is inversely related to the use of mental health services (Johnstone 1999).

However it could be contended that the negative perceptions of people with mental health problems, held by society, prevents empowerment of these people (Campbell and Lindow 1997). One would also suggest that nurses themselves are disempowered and thus cannot empower service users. These views concur with Morrall (1998b) who suggests that it is not in health professionals' interests to give up power.

This imbalance in power is highlighted by Coleman (1997) who maintains that once in the mental health system; it is difficult for a person reclaim personal power.

Hospitals prevent recovery by preventing the development of good self-esteem, self-confidence and self-acceptance. Coleman (1999) asserts that reclaiming power is a prerequisite to recovery and that power can only be taken by the service user, not given by the health professional. Moorey (1998) proposes that a source of disempowerment is the diagnostic relationship in which the health professional identifies the problem, its cause and delivers the solution to the client.

Bertram and Stickley (2005) found that health professionals believed that they had a responsibility for their client group, and that this interpretation of duty of care may have disempowered service users. Furthermore they discussed barriers to empowerment and established that staff attitudes prevented practices to promote empowerment.

The service user's right to autonomy was sacrificed to promote public safety in the name of risk management a view also endorsed by (Campbell and Lindow 1997, Ryan 1999, Barker 1999).

Barker (1999) and Moorey (1998) assert that the diagnostic relationship between service user and health professionals is part of the problem as they suggest that the health professional's power to diagnose the problem and offer solutions disempowers the service user. Thus it can be argued that the service user's participation is controlled by the health professional as compliance is a goal valued by nurses.

It is clear that a way forward must be found in order to develop a better quality of life for service users, consequently Coleman and Smith (2005) assert that service users must cease to be victims and empower themselves. They must redefine themselves as people who have unusual experiences as this shows oneself and one's illness in a more positive light according to Williams and Collins (1999).

Nurses should promote wellness and this means working with clients, joint decision making, helping clients to work towards their own development. Nurses should challenge social norms (Barker 1998), however this may be difficult as nurses are subject to cultural bias (Bilton et al 1996) and governmentality (Rose 1999) in the same way as service users and may be unable to challenge social norms.

Despite all the initiatives and recommendations there remains a number of barriers to establishing suitable working relationships. The National Institute for Clinical Excellence (NICE) (2002) emphasise the importance of partnership. This means building supportive relationships with users and carers, giving clear information and promotion recovery, and empathising with individuals

Morrall (1998a) contends that nurses do not engage in partnership with clients, more that they engage in surveillance of individuals, and the surveillance role is supported by medicine and the mental health system, a point supported by Bracken and Thomas (1999). Furthermore Devaney et al (1998) suggest that nurses have poor collaboration and partnership skills a view endorsed by Hickey and Kipping (1998) who contend that mental health services medicalise distress and promote dependency, thus preventing equality in the nurse-client relationship.

It may be the case that one barrier comes from the dependency of the service user, who may not want to engage in decision making (Hickey and Kipping 1998, Barker and Davidson 1998). However, health professionals appear to create barriers to partnership.

There is a view expressed by Crawford (1996) that in order to measure the effectiveness of the service delivered to recipients of health care, an expanded view has to be taken into account. This concurs with the expectation that health care consumers and health care providers who will now have a new role of evaluating health care services in terms of positive, longitudinal consumer-related, quality of life outcomes. Bruegel (1999) indicates that these groups will critically evaluate health care outcomes to determine the best health care services for specific populations.

Many health care organisations are beginning to embrace the concept of empowerment but find actualising the concept to be challenging. In order to fully understand the use of empowerment within organisations it is imperative that we have an understanding of what is meant by the concept. One of the advantages of utilising empowerment within health care organisations is that it enables collaboration with other agencies and it addresses the issues of service providers.

Zimmermann (1990) took this a stage further when describing empowerment as a multi-level construct that occurs at three levels, individual, organisational and community. Zimmerman & Rappaport (1988) define empowerment as "a construct that links individual's strengths and competencies, natural healing systems and proactive behaviours to matters of social policy and social change"

Crawford (1999) suggests that empowerment is the reallocation of decision making to promote direct and desired change on people's lives. It can be argued that this is a process by which individuals gain control over their own lives and have democratic participation in relation to the control of their own lives. The very fact that service users will begin to utilise empowerment strategies indicates that service users will have a greater understanding; participation and influence upon their health status.

Bruegel (1998) states that there are a number of indicators that would suggest an increased desire for service users to have more involvement and say in their health status. Bruegel goes on to say that there is an increasing trend of the consumer to demand more information in all aspects of their relationships with any external organisation. This has become more evident as information has become more available due to various sources such as the internet and the media.

2.14 Government policy and legislation

There have been a number of Government initiatives aimed at improving and modernising health and social services, including the National Service Framework (NSF), which incorporates the role of NICE.

The fundamental role of NICE will be to implement guidelines on issues such as assessing drugs and treatments for their clinical and cost effectiveness.

Further initiatives from the Government include Modernising Mental Health Services (1998), which suggests that "community care has failed" and blames amongst others under funding, inadequate services, overburdening of families among others. However this paper acknowledges that the reduction in side effects offers scope for the improvement of the effectiveness of drug treatment and the long-term benefits of improved tolerance for the patients and their family or carers.

One of the major components of this paper is the notion of increased investment; the extra funds would include new treatments including atypical neuroleptics, and the clear link between improved compliance with atypical antipsychotics has reduced risk in the community.

A number of recommendations and initiatives have now been put into place in an attempt to address this imbalance including; The National Service Framework for Mental Health (NSFMH) (1999) which acknowledges the need to tackle stigma and reduce discrimination.

The Royal College of Psychiatrists initiated a campaign between 1998 and 2003 entitled 'Changing Minds-every family in the land' which aimed to reduce stigma in mental health, by focusing on public education and awareness (Crisp 1998, ODPM 2004a:30).

The campaign produced a series of educational booklets focusing on a range of mental health problems this was a collaborative initiative involving service users, carers, professionals, the media, the general public and those involved in education.

In order to promote this £1.1 million was invested in 2004-2005, with the goal of challenging stigma and discrimination against people with mental health problems with more effective and closer co-ordination between the voluntary sector and the government

Following on from this a report concluded that there is a need for continued work to target discriminatory behaviour with a desired outcome as a positive change in attitudes and behaviours towards individuals with mental health problems (ODPM 2004a).

The NIMHE (2004a) plans to work with different forms of media to redress the balance and have produced a five year antidiscrimination plan, which commenced in 2004, making the case for working in partnership with health promotion with the specific goal of reducing stigma and discrimination.

This five year plan includes the Disability Inclusion Model which challenges discrimination at all level: legal, attitudinal and institutional.

 NIMHE (2004b) recommended that service users and carers should be consulted about the impact of discrimination and should be helped to challenge stigma, discrimination and stereotyping

They also recommended that there should be national programmes to support local activities and a combination of activities and methods. There should be programmes to address behavioural change, as changing attitudes and raising awareness alone, do not reduce stigma and discrimination. There must be activities which explicitly address discrimination. Target audiences are to be focused on, using a clear consistent message. There is to be long term planning and funding for these activities and evaluation of these programmes. (NIMHE 2004b)

One of the major advances in treatment and delivery of care for people in the community is the Community Mental Health Teams (CMHTs), who on the evidence of Onyett and Ford (1996) can deliver good quality care to people with severe and enduring mental illness.

CMHTs have produced a fundamental shift in the delivery of services to patients with schizophrenia in recent years, demonstrated clearly by the ability to provide quality services in the community to patients once deemed impossible to discharge from hospital. However the development of such services requires careful planning and the involvement of clinicians who feel confident in using this approach and, most importantly, who are equipped with sufficient resources to deliver such a service safely and effectively.

In contrast to the above a range of factors are identified as barriers to partnership: professional socialisation, with health professionals holding negative assumptions about service users' ability to hold a valid opinion, negative stereotyping within wider society and the perceived need to control individuals with mental health problems, lack of commitment and low staffing levels (Hickey and Kipping 1998). It is proposed that health professionals, and specifically mental health nurses, are disempowered by medicine and are unable to facilitate partnership (Campbell and Lindow 1997, Morrall 1998a, Hickey and Kipping 1998).

Stigma may prevent people from accessing services when they are in crisis. It has been suggested that if services were located in community centres where other members of the local community attend for various reasons this may reduce stigma (Patel and Fatimilihen 1999).

McCann (2004) concluded that there is a need for a participatory approach with the emphasis on partnership, rather than an expert led approach. He criticized the deficit model of education, in which the underlying assumption is that the person with the diagnosis of schizophrenia is assumed to know very little about schizophrenia. He proposed that the collaborative interactional model is effective because the experiences of the client are focused on. It was suggested that there is a transitional process to partnership, in which nurses give up control over time and the client becomes more enabled and can achieve self-determination (McCann 2004).

Bury (1991) proposes that there are three adaptations to chronic illness and disability: disclosing the condition, disguising the condition and normalisation of the altered public identity. Disguising the diagnosis of schizophrenia, which involves not disclosing and actively denying the diagnosis, may be result of stigma, this point is also supported by ODPM (2004). It could be argued that in doing this, a person avoids identification as a person with schizophrenia and rejection as a result of this spoiled identity (Goffman 1968, Giddens 2001). In normalisation stigma is challenged by members of user groups, and the aim of this may be self-management, taking control of one's own life, support from others in a similar situation and maintaining positive self-concept.

What has been shown is that stigma undermines social adaptation, reduced adherence to treatment, nondisclosure and secrecy, reduced supportive social networks, self-esteem and psychological well-being. It leads to unemployment which results in further social isolation and a reduced quality of life; what's more the public perspective of mental illness is damaging to people with mental illness and leads to stigma, a perception which is often informed by the media, what's more carers also share a negative identity because of stigma.

In order for things to change it can be recommended that more support is available for families/carers, we should work with people to improve self-esteem, help people develop better/optimal functioning, work with people to improve and increase their supportive social networks, pay attention to psychological barriers to recovery, address impact of stigma, continue to promote more positive reporting of mental illness by media, change public view of mental illness and support people in employment and promote employment as an option for others who are unemployed.

What is abundantly clear is that more collaborative work needs to be done to determine and assess what service users actually do with their lives on a daily basis in order to see a reduction in the impact of stigmatisation.

Discrimination has also emerged, but not just from in the context of social relationships with friends, family and the public but also in their contact from mental health professionals, who often give a negative prognosis such as "You've got schizophrenia, you will be ill for the rest of your life" or "your illness means that you will end up committing suicide"

Further themes emerging which have an impression on individual's lives include the negative impact on individual's relationships due to side effects of medication, again this causes patients to avoid social contact with others and reduces their self-esteem.

There also emerges a differentiation amongst the variations of mental illness, with negative views being associated with schizophrenia and linked with unpredictable behaviour and personal failure rather than being considered an illness, whereas anxiety and depression are viewed more positively and are becoming increasingly accepted.

A further impact of discrimination can be seen in the deficits of quality of care provided due to the inequitable distribution of resources within the health care system, patients feel that the range of services are disadvantaged and limited to psychotropic medication. Mechanic (1989) pointed out that resources are always limited and priorities depend on values, attitudes and beliefs influence resource allocation to the various needs of society. Lefley, (1992; 1996) further suggests that when adequate resources are given to the mental health services then the recovery of patients as well as their quality of living will be affected.

Tsang et al (2003) identified that unemployment and financial burden also had a major impact upon the quality of life of patients, many patients have their job terminated due to their illness.

Schizophrenic patients identified that the diagnosis of schizophrenia resulted in a *'reduction of social contacts'* and that people have little understanding of the behaviour or difficulties people with schizophrenia face. An important consequence of stigmatisation encountered by schizophrenic patients is that of secrecy, Schulze, Matthias and Angermeyer (2003) found that patients described their contact with psychiatry as *" a stain on one's reputation"* and tried to conceal it from friends and relatives due to a desire to maintain a "normal life" which they as compromised due to their schizophrenia. Tsang et al (2003) showed that by concealing the illness, they were unable to receive the support they needed help. This often resulted in what patients describe as loneliness.

Chapter 3

3.0 Research Theory

3.1 Introduction

In this chapter I will give a rationale for the use of a qualitative research within the study and explain why I am using diaries and semi structured interviews as methods for data collection. The chapter will also look at the benefits of the methods chosen and justify the use of a phenomenological approach to understanding lived experiences.

3.2 Why take a Qualitative Approach?

Sofaer (1999), Babbie (1998), Bryman (1998), Seale (1999) and Silvermann (1993) contended that qualitative research methods are valuable in providing rich descriptions of complex phenomena such as an insight into the lived experiences of individuals with schizophrenia. Furthermore Babbie (1998) suggested that this method enabled the researcher to illuminate a person's experience gaining an interpretation of events and viewpoints that may not normally be heard. Qualitative research can also conduct initial explorations to develop theories and to generate and even test hypotheses; and thus move towards explaining peoples lived experiences.

Sofaer (1999) suggested that qualitative methods have the potential to contribute significantly to the development of meaningful 'amounts ' and one could suggest that quantifying these results is an excellent way to look at phenomena so that they become manageable and discrete elements of an overall conceptual framework or analytic plan. Bowling (2002) has suggested that qualitative methods help provide rich descriptions of phenomena as in the case of exploring the lived experiences of individuals. Furthermore Bryman (1998) indicated that they enhance understanding of the context of events as well as the events themselves. And suggested that qualitative methods can indeed help to identify patterns and configurations among variables and to make distinctions.

Thus, qualitative research not only serves the desire to describe it also helps move inquiry toward more meaningful explanations which is a useful strategy for this study.

 Bowling (2002) has argued that the use of qualitative methods is growing in health services and health policy research, yet as she mentions many decry qualitative methods as inherently biased because these methods depend so much on the perspective and skills of the researcher however in this study it is more appropriate to gather a persons lived experiences in this way.

One of the recurrent themes in the discussion of qualitative methods has been the question of whether quantitative and qualitative methods are compatible.

Opinion has been divided; Gibbs (1979) made a plea for complementarity of subjectivist and objectivist methods in psychology, whereas Mahrer (1988) has advocated discovery oriented research in the field of psychotherapy. While Sperry (1988 has suggested an integration of positivistic and phenomenological thought to form a more naturalistic approach to the study of brain and consciousness.

Osborne (1994) has suggested that the early eighties marked the growth of an interest in qualitative methodology which has paralleled the growing disenchantment with traditional logical - empirical research methods.

The supremacy of natural science type research methods has been increasingly challenged by descriptive and hermeneutically oriented methods (e.g., Giorgi, 1986; Packer, 1985; Palmer, 1969; Polkinghorne, 1983; Rommetveit, 1987) Contextualism (Rosnow & Georgoudi, 1986), social constructionism (Gergen, 1985) and deconstructionism (Derrida, 1977) have also challenged the objectivity of traditional natural science methodology by emphasizing the socially derived theories.

3.3 Developmental research

Seale (1999) indicated that conceptualising the process of reducing our uncertainty about important phenomena or questions is useful within research as would help developmental approach to inquiry. Furthermore Silverman (1993) then contended that it becomes evident that, at the outset, there is uncertainty not only about answers, but about what the right questions might be and how they should be framed to get meaningful answers. Seale (1999) then suggested that as understanding increases, some of the right questions emerge, but uncertainty remains about whether all of the right questions have been identified. As a researcher develops in this area of research confidence grows that all of the important questions have been identified and perhaps framed in more specific terms, but uncertainty still exists about the range of possible answers to those questions.

One can then argue that as the research develops it can move from being quite unstructured and probably largely qualitative in nature, to being quite structured.

In this developmental framework, initial questions are very open-ended; often the researcher just asks what appear to be relevant individuals to describe, in their own way, their experiences and responses concerning a given situation or issue. Over time, questions

remain open-ended but become more specific, either in their initial wording or in accompanying 'probes.' as were the case within this data collection.

Another way to shed light on reasons to use qualitative methods is to address the issue of theory. It has been suggested according to Luft (1986) that Health services researchers tend to borrow theories from social science disciplines and they have done little to develop full-scale, independent theories. Given this dilemma it can be argued that the field has reached the point at which it has become most valuable to pay greater attention to the construction of theories that integrate understandings from a variety of disciplines.

A shared set of concepts or constructs derived from more integrative and generic theories could help ensure that key questions are addressed and that key variables are measured and measured consistently, across studies in widely different settings and over time. This would contribute greatly to building a coherent body of knowledge. In order to develop theory that may influence policy decisions then the theory must be developed from qualitative research as in the case of lived experiences. In the field of health services research, qualitative methods have been used to describe many kinds of complex settings and complex interactions. These include interactions among patients, families, and clinicians; within, between, and among professional groups and organizations; in communities.

Corbin and Strauss (1988) have confirmed that qualitative research plays an important part in clarifying the values, language, and meanings attributed to people who play different roles in organizations and communities. This approach which will be utilised in this study allows allow people to speak in their own voice, rather than conforming to categories and terms imposed on them by others as has been suggested by Goffman in face to face interactions.

Often, qualitative researchers find that they are giving voice, in particular, to those who are otherwise rarely heard such as those with a mental illness. Qualitative research methods have proved to be very useful, in understanding groups of people with similarly distinctive cultures who live in our society, who are often either almost invisible (e.g., patients in nursing homes or mental hospitals) or alienated from mainstream society. It follows then that Goffman's classic study of mental hospital patients as 'inmates' (1961) to Diamond's study of nursing homes (1992), has developed a sensitivity to the ways in which roles are socially constructed and reconstructed and this then enables the unspoken assumptions underlying relationships between 'health care providers' to be examined and developed further.

One of the great advantages of qualitative methods is that they enhance the capacity not only to describe events but to understand how and why the same events are often interpreted

in a different, sometimes even conflicting manner, by different individuals within the same field.

3.4 Naturalistic Inquiry

The 'purest' form of qualitative research, with roots in anthropology and sociology, is often known as ethnography or naturalistic inquiry. Naturalistic inquiry most often involves a long-term exposure to a setting and/or a group of people (Lincoln and Guba 1985). Within this type of research, the investigator makes extensive use of unstructured observations as well as conversations, and this method of research is most likely to be used when the level of uncertainty is high or when we are unsure of what questions to ask or when there is little or no theory to direct our awareness, and when situations are novel or complex.

However a drawback of this method is that within many settings, it can be impossible (or as near as makes no difference) to get sufficient exposure to a setting or a group without becoming a participant. It has been suggested that many ethnographers assert that it is impossible to understand the life experience of someone in a 'total institution,' such as a mental hospital, without not just spending a good deal of time in such an institution but also being subject to the same constraints as those who find themselves forced, by circumstance or the law, to be there. Nor would one be able to gain a fuller understanding of someone with mental illness in the community without spending long periods in their company thus one could assert the use of diaries and interviews would give a clearer and more accurate understanding of their lives.

3.5 Case study methods

A more common set of qualitative methods are those used in case study research (e.g., Yin 1994). In virtually all instances, case studies use not only purposive sampling of sites, but purposive sampling of informants and experiences. The methods used in case study research are similar to those of naturalistic inquiry, except that data collection is typically more structured.

The most common methods used are key informant interviews, structured observations of events and interactions, and the collection and content analysis of relevant documents. Interviews can vary from the unstructured to the highly structured, but the questions remain overwhelmingly open-ended. Typically, a list of questions is specified and there are 'probes' associated with certain questions.

Content analyses of documents can also vary. In some cases, documents are being examined in order to identify the 'facts' of a situation or a series of events such as how people

construct and live their lives. A further point is that in some cases the analysis focuses more on the meanings embedded either in language or, in some cases, in images. This kind of analysis typically involves the identification of assumptions, values, and priorities. It can also help to illuminate differences in the perception of similar events across different actors.

Within the context of this research it is impossible to ignore the potential contributions of qualitative methods in identifying important questions, in building the capacity to conduct and replicate research, and in constructing useful theories.

The value of qualitative methods should not be underestimated as one value is its ability to deal with unforeseen events, which tend to occur in everyday lived experiences, however, the contributions of qualitative research will not be maximised unless the methods are applied with rigor as well as creativity.

3.6 The Methodology: why Phenomenology?

Phenomenology is rooted in the philosophical tradition developed by Husserl (1859-1938) and Heidegger (1881-1976) and can refer to a philosophy, a research method or an approach (Dowling 2004). Within his study is an approach that will analyses the life experiences of people with schizophrenia and places emphasis on the description of the human experience. Husserl developed descriptive phenomenology as a philosophical method for investigation structures of consciousness. Hence this study encapsulates a phenomenological approach to appreciating the meanings humans attach to their lives and utilises a research methodology consistent with this.

This puts a patient's perspective at the forefront of attention. It has to be questioned as to whether quantitative methods are adequate as an approach to researching human life experiences or lived experiences, which forms the basis of nursing practice. Oiler (1982), Omery (1983) Benner (1985) and Cohen (1987) question the use of these quantitative methods when trying to understand the person as an individual, and whether those quantitative methods could describe human experience in its entirety.

Diekelmann, Allen & Tanner (1989) put forward the notion that many methods have been used in phenomenological research, and that generally, inductive or qualitative methods involve transcribing material (usually interview transcripts), coding data into themes, and drawing conclusions regarding the phenomena based on these themes.

It is necessary for researchers to seek methods that fit with the philosophy and methodology of their research question and to choose methods congruent with the research topic and assumptions, hence the use of phenomenology within this research.

Pure phenomenology was concerned with real contents of experience rather than real existence (i.e. the world for the person rather than the objective world). Phenomenology has its origins in interactionism, thus a key idea in interactionism is that meanings are interpretations as Goffman would suggest. They are the product of practical concerns with practical problems that people encounter in everyday life. In interactionism, people are social actors and their interactions are the basis of all social life and all ideas have meanings which are located in experiential consequences. People define objects and their context, identify courses of action, types of conduct, imagine the consequences of their choices of conduct or action and select a course of action. George Herbert Mead focused on the social context of the shaping of choices and believed that the concept of self changes through interactions. Mead believed that people think about and imagine how they look to others, imagine how others judge them, have an emotional response to this imagined judgement, and in this way monitor themselves. Mental health clients display patterns like this. There are internal processes, where people define themselves, and external processes where people understand their social positions. In this way identity is created by internal and external processes (Smith 1998).

According to Osborne (1994) "Phenomenological methods attempt to explore conscious experience directly through a specialized form of introspection rather than inferentially through overt observation. Exploration of the inner world of experience by phenomenology enables researchers to reclaim that part of human being that has been so long neglected due to the prevailing view that human science must be natural science"

The focus of phenomenological research is the individual's experience of the phenomenon and generalization to others through empathic generalizability, in contrast ethnographic research focuses on the experience of the group through abstraction of a shared experience. Phenomenology can be applied across groups; however, its primary focus is the individual and the illumination of a specific phenomenon, such as their lived experiences.

3.7 Life experiences through a phenomenological approach

As the study examines the lived experiences of schizophrenic patients, it is imperative that a method is used which provides understanding of the person's reality and experiences. It is also essential that it values the individuals by embracing a holistic approach to the person; hence we can say that phenomenology is participant centred.

The aim of this study was to gain a greater understanding of the meaning and experience of how people with schizophrenia lived their lives. Phenomenology is the most appropriate methodology for exploring this research aim and question. People evaluate their lives, their responses to situations and other people's responses to them. There are events or phenomena, and meanings are given by individuals to these phenomena. People have perceptions of physical and mental phenomena and they reflect on these, thus phenomenology captures these reflections. This methodology captures the process of constructions of meanings and interpretations. Within this study you can examine the processes whereby people's constructions of reality are arrived at. Different people experience the same phenomena in different ways and attach different meanings and interpretations to these. This methodology highlights these different meanings and interpretations, using constant comparison.

Qualitative research examines life experiences (i.e. the lived experience) in an effort to understand and give them meaning. This usually is done by systematically collecting and analysing narrative materials using methods that ensure credibility of both the data and the results. Benner (1994) describes phenomenology as one of many types of qualitative research that examines the lived experiences of humans. Phenomenological researchers hope to gain understanding of the essential 'truths' (i.e. fundamental nature) of the lived experience.

Robson (2002) describes phenomenological research as focussing on the subjective experiences of the individuals studied, and asks what their experiences are like. How can one understand and describe what happens to them from their own point of view? Phenomenology is an attempt to understand a particular phenomenon and, as such, will be utilised to explore patients' lived experiences.

The term phenomenology often is used without a clear understanding of its meaning. Phenomenology, according to Hallett (1995) has been described as a philosophy, methodology, and method, whilst Koch (1995) furthering confusion, adds that the term phenomenology has been used interchangeably with the term hermeneutics (i.e. analyses of the written word).

Walters (1995) cited in Byrne (2001) mentions that phenomenologists believe that knowledge and understanding are embedded in our everyday world, and it could be interpreted that they do not believe knowledge can be quantified or reduced to numbers or statistics, furthermore phenomenologists believe that truth and understanding of life can emerge from people's life experiences. Byrne (2001) has suggested that "although phenomenologists share this belief, they have developed more than one approach to gain understanding of human knowledge".

Spiegelberg (1982) advocates the use of phenomenology when mentioning that many early philosophers however, found the scientific method too reductionist, objective, and mechanistic; therefore, they advanced phenomenology as a preferred method to discover the meaning of life experiences as is the case within this study.

Goffman (1961) indicated that any group of persons can develop a life of their own that becomes meaningful, reasonable and normal once you get close to it, hence it is important that we seek to identify what patients actually know and understand by trying to investigate lived experiences from their perspective.

Bowling (1997) asserts that social facts are characterised and recognised by their meaningfulness to people. The aim of phenomenology is to discover these social meanings. As Goffman has described all human action is a response to interaction with others and the meaning of this to the individual. The research setting in phenomenology is natural, unmanipulated, interactive and jointly participative by researcher and respondent. Smith (1998 p.164) maintains that in phenomenology we explore the taken for granted assumptions of social research and, by describing the experience, we can create an object of analysis (e.g. the lives of people).

A phenomenological approach within this study is important due to bringing to the fore deep issues for service users which may not always be comfortable for prescribers or fund holders as this ensures that they have a voice that may not have been heard previously.

Green & Britten (1998) argue that qualitative research has the potential to contribute to the 'evidence base' of medicine because it can answer questions that experimental methods cannot address, such as medication issues for patients and the lived experiences on a daily basis.

Questions invariably arise about the sample size, whereas large samples are used in quantitative research in order to formulate statements about the phenomena under study (nomothetic), the author is concerned with individual experiences in depth of specific individuals (ideographic) in order to map out their understanding and experiences of the phenomena.

Phenomenology highlights the active role that people with schizophrenia play in their socially constructed world. It offers deep insight into experiences and the significance and meaning of these, particularly the social, personal and moral dimensions of living with schizophrenia. This methodology focuses on issues that participants identify and it is good for examining issues and identifying problems that arise as people live their lives on a daily basis.

Finally there remains a pragmatic view that the 'usefulness' of qualitative findings are of value at practise and policy level, individuals are often more sensitive to patients views following this type of research.

The usefulness lies in the potential to alert practitioners to patient's perspectives and how they affect health behaviour, at policy level, the potential to provide evidence for population needs, the development of new and appropriate policy and evidence on how to implement policy with health care staff. Thus within this section of the study it is vitally important that a phenomenological approach is adopted.

3.8 Approaches to Phenomenology

According to Osborne (1994) phenomenology has its roots in the work of Husserl (1977) and has been influential in fields such as nursing and the health sciences (Nieswiadomy 1993). It is highly relevant in answering questions about subjective experiences. A phenomenological approach allows the researcher to illustrate and evidence patients' daily experiences, and thus inform future practice and policy making. Van Manen (1979, 1997a, 2002) has suggested that phenomenology attempts to provide an understanding of the internal meanings of a person's experience in the lived world by careful description of that experience, rather than to provide causal explanations

Spiegelberg (1965) states that phenomenology illuminates the various ranges of human experiences that are possible, the context of these experiences and how these experiences may be described.

Some aspects of the qualitative methods associated with symbolic interactionism follow normative natural science practice while other qualitative methods use a mixture of natural and human science approaches to research. Giorgi (2008a) indicates 'that qualitative research methods such as phenomenology and the phenomenological aspects of ethnography, participant observation and grounded theory are based on meta theories that are associated with a human science approach to psychology.'

Within the context of this methodology the major aspect of this research is the emphasis upon discovery, description and meaning rather than the traditional natural science criteria of prediction, control and measurement. It can therefore be suggested that traditional notions of random sampling, reliability, validity, replicability etc. are not necessarily appropriate in the qualitative context, especially in relation to this study of lived experiences.

Hallett (1995) contends that methodology links a particular philosophy to the appropriate research methods and bridges philosophical notions to practical and applicable research strategies. He puts forward the notion that Husserl, for example, purported that fundamental

nature serve as the ultimate structure of consciousness. He contended that bracketing (i.e. setting aside preconceived notions) enables one to objectively describe the phenomena under study.

Heidegger acknowledged that gender, culture, history, and related life experiences prohibit an objective viewpoint yet enable people to experience shared practices and common meanings, (Spiegelberg 1995). According to Benner (1989) Heideggerian phenomenology can be defined as a way to interpret experiences of shared meanings and practices embedded in specific contexts.

This issue is a major point of division between two primary branches of phenomenology. Osborne (1994) indicates that phenomenology provides a way of exploring lived - experience or the actuality of experience, from the inside rather than from the natural science perspective of observation and measurement, which is what this study is attempting to do.

3.9 Narrative analysis

MacIntyre (1981) assumes patients are their narratives and that their sense of self and world of experiences, (including their experiences of others) are inextricably tied to the life story and the meanings generated within it. Barker (2002) suggests that the narrative focus on patients is not concerned with unravelling the causative course of their problems. Rather it aims to use the experience of a patient's journey and its associated meanings to chart the next step to be taken on the life journey. Bochner (2002), Carr (1986), and Kirby (1991) have identified that, by relating to our lives through the lens of the whole, we can create coherence and meaning in our lives.

However narrative story-telling enables a patient to give a coherent account of what has happened and currently is happening to them in light of their personal lived experience. As Bochner (2002) comments, stories should be thought of as social performances. Moreover our life narrative is reflexive; we both tell and create our reality through our stories, and these stories influence what others believe about us and the actions that are that are available to us in the future (Bruner, 1987: Robinson and Hawpe, 1986).

 These accounts are most meaningful when framed in the patient's languages this is drawn from the patient's own experiences and socio-cultural context. Barker (2002) highlights that the traditional medical model has deflected attention away from the lived experiences, interpreting these subjective accounts into their own language of medicine, thus reframing the lived experiences in some other conceptualised format. This indicates that the personal account is diminished and undervalued and reduced to the level of its apparently commonly

occurring parts. In itself this highlights the limitations of relying on the medical model within psychiatry.

An advantage of looking at the lived experiences of patients is that, by placing life narratives at centre stage, this will enable nurses to provide the necessary support to ensure patient's holistic needs are met. This also enables the patient to explore and identify what is needed to facilitate recovery and to examine the roles of professionals, family and friends within this recovery process.

Only by utilising a phenomenological approach can sufficient data be generated that will allow exploration of a patient's lived experience whilst the use of patient diaries will allow the author to develop more in depth and valid meanings to how a patient actually lives their lives every day, minute by minute.

3.10 Symbolic interactionism

It has been suggested (Osborne 1994) that symbolic interactionism expresses the unity in the way in which meaning is shaped by the environment and also how it is construed by the person. This research intends to utilise the content analysis framework of Burnard (1991), content analysis can be used quantitatively or qualitatively like most of the research methods associated with symbolic interactionism. The similarities and differences among phenomenological research methods and those influenced by symbolic interactionism are, to a large extent, the result of similarities and differences between the two meta theories upon which they are based.

The principal founder of symbolic interactionism is thought to be George Herbert Mead (1863 - 1931) who along with Herbert Blumer, founded the Chicago School of Symbolic Interactionism, and the major influences upon symbolic interactionism were philosophical pragmatism, Darwinism and behaviourism. However it would be fair to say that there major concern was with both the subjective world of the individual and the public world. This version of symbolic interactionism is similar to existential phenomenology's emphasis upon the way in which the person and his/her world co - constitute each other. Whilst there are two other significant forms of symbolic interactionism; the dramaturgy of Goffman (1959) and the ethnomethodology of Garfinkel (1967).

Existential - phenomenological research avoids the problem of primacy of person environment relations by adopting a co - constitutional stance: the subject construes the world but the world influences the way(s) in which the subject construes the world. There is no world without a subject and no subject without a world (Luijpen & Koren, 1969). Both Mead's symbolic interactionism and existential phenomenology seem to be expressing the

same basic idea; person and environment cannot be considered in isolation. Symbolic interactionism exhibits both a subjectivist focus and an environmental focus. Thus, in practice the research methods based upon this meta theory are concerned with both human subjectivity and observations of events.

3.11 Methods of data analysis

The data sources for phenomenological research are usually spoken or written accounts of personal experience and the use of diaries is a unique way of collecting data from this sample group whilst interviews are the most commonly used means of data gathering. The aim is to elicit naive descriptions of the actuality of experience as it is lived rather than to collect embellished and narrative accounts that are based upon what the participant believes is expected by the researcher, hence the use of diaries to elicit these experiences. The human science method of phenomenology acknowledges that personal descriptions of experience are attempts to interpret and communicate awareness's in a form that is meaningful to both the subject and the researcher (Giorgi, 1970 p 181). The presence of interpretation in existential phenomenology is multi - layered: the subject interprets experience, then attempts to express that experience in veridical terms, then the researcher attempts to interpret those expressions in terms of meaning structures. It is the researcher's ability to go beyond the surface characteristics of the expressive behaviours to the meaning structures that distinguishes phenomenology from natural science's observation and measurement of expressive behaviours; hence this is what is unique about this data collection in that it does not lend itself to quantitative data collection methods.

Accounts of personal experience can be treated in a variety of ways, methods of analysis range from unstructured whole impression descriptions, to systematic thematic analyses employing tabular presentations of data (e.g., Giorgi, 1975; Osborne, 1990). The researcher identifies all the themes in the protocol for each participant then sorts them into thematic clusters which are then sorted into higher order clusters as identified within Burnard's (1991) content analysis.

The majority of the data collection will be generated from daily diaries and a narrative accounts of their lives hence the use of a thematic content analysis (adapted from Burnard, 1991).

The method of data analysis very much depends upon the data collected as the use of patient diaries will generate much rich and detailed data which will require analysis, again the use of content analysis will be adapted in this case.

The method adopted is one that was developed out of the work described on grounded theory literature (Glaser & Strauss 1967); the literature on content analysis (Babbie 1979; Couchman & Dawson 1990; Fox 1982) and out of other sources concerned with the analysis of qualitative data (Bryman 1988; Field & Morse 1985). This method has been tested, has a high reliability and has been used in previous qualitative studies (Morrall, 1998).

Burnard (1991) states that the aim of the analysis is to produce a detailed and systematic recording of the themes and issues addressed in the interviews and link the themes and interviews together under a reasonably exhaustive category system.

A full detailed explanation of the content analysis can be found in the methodology in chapter three

3.12 Methods of data collection

3.13 Diary methods

A diary is a research tool that requires respondents to make regular records of their daily activities and experiences (Marino et al. 1999; Bowling 2002). They are typically used in contexts where particular activities or events are expected to change over time, where contextual information such as the circumstances leading up to or following an event are deemed important, and where respondents are likely to experience difficulties recalling past experiences. In comparison to other uses of diary collection, lifestyle diaries have typically been used to document the behaviours of groups considered to engage in 'high-risk' activities and occupations. They have been a particularly popular method for collecting data on the sexual behaviour of commercial sex workers (Coxon et al. 1993; Fortenberry et al. 1997; Minichiello et al. 1999; Gysels et al. 2002).

Much of the literature on diaries focuses on empirical results as opposed to methodological insights. Nonetheless, it is possible to draw some valuable insights about the relative strengths and weaknesses of diaries based on this rather narrower evidence base. In many instances, simple snap shots of behaviour can be misleading. Diaries allow for the analysis of events over time (Marino et al, 1999). Diaries, like many observational methods, can also help to place events in a broader social, economic and political context.

It has been reported that, over time, participants become tired of keeping records and become less thorough in their reporting (Grosh and Glewwe 2000). While participants may not formally withdraw from a study, they may communicate their reluctance to participate by in effect dragging their feet and comply less and less with the filling in of their diary.

3.14 Data Collection: Why use Diaries and Interviews?

In order to generate sufficient detailed data the use of daily diaries which will encourage participants to record things as they perceive them and encourage them to use a narrative account of their lived experiences. These are seen as the most appropriate methods to explore the lived experiences of patients, allied with interviews and observational methods when the researcher meets with participants. Every two weeks during the daily diaries the researcher will meet with participants to discuss their lived experiences and to clarify any issues.

The use of diary techniques will also be utilised within this approach as it will enable the patients to describe in detail issues that are meaningful and relevant to them as individuals. This will also enable a vast amount of rich and valuable data to be collated.

The use of diary techniques will also be utilised within this approach as it will enable the patients to describe in detail issues that are meaningful and relevant to them as individuals. This will also enable a vast amount of rich and valuable data to be collated.

It has been suggested by Kvale (1996) that an interview was a moral endeavour, claiming that the participant's response was affected by the interview, and that the knowledge gained through the interview affects our understanding of the human experience and in this case their lived experiences. On the other hand Punch (1994) suggests that the personal interaction between researchers and participants is crucial in data gathering by keeping in mind the research focus and being clear about the role of researchers. The researchers' perceptions of collecting data in this situation can be argued as situations which are determined by personality and the nature of the interactions, whereas Hutchinson, Wilson, and Wilson (1994) identified the benefits of qualitative interviews as catharsis, self-acknowledgment, and sense of purpose, self-awareness, empowerment, healing, and providing a voice for the marginalised

The main focus of this study stems from the research carried out to meet the requirements of an Msc, which looked at the quality of life of patients and how this may be influenced by side effects of medication (Gill 2003).

It was shown that patients quality of life is greatly influenced by the side effects of their medication, and those prescribed the newer atypical antipsychotics had a marked improvement in their quality of life. The study showed that atypical neuroleptics have an impact on patient's quality of life, due to an improvement in their side-effects; furthermore this confirms previous studies, which have looked at atypical neuroleptics and their impact on quality of life;

Aitchison & Kerwin (1997) reported a 20% improvement in patients Quality of Life Scale (QLS) when treated on an atypical neuroleptic (clozapine) as opposed to a typical neuroleptic.

In this particular study many of the patients recognised their improved quality of life and there were no cases of non-compliance due to adverse side-effects,

The results of the study confirm that a patient's quality of life is enhanced by the use of atypical neuroleptics, but to give further validity to this study a recommendation was that it would be reasonable to conduct a larger more pragmatic study over a longer period of time. This study proposes to look at the lived experiences of schizophrenic patients and see how their quality of life is influenced by a number of emerging themes.

3.15 Sampling

Purposive sampling is used within phenomenological research and will be adopted in this data collection; the phenomenological researcher thus seeks out those who have experienced the phenomenon in question (i.e. lived experiences) and who can communicate their experiences. Such persons do not necessarily have to be verbally fluent, and phenomenological research is usually more constrained in terms of numbers of participants.

The aim of phenomenological interviewing is to get as close to the pre reflective experience of the person as possible by making the interview process minimally intrusive and allowing the individual's experience to present itself as spontaneously as possible. An invitation to talk about the experience of the phenomenon in question may be all the structure that is required. The approach to interviewing in phenomenological research is usually open - ended and if structure is used it is minimal as is the case within this data collection. Within this study it is hoped that using phenomenological interviews it will emphasize to the subjects that they are to recount their experiences as they happened and not worry about what they think the researcher might want.

Another important factor in establishing a facilitative climate for the data collection within each interview is the rapport between researcher and the subject, it could be suggested that in phenomenological research, participants are often referred to as co - researchers because they are always volunteers who have a personal interest in illuminating the phenomenon in question. If they are not interested in exploring their own experience then they are unlikely to provide illuminating data.

Dramaturgical interviewing is based upon the metaphor of the stage (Berg, 1989) and Goffman's (1959) view that people engage in impression management as they present themselves to others.

3.16 Reflexivity

According to Nightingale & Cromby (1999); reflexivity can be defined as awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining outside of ones subject matter while conducting research.

Within this phenomenological methodology the researcher has immersed himself in the data and has tried to uncover commonalities and differences and contexts (Cohen and Manion 1994, Benner 1994). Bracketing (Hycner 1985, Benner 1994, Burns and Grove 2001), which means refraining from judgment, suspending ones beliefs and interpretations of events (Hycner 1985) has been attempted.

Smith (1998 p.164) highlights bracketing, meaning suspending our beliefs and abstaining from making judgments about whether the objective world exists or not (Smith 1998 p.164). It has been suggested (Wall et al 2004) that successful bracketing leads to a presentation of a phenomenon from a participant, in a clear unaltered manner, exactly as the participant describes it, and it is a true representation of what has been described.

It is important that the researcher identified any factors that would have influenced situations, and provides evidence of critical analysis on the extent to which bracketing was achieved. The researcher has to ask if his own ideas intruded into the interview. One of the advantages of the method used was that the participants had ownership of the diaries within their own home. The experience of the author was paramount in developing relationships with the participants, it was important to have them feel at ease and be comfortable with me hence the experienced gained as a practitioner was valuable in this situation.

It was important to reflect on my behaviour and actions when visiting participants and to see if any amendments to the process needed to be made. After each visit I was able to identify what new learning had taken place as a result of each new situation or interview. It followed for example that as a result of conducting interviews that the researcher needed to use fewer questions and allow the participant to talk about their diaries as they wished and to follow their conversation. As the research progressed I was able to attend interviews with no pre conceived ideas of what I wanted to find or discuss thus allowing the participants to take the conversation whichever way they wanted, again this enabled them to feel more at ease and relaxed, it was their diary and their lived experiences. The ability to show some humility and sincerity in a person's home was vital in order to bring out the best in the participants.

I was very aware that I went into participants homes as a researcher but because of my experience as a mental health nurse I often fell into the role of a nurse as this ensured I came across as genuine, honest and very open, which I believe resulted in gaining a more rich and valid set of data.

The author is aware that because of his mental health background there will be occasions when he will make assumptions about what the participants are trying to confer to him. It is the ability to acknowledge this and reflect upon the authors influence upon the process that will enhance the validity of the research.

The ability to shift between the role of practitioner and researcher maybe adopted within the research process. However this should not present a problem as long as the author is able to reflect upon feelings about the informants; second thoughts about what their remarks meant; doubts about data quality; new hypotheses and ideas; cross referencing to and clarifying of previous events (Miles & Huberman 1994).

3.17 Reactivity

There are a number of specific threats to qualitative research validity within this study which include reactivity (Maxwell, 1992) researcher bias, and respondent bias. Reactivity refers to the way in which the author's presence may interfere in some way with the setting which forms the focus of the study, and in particular with the behaviour of the patients involved.

Reactivity is the effect of research on the setting or the individual being researched (Maxwell, 1992).Respondent bias can take various forms, ranging from obstructiveness and withholding information, e.g. when the researcher is seen as a threat, or when the patient gives the answers that he thinks the author wants.

An important goal is to understand how the author as a clinician may be influencing the patient's participation during the interview process and how such influence may affect the validity of the research findings (Maxwell, 1992). Asking open-ended, non-leading questions will serve to reduce undue influence of the author's perspective on the patient's response.

Chapter 4

4.0 Research Method

In this chapter I will give a detailed description of the way the study was carried out, including the seeking and gaining of ethical permission. It will give a description of how participants filled in their diaries and the problems faced by individuals. There will also be a discussion of how consent was sought and approved and the rationale for the methods adopted. There will be a discussion about how the participants were recruited and the difficulties faced due to this being a difficult to reach group. There will be a review of the pilot study and a discussion of amendments to the process. A review of the data analysis will follow and a discussion of the credibility of the research data gathered in context with the chosen methodology.

4.1Methodology and setting.

The aim of the research was to look at the lived experiences of people with a diagnosis of schizophrenia (according to the criteria laid down in DSM-IV-R.) prescribed atypical neuroleptic medication; and to investigate how it impacted on their social well-being and how they interacted on a daily basis.

This method draws on the experiences of using diaries for research into the lives of people with schizophrenia. The research involved nineteen individuals (N=19) with schizophrenia keeping a diary for around one month about their experiences of their everyday lives and the difference they believed it made to their own, and other peoples' lives. In conjunction with the diary were two intensive interviews at the mid and end point to clarify and validate what had been written in their diary. These interviews also gave participants and opportunity to express freely what they had encountered during the process.

I have chosen to use diaries to collect data for this study for a number of reasons. First, methodologically, it seemed the most appropriate method for gaining rich insights into a person's inner thoughts and feelings about their daily lives. Furthermore it is relatively unobtrusive, as people can record information in their own time and at their own pace; plus it puts the person keeping the diary (as opposed to the researcher) in control.

This was especially important, as the researcher did not want the data collection method to become an additional burden to people who were already dealing with a serious disability diaries encourage participants to record thoughts and feelings as and when they occur and wherever they feel most comfortable; plus it could help to minimise 'respondent burden'

traditionally associated with interview based studies involving people with schizophrenia (Cottrell and Schulz, 1993, p. 209).

The traditional diary method involves research participants keeping a written diary, however this excludes people who cannot write, and may not appeal to people who think visually, it is therefore recommended that researchers adapt the method and make it 'bespoke' for their study (Kenten, 2010). In thinking about some of the modifications made to how the diaries were completed the researcher took into account the fact that a person's language skills were likely to be impaired to some degree by the schizophrenia, therefore to this extent the inclusion of interviews allowed some validation of people's experiences, whilst the inclusion of drawings and paintings was also encouraged.

At a very early stage it was decided not to include anyone whose first language was not English and this was discussed at the local ethics panel. The rationale for this included the practical cost of interpreting, translating and ensuring that what was written was what was translated. The cost and time of ensuring an interpreter could be available who was impartial was also taken into account as was the aspect of being allowed into another's persons home who may not feel comfortable with someone from a different cultural background.

An advantage of this study was that participants were interviewed at their home following a discussion to a suitable date and time. The participants owned the method in many contexts as they completed their diaries in their own home, whenever they felt comfortable and when it was most suited to them. Interviews were conducted when they had time, and when they were able to meet the researcher, thus ensuring that they had control over the setting, and in many ways this encouraged a more interactive and relaxing setting. If the participants had been asked to attend a day setting or a hospital setting, then the researcher contends that some may not have turned up and that the results may have been negatively influenced due to their previous experiences. For example having been a 'patient' within that setting may cause them to adapt in some way to their previous role as a patient and not be as open and free with their responses.

Everyone involved in the study was provided with a 'diary-keeping pack' which included an A5 notepad, pen, contact information, personal copy of consent forms, written instructions about what to record in their diary.

There were several advantages of using diaries, the main one, which has been allured to above is that it allowed people to be in control of the pace and means of data collection. However one well-known problem with diary method is 'respondent fatigue' – having to keep a regular record of one's actions over a specified period of time can be tiring for anyone, but for someone with schizophrenia it can be particularly demanding.

The method utilised for this study has the potential to be used much more widely with this group and one of the key features and advantages of this method is that unlike interviews, the diarist, rather than the researcher, is ultimately in control of how and when data are collected. As long as people are happy and able to record their thoughts and feelings on a regular basis, and are informed at the outset that the process may be tiring and frustrating at times.

Finally one could argue that the diary method has the potential to be used much more broadly in relation to any group of people for whom communication can be an issue. This is not least because it offers another way for individuals (and their families) to tell service providers about the quality of care – e.g. a spoken account or image might be more powerful than a written description, as can be see with the images in the findings in chapter 5.

4.2 Diaries

The most accepted and appropriate methods to gather data for phenomenological research are spoken or written accounts of personal experience and the use of diaries is a unique way of collecting data from this sample group whilst interviews are the most commonly used means of data gathering.

Hence the overall aim of this study is to elicit simple descriptions of the realness of experience as it is lived rather than to collect exaggerated accounts that are based upon what the participant believes is expected by the researcher, hence the use of diaries to gather these experiences.

The use of diaries has been adopted due to their successful work as a data collection tool in many other different fields of research; two more common areas include nutrition and sleep research. Dietary or nutrition diaries have classically been used to monitor the dietary intake of particular groups such as infants (Taylor et al. 2004), school children (Rush et al. 1988a,b; Andersen et al. 2004), adolescent girls (Striegel-Moore et al. 2004) and pregnant women (Buhling et al. 2004. Wiseman et al (2005) indicate that many of these studies have focused on particular medical conditions such as diabetes (Reynolds and Anderson 2004), binge eating (Freeman and Gil 2004) and bulimia nervosa (Alpers and Tushcen-Caffier 2004).

However lifestyle diaries have typically been used to document the behaviours of groups considered to engage in 'high-risk' activities and occupations, whilst Stopka et al (2004) indicates that diaries have also been used to understand drug-user risk behaviours such as the activities related to syringe acquisition, use and discard. Other uses of diaries include

monitoring patterns of physical activity (Henry et al. 2004) and the frequency of injury events (Morrongiello et al.2004).

Health-related behaviours including medication adherence (Garber et al. 2004) have also utilised diaries whilst specific health conditions such as cystic fibrosis (Finkelstrosis et al. 1992), hormonal patterns (Landgren et al. 2004), chronic mental health problems (Delespaul and de Vries 1987) and pain-stress levels (Gil et al. 2004) have also used diaries in their data collection.

 Wiseman et al (2005) indicate that a lot of literature on diaries as a data collection method has focused on empirical results as opposed to the methodological insights that may be found. However it is possible to draw some valuable insights about the relative strengths and weaknesses of diaries, despite a rather narrow evidence base. They go on to suggest that in many instances, simple snap shots of behaviour can be misleading. Marino et al (1999) states that diaries allow for the analysis of events over time and that one of the benefits of keeping diaries is that they can also help to place events in broader social, economic and political context.

It has been suggested (Verbrugge 1980; Marino et al. 1999)   that diaries can be perceived as retrospective in the sense that events and behaviours are recalled and reconstructed with the aid of a diary, but they are often prospective insofar as events are recorded as they occur or close to that time.

One of the issues that the researcher needed to be aware of was that of tiredness. Verbrugge (1980), Wheeler and Reis (1991) have described tiredness as a form of conditioning effect whereby, as the diary period lengthens, participants become tired of keeping records and may become less thorough in their reporting. Furthermore it has been indicated that respondents may also be left to their own devices in terms of completing the diary. In these situations, missing or unclear data may be difficult to resolve (Verbrugge 1980; Marino et al. 1999.Grosh and Glewwe (2000) have reported that over time, participants become tired of keeping records and become less thorough in their reporting, a concern for the researcher with people having a diagnosis if schizophrenia. Furthermore while participants may not formally withdraw from a study, they may communicate their reluctance to participate by in effect dragging their feet and comply less and less with the filling in of their diary.

Grosh & Glewwe (2000) also suggest that the length of data collection for a diary should not exceed a month; this concurs with Coxon et al (1993) who suggest that diaries generally should not cover a period of over 1 month, hence the rationale for conducting this study over a month. In order to generate sufficient detailed data the use of daily diaries which will encourage participants to record things as they perceive them and encourage them to use a narrative account of their lived experiences. These are seen as the most appropriate methods

to explore the lived experiences of patients, allied with interviews and observational methods when the researcher meets with participants. Every two weeks during the completion of the daily diaries the researcher will meet with participants to discuss their lived experiences and to clarify any issues which may have arisen.

It is also pertinent to note that this type of data collection enables the researcher to recognise and record any subtle verbal or non-verbal cues which accompany this interaction. It can be suggested that this type of data collection enables the researcher to record in as much detail as possible the events, the actions and behaviours of all participants involved in the study.

It has been suggested by Marino et al (1999) and Bowling (2002) that a diary is a research tool that requires respondents to make regular records of their daily activities and experiences. Furthermore Bowling (2002) goes on to state that they are typically used in situations where particular activities or events are expected to change over time. Importantly Bowling states that they are utilised where respondents are likely to experience difficulties recalling past experiences. However as Bowling (2002) suggests diaries tend to be overlooked as a method of data collection and she goes on to state that they are often seen as the method you use when 'there is no other method available'.

In order to generate sufficient and relevant data each participant was given detailed instructions on how to fill in their diary which included the following salient points (adapted from Alaszewski (2006, p66-83)

- I am interested in your account of things that you do day by day and how you feel about them.
- Please remember that this is your diary and I am interested in what you do, how you feel and what your thoughts are. If you are unsure about including something, please do, I would rather have too much information than too little.
- Please don't worry about spelling, grammar or 'best' handwriting, but do try to write as clearly as you can.
- Try to fill in the diary each day; we can discuss the best time for you when we meet. If you cannot make an entry for a particular day, then you can fill it in the following day. Try not to fill in the diary more than one day after the entry was due. For example, don't try to fill in Wednesday's entry on a Friday.
- Please try to make a note of the date for each entry in your diary.
- Try and write a paragraph about what you did each day and explain your thoughts on events. For example, you might put
  - "What I did today was…",
  - "How I felt today was…",
  - "My medication today caused me to feel…"

- o "People I met today were …"
- o "Today I felt good because…"
- o "My plans today include …"

It was also explained that the principal researcher would arrange to meet the participants after 2 weeks and again after 4 weeks. This was to discuss in more detail what had been written and to discuss any concerns that participants may have.

4.3 Interviews

During the course of the study participants kept a diary for four weeks, during that time at a two week and the end point an interview took place to clarify any issues that arose during the filling in of the diaries. Since a qualitative method had been utilised and a sociological theory relating to how people interact socially hence the methods adopted within this study. Semi-structured interviews were conducted and a schedule developed to enable the most efficient collection of data within the time frame. The rational for using semi-structured interviews is that it will allow the researcher to develop a keen understanding of what has been written within each participant's diary.

The inclusion of an initial set of open-ended questions was to enable the researcher to follow relevant topics that may have arisen from the diaries which would allow an opportunity for identifying new ways of seeing and understanding the topic at hand. However as the diary was unique in that each participant was encouraged to write what they had experienced there was no guarantee that what the researcher had surmised may be in the diary was actually there.

Modifications were made to the questions following an initial pilot study involving five of the participants and subsequent questions were altered to enable a better dialogue and discussion to develop. The modifications included the appropriateness of the questions and acceptability of recording the interviews and care was taken to minimise the risk to each of the participants. During the study the researcher maintained contact via telephone and each interview was conducted in the participants own home in a quiet place so that confidentiality could be maintained.

The interviews were scheduled to be no longer than 20-30 minutes however this depended on the content of the diary and how much had been added since the last visit. On two occasions a lot of data had been added and interviews did approach 40 minutes.

Interviews were recorded and transcribed verbatim before they were checked for accuracy and any amendments were made .The typed up interviews were checked by a fellow mental health nurse and fellow researcher to ensure that what was said was what was transcribed

and any difficult words or difficult sounding phrases were altered. A sample set of transcribed diaries and interview transcripts were sent to both supervisors for scrutiny and to check what themes were emerging and to ensure credibility and dependability. A supervision meeting was then arranged to discuss findings and to ensure that we were all consistent in the emerging themes.

4.4 Sample

This study used patients/participants attending Day Hospitals, Community Mental Health Teams' and/or in the rehabilitation services who were prescribed oral atypical neuroleptic medication.

Patients were included if they had a diagnosis of schizophrenia and were only on atypical medication, patients would have also been include if they were prescribed one or more atypical neuroleptics.

The client group to be included was a complex group and potentially difficult to engage due to the nature of the illness itself, some of the effects of schizophrenia have been discussed in detail in chapter 2 such as social isolation, lack of engagement with services.

To ensure that there was a sample group within the area identified by the researcher participants were initially identified with the help of the ward pharmacist who had conducted a medication audit within the area in which the researcher worked. This enabled a detailed list to be produced of patients who were on antipsychotic medication. To confirm that they were still prescribed this medication the researcher was then able to cross reference with existing records which enabled him to confirm which patients were still on antipsychotic medication. Pharmacy keeps a complete record of drug ordering for units within the trust therefore enabling identification of trends and drug prescribing. This detailed list ensured that there was a potentially large sample group within the area identified, it is worth noting that no participants were to be recruited via this method: this was only done to ensure the study was a viable proposition.

At the same time as this explorative investigation was taking place, the researcher wrote to all the consultants within the local NHS to ask permission to include any (if they met selection criteria) of the patients under their care to be included in the study, a copy of the consent form and information leaflet was also given to the consultants, and if any requested a copy of the research proposal was also included.

The researcher would attend team meetings at various locations within the area to discuss the study and to explain who was suitable to take part in the study. A form was initially sent (appendix J) from the consultant to identify potential participants. Once permission was

given by the consultants to the researcher a telephone call or a meeting was arranged between the researcher and the care co-ordinator to discuss any potential patients that may be included in the study and how to contact them. At this point it was also noted that any patient who had to be contacted via a CPN or a day hospital, the same permission was sought from the care co-ordinator for the patient so that everyone was aware of what the study entailed, hence the attending of team meetings over a period of months. After identification of the patients to be included in the study the researcher then liaised with either the ward manager of the rehabilitation unit or the key worker for patients in the community and a visit was arranged to see the patient. The researcher arranged to meet each participant in their own homes or a place of their choice such as a local day centre where the study was discussed at length and any questions answered. Each individual was given a copy of the information leaflet (Appendix M) and a copy of the consent form (Appendix L). Once they had read and understood the nature of the study then their consent was obtained, however if anyone needed to discuss with their relatives they were allowed time to do so and another appointment was made. If people said that they would initially take part in the study and then changed their mind that was acceptable and nothing more was expected of them.

There was an initial problem of the researcher changing jobs during the study, but having written to the ethics committee he was able to include another hospital as part of his study thus enabling him to access and include a wider range of patients.

The next stage of the study was to analyse these results and write up the study in more detail, including sections on results, discussion and a conclusion of the study itself and any recommendations that could be made from the study.

Sampling in qualitative research is usually purposive rather than random, due to the rich in depth study of the particular phenomena to be studied. In this case the lived experiences of people with schizophrenia as opposed to the generalizability of quantitative research methods which would not generate the in depth data we require in this study.

The sample that has been identified for this study is 20, this will allow for any participants withdrawing from the study for any particular reason, it is hoped to have a ratio of 12 males to 8 females which corresponds to the incidence of schizophrenia as discussed previously in the literature review. The sample that was generated would provide sufficient data through 20 diaries and 40 interviews, however if the researcher felt that saturation point had been reached where the data was repetitive or new data was not emerging then the sample would be deemed sufficient. If there was not enough data emerging then a larger sample would be sought, to ensure that the themes and lived experiences were explored fully. However due to

the rigorous methodology employed by the use of diaries and interviews the sample was deemed to be sufficient.

Each patient was asked to complete a diary of their daily lives over a period of four weeks in order to gain deeper meanings of their lived experiences.

A timescale for the participants diary completion can be seen in appendix two, the flexibility of this is such that it enables the researcher to analyse each completed diary over longer period, rather than have a huge amount of data to analyse at one time. The key to this is that A corresponds to the setting up and explaining what is required from the participants; B is when the researcher meets with each individual to clarify and explore any issues arising; whilst C is when the participants are seen at the end of the diary collection, again to clarify and explore any issues arising. The flexibility of this schedule enables the researcher to collect and analyse data on a regular basis, it also enables the researcher to complete the data collection earlier when his workload is quiet and more time is available such as in academic holiday periods.

Patients can also be include if they were prescribed one or more atypical neuroleptics

Patients will be excluded if they are on one of the acute admission wards, they do not have a diagnosis of schizophrenia.

The majority of patients will be selected from either a rehabilitation unit or based in the community and receive visits from a professional as part of a CMHT.

4.5 Pilot study

A pilot study was carried out initially on five patients to confirm and validate the design of the study; the researcher spoke to each patient and explained the rationale behind the study before giving each an information leaflet to read, a consent form was then signed if they wished to participate in the study. Initially the researcher went to each of the five with a pre-determined set of questions, however once the researcher was given the diary it became apparent that the questions would vary greatly due to the unique content of each person's diary.

Following each visit the content of each person's diary varied from person to person, hence the questions began to vary depending on the content. The researcher became aware that to discuss each person's diary it would require him to go into the participant's home with a clear and open mind. The advantage of this was that the interview along with the diary was owned by the individual, and they were free to discuss what they wanted, freely and in an honest way. The researcher also allowed the content to be developed by each individual as it was their lived experiences that were to be discussed.

The pilot study showed that the data collected was indeed very raw and unique, hence only minor alterations were made to the questions to enable a dialogue to commence.

 Once the pilot study was completed and the results analysed to confirm that the research design was appropriate then the rest of the study went ahead.

4.6 Data analysis

It is postulated that the majority of the data collection will be generated from daily diaries and a narrative account of their lives hence the use of a thematic content analysis (adapted from Burnard 1991). Permission has been sought from and given by Burnard to use his method of analysis and he confirmed that it is relevant and still in use today. This method has been tested, has a high reliability and has been used in previous qualitative studies (Morrall, 1998, Duffy 2009, Sedgewick 2010, Brorson, Plymoth, Ormon and Bolmsjo 2013) The method of data analysis very much depends upon the data collected as the use of patient diaries will generate much rich and detailed data which will require analysis, again the use of content analysis will be adapted in this case.

Accounts of personal experience can be treated in a variety of ways, methods of analysis range from unstructured whole impression descriptions, to systematic thematic analyses employing tabular presentations of data (e.g., Giorgi, 1975; Osborne, 1994).

It is postulated that the majority of the data collection will be generated from daily diaries and a narrative account of their lives hence the use of a thematic content analysis (adapted from Burnard 1991).

The method of data analysis very much depends upon the data collected as the use of patient diaries will generate much rich and detailed data which will require analysis, again the use of content analysis will be adapted in this case.

Burnard (1991) states that the aim of the analysis is to produce a detailed and systematic recording of the themes and issues addressed in the interviews and link the themes and interviews together under a reasonably exhaustive category system.

It is worth stating at this conjuncture that I had to be aware of the first potential problem with the data, which is to what degree it is reasonable and accurate to compare one patient's lived experiences with that of another.

Within the method adopted for analysis it is reasonable to accept that this is possible, and it is hoped that the skills and experience I had as a clinician and researcher will enable me to be more aware of any complications in the process.

Burnard (1991) offers a framework for organising data and is described in detail below.

The initial stage of analysis consists of making notes after each interview regarding the topics talked about in that interview allied to the content of the diaries; also as the data is collated the researcher will make notes about ways in which the data can be categorised (Field & Morse 1985). This will serve as a memory aid to the researcher and will enable him to record any themes or ideas as the data is collected that may attract his attention.

Immersion in the data allows the researcher to identify the context and 'lived world' of the participant (Burnard 1991 p.462). There was a total focus on the raw data and how each theme related to other themes. Major categories were identified (e.g. social isolation). The researcher immersed himself in the data. This meant listening to the tapes, and reading notes and transcripts repeatedly, to ensure concentrated reflection on the data. In the Burnard (1991) model, the transcripts are read in stages two, three, seven, eight, twelve and thirteen. Observations are recalled. In this immersion in the data, the researcher gained access to feelings, emphasis and nonverbal communication in addition to verbal content of interviews. Burns and Grove (2001) term this dwelling with the data and propose that there is a dynamic interaction between self and the data which leads to reflexive thought.

In stage two all transcripts were read and general themes were identified (e.g. loss of identity, labelling, stereotyping, loneliness, family and friends, coping, lack of motivation). The headings or category system should account for almost the entire interview data, this stage is known as open coding (Berg 1989), as categories are freely generated at this stage.

In stage three, open and unrestricted coding was used to identify all elements of the experience, (this included how people were looked at on public transport, how people were spoken to, how they felt etc).
 The transcripts are read again and many more codes are identified.

In stage four, higher order headings were created and the categories from the open coding are grouped together into a broader category (e.g. social isolation, stigma, confidence, quality of life and social networks).

Stage five consists of removing repetition from the categories and subheadings. In stage six, Burnard (1991) proposes that two colleagues examine the transcripts and generate category systems with three resulting lists of categories to be discussed with the aim of reducing researcher bias and enhancing validity. The researcher was unable to do this with his supervisors but achieved this by asking a fellow mental health nurse examine the categories.
 In stage seven the researcher re-reads the transcripts alongside the categories and subheadings, the aim of which is to check that the categories accurately reflect the interview transcripts, and at this stage changes can be made.

In stage eight the researcher reads each transcript, with the category and subheading list, and the coding scheme is typed up. There are computer packages that enable this to be done but

the researcher did this himself so as to remain immersed in the data. In stage nine, all items of each code are collected together or clustered (e.g.no hobbies, lack of coping,). Stage ten involves taking these cut out sections and pasting them onto sheets under the appropriate headings and subheadings.

Stage eleven involves selected participants being asked to check the category system for appropriateness, with the aim of enhancing credibility of the categorising process. This was done via telephone contact due to geographical logistics.

In stage twelve, all the cut out sections are filed together to refer to when writing up the findings. Copies of the full transcript are also read at this stage for clarification of themes, codes, categories and contexts. Tapes are listened to again. Stage thirteen involves writing up the first section, looking up examples of data filed under that section in stage ten, and linking these examples together. It is important here to remain true to the original meanings and concepts. Therefore referring back to the original complete transcripts is necessary at this stage.

In stage fourteen, now that the researcher has all the sections together the writing up process can begin, starting with the first section, the researcher will offer a commentary that links all the examples together, and this continues until all the sections are complete.

Following on from this the researcher will then decide whether to link the findings with the literature; this will enable any comparisons and contrasts to appear. The findings will then become both a presentation of the findings and a comparison of those findings with previous work.

In concluding there will always be a dilemma of what to leave out of the analysis of a transcript, it is hoped that all the data can be accounted for under a category or sub-category (Glaser & Strauss 1967), but it is acknowledged by the researcher that there will always be elements of interviews that are unusable in an analysis (Field & Morse 1985). .
The list of categories will now be looked at and grouped together in higher-order headings, this will enable the researcher reduce the number of categories by collapsing some into similar broader categories. Any repetitive or very similar headings are now removed and a final list is produced form the headings and sub headings.

4.7 Ethical issues

4.7.1 Ethical dilemma's

The nature of ethical problems in qualitative research studies is subtle and different compared to problems in quantitative research. For example, potential ethical conflicts exist in regard to how a researcher gains access to a community group and in the effects the researcher may have on participants. Punch (1994) claimed that one hardly ever hears of

ethical failures in qualitative research. However, Batchelor and Briggs (1994) claimed that the failure of researchers to address ethical issues has resulted in those researchers being ill-prepared to cope with the unpredictable nature of qualitative research. Qualitative researchers focus their research on exploring, examining, and describing people and their natural environments.

Orb, Eisenhauer, and Wynaden (2000) contend that embedded in qualitative research are the concepts of relationships and power between researchers and participants and the desire to participate in a research study depends upon a participant's willingness to share his or her experience.

Ramos (1989) has suggested that one of the dilemma's faced by nurses is one of having to balance research principles as well as the well-being of clients. It can be suggested then that in this context qualitative health research is focused on the experiences of people in relation to health and illness; however nurse researchers may find that their roles as researchers and as clinicians may be in conflict. Qualitative studies are frequently conducted in settings involving the participation of people in their everyday environments as in this study.

Therefore, suggest Orb, Eisenhauer, and Wynaden (2000) any research that includes people requires an awareness of the ethical issues that may be derived from such interactions. Ethics in health research includes appropriateness of the research design, the methodological design, and the funding sources, as well as behaviour's in reporting data.

Dresser (1998) has suggested that although ethical review boards scrutinise most nursing research proposals, the researchers are ultimately responsible for protecting the participant. Furthermore she argues that in qualitative studies, researchers rely heavily on collecting data through interviews, observations, written materials, and filmed material.

Once access to participants has been granted and the first steps of data collection are taken, researchers may experience ethical dilemmas that may not have been anticipated in the research plan (Field & Morse, 1992).

The purpose of this qualitative study is to describe a phenomenon from the participants' points of view through diary collection and interviews. The intention of the researcher is to see from their diaries what experiences they have within their daily lives and to listen to the participants in their natural environments. The researcher's interpretation of these experiences is usually described as an emic perspective (Field & Morse, 1992). The acceptance of this statement means that the researcher recognises that the participants are autonomous people who will share information willingly. A balanced research relationship will encourage disclosure, trust, and awareness of potential ethical issues.

4.7.2 Ethical method

Prior to the commencement of the study ethical approval (appendix G was sought from a local ethics committee at a nearby hospital, following this approval the study was able to begin with the data collection. Within this context approval was sought from the medical director of a local community hospital who then agreed to allow the researcher to speak to the consultants who may have had service users who matched the inclusion criteria for the study.   The participants had to meet the inclusion criteria of living in the community; they had to be on atypical antipsychotic medication and were deemed not to be acutely unwell and able to complete a diary and two taped interviews over a period of one month. Recruiting participants was a long and lengthy process, cascading information through a plethora of consultant psychiatrists attending team meetings and travelling long distances to meet the participants before assessing if they were in fact eligible to participate in the study.

Prior to commencing in the study each participant was given an information leaflet (appendix M) which they were asked to read and discuss with anyone they felt appropriate such as their spouse, carer or next of kin. Following this they were asked to give their informed consent by signing a consent form (appendix L) and then were given a diary and instructions on how to complete this for the month (appendix N) contact details of the researcher were on the information leaflet and any problems or queries the participants were encouraged to contact the principle researcher to discuss.

Approval was also sought from the local research and development centre and a copy of their permission is enclosed in appendix (I) Appointments for the mid-point and end-point interviews were then made and the participants left to carry out their daily activities and filling in their diaries.

Each participant was assured of their anonymity and confidentiality having been allocated an arbitrary number of which only the principal researcher was aware of, whilst any future publications would ensure their continued anonymity.

The authors' primary concern was that of confidentiality, each patient was given an information leaflet to read, if they then agreed to participate in the study a consent form was signed and kept separate from all other documentation, the researcher was the only person to have access to this and each patient was given an arbitrary number such as 001, 002 up to 020. The only person who could identify a patient from the number was the researcher himself, no names have been used, and any reference to a patients history has been done so with the full approval of the patients themselves.

Patients have also retained the right to withdraw at any time during the study and the researcher will respect their wish to do so also any patient that participated in the study, but

then wanted at some later stage to withdraw consent retained the right at all times for their information supplied to be destroyed. However due to the problems in recruiting patients none of those who consented actually withdrew their consent and all patients were more than happy to take part in the study.

Throughout the study the researcher has be open and honest with each participant and has answered any queries or questions that participants have had in relation to the study.

Each patient that participated in the study was invited to do so and was given information on all aspects of the study explaining what the study was attempting to achieve in a patient information leaflet.

All participants were given information on how to contact the researcher within the given timescale, but none of the patients have done so in relation to any queries, concerns or questions in relation to the study

A copy of the ethical approval is included in the appendix and also the amendment to the original to include another hospital also included are letters of approval from various consultants to carry out the study and any other relevant ethical issues.

Interviews were tape recorded and transcribed verbatim and analysed using Burnard's analysis.

Chapter 5

5.0 Results/findings & discussion

5.0.1 Participants and their sample characteristics

Nineteen participants provided data, and they were aged in the range 28-56 (median 46), with 13 males and 6 females.

The length of time of having being diagnosed with schizophrenia ranged from 6 to 40 years with the mean being 21.2 years.

Of the 19 participants only one has ever been prescribed just one antipsychotic medication, with the other 18 having been on a range of medications. At the time of the study, 9 were prescribed Clozaril, 3 Aripiprazole, 3 Amisulpride, 2 Olanzapine and 2 Quetiapine.

5.0.2 Pen portraits of the 19 participants

Participant one

This participant has had schizophrenia for 18 years, has been taking Risperidone, Olanzapine and is now taking Aripiprazole. She lives on her own with her son; she is good at art and enjoys it immensely.

Participant two

She has had schizophrenia since 1983 and is now taking Aripiprazole; she has previously been taking Chlorpromazine and depot injections. She has lived in supported housing but now lives in her own home with her husband. She would have studied music at college if it was not for her schizophrenia, and she still enjoys playing the piano.

Participant three.

A 48 year old woman living in a hostel, who has had schizophrenia for 24 years, she has been taking Haloperidol, Olanzapine, and Thioridazine and is now taking Clozaril. She has a long history of needing support and help, and now lives in a hostel and is doing things on her own and beginning to live independently. She had trouble writing the diary on a daily basis due to her poor hand writing, however was very articulate in her interviews.

Participant four

A 54 year old woman lady taking on Quetiapine who has had schizophrenia for 40 years she has been taking Thioridazine and has a long history of hospitalisation. She now lives in a hostel living independently for the first time. She was admitted to hospital for the first time aged 14 and has been resident in the hostel for the past 8 years.

Participant five

A 49 year old woman taking Clozaril who has previously been on depixol injections, and Chlorpromazine. She has had schizophrenia for 29 years, is now living in a hostel and living independently for the first time.

Participant six

A 49 year old man who has had schizophrenia for 28 years and who is now taking Olanzapine has previously been on Risperidone, and Chlorpromazine. He lives with his wife and children. Used to be very isolated, spending time alone in his room. He has a history of many hospital admissions and is now stable.

Participant seven

A 51 year old man who has had schizophrenia for 28 years, since the age of 23. He is now taking Clozaril has previously been on Amisulpride, and Chlorpromazine. He lives in sheltered housing with support.

Participant eight

A 38 year old man with schizophrenia for 18 years has been taking Clozaril for the past 11 years and has previously been taking Chlorpromazine. He is now living on his own in a flat. He describes how he was unable to do anything or go anywhere when taking his older medication, believing there were cameras following and watching his every move even when he went to the toilet. Hence he became very withdrawn and isolative. He describes two voices, one which criticised him and the other which defended him, whilst he believed there was a bug in his room.

Participant nine

A 39 year old man who has had schizophrenia for 20 years and who is taking Clozaril for the past 7 years. He describes this as his best period for some time. He has previously been taking Chlorpromazine, Haloperidol, and Risperidone, all of which has given him bad side effects. He has had several hospital admissions but now lives in a supported living environment where he has his own room.

Participant ten

A 39 year old man taking Olanzapine for the past 10 years, who has had schizophrenia for 23 years, and has been on Depixol in the past, He lives in a hostel and is very independent, and tends to take charge of group meetings he is involved with. He started taking medication at the age of 17 and has had long periods of being in hospital, including 26 weeks at one time, and he has lost count of how many admissions in all.

Participant eleven

A 59 year old man who has been taking clozaril for the past eight years and been on Modicate injections, and Chlorpromazine has had schizophrenia for 25 years, has had long periods of time spent on locked wards. He had spent long periods on a forensic ward and was only allowed anywhere with an escort. He now lives independently in a hostel and has trips into the local town on his own.

The difference in this individual's life has to be put into context, from spending his whole time on a secure unit and being escorted everywhere, he is now an independent individual who enjoys life and travelling to places on his own and is able to care for himself and describes living a normal life.

Participant twelve.

A 58 year old woman who is taking Aripiprazole, she has had schizophrenia for 30 years, and has previously been taking on Chlorpromazine, Risperidone, Olanzapine, Quetiapine. She lives in a house supplied by a housing federation.

Participant thirteen

A 43 year old man with schizophrenia for 9 years, now taking Aripiprazole and has been taking Olanzapine, now lives in hostel accommodation and is living independently. This man

was diagnosed with schizophrenia in 2003 and has spent long periods on a secure unit detained under Section 37/41 of the Mental Health Act (due to consistently setting fire to his Mother's house), which was imposed from a court. This led to him spending 3 years on a locked forensic unit. Prior to his illness he was the main carer for his elderly mother. Whilst on the older medication concerns grew about his high blood cholesterol levels and it was only these concerns about his physical health that prompted a change in his medication to Aripiprazole.

Participant fourteen

A 48 year old man, who has been taking Clozaril for last 2 years, has had schizophrenia for the past 25 years. He spent 10 years in a high security hospital and now lives in independent hospital accommodation and is hoping to get his own place soon.

Participant fifteen

A 52 year old man who has had schizophrenia for the past 11 years. He has only ever been taking Amisulpride. He lives in a flat and is independent.

Participant sixteen

A 50 year old man with schizophrenia for 18 years, he is now taking Clozaril and has been for the past year, has previously been on Aripiprazole.

Participant seventeen

A 31 year old man with an 11 year history of schizophrenia is now taking Amisulpride and has been taking Risperidone. He lives alone in a single bed-roomed flat.

Participant eighteen

A 31 year old man with a 14 year history of schizophrenia who is now taking Clozaril for the past year and is stable. He lives at home with his parents having spent a long period of time in hospitalised care settings.

<u>Participant nineteen</u>

A 47 year old man taking Quetiapine has had schizophrenia for 23 years has been on 9 other medications. He is now studying for a degree at a local University. He has struggled with relationships within his family and believes he has had most of his choices made for him in his life.

Data analysis

5.1 Introduction

This chapter presents the findings of the study in this thesis from diaries and interviews that aimed to: **Assess the Lived Experiences of People with Schizophrenia Prescribed Atypical Antipsychotic Medication.**

The study objectives were to;

- 5.2.3Establish the difference in socialising for patients on atypical antipsychotic medication and to explore how schizophrenia may have an impact upon face to face interactions.

- 5.4 Assess the nature of the relationships with health care professionals for patients on atypical antipsychotic medication and how patients' relationships with their family and social contacts affect their quality of life.

- 5.1 Assess how a patients' perceived loss of control and loss of identity has an impact on activities of daily living (e.g. eating patterns, work, sleep and play).

- 5.3, 5.4 Investigate how the mood and motivation of a person with schizophrenia may be influenced by choice of medication and how this may impact on self-esteem.

- 5.2, 5.5 Explore how the views and opinions of others may affect the daily living of patients with schizophrenia, and to look at the consequences of side effects of atypical antipsychotic medication for patients with a diagnosis of schizophrenia.

As has been discussed in the previous chapter the analysis of the data has been based within a phenomenological approach that encompasses the work of Erving Goffman. The diaries and subsequent interviews have been analysed using Burnard's (1991) content analysis, leading to five key concepts and ten themes. Throughout the discussion of the results in this chapter, direct quotations are presented in italics to show how participants view their

experiences in relation to the identified concepts and themes, and in relation to phenomenological theory.

The chapter begins by discussing the first core concept identified within participants' lived experience 'social isolation: how a loss of identity and control impacts on the self' in section 5.1. The key themes in relation to social isolation are discussed in section 5.1.1 and relates to how an individual carries out their daily activities. This concept of a loss of control and or loss of identity is prevalent throughout the chapters and is a key aspect in how people live their lives. The loss of control and loss of identity is explored in detail and how it can have an impact on the self and how individuals tend to be socially isolated. This is followed by a summary of the concept of 'social isolation: how a loss of identity and control impacts on the self. Within this section the findings are contextualized alongside existing research and relevant literature to show how the study fits into and contributes to the current body of knowledge.

Section 5.2 then explores the concept of 'stigma' as experienced by participants, and the key themes associated with this concept are discussed in sections 5.2.1 to 5.2.2 including the knowledge, public and media perceptions of stigma. The impact of labelling on individuals leading to stereotyping and deviancy and how this impacts on their everyday lives in terms of secrecy and discrimination.

Once again these themes are contextualized alongside existing and relevant literature and the concept of stigma is summarised.

Section 5.3 looks at the concept of 'confidence' as acknowledged by participants and in sections 5.3.1 to 5.3.2, key themes including motivation and self-esteem are explored in detail. How they link to coping are discussed and analysed in relation to existing and relevant published literature. A summary of the findings can then be found in section 5.3.5.

Section 5.4 address the key concept of 'quality of life' as experienced by participants and this is explored in more detail through the theme of side effects of medication and is contextualized alongside existing research and relevant literature. A summary of this concept is then presented in section 5.4.2.

The final part of this chapter looks at the concept of 'social networks' in section 5.5 and explore key themes in 5.5.1 to 5.5.3 exploring family & friends, social contacts and normality. The concept and themes are summarised in section 5.5.4 and contextualized.

Within the results chapter the following abbreviations are used:

P1 = Participant number one;

P2 = Participant number two;

P3 = Participant number three, etc. up to P19;

I1 = Interview one and I1P1 is 'participant one interview one';

I2P1 is participant one's interview 2 and I1P2 is participant 2 interview 1;

I2P2 is participant 2 interview 2 etc. up to I1P19 and I2P19;

DP1 is participant one's diary, DP2 is participant 2's diary.

5.2 Core Concept 1: Social Isolation: how a loss of identity and control impacts on the self

5.2.1 Loss of identity and loss of control

The accounts of a person's lived experiences as identified by the 19 participants enables us to establish to what degree people function within society, many of whom compare their current lives with when they were on previous medication with more debilitating side effects. Furthermore the impact of deinstitutionalisation upon individuals has led to the notion of patients being socially isolated once discharged from hospital. Not only are they socially isolated but in many cases they feel that they are not part of society and thus do not feel socially accepted, leading to a feeling of a loss of their identity. This loss of identity has a huge impact on their lives and how they actually live them, many feeling that they have no control and that they have wasted large parts of their lives.

What unfolds in this chapter is a unique insight into the world of someone with schizophrenia and how their lives have been affected by the illness, and the impact it has on them, their family and friends.

The very notion of being able to carry out 'activities of daily living' has given participants the opportunity to move away from institutionalised care and develop a sense of well-being that was not available under the old medication regime.

Independent living is now very much a viable possibility for many participants as they continue to make progress on the newer medication and as can be seen from the emerging themes. These themes have emerged from their own lived experiences and when discussed in more detail show how much each of their lives has altered. What I have tried to do within these sections is encapsulate the lives of people with schizophrenia and to look at how things have changed since they were given the opportunity to try new medications, and how their everyday lives are different in many aspects.

Participant 12 describes what many feel when carrying out simple everyday tasks and the impact of schizophrenia and how someone can lose their sense of identity:

"Even though I went shopping for food and cooked or even went for a walk, I gained no pleasure or sense of achievement out of it, I just wanted that chair to stare into space and do nothing while all the while inside, it felt like I was dying. Another area of great concern was that I was aware that I couldn't talk, hold a conversation. My social contacts were nil. I felt like I had stopped existing and had no personality likes or dislikes" DP12.

It is not difficult to see or imagine how this impacted on her lifestyles as she continues to state:

"I never joked, laughed, disagreed or felt anger. If I knew something was wrong I couldn't react. I couldn't shout or even cry or laugh" DP12

P12 continues to describe how she lost control of her life and how she was at the mercy of the psychiatrists, and explains that psychiatrists could be very 'conservative' in their views providing that you are well, as P12 comments not causing them any problems so they can keep you on the same dosage. As she remarks:

"It is easier for them because they don't want to take the risk of patients becoming ill again" DP12

P12 gives an insight into how she felt like she had no control describing the period she was on injections and how they were administered to her. P12 describes the process and how it made her feel;

"I wonder how many people were injected in this fashion every day. It must have been like a chain factory. The whole thing hardly took 5 minutes and then you were sent on your way. How I hated the whole thing…. I also found the way they were administrated degrading" DP12

P12 describes how like many others she felt that she was not in control, and links this with some of the side effects of medication stating:

"It is not surprising that people stop medication when their hair stars falling, they gain weight, periods stop and they live in a zombie like world where they are no longer the person they used to be. I am not condoning it but it is natural to want control over and regain the body you once had and the life you did have"DP12.

P12 continues in her diary to mention how she misses the activities and hobbies she used to do such as dancing and swimming and attributes this to the drugs he has been on, explaining that the drugs have limited my life so much in so many ways.

This loss of control and loss of identity continues in terms of having the ability to function in a normal way on a daily basis and to carry out simple tasks, something that is explored in more detail in the following section. In terms of a loss of identity this can be best illustrated by P1 who found it hard to look into the mirror when unwell as she felt the voices were taking her face away, this damaged her so much she removed all of the mirrors away in her home, she often felt as if part of her face was missing. To best show this she painted a picture to show me what she saw.

Image 1 Can you see all of me

She states that

"This is what I used to see of me in the mirrors when they had parts of me missing. Areas of my face would be just missing" DP1.

Participant 3(P3) is a 45 year old woman who was living in a hostel and who has had schizophrenia for 21 years, describes how after a long history of needing support and help, is now doing things on her own and beginning to live independently. Whilst on the older typical antipsychotic medication she suffered from very bad side-effects and she was unable to even make a cup of tea:

"I was frightened of falling whilst I was holding the kettle" (I1P3)

However she is now able to go out and do her own shopping, and cook her own meals a massive step for her, being able to carry out daily activities which has also helped to build up her confidence and self-esteem.

"I did my own washing, did that this morning" (I1P3)

Being able to cook is a key aspect of many people's lives as they pursue independent living, P8 concurs with this notion as he describes how he cooked a rabbit stew, and also a stir fry for his tea (DP8) something he was unable to do on his previous medication because of a lack of drive and energy (I1P8) whereas on clozaril P8 describes having more drive and is not as withdrawn as he was on previous medication. P13 also mentions how he is able to cook and care for himself with daily activities such as cleaning; again something she lacked the drive and motivation to do so previously.

P3 also describes how she neglected her hygiene whilst on haloperidol, however she now goes on to say that she is now quite pleased with herself as she is able to take better care on the clozaril,

"I feel proud of myself, I smell better and everything" (I1P3)

P5 reiterates what has been said as she talks of how she takes care of her skin now, (DP5) and keeps herself clean by having baths and showers in comparison to how she was on the older medication as she was unable to do anything for herself. P6 describes his ability to maintain a high standard of personal hygiene, is able to shave and ensure that he has clean clothes (DP6) something he was unable to do previously.

P4 also is happy that she can carry out normal activities such as washing and ironing, something she was unable to do on the older medications. (DP4), and she also talks about her enjoyment of doing things as she attends a church fair to help raise money, whilst P6 mentions how he wasn't interested in doing anything on the older medication. (I1P6) and P10 confirms that he is now able to tidy his bedroom watch television and enjoy the company of other residents (DP10).

The issue of personal hygiene is echoed by P11 who talks of having to be shaved (I2P11) and how he neglected his hygiene, whereas nowadays he is able to shave himself and keep himself clean.

In one interview P13 describes how he spent days unable to shave or wash his hair and was described as being a 'tramp' by another patient as he had been unable to wash for over a week, lacking the motivation to carry out personal hygiene. However P13 mentions how he now receives positive feedback from people he meets due to having the confidence to look after his appearance and his personal hygiene, this gives him an increase in his self-

esteem.I1P13 describes how he stopped going out as he believed that people knew he was on medication due to the side effects thus affecting his daily living in a negative way.P13 goes on to talk about how he became quieter and isolative when he was first admitted to the Forensic ward and was not as open as he used to be tending to isolate himself and conform to what the staff expected him to do.

Participant 4 (P4) a 54 year old woman taking quetiapine has had a diagnosis of schizophrenia for 40 years with a long history of hospitalisation. She now lives in a hostel, living independently for the first time and she describes herself as being dirty and unhygienic whilst on the older medication and unable to cook or clean for herself. She was also unable to go shopping because she could not read the labels on the food because of the blurred vision, and being over sedated. However this is a different picture on the atypical antipsychotic medication as she is able to go shopping for herself and can now cook herself meals. DP4 also describes how she sleeps better, and eats better whilst on atypical medication as opposed to the older typical medication.

P6 describes how he sleeps well on the newer medication and identifies having a reasonable night's sleep (DP6) something he acknowledges as being important in his remaining well, whilst on the older medication he describes how,

"He would have stayed in his bedroom with the door shut; I just stayed in my room all day and night" (DP6)

When asked how long that would have gone on for

"A week or two and my Dad was unaware of it, he wouldn't have known" (I1P6).

A simple task that P4 can now carry out is that of going to a cash machine, a task she would not have been able to do on the Stelazine. She is also now able to clean and tidy her room and do her own cooking, something that P2 readily acknowledges as a sign of the increased motivation she has which enables her to carry out daily tasks (DP2) such as cleaning, cooking and washing.

This is evidenced by P7, a 48 year old male who has had schizophrenia for 25 years, and is now on clozaril, and living in sheltered housing with support. He describes spending the day at home and talking to nobody, being very isolated and in the mood for doing nothing.

He also states that the weekends are the worst as he is on his own but feels that he copes better now on the newer medication than he did when on the older medication, he finds things to do now whereas in the past he would have become very depressed and done nothing all weekend.

He describes the impact of the isolation as thus

"I used to be depressed all of the time, but I only get depressed when something triggers it off, like isolation, days of isolation"(I1P7).

It is this isolation that stops him from doing the normal things, and he describes it as

"I end up doing nothing rather than doing something" (I1P7).

P3 concurs with this aspect of isolation as she describes how she would spend half a day sat in her room because of the medication, isolating herself whereas nowadays she has more social contacts and more of a social network (I1P3) and admits she is better on the clozaril, stating she is the best she has ever been (12P3).

P11 is a 59 year old man with a diagnosis of schizophrenia for 25 years and who has been on clozaril for the past eight years and who has previously spent long periods on a lock up ward and managed on a section 37/41(Mental Health Act Law Online) and who needed an escort wherever he went .He describes how his life has changed dramatically as he is able to go on public transport into Leeds to get his own money from the post office (DP11), a theme mirrored by P2 who travels around with her partner on public transport to local towns thus enabling her to carry out day to day activities such as shopping (DP2). P2 continues with this as she explains how she will walk into the local shops to buy books to read as she enjoys reading (DP2). P19 describes how he feels that he can now cook and take care of himself but still tends to isolate himself when things get too stressful for him or if someone is not very friendly towards him. I2P19, mentions how he keeps himself away from others in order to protect himself a bit, and goes on to say,

'I can count my friends on one hand... erm I have a handful of close friends' (I2P19)

And yet he also talks how friends have faded away due to his illness and never got back in contact with him.

P5 writes in her diary about being able to go to the hairdressers as well as visit her father which is something she was unable to do on previous medication (DP5) and is able to spend time helping to look after her elderly father.

P11 also reiterates how independent he has become by explaining that he can now shave himself (DP11) whereas previously he had to have someone do it for him because of his medication and the side effects. Furthermore his ability to use public transport on a daily basis is evidence of how much his confidence has grown and how he no longer suffers intense periods of isolation.

P11 also talks about the future in a more positive way as he identifies the need to get a flat of his own in the future (DP11), whilst a major factor in his life nowadays is going into a shop and buying his own cigarettes, a basic concept that was unheard of prior to the change onto clozaril.

In terms of social isolation many patients rely on day centres and people they have met whilst in hospital as contacts and as P12 puts it;

"The government's buzz word for mental health at the minute is integration well where I live at present there is no chance of integration if it wasn't for my day centre I'd be completely isolated" DP12.

The day centre is a tool that is used by many for support and for making contacts but one in which patients often see their Community Psychiatric Nurse (CPN), and undertake some form of therapy. However as P12 states the decision to have therapy often rest with the psychiatrist, when P12 asked for therapy with the charity MIND it was refused and she returned to speak with her CPN who continued to emphasise the need to take her medication, stating that:

"It left me totally disempowered: there was so much to come to terms with my illness, what I had done when I was ill, my treatment and what my life had become. There didn't seem to be a future and I was bordering on suicidal"DP12.

5.2.2 Summary

This section presents a summary of the findings in relation to the core concept of 'social isolation: how a loss of identity and control impacts on the self'. Existing research has reported this concept, illustrated below.

To begin to discuss the impact of schizophrenia on an individual it is worth noting that Goffman (1968, p.3) contends that the stigma associated with schizophrenia is deeply discrediting and makes the individual different from others and of a less desirable kind. Furthermore Goffman (1968 p3) identifies that the stigma associated with schizophrenia has attributes that disqualifies an individual from full social acceptance and individuals then try to hide the mark from others; thus the resulting social isolation of individuals.

Armstrong (1994) has argued that individuals lose their individual identity and people are treated more like an object than a person and there is clear evidence that this occurs with the participants in this study. As Goffman contends people who have had periods of stay in hospital are now less of a person than they took themselves to be, and that institutions limit social contact.

Furthermore Goffman (1963) talks about how people are discredited who have schizophrenia and are deemed deviant a theme that is evident in the diaries of participants. The participants (P12) describe how they felt like they had '*stopped existing and had no personality'* and how they had lost their sense of identity.

One theme to emerge is that people with schizophrenia have had their lives altered permanently and that they feel that they are defective.

This further compounds the issue identified many years ago by Goffman (1963) that if people with schizophrenia are not accepted fully into society how is it possible for them to live a 'normal' life within society.

This social isolation is linked with a loss of friends and a situation that can only be described as people not wanting to be seen with them as they become more and more socially excluded. One service user describes that he is unable to take part in '*a higher social life or any kind of social life'*. Patients are unable to make friends or keep friends

with people they had known for some time and this in itself forms part of the social exclusion.

It is clear that individuals with a diagnosis of schizophrenia have difficulties being accepted in society and the loss of identity and loss of control over their lives makes social isolation an almost inevitable consequence. Dorner (1989) and Baumann (1989) reiterate this view when they argue that by eroding a group of people from society it then becomes almost impossible to recognise them as people. The very concept of losing one's identity and dehumanising individuals recognises the impact of schizophrenia upon the lives of people and how society has taken away that identity. Barham (1992) suggests that we never hear from the patients themselves about their experiences and that according to Finzen(1996) the reactions of the social environment lends itself to social isolation, limited life chances and delayed help seeking behaviour.

5.3 Core Concept 2: Stigma: and its impact on individuals.

5.3.1 How the media and publics knowledge influences their perceptions of schizophrenia.

This section aims to look at how people's knowledge and understanding of schizophrenia impacts on their perceptions of the illness and how it can lead to labelling and stigmatising. This in turn can lead to a role development in individuals, thus resulting in secrecy and often discrimination.

The issue of a lack of knowledge can manifest itself in many diverse and complex ways and as P3 comments that her own father was ignorant which she describes when asked as a lack of knowledge of schizophrenia (I2P3), emphasized further when she states that

"I don't really think my sister understands herself about the schizophrenia" (I2P2)

Further on in the interview she then states:

"I shouldn't say it about my own sister, but she's ignorant like my dad was" (I2P2)

P3 also states that people in general are ignorant about schizophrenia and people don't understand it. (I2P3) when asked about this P3 talks of people lowering their standards and

treating you differently. A theme which is mirrored by P7 who believes people have an attitude towards someone with schizophrenia;

"You tell someone that you've been on sick because you're diagnosed as paranoid schizophrenia and they instantly shy away from you for a moment and think to themselves he's some kind of mass murderer or something you know. With the bad press in the paper it makes people think who suffer from this are kind of axe murderers and criminals and that kind of thing" (I1P7)

P7 further goes on to say that people have the wrong perception of people with mental illness and that's its wrong, having such a wrong attitude. (I1P7). P8 portrays how people in general don't understand the illness and how he doesn't like to like to be seen by the neighbours (I2P8) due to their negative perceptions of people. P12 describes how she only socialises with people who have mental illness and that when she meets new people she doesn't disclose her illness citing an example of a new walking group she joined;

"Nobody asks what the illness is so I am relieved when they ask the dreaded question 'what do you do' this question is usually the first thing people ask on meeting 'normal' people. I just can't see myself saying "I don't work, I couldn't cope with work I have schizophrenia" I am sure that would mark the end of the conversation and the end of a possible relationship. I have very few friends now, I lost most of them after my first episode, regardless of what people in the mental health field say, people do not understand and fear the label "schizophrenia" DP12

P17 talks about how he is viewed differently and gives an example of when he went for a job interview,

Researcher "and do you think that people treat you differently"

"Yeah I've even had things when I went for a job interview where I was getting on great with the interview and then, as soon as I told them I had ... didn't tell them what I had, I just said I had a mental illness, she started speaking to me completely different as if I was not very bright sort of person really... like I was stupid or something" (I1P17)

(How peoples social networks have been affected are described in more detail in 5.5)

P6 describes how his family accept the illness and because of the new medication see and treat him as normal (I1P6) whereas he acknowledges that his Dad didn't have much understanding of him (I1P6).

P12 conveys her concerns about the labelling process in her diary, mentioning how she was never given an explanation of her illness;

"I kept asking "what's wrong with me?" and the best I got was from the consultant who said "I believe you've been quite unwell, but you are getting better now" no mention schizophrenia from anybody. It took a medical certificate which was sent to my workplace to discover the awful truth. Schizophrenic I went into denial" DP12

Following on from this she explains how she feels it's an ugly word and that as soon as you mention it people cower behind the scenes, she explains she was scared of what she could do and that she was frightened of 'normal people'. The public perceptions are often influenced by the media as P12 comments,

"My bi-polar cousins do the same sort of thing but are not labelled 'Schizo' or 'Psycho' they've got a mood disorder and have people such as Stephen Fry, Spike Milligan and countless actors, singers , artists you name it these people are talented they even recruit Churchill into their clan. But the Schizo's …….well we do have John Nash…" DP12.

These perceptions influence how people are perceived and in any face to face interaction some pre conceived ideas will influence how people interact, thus resulting in an adoption of a role of a patient as this is expected by others. Hence the perceptions of others will lead to not being fully accepted within society, a concept developed by Goffman and one which is still prevalent today.

P11 identifies how he felt a bit nervous on previous medication and felt that people were watching him and that he was aware of the label attached to his illness (I2P11) and goes on to illustrate the role of his psychiatrist who reinforces his positive improvement. However P11 reiterates the negative influence of the public as he describes the difference between the medication regimes:

"I used to feel ashamed of myself" (I2P11)

Thus resulting in a negative effect upon his self-esteem. This is a view shared by P13, who writes about how he was very conscious that the public knew he was on medication as he felt like he looked like a patient (I1P13), hence he became isolative as he was quite concerned about how he was perceived by others. P13 goes on to suggest that he was very aware of the public perceptions as he found it difficult to build relationships because of the negative impression that people perceived about schizophrenia. He describes (I1P13) how people would

'Tiptoe around you a bit. .

*'*As they didn't know how to deal with the concept of schizophrenia, P13 continues to say that

'People have a negative perception of mental illness because of a lack of understanding on their behalf' (I2P13)

This idea of a negative self-concept has a huge impact on how individuals live their lives and how they interact with others, having a public prejudice can often lead to discrimination and social exclusion. This is a concept which has been identified by P2 who describes not having the confidence to sit in her own garden (I1P2) as she felt that people were looking out of their windows and thinking she's a bit eccentric sitting in the garden. P10 concurs with the above as he describes how people don't know how to react to you:

"It's because they think you have learning difficulties or that I've got something..... (I1P10)

' Further on in interview describing an incident in a local pub,

' A woman came across to me and said so you're our mad neighbour aren't you" (I1P10).

P19 continues this theme of not fitting into society as he feels that he has to be super friendly with supermarket operators because if he isn't then he feels like he has failed socially in some way (DP19).P19 goes on to describe how people talked about individuals when they left the local café and he states:

'I felt anxious and insecure. Seemed to trigger off loads of insecurities as to how I was viewed by the rest of the world, picking up on some flaws in my character' (DP19).

P19 then mentions a role that he adopts, becoming quite passive and almost a childlike role in order to be accepted more by society, (I1P19) and describes a kind of labelling that people have about you, confirming that he feels that the general public are not accepting of people with schizophrenia (I1P19).

Other people were offensive and treated individuals with mental health problems as incompetent as is highlighted in the case of P6 above. This often has an impact on a person's social network and ultimately social acceptance, for as P12 contends she doesn't have friends amongst 'normal 'people. Her friends are those who have a history of mental health problems, and that like many she finds it difficult to make conversation with people. She concludes by saying;

"like it or not, our lives are limited by the drugs and the often traumatic experiences we've gone through and we feel uncomfortable exposing ourselves to "normal" people because of the fear they won't understand and reject us"DP12

This is a notion that Goffman (1968) described about not being accepted fully into society and one in which is still relevant in society today, it is almost as if the mentally ill are being forgotten about and not being accepted into society.

P4 describes getting onto a bus and having people stare at her, thinking that she is stupid as she indicates that she felt really embarrassed when this happened (I2P3) whereas P7 describes how local children have thrown eggs and dog excrement at his windows, something which has gone on for some time, he believes they treat him differently due to his mental illness (I2P3) as they don't do it to anyone else's windows.

5.3.2 Summary: How the media and publics knowledge influences their perceptions of schizophrenia.

This section presents a summary of the findings in relation to the theme of 'How the media and publics knowledge influences their perceptions of schizophrenia.' I have broken this section down into a summary of each theme with an overall summary of stigma at the end of section. Existing research has reported this theme as illustrated below.

Goffman (1986) has argued that those with schizophrenia first and foremost feel that their illness and the stereotypes associated with it often shape peoples' perceptions of them, thus imposing an illness identity upon them. This is illustrated by P10 who gives the example of a *'woman came across to her and said so you're our mad neighbour aren't you'*. These negative attitudes (according to Weiss 1994) to people with mental illness start at playschool and endure into early adulthood, and can continue throughout a person's life (Green et al 1983, Huxley 1993). Furthermore as Knight (2003) has suggested public prejudice has led to discrimination and stigma leading to a negative self-concept, and social exclusion.

As has been identified previously (section 5.1) a person may endure a loss of identity due to their illness. Goffman (1986) argues then that this is also compounded by the perceptions and stereotypes others have of them and thus imposing an illness identity upon them.

As mentioned by participants P2, P7, P11 and P12, the media portray people with schizophrenia in a negative light; this is confirmed by the Royal College of Psychiatrists (1998) who reported that 70% of people believed that people with schizophrenia were violent and unpredictable. Furthermore Byrne (1997) suggests that people with mental

illness are frequently portrayed as victims, pathetic characters, or the deserving mad, emphasising the negative connotations associated with mental illness.

An interesting concept is put forward by Sayce (2000) who suggests that the focus should move away from the person who is stigmatised to those people or agencies causing the stigma and as Goffman (1968) suggests many peoples' knowledge of schizophrenia has been informed by studies of attitudes and beliefs. Goffman argues that the public in general has a negative picture of people with schizophrenia, deeming them to be unpredictable, aggressive, dangerous, unreasonable, of little intelligence, frightening and lacking in self-control.

P13 described how people had a lack of understanding leading to a negative perception of schizophrenia and P12 describes how schizophrenia would often end any possible relationships with what she calls the 'normals'. This view is confirmed by Angermeyer and Matschinger (1995b) who have shown that many of the general public would reject entering into any kind of social relationship with someone with schizophrenia and would not recommend anyone with schizophrenia for a job. What is clear is from the participants is that the impact of becoming a member of a stigmatised group has not been addressed and the reported media accounts of mental illness remains offensive.

5.3.3 The impact of labelling on individuals leading to stereotyping and deviancy and how this impacts on their everyday lives in terms of secrecy and discrimination.

Once a person has been labelled with schizophrenia their lives are altered forever as with this labelling comes isolation, discrimination, low self-esteem and feelings of worthlessness. The impact that this has on an individual's daily living has been identified in their diaries and interviews.

A complication in relation to this label is the issue of trust and a feeling that people with schizophrenia are not listened to, however P1 (DP1) identifies being positive and doesn't mind taking this medication (Aripiprazole)

"I don't like the doctors in X...., questions and questions I couldn't handle that then……. Dr A knew why I acted in certain ways when I told him stuff he knows which is reassuring. It took me years before I could trust him."(DP1)

P12 describes how the label that she has due to her schizophrenia impacts on what she does including going to see her GP, citing that;

"when you have mental illness then you always run the risk that they're going to say 'it's your illness' or even worse give you anti-depressants" DP12

She further states that when dealing with say workmen they also lack understanding and treat her differently describing the way she was treated by council electricians.

"They ignore me again and explain to him (support worker) what to do about it. It is an insult to my intelligence, they equate mental health problems with learning difficulties, but what do they know? DP12"

P19 describes how the label that has been bestowed upon him as been quite disabling and that people treat him differently because of this label, providing not to trust anyone. P19 does state that if he does trust someone they then tend to look at him and try and see things as symptoms and finds it very difficult to fit into a normal role within society (I2P19).

The issue of trust then enables the participant to have belief in herself and reaffirms her trust in the medical profession, thus encouraging a more positive outlook on life. P2 acknowledges the need for medication as she is aware that she 'can't live' (DP2) without them a point confirmed by her psychiatrist however as participant one remarks in her diary (DP2)

"Now I'm well I do cope with things, well I like to think I'm quite a capable person. With the medication I'm on I feel like I've got a clear head which is unusual with these types of medication."(DP2)

One of the key components within any person's life is the ability to make decisions and choices, something which P11 identifies as having been taken away from you when diagnosed with schizophrenia citing that when decisions are made about his choice of medication, (I2P11) he was not involved and had no say in his medication regime.

To elaborate on this theme P10 describes how things were never fully explained to him in relation to his medication and how he was told he would be having injections as this was the best treatment for him (I1P10) however P10 confirms that he was never given any choice from the psychiatrist and just let it happen describing himself as being disempowered (I1P10).

P10 does go on to state that on the newer medication he now has more freedom as well as having more choices in his life. (I1P10), this freedom and choice could come from how

others respond to him as a labelled person's self-concept comes from how others respond to them.

The impact that schizophrenia has on families should not be underestimated, one participant cited in Barham & Hayward (1992) confirms the continued support she receives from her family, balanced by the fact that she doesn't speak to her brother since her illness. This is a common feature amongst schizophrenia sufferers who have lost contact with siblings despite having supportive relationships with parents.

I1P1 concurs with this aspect of family as she identifies a strong bond with her mother who is supportive and yet her brother doesn't talk about the illness, participant one however does encourage her own children to speak of schizophrenia:

'I've told him to talk with other children about it, how I've been and stuff like that' (DP1).

P8 describes how he doesn't want to tell anyone but would only if it came up in conversation, preferring not to discuss his illness (I2P8) and wants his friends to treat him like they did before he became ill, and to treat him as a good friend. P19 confirms this concept by stating that he would not tell anyone he has schizophrenia as

'*They aren't going to accept it'* (I1P19) and would prefer to keep it a secret, stating that

'*Experience has taught me not to be open about it; yeah there was this thing about being off work long term as well' (I2P19).*

5.3.4 Summary: **The impact of labelling on individuals leading to stereotyping and deviancy and how this impacts on their everyday lives in terms of secrecy and discrimination**

This section presents a summary of the findings in relation to the theme of 'the impact of labelling on individuals leading to stereotyping and deviancy and how this impacts on their everyday lives in terms of secrecy and discrimination' In this section I have developed the themes of labelling and stereotyping further to incorporate how they have impacted on the participants lives and linked this to secrecy and discrimination. Existing research has reported this theme as illustrated below.

The impact of labelling an individual has far reaching consequences and links to the notion of what Goffman terms a moral career, something that is valid and relevant in today's interactions between individuals.

The impact of this labelling is highlighted by Barham and Hayward (1995) who assert that a psychiatric diagnosis (or label) creates a stigmatised life for people with a mental health diagnosis. Labelling involves individuals with a diagnosis of schizophrenia being identified as different and being assigned a lower value than others. As has been explored in section 5.1 individuals with schizophrenia have no power to prevent this external social process. As Goffman has suggested sick individuals now an act in a deviant way compared with the social norm. In the biomedical model of health the expert and health professional validates the illness status. Haralambos and Holborn 2004 confirm that this is a disempowering position for the sick individual and has an impact upon their role within society as has been shown in the previous section.

As has been evidenced by participants psychiatrists have increasingly abandoned the social view of psychiatry for a strictly medical stance. Hence this makes it more difficult to be fully integrated back into society and people with schizophrenia are still thought of as in the community and not as an integral part of the community.

P12 confirms a key effect of the illness is not wanting to talk about the illness (Barham & Hayward 1995), and as she suggests, people with schizophrenia do not want to talk about being psychiatric as others feel embarrassed and the topic itself is taboo, 'you mustn't talk about it'. This concept is confirmed by Dickerson (et al 2002) who reported that people with schizophrenia did not disclose their diagnosis because they were concerned about the negative perceptions of others.

An important consequence of stigmatisation encountered by patients with schizophrenia is that of secrecy as evidenced by P12 in her walking group. Schultz, Mathias and Angermeyer (2003) found that patients described their contact with psychiatry as *"a stain on one's reputation"* and tried to conceal it from friends and relatives due to a desire to maintain a "normal life", which they perceived as compromised due to their schizophrenia.

Haralambos et al (1993) suggest that after public labelling as deviant, the person may be rejected or excluded by others and sees himself in terms of the label and acts accordingly, furthermore Haralambos et al (1993) proposed that being labelled and defined as deviant depended on interactions between those in power, the labellers and the labelled. The status of deviant, (e.g. schizophrenic), overshadows other statuses (e.g. parent, worker). Labels are attached to the behaviour of the labelled by those in authority. The categories of deviancy which are created by those in power reflect the power structures in society (Giddens 2001).

Discrimination is defined as "being treated unfairly or denied opportunities" (ODPM 2004a: 24), and the concepts of stigma and discrimination are related as stigma leads to discrimination. The Office of the Deputy Prime Minister (2004a: 24) maintains that "stigma arises from negative stereotypes associated with the symptoms of, or diagnosis of, mental health problems. Hence although stigma is often seen as the problem of   people with mental health problems they lack the power to change the way they are seen". Discrimination is not just about how society treats its mentally ill but about the conditions in which they live, mental health budgets and the priority which we allow these services to achieve.

Hence the reality of discriminatory practices lends itself to keeping mental health problems a secret and thus social withdrawal by the person with schizophrenia, resulting in a more insular support network as has been evidenced in participant's diaries.

It could be argued then that the external processes of labelling has been carried out by health professionals who are perceived to be experts in society, and that the clinical gaze leads to labelling, and as Barham and Hayward (1991) suggest labelling can lead to social exclusion.

Thus it could be inferred that labelling is a prerequisite for the very existence of deviance that could justify stigmatisation, for as Becker (1963: 9) points out "the person with deviant behaviour is a person to whom this label has been successfully applied: deviant behaviour is behaviour that has been labelled as such by others".

Tsang et al (2003) showed that by concealing the illness, they were unable to receive the help and support they needed. This often resulted in what patients described as loneliness or social isolation.

This section aims to look at how people's knowledge and understanding of schizophrenia impacts on their perceptions of the illness and how it can lead to labelling and stigmatising. This in turn can lead to a role development in individuals, thus resulting in secrecy and often discrimination.

 The issue of a lack of knowledge can manifest itself in many diverse and complex ways and as P3 comments that her own father was ignorant which she describes when asked as a lack of knowledge of schizophrenia (I2P3), emphasized further when she states that

"I don't really think my sister understands herself about the schizophrenia" (I2P2)

Further on in the interview she then states:

"I shouldn't say it about my own sister, but she's ignorant like my dad was" (I2P2)

P3 also states that people in general are ignorant about schizophrenia and people don't understand it. (I2P3) when asked about this P3 talks of people lowering their standards and treating you differently. A theme which is mirrored by P7 who believes people have an attitude towards someone with schizophrenia;

"You tell someone that you've been on sick because you're diagnosed as paranoid schizophrenia and they instantly shy away from you for a moment and think to themselves he's some kind of mass murderer or something you know. With the bad press in the paper it makes people think who suffer from this are kind of axe murderers and criminals and that kind of thing" (I1P7)

P7 further goes on to say that people have the wrong perception of people with mental illness and that's its wrong, having such a wrong attitude. (I1P7). P8 portrays how people in general don't understand the illness and how he doesn't like to like to be seen by the neighbours (I2P8) due to their negative perceptions of people. P12 describes how she only socialises with people who have mental illness and that when she meets new people she doesn't disclose her illness citing an example of a new walking group she joined;

"Nobody asks what the illness is so I am relieved when they ask the dreaded question 'what do you do' this question is usually the first thing people ask on meeting 'normal' people. I just can't see myself saying "I don't work, I couldn't cope with work I have schizophrenia" I am sure that would mark the end of the conversation and the end of a possible relationship. I have very few friends now, I lost most of them after my first episode, regardless of what people in the mental health field say, people do not understand and fear the label "schizophrenia" DP12

P17 talks about how he is viewed differently and gives an example of when he went for a job interview,

Researcher "and do you think that people treat you differently"

"Yeah I've even had things when I went for a job interview where I was getting on great with the interview and then, as soon as I told them I had … didn't tell them what I had, I just said I had a mental illness, she started speaking to me completely different as if I was not very bright sort of person really… like I was stupid or something" (I1P17)

(How peoples social networks have been affected are described in more detail in 5.5)

P6 describes how his family accept the illness and because of the new medication see and treat him as normal (I1P6) whereas he acknowledges that his Dad didn't have much understanding of him (I1P6).

P12 conveys her concerns about the labelling process in her diary, mentioning how she was never given an explanation of her illness;

"I kept asking "what's wrong with me?" and the best I got was from the consultant who said "I believe you've been quite unwell, but you are getting better now" no mention schizophrenia from anybody. It took a medical certificate which was sent to my workplace to discover the awful truth. Schizophrenic I went into denial" DP12

Following on from this she explains how she feels it's an ugly word and that as soon as you mention it people cower behind the scenes, she explains she was scared of what she could do and that she was frightened of 'normal people'. The public perceptions are often influenced by the media as P12 comments,

"My bi-polar cousins do the same sort of thing but are not labelled 'Schizo' or 'Psycho' they've got a mood disorder and have people such as Stephen Fry, Spike Milligan and countless actors, singers , artists you name it these people are talented they even recruit Churchill into their clan. But the Schizo's …....well we do have John Nash…" DP12.

These perceptions influence how people are perceived and in any face to face interaction some pre conceived ideas will influence how people interact, thus resulting in an adoption of a role of a patient as this is expected by others. Hence the perceptions of others will lead to not being fully accepted within society, a concept developed by Goffman and one which is still prevalent today.

P11 identifies how he felt a bit nervous on previous medication and felt that people were watching him and that he was aware of the label attached to his illness (I2P11) and goes on to illustrate the role of his psychiatrist who reinforces his positive improvement. However P11 reiterates the negative influence of the public as he describes the difference between the medication regimes:

"I used to feel ashamed of myself" (I2P11)

Thus resulting in a negative effect upon his self-esteem. This is a view shared by P13, who writes about how he was very conscious that the public knew he was on medication as he felt like he looked like a patient (I1P13), hence he became isolative as he was quite

concerned about how he was perceived by others. P13 goes on to suggest that he was very aware of the public perceptions as he found it difficult to build relationships because of the negative impression that people perceived about schizophrenia. He describes (I1P13) how people would

'Tiptoe around you a bit. .

*'*As they didn't know how to deal with the concept of schizophrenia, P13 continues to say that

 'People have a negative perception of mental illness because of a lack of understanding on their behalf' (I2P13)

This idea of a negative self-concept has a huge impact on how individuals live their lives and how they interact with others, having a public prejudice can often lead to discrimination and social exclusion. This is a concept which has been identified by P2 who describes not having the confidence to sit in her own garden (I1P2) as she felt that people were looking out of their windows and thinking she's a bit eccentric sitting in the garden. P10 concurs with the above as he describes how people don't know how to react to you:

"It's because they think you have learning difficulties or that I've got something..... (I1P10)

 Further on in interview describing an incident in a local pub,

 A woman came across to me and said so you're our mad neighbour aren't you" (I1P10).

P19 continues this theme of not fitting into society as he feels that he has to be super friendly with supermarket operators because if he isn't then he feels like he has failed socially in some way (DP19).P19 goes on to describe how people talked about individuals when they left the local café and he states:

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Other people were offensive and treated individuals with mental health problems as incompetent as is highlighted in the case of P6 above. This often has an impact on a

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Goffman (1986) has argued that those with schizophrenia first and foremost feel that their illness and the stereotypes associated with it often shape peoples' perceptions of them, thus imposing an illness identity upon them. This is illustrated by P10 who gives the example of a *'woman came across to her and said so you're our mad neighbour aren't you'*. These negative attitudes (according to Weiss 1994) to people with mental illness start at playschool and endure into early adulthood, and can continue throughout a person's life (Green et al 1983, Huxley 1993). Furthermore as Knight (2003) has suggested public prejudice has led to discrimination and stigma leading to a negative self-concept, and social exclusion.

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P13 described how people had a lack of understanding leading to a negative perception of schizophrenia and P12 describes how schizophrenia would often end any possible relationships with what she calls the 'normals'. This view is confirmed by Angermeyer and Matschinger (1995b) who have shown that many of the general public would reject entering into any kind of social relationship with someone with schizophrenia and would not recommend anyone with schizophrenia for a job. What is clear is from the participants is that the impact of becoming a member of a stigmatised group has not been addressed and the reported media accounts of mental illness remains offensive.

5.3.3 The impact of labelling on individuals leading to stereotyping and deviancy and how this impacts on their everyday lives in terms of secrecy and discrimination.

Once a person has been labelled with schizophrenia their lives are altered forever as with this labelling comes isolation, discrimination, low self-esteem and feelings of worthlessness. The impact that this has on an individual's daily living has been identified in their diaries and interviews.

A complication in relation to this label is the issue of trust and a feeling that people with schizophrenia are not listened to, however P1 (DP1) identifies being positive and doesn't mind taking this medication (Aripiprazole)

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It took me years before I could trust him."(DP1)

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She further states that when dealing with say workmen they also lack understanding and treat her differently describing the way she was treated by council electricians.

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P10 does go on to state that on the newer medication he now has more freedom as well as having more choices in his life. (I1P10), this freedom and choice could come from how others respond to him as a labelled person's self-concept comes from how others respond to them.

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'*They aren't going to accept it'* (I1P19) and would prefer to keep it a secret, stating that

'*Experience has taught me not to be open about it; yeah there was this thing about being off work long term as well' (I2P19).*

5.3.4 Summary: The impact of labelling on individuals leading to stereotyping and deviancy and how this impacts on their everyday lives in terms of secrecy and discrimination

This section presents a summary of the findings in relation to the theme of 'the impact of labelling on individuals leading to stereotyping and deviancy and how this impacts on their everyday lives in terms of secrecy and discrimination' In this section I have developed the themes of labelling and stereotyping further to incorporate how they have impacted on the

participants lives and linked this to secrecy and discrimination. Existing research has reported this theme as illustrated below.

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As has been evidenced by participants psychiatrists have increasingly abandoned the social view of psychiatry for a strictly medical stance. Hence this makes it more difficult to be fully integrated back into society and people with schizophrenia are still thought of as in the community and not as an integral part of the community.

 P12 confirms a key effect of the illness is not wanting to talk about the illness (Barham & Hayward 1995), and as she suggests, people with schizophrenia do not want to talk about being psychiatric as others feel embarrassed and the topic itself is taboo, 'you mustn't talk about it'. This concept is confirmed by Dickerson (et al 2002) who reported that people with schizophrenia did not disclose their diagnosis because they were concerned about the negative perceptions of others.

An important consequence of stigmatisation encountered by patients with schizophrenia is that of secrecy as evidenced by P12 in her walking group. Schultz, Mathias and Angermeyer (2003) found that patients described their contact with psychiatry as *"a stain on one's reputation"* and tried to conceal it from friends and relatives due to a desire to maintain a "normal life", which they perceived as compromised due to their schizophrenia.

Haralambos et al (1993) suggest that after public labelling as deviant, the person may be rejected or excluded by others and sees himself in terms of the label and acts accordingly, furthermore Haralambos et al (1993) proposed that being labelled and defined as deviant depended on interactions between those in power, the labellers and the labelled. The status of deviant, (e.g. schizophrenic), overshadows other statuses (e.g. parent, worker). Labels

are attached to the behaviour of the labelled by those in authority. The categories of deviancy which are created by those in power reflect the power structures in society (Giddens 2001).

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Hence the reality of discriminatory practices lends itself to keeping mental health problems a secret and thus social withdrawal by the person with schizophrenia, resulting in a more insular support network as has been evidenced in participant's diaries.

It could be argued then that the external processes of labelling has been carried out by health professionals who are perceived to be experts in society, and that the clinical gaze leads to labelling, and as Barham and Hayward (1991) suggest labelling can lead to social exclusion.

Thus it could be inferred that labelling is a prerequisite for the very existence of deviance that could justify stigmatisation, for as Becker (1963: 9) points out "the person with deviant behaviour is a person to whom this label has been successfully applied: deviant behaviour is behaviour that has been labelled as such by others".

Tsang et al (2003) showed that by concealing the illness, they were unable to receive the help and support they needed. This often resulted in what patients described as loneliness or social isolation.

5.3.5 Summary: Core Concept 2: Stigma

The core concept of stigma has a huge impact on individuals due to the labelling placed on individuals and the wide and far reaching consequences it has on individual's lives Participants have described the negative impact of the label, the secrecy and the discrimination they face on a daily basis.

It is worth noting that Goffman (1986) conceptualised stigma as an "attribute that is deeply discrediting…" and which makes the person carrying it "…different from others and of a less desirable kind" (p.3). Goffman (1963) also defines stigma in terms of undesirable

'deeply discrediting' attributes that 'disqualify one from full social acceptance' and motivate efforts by the stigmatised individual to hide the mark when possible.

This study has shown that the public in general have a negative picture of people with schizophrenia, deeming them to be unpredictable, aggressive, dangerous, unreasonable, of little intelligence, frightening and lacking in self-control. The labels of mental disorders can have a long-lasting negative consequence on employment, quality of life, and self-esteem of patients due to stigma resulting from the labels (Wright, Gronfein & Owens, 2000).

Goffman (1968) & Giddens (2001) would contend that by accepting a secondary deviancy this then leads to a lower social status and disempowerment, this concept is similar the concept of internal stigma proposed by Scambler (2004). This may lead to a negative self-concept in people with schizophrenia. Failure to retain a positive self-concept may lead to further mental health problems and relapse.

The concept of needing to be accepted into society is confirmed by the participants in the study who identify company and communication as a fundamental prerequisite to avoid isolation and loneliness. Repper and Perkins (2003) suggest that there is a great deal of prejudice and discrimination associated with mental health problems resulting in a profoundly negative impact on individuals, both directly and indirectly resulting in social exclusion.

Manning and White (1995) reported that employers within the UK were reluctant to hire someone with mental illness though tended to be more tolerant of people with depression than of people with schizophrenia.

Despite national action to tackle stigma and discrimination there has been a reduction in tolerance in public attitudes to people with mental health problems since 1993 (ODPM 2004a),whilst Dickerson et al (2002) propose that more strategies are required to help individuals cope with stigma

In concluding it can be seen that stigma has a huge impact on people's lives and that by assigning a label to individuals the quality of life is affected and their position within society.

5.4 Core Concept 3 Confidence: how confidence can lead to motivation and enjoyment in coping with daily living.

5.4.1Motivation leading to an increase in self–esteem.

In this section I will aim to provide details of how having the confidence to do things in a 'normal' context can help an individual cope and enjoy doing daily activities. This looks at

how individuals have now gained enough motivation to make choices about their lives and are starting to enjoy the hobbies they have missed out on for so long.

When asked about having the energy to do things , P3 said she was more motivated about cleaning the flat and keeping things tidy than she had ever been, she also indicated that she now had the motivation to go out and think about playing tennis, something she had not done since she was captain of her school team. On the older medication she would have been unable to even stand on the court, let alone be able to play and as she has described earlier spent most of her days just sitting in a chair unable to move.

She describes having more interest in everyday things

"I take more notice of the news and things you know" (I1P3)

Having the confidence to do things is a concept taken for granted by many, however this is a huge part of someone's life with schizophrenia, P5 talks about having the confidence and motivation to do a part time job with a local voluntary organisation, which was what P11 has allured to. The confidence to go out and actually work is a key aspect of P13's daily life as he now feels more valued as an individual and describes how he enjoys his day (DP13), and how this makes things normal for him.

P17 described how excited he was about the prospect of writing a diary following the initial visit from the researcher "was happy with his proposal and felt excited about the proposals. Have wanted to write for weeks just not got round to doing it, and this gives me something to be constructive to do" (DP17). This motivation was evident throughout his diary as he described how he was now motivated to apply for a part time job.

Whereas DP6 mentions that he has been on a course at a day centre for the past six months and is also motivated enough to apply to do voluntary work with MIND, the course has enabled him to become more confident around people and has enabled him to develop more of a social network. P19 confirms that if it was not for the increase in confidence he would not have the motivation to do a degree at university (I1P19), and states that he has more motivation now than in the past.

P14 reiterates the benefits of becoming more confident as he describes (I2P14) how he is starting an NVQ level 2 at Local football club, but confirms that he would have been unable to do this on his older medication regime, as

"The thought of doing it would have frightened me off" (I2P13)

P8's view coincides with others as he admits that his increase in confidence has enabled him to work in the tea bar at the day centre and the benefits are that it enables him to socialise and not become isolative and withdrawn (I2P8), whilst he also contributes to group discussions, something he would not have been able to do previously. P14 describes how his self-confidence has enabled him complete his GCSE in Maths & English (DP14) whilst he confirms his desire to get a job (I1P14) after he completes an A level course.

P6 also describes working as a form of therapy (I1P6) and reiterates that he would not have had the confidence to do voluntary work if not for the olanzapine.

Researcher

"Would you have done that on the Chlorpromazine or anything?"

P6 "no, no far from it no, ……..I find it easier now, with my recovery that's part of it as well, I find it easier, I would not have done it on the Chlorpromazine , would not have done it on the older meds" (I1P6)

P3 mentions that the clozaril has made a big difference to her life, and that she now has more confidence to do things, and is motivated to carry out daily tasks that she was unable to do previously, whilst P2 comments that she has more motivation which has enabled her to communicate with people better (I1P2).

P4 states:

"I found it hard to motivate myself to do things when I was taking the trifluoperazine" (I1P4)

Whereas she now states that her confidence has improved because she has got a couple of good friends that she can go out with sometimes. P4 also went on to say:

"I am a bit more motivated, plus I look forward to going out to the café with Peter sometimes" (I1P4)

P7 describes how his confidence to do shopping and buy music gives him a lift and helps to increase his pleasure when browsing around the charity shops. P10 reiterates how having more confidence has enabled him to use public transport and has enabled him to go shopping and have a haircut (DP10). Having new found confidence enables people to use

public transport as described in the diary of P13, as he regularly uses public transport to go to his voluntary work and visit friends. This motivation also according to P13 enables him to take regular exercise and lose weight, something he wanted to do on his previous medication regime but was unable to do so.

P7 also portrays how his increased motivation helps with everyday activities of living.

"Oh yeah, I'm motivated, this morning I'm motivated to actually get washed, changed and out of the flat and down to the local city centre" (I1P7).

P11 explains how his good mood has helped him to use public transport and also make an appointment at the job centre which he attended on his own (DP11), this new found confidence highlights how much there has been a change in his life in comparison to his isolated self when locked up in the hospital where none of this would have occurred.

He further attended a second appointment at the job centre again via the use of public transport and on his own (DP11). Furthermore this increase in motivation possibly due to an increase in confidence as allowed P11 to work at a local farm (DP11) and also goes on to state that this has given him a lot of enjoyment as he spends most afternoons gardening (IP11).

Having the confidence to do new things is evidenced by P11 who describes working on a local farm which has given him a lot of confidence to meet new friends and which has increased his motivation (DP11), this has to be taken into context when comparing his many years spent on a lock up ward where he was unable to carry out the most basic of tasks.

P6 describes the value of having more confidence as it enables you to have greater self–esteem and how it has made a massive difference to his life, enabling him to do things he wouldn't have done previously citing going to the park with his family and going to the day centre:

"well going down to the day centre, I would never have done that before, and that's socializing with other people, you know going down to the day centre once a week I'd never dream of doing that"(I1P6)

For P11 this increase in self-esteem is prompted by an upsurge in confidence (I1P11), has enabled P11 to think of the future and acknowledges he is able to move forward and look forward to things he can achieve in the future.

There is a relationship between stigma social roles and self-esteem (Williams and Collins 2002) as they suggest that social processes create a negative identity which is associated with illness. Society constructs one's identity by stigmatising people, rejecting and socially excluding people. Williams and Collins (2002:302) refer to it as the "disabled self".   The social isolation of people with schizophrenia is acknowledged, and society withdraws from, and rejects people with schizophrenia and exposes them to stigma. They conclude that disability in schizophrenia is constructed by others (Williams and Collins 2002).

5.4.2 Hobbies and coping

P12 talks about how she can cope with her life or as she puts it 'what my life has become' as she mentions that it has echoes of everything from the past such as being locked up, loneliness and most of all being rejected. Her difficulty in relating how this felt led to her psychiatrist declaring her depressed whilst she explained that;

"*I wasn't depressed as such but also I couldn't combat the effects of the dreaded antipsychotic injections. At that point I was contemplating suicide, I knew I had an illness but the remedy was so awful, I couldn't live with either of these*" DP12

P12 describes how her life was altered so much not just by the illness but by the medication she was placed on and its dreadful side effects losing all interest in her hobbies. She describes how she used to be an incredible swimmer and found it hard to resist water, stating that it lost its appeal and she hardly swam at all, declaring it was too much of an effort. She even described having a bath as a chore under the injections. P12 mentions that another area of her life which has disappeared is dancing and she states that the drugs have limited my life so much in so many ways DP12.

P11 verifies that he spends a lot of time walking which enables him to cope but also because he enjoys it, something he was unable to do freely when on previous medications and because of his section 37/41, in addition to this P11 goes on to confirm that he gets more enjoyment out of walking (IP11) than he used to.

P2 now has the confidence to play and enjoy her guitar (DP2) whilst she also enjoys playing the piano which she finds relaxing (DP2) and spends time buying and reading music, something which she wanted to do at Music College before her illness took over her life.

P2 also spends time listening to music which she not only finds enjoyable but relaxing, something she was unable to do on the previous medication regimes (DP2). This talent for music has always been evident as she has always played the piano (I1P2) but has gained more enjoyment out of it on her new medication, as she often plays it till late in the mornings. P6 also talks about enjoying his music and how he finds it as a comfort (I1P6) whereas on his previous medication regime he wasn't interested in doing anything, he also spends time gardening and playing on the X-box with his son which he perceives as normalizing things. P6 also gains a great deal of pleasure out of walking his dog (DP6) something he was unable to do due to his isolation and paranoia on the previous medication.

P3 confirms that due to the increase in confidence allied with a new found motivation she would like to take up tennis again, having been captain of her school tennis team she now has the desire to play again and talks of having someone to train and play against (I2P3).

P5 has managed to embrace her new found confidence and motivation by returning to hobbies she enjoyed such as her knitting, sewing and embroidery, the increase in confidence has enabled her to set up a group within her home where she teaches other residents how to sew and embroider. (DP5), and she has also done some work at a local charity shop. (DP5). Whilst P5 also attends a dance class and a craft class as she demonstrates how she is able to be motivated and confident enough to pursue these hobbies which she has always enjoyed. (DP5) and at the same time make her own dresses and clothes (DP5). P10 confirms the improvement on his new medication citing that it allows him to be more creative thus enabling him to enjoy writing poetry and script writing (DP10). P14 also concurs with this as he confirms more enjoyment with his artwork and chess (DP14).

DP13 and DP19 describes how they both enjoys reading books and listening to music and how they are now able to relax and enjoy themselves and how this enables them to cope with life on a daily basis, and that gaining enjoyment out of these activities is something that they were unable to do previously.

P3 describes an inability to make decisions and this leads to a failure to cope; furthermore she describes the issue of mental illness as having a stigma that has been bestowed upon her by society.

The issue of coping and dealing with everyday activities of living then lends itself to an increase in confidence and motivation as evidenced by P3, who doesn't want to come off the newer medication,

"I hope he doesn't take me off the clozaril because it helps me so much, a good drug it is………… The best I've been since I left high school, since I was 16" (I1P3)

P7 describes how his increase in confidence has enabled him to get on better with people

"I've gained a bit of confidence, when I talk to people I could talk for ages about things…" (I1P7)

This confidence has enabled him to face his isolation at weekends, having more confidence has enabled him to plan ahead and occupy himself to tackle the loneliness by sorting out plans for the weekend. How people cope varies from individual to individual P10 describes how reading enables him to cope with his problems (DP10) and how it still gives him a 'buzz', this has enabled him to have a busy schedule and do important things within social services such as chair a committee for service users. (DP10).

P6 describes how he is able to cope on his own whilst his wife went away on a holiday cooking and looking after his older son:

"if I was on the older meds I would not have been able to structure the day in the same fashion because I would have remained too tired to have got up at 9.00am each day" (DP7)

This ability to cope without his major support network highlights just how much progress he has made on the newer medication as he states that he is now able to cope with life's ups and downs (I1P6) and has found completing the diary a help as he states that it has helped him focus his thoughts as he didn't realise what he did from day to day.

A common dilemma faced by many is the ability to cope with crowds as many could not face these when on the older medication, P8 talks of now being able to cope with the crowds at a rugby match (I1P8) and how he handled a friend's wedding something he readily admits he would not have done previously. (I1P8). He also succeeds with going on public transport (I1P8) and has attended a large beer festival in a local town coping with the crowds that were there. P10 identifies coping with crowds at a big football match as a step forward and that he enjoys the football immensely at weekends (DP10) and is also able to cope with public transport often taking a bus (sometimes two) to get into town (DP10).

I2P13 describes how he has gained in confidence and how this enables him to be more positive*:*

"Oh yeah I'm more positive, I think in myself I'm a lot better. You know my confidence is growing, seems to be growing every month" (I2P13).

5.4.3 Summary

The inability to carry out simple daily tasks has been discussed in earlier sections and this very concept of having the opportunity to do something is not always explored by the adoption of the medical model. Thus only by exploring the experiences of individuals are we able to gain a fuller understanding of how they have gained an increase in confidence and thus become a more motivated individual who copes with their illness. It has been suggested by Creer & Wing (1974), Lefley (1987) that it is the acute socially disturbing behaviour, which is directly related to the illness which families find most difficult to cope with.

This rejection from and by society has had a huge impact on individuals with schizophrenia and as has been seen previously people with schizophrenia are undermined by some form of impairment to humiliation and manipulation.

The stigma and experiences associated with schizophrenia can then lead to the view that their self-concept may be negatively influenced. Hence the individual is progressively redefined in a process that isolates them from groups and significant others outside the institution. This concept has been explored by Goffman in relation to secondary deviancy.

This secondary deviancy occurs when individuals with schizophrenia accept their deviancy and lower social status and feel disempowered (Goffman 1968, Giddens 2001).

 This concept is similar to the concept of internal stigma proposed by Scambler (2004). This may lead to a negative self-concept in people with schizophrenia and failure to retain a positive self-concept may lead to further mental health problems and relapse. This is an issue discussed by P12 when she is perceived by her doctor to be depressed, and not been listened to is again mentioned by P1.

The concept of labelling is enhanced by psychiatrists who tend to look for symptoms, (as in the case above with P12) thus leading to concepts of shame and anger and their reaction to

the label reaffirms the negative effect of their illness. This then confirms what Goffman has developed as it spirals into a career of mental illness.

This viewpoint is then endorsed by Porter (1990) who supports this theory as he claims that a person's morale is crushed under the weight of this labelling and thus the only option for individuals is to embark on a career of being mentally ill.

As with their loss of identity and loss of control a loss of self-esteem can have the same negative impact on an individual especially if the individuals are not given any choices in their treatment or if they are not involved in meaningful discussions.

Furthermore the issue of choices in relation to medication revolve around a complex relationship between the doctor and the patient where one 'appears' to have a superior role to the other. This relationship based on a medical model can create conflict and it can have a negative impact on an individual's confidence.

This conflict manifests itself in the simple assumption that 'patients' feel that there is insufficient opportunity to talk through problems and that some state (Barham 1992:p49) that too much importance is given to drugs.

Allied to the above is the concept of lowered self-esteem, which has a devastating effect on individuals, many of whom describe being an inferior person; however the confidence that the participants have gained in the study highlight that change and progress can be made.

Despite the lack of confidence many of the participants have experienced there is clearly a marked improvement in their lives that has given them confidence and the motivation to attend the farm, go shopping, attend dance classes and re kindle their passion for hobbies thus enabling them to cope with their everyday lives.

5.5 Core Concept 4: Quality of Life how the side effects of medication have impacted on a person's Quality of life.

5.5.1 Side effects of medication

The impact of the side effects of medication upon an individual's quality of life should not be underestimated, within this section I will explore these issues further and give a detailed account of the impact it has had on people with schizophrenia.

Iatrogenic stigmatisation starts with labelling but the use of medication which causes extrapyramidal side effects, increases the stigma as these side effects identify the person as someone with a mental illness more effectively than the original mental illness. Sartorius (2002) suggests that health professionals are not sufficiently engaged in challenging stigma

and discrimination, which are a barrier to a better quality of life for individuals with mental health problems.

The impact and severity of unpleasant side effects should not be underestimated on the impact of a person's quality of life, I1P11 mentions how the Clozaril has not only stopped the voices:

"It's stopped me hearing voices, I feel better in my head" (I2P11)

but has also made things clearer and cites an example of being able to go into Leeds on his own through the use of public transport (something he would not have contemplated previously), whereas in comparison to his life on the older medication he describes the side effects as thus;

"Making the voices worse and I felt nervous ....had the shakes" (I1P11)

P19 concurs with the side effects of medication and how it affected his daily routine, citing that he could not think straight and was often sedated, whereas now he states that the dull feeling has gone and yet the symptoms are under control without being sedated (I1P19).

P12 describes how she realised she wasn't the same person describing how her waist line expanded and how she fainted at regular intervals when she stood up, declaring it as a black hole when she got up and fainted. She further goes on to state;

"And then of course when I realised I was getting like a vegetable, increasing in weight plus the suspicion about the medication (I trusted my instincts) the meds didn't make me feel good plus I knew that the professionals often denied what they knew to be true,"DP12.

And she goes on to state

"this is what happened to me during the my first ten years as a patient, I was medicated, zombified I had no life and it was so serious that I did contemplate suicide but chose not to comply with the medication instead" DP12

This non-compliance is an issue that recurred many times with each individual, and many of the participants spent many years with what was termed the 'revolving door syndrome' constantly in and out of hospital and on huge amounts of sedative medication

Not only did the typical medication have severe side effects but the impact on an individual's quality of life was such that people talked about losing years at a time, as P12 comments

"The remedy was worse than the illness which was possibly could have been managed differently. No-one ever talked to me as a human being. Only as a patient, someone you feel sorry for but also someone who hasn't got a clue, oh I hated that!! It robs me of my humanity and of my choices." DP12

However P12 who is now on Aripiprazole has now a better quality of life as she talks about going out and about and having choices, enjoying the countryside and being able to fill in days which were previously very empty, and as she comments, on injections her life was taken up sitting in a chair unable to move staring into space, no TV or music just silence.

Having troubled voices which impacts on your life is echoed by P9 and P16 who confirmed that these voices stopped him from doing the normal everyday things that he managed to do now (I2P9) and described having 'lots of involuntary movement' and relates the over sedation as thus:

"I was like a cabbage" (I2P9)

Whilst P16 talks about *"I slept for long periods, nearly a day a t a time, I was so tired and drowsy that sometimes I didn't eat or drink" (DP16.*

This phrase has also been used to describe how they were previously by other participants P12, P15, P18 and P9 all citing that they were like a vegetable/cabbage on the older medication and how their days were spent sitting staring into space, unable to move or do anything.

The impact that voices have on individuals should not be underestimated and the distress that these voices cause, P1 a keen artist tried to explain the impact of these voices on her life and painted what she described as faces at the window

"Did artwork last night and yesterday, I know some people won't appreciate the subject matter, "faces at the window" but it's relevant to me!!!! (DP1)

Image 2 Faces at the window.

These faces at the window had some control over her life limiting her movements and stopped her from going outside making her so frightened that she stayed within the confines of her own four walls scared to go outside or even in her own garden.

A further impact of discrimination can be seen in the deficits of quality of care provided due to the inequitable distribution of resources within the health care system, patient's feel that the range of services are disadvantaged and limited to psychotropic medication.

P8 admits that his quality of life was poor on the older medication and was unable to socialise with friends, commenting that he was unable to do a quiz with his friends in a pub something he now enjoys doing. (I2P8).

P6 describes how the older medication made him very irritable and tired, wouldn't get up (I2P6) how he lost 'any get up and go' and how he would not leave the house at all (DP6), he also talks of isolating himself and refusing to come out of the house;

"I wouldn't, that was many years ago that I was on the older meds but I never came out of the house on the older meds, I was still paranoid, even on the medication, it wouldn't ease that for me…… further on in interview

But on the Olanzapine I don't have that; I'm more or less normal so to speak (I1P6).

P13 describes how he put a large amount of weight on when he was first admitted to hospital and felt that

"People could tell I was on medication" (I1P13)

And this stopped him from socialising as he tended to isolate himself as he stopped going out. He describes the impression that 'others' could tell he looked like a patient (I1P13). P13 describes how his physical health deteriorated and that he only had his medication regime changed when they discovered he had very high cholesterol levels, and so moved him onto Aripiprazole. Interestingly P13 describes how he is more compliant on this medication, and admits that on the other medication was as not compliant and that he feels much more able to carry out daily activities and socialise more. P13 states that

'*This is the best he has ever been in a long time, even before he became unwell'* (I2P13).

This is further highlighted as P3 describes how the haloperidol knocked her out so much that when she got up she was rigid and also describes the rocking of her legs as intense and how it was so bad that she rocked herself to sleep at night (I1P3) whilst being on the haloperidol often 'knocked me clean out for the day' (I2P3). A theme echoed by P10 who states that he is now more alert and able to enjoy the day as opposed to being fatigued all of the time (DP10). P3 also describes herself as being very stiff with a dry mouth that would often last for a whole day or so (I2P3), P4 shares this view talking of being 'knocked out' and being drowsy, having blurred vision and having the shakes (I1P4), this itself having a huge impact on their quality of life and the ability to function as an individual within society, as they lacked motivation to do things and P4 describes having spent most of her adult life asleep. The theme of being drowsy is echoed by P5 who comments that

"Since I have been on this new medication I have been a different lady altogether, this medication has most definitely changed my whole life…… I was spending my mornings in bed with such fatigue that I couldn't get out of bed… I spent every day in bed and I only got up for lunch and tea in my night clothes" (DP5).

This is further enhanced during the interview process as P5 comments that it's been marvellous and how she is a different woman altogether with this new medication they've

invented (I1P5), when asked for something she feels a different woman P5 replied that she could knit, could sew, and lead a normal life and not feeling like a zombie as she did on the other medication.

Further on when asked P11 felt that the depixol medication stopped him from doing things he replied:

*"I was a bit frightened to go out" (I1P11)……..*whereas on the newer atypical medication he states that *"it helps me to interact better ……….and I am able to speak my mind, it's more of me coming out"*

P2 concurs with P11 as she comments that she is really happy on her medication and it has sorted out her thoughts and now doesn't have any problems with this (I1P2) ….is much more confident and is able to go out and about on public transport and feels better now when she is out than previously. P2 also confirms that she is a lot clearer about things now and has the confidence to do more things and in many ways she can't believe it (I1P2), whilst P3 admits it is the best she has been since she was 16 (I2P3).

It is clear that P11 identifies an ability to think clearer and that has enabled him to express himself more as he acknowledges more of his own personal character coming out, and he comments (I1P11) that his lifestyle has changed for the better since he was prescribed clozaril. Furthermore he testifies that this is the best he has felt since his illness began and reiterates that he feels he would have had a better quality of life if he had been on clozaril many years earlier (I2P11).

P2 identifies some of the negative side effects which have had an effect on her life citing the producing of facial hair and the extra weight she has put on as worrying side effects (DP2) however acknowledges that she is better on these drugs than not stating:

"I felt really happy in mood today as I am well at the moment on the medication I am on" (DP2)

As a female one of the more demoralising and humiliating problems with medication is the physical side effects and as P12 describes

"The reason I kept changing medication is because of the physical side effects Olanzapine gave me incredibly sore breasts. It was both frightening and unbearable the risperidone

raised my prolactin levels to alarming levels. My psychiatrist was so conscientious that je would check my bloods and was very alarmed at the results."(DP12)

She also goes on further in her diary to describe complications and how it changed her life

"Very quickly after starting the injections my periods stopped, of course I was alarmed and mentioned it to nurses, doctors and psychiatrists but they all brushed my worries aside and said it didn't matter, there was nothing to worry about. I only found out later that this was not natural and it was due to the prolactin levels being high. And those after prolonged periods of time of not having periods you run the risk of osteoporosis, and so I realised that I was right to be worried and that all those people had lied to me all along."DP12

P11 certifies that his illness has stopped him from doing many things and cites not being employed as a huge barrier to normalizing things but due to his increased confidence and motivation he has applied to the job centre for employment, whilst at the same time he does voluntary work at Hollybush farm (I2P11), again something he confirms he would have been unable to do on previous medication regimes.

However whilst many people with a diagnosis of schizophrenia do voluntary work Tsang et al (2003) identified that employment and financial burden also had a major impact on the quality of life of patients .   Many patients have their job terminated due to their illness.

Another aspect of his increased confidence and motivation which he associates to his perceived improvement in quality of life is his ability to cook for himself, a task he was unable to carry out previously (I2P11).

P6 describes how his sex drive has altered on the medication and that it has become normal and his mood has stabilized and how he can go out of the house without any thoughts of paranoia (DP6).

P12 concludes this section by explaining the overall cost to individuals with schizrenia in relation to side effects,

"It is very sobering to see in black and white, printed in the article, that we live on average 14 years less than the rest of the population, psychiatry must improve because the drugs cause as much harm as they do good, not only by poorer quality of life but also by the physical side effects. We can't live with the illness but we can't live without the drugs either" DP12

5.5.2 Summary

As has been shown the impact on an individual's quality of life can be severe both physically and mentally leading to social isolation and withdrawal, as has been discussed in 5.2 the impact of labelling someone has a huge negative impact on individuals. The very nature of the side effects of medication has a secondary issue, that of attaching another label to individuals as some have allured to in their descriptions.

Harrison & Gill (2010) suggest that iatrogenic stigmatisation starts with labelling but the use of medication which causes extrapyramidal side effects, increases the stigma as these side effects identify the person as someone with a mental illness more effectively than the original mental illness.

As has been mentioned by P12 the fact that she was placed on medication and had no choices, and that the side effects were not explained concurs with Sartorius (2002) who suggest that suggests that health professionals are not sufficiently engaged in challenging stigma and discrimination Furthermore Sartorius contends that these aspects are more of a barrier to a better quality of life for individuals with mental health problems.

In conjunction with the previous section Schulze, Mathias and Angermeyer (2003) and Link and Phelan (2001) have indicated that there exists an imprecise nature of stigma associated with schizophrenia due to the way in which society perceives the illness. The very nature of schizophrenia has a more debilitating effect that anyone can imagine, not only do they have a label from the illness but are stigmatised due to the very medication that is prescribed to help combat schizophrenia.

This view is echoed by Wright, Gronfein and Owens (2000) who suggest that the labels of mental disorders can have a long-lasting negative consequence on employment, quality of life, and self-esteem of patients due to stigma resulting from the labels.

It can therefore be argued that the behaviours which are labelled as mental illnesses can be seen as social practice and social discourse, rather than forms of mental states (Green and Davis 1985).

Due to the unpleasant and visible side effects Hudson (1999) indicates that other people invalidate people with schizophrenia and make them feel weak, stigmatised, negatively judged and are treated differently from others. People with schizophrenia are deemed to be mad when they enter the mental health system and after entry they are perceived by others to be failures, something which society needs to address if any help is to be given to people with schizophrenia.

It has been shown that a patient's quality of life has been affected by stigma and that patients tend to adopt strategies such as secrecy and withdrawal in order to avoid negative reactions (Link et al 1989).

Lefley (1992, 1996) further suggests that when resources are given to the mental health services then the recovery of patients as well as their quality of living will be affected.

There may be discordance between providers' and patients' views in relation to their quality of life; it is possible that some providers might implicitly formulate their own judgments of quality of life, which might differ from their patients' judgments.

Greene et al (1989) suggests that concordance between providers and patients is the exception rather than the rule, and little is known about patients' values and preferences within mental health. This has been shown to be true within this study and the objective views and opinions of participants should be taken into consideration.

Two studies by Van Putten (1974) and Van Putten et al (1984) established that patients' subjective reactions to treatment were often more reliable than that of an observers as they tended to recognise the more subtle extrapyramidal side-effects. Van Putten (1974) also reported that non-compliance was significantly associated with extrapyramidal side effects especially akasthesia and he emphasised the importance of taking this into account in evaluating the clinical effectiveness of any treatment. These studies were conducted some time ago and yet the finding are still valid and applicable in society today, surely the best and most reliable source of information regarding a person's quality of life is from the individual themselves. There remains a discrepancy between rating scales and the subjective and objectives viewpoint of who is filling them in, thus not giving a true impression of a person's quality of life.

What is clear is that a more in depth view of a person's quality of life is needed which will in turn influence policy and decision makers.

5.6 Core Concept 5: Social Networks and how they have impacted on friends, family and an ability to live a 'normal 'life.

In this section I will draw together the main aspects associated with social integration or social isolation in relation to how a person's perceives their social network system. This is

important for many individuals but more so for people with schizophrenia as this may be their major source of support following a spell of hospitalisation. The impact on a person's relationships is also discussed in this section which can include personal or professional.

Service users also highlight the need for social acceptance, commenting that society accepts people who are successful; having a nice car and a nice house indicating that this deems one 'as more normal than I thought'. Thus being integrated into society and accepted is a vital component for many schizophrenic sufferers, a view shared by another of Barham & Hayward's participants who describes feeling very separate from society due to wasted years because of the schizophrenia.

5.6.1 Family & Friends

The negative connotations from being stigmatised impacts on a person's socialising and support network and can have huge impacts on the family and friends.

DP1 describes attending a family party and the anxiety about meeting the family;

"Will be seeing people I haven't seen since my illness became public knowledge last year, last time I was unwell I decided to let family and friends know, it was such a hard decision to make, to let people know about my schizophrenia. There's such a stigma attached to it!!"
(DP1)

P1 describes feeling nervous about the part due to people's perceptions about her and identifies the negative connotations associated with not feeling part of the social group whereas P2 has a supportive partner who she socializes with most days and has also spends time with her mother and brother (DP2) both of which she has a strong bond with and describes having a nice few hours chatting and laughing in garden (DP2).

P17 describes how he met a close friend from school following his illness, when his friend asked where he had been for the past 8 years. P17 explained he had had schizophrenia but was now recovering, his former friend then got up and walked away (DP17)

P2 talks of how her family have supported her through 25 years prior to moving into independent living accommodation (I1P2), however she further went on to mention how her family had a lack of understanding about her illness and were quick to contact her medical team if anything seemed untoward. Families are a huge support network as P6 indicates citing his main network as his immediate family which includes his wife and kids whilst he also mentions his brother in-law and a day centre as vital support networks. (DP6), however he does state that he has lost most of his close friends since his illness started.

P2 also goes on to mention that her family;

"They think I'm better on this medication in one sense because I am going out more like and I 'm doing more things than I was doing before" (I1P2.)

Whilst P8 places a huge amount of emphasis on the support he is given by his parents and enjoys their company spending time watching rugby with his dad and helping around the house with gardening (DP8). P13 speaks in detail how he relies on the support from his family for social contact and visits his mother and sister on regular occasions, the relationship with his mother has developed and grown over the years and is now one of a supportive role.

However there can be conflict within a family as relationships can be strained, maybe due to a lack of understanding about schizophrenia as related by P13. He describes how he doesn't trust his sister stating

"I would rather not have Jean as a trustee, issues of control, our relationship not been great and jean been in control of financial part of my life and exercised it…."(DP13)

He backs this up by talking about the issue of control and confirms it's partly due to having a lack of choice in his affairs (I1P13) and likens it to the control and lack of choice exercised by doctors when telling him what he has to do. Due to the conflicting relationship that this causes P13 states that

'I try and keep a distance from my family… it's that I just don't get much joy from them, it's too difficult, it's a thing about roles' (I1P13).

P8 also places a lot of faith in the day centre he attends for support citing that working behind the coffee bar has helped him to develop a more robust social network. P8 describes a small but close network of friends who have helped support him over the years and spends time socializing with them on a weekly basis something he was unable to do on his previous medication regime. (I1P8)

P11 who has grown in confidence and self-esteem during the course of writing his diary wrote of arranging to meet his sister in the nearby town and spent time at her house having tea, a situation which wouldn't have occurred on his previous medication regime (DP11).

Interestingly P11states that his sister is accepting of his illness and feels that people would treat him the same regardless of his illness, in comparison to this P3 talks of how her sister doesn't want to know her (I1P3) and states that she never gets out of the car and avoids her, whilst many years previously her father commented:

"I used to walk through the house you know, up and down stairs and things so my Dad said you want locking up and the keys throwing away and my sister said she's going out of her head she is" (I1P3).

P3 has accepted that the label which has been attached to her has had an impact on her life yet mentions she now feels that people need to accept someone for what is inside them and not just at face value (I1P3).

P10 admits that his main reason for coming to Leeds was to be with his father and three sisters; however that has not materialized and has little contact rationalizing this as them having busy lives having not seen one of his sisters for three years (DP10 & I2P10)

5.6.2 Social Contacts

P3 describes how she used to sit in her room for over half a day on the older medication, and comments that:

"I think it stopped me from having lots of friends, like you say, I've got friends here but it stopped my life from opening up" (I1P3)

DP13 describes how he now has the confidence to visit friends and socialise, something he was unable to do on previous medication regimes (I1P13). Furthermore P13 describes that having the ability to talk to people face to face and be treated as an individual is something he was unable to do previously.

Furthermore Goffman (1963 p3) indicates that an awareness of the attribute then results in the belief that "…a person is not quite human". This notion of stigma then affects the very identity of those the negative identity is ascribed to, and complicates interaction situations with those that Goffman called "the normals".

P12 reiterates Goffman's viewpoint about 'normals' describing how she was listened to by her new psychiatrist and treated her as a 'normal' person.

"*I must say that here as well as finding the right medication the relationship with the psychiatrist is very important. I didn't trust the previous ones because they brushed aside my poor attempt at asking for something else. In psychiatry you have to make a bit of noise to be heard (provided the psychiatrist is willing to listen) but you are very unlikely to do so when you are under the power of the chemical cosh! Plus if the psychiatrist signals are negative you know you can't get through to them and haven't got a chance. So you are left with no hope of a better life and if you have no hope, just the thought of sitting in a chair, staring into space then suicide is very tempting*"DP12.

Thus relationship of trust has also been touched upon by P1 who would not trust doctors in another area as discussed in 5.1.

However on the newer atypicals P3 describes herself as having more friends, everything's improved and she is able to carry out the daily activities that she struggled to do on the older medication. This is a theme echoed by P11 who states that he has lots of friends in the hostel is able to interact better whilst at the same time having lots of independence.

For P11 this is huge progress from his previous lifestyle where he was escorted everywhere and had no freedom due to being on a section 37/41, thus reducing his social networks and interactions with others.

P6 talks of now being able to get out of the house as being a prime objective as when he was on the older meds he just couldn't face people and look them in the eye, had no confidence and he remained isolative with no social contact spending weeks at a time in his bedroom.(I1P7).

In comparison to this isolation P6 confirms an ability to socialise with others when attending a day centre and how he now has the confidence to do that (I2P6) and is happy with the things he does nowadays, including pick his daughter up from school (I2P6) something he would have been unable to do on the previous medication.

P2 confirms what has been identified above as she describes meeting up with friends she has known in past but has not met up with them yet but is next week (I2P2).

P3 feels that this kept her from making friends and socialising. Whereas on the newer atypicals she says she would rather socialise and mix with people than isolate herself in her flat. In terms of isolation she confides that

"It kept me isolated, I never socialised with others, and they didn't accept me for who I was" (I1P3)

This aspect of socialising and having friends is explore deeper as P12 confides what it is like to lose someone close in terms of a personal relationship and the impact her illness had on this relationship.

"I have vaguely touched on sexuality at the beginning with my failed relationship even though by head and heart said yes my body just wouldn't respond. I was not aroused by a man I loved, it must have felt weird for this man too. We were very close and loving yet sex wasn't enjoyable. No wonder then he left me; I was also so very unconfrontational/unassertive that it must have frightened him. Who wants to make love to a zombie/robot?! I wasn't a real person with wishes and desires and emotions I was just 'flat' always on an even keel and below par"DP12.

P12 continues to describe how she was unable to continue with another relationship for the same reasons and describes how she spent 18 years not having a proper relationship due to the impact of the medication. However she then describes how Aripiprazole gave her the opportunity to show that she wasn't a robot and was capable of having sex with a man as she enjoyed a 2 year relationship. P12 also states that when interviewed by a psychiatrist the issue of sex is never touched upon as if it is a taboo subject, hearing phrases such as how are you sleeping? How are you in your spirits? But they never ask how is your sex life?

As P12 suggests the subject is taboo and another example of assuming that people with schizophrenia are not treated as 'normals' and implying that because you have schizophrenia you won't have a sex life.

P5 describes in detail how she takes part in quizzes and enjoys the company of others, something which she was unable to do previously (DP5), furthermore P10 now socializes with others and enjoys playing pool stating that he enjoys the company of his friends (DP10). P10 admits that the benefits of the newer medication has allowed him to be more relaxed in peoples company, and states that he has a few good friends (DP10), whilst he is now able to take part in group games, something he was unable to do at the height of his problems with his illness (DP10).

One of the concepts of a normal life can be a simple task of sitting in the garden or socialising with friends, however if one is disabled by the illness then this is a difficult thing to do and gaining an understanding of this is also difficult. P1 demonstrates how she was

unable to move out of her house, for fear of her voices; again she has painted what she terms vulnerability

Image 3 "Vulnerability"

P1 describes the rationale behind her vulnerability

"It represents me at my most vulnerable I had to put up with the voices constantly putting me down, at one point I didn't know how to think for myself. It's like they had observed me, my thoughts were no longer my own. They were constantly bombarding me with their thoughts and instructions."DP1

However, now she recognises that this was not her and describes her feelings now as she is starting to live her life and be in control of the schizophrenia and as she states I am normal.

Think I cried because I realized I am a proper thinking and feeling individual, I can think and feel for myself, I think crying shows that!!!! Or it might just be a release???? Or I'm just so damm pleased to be well!!!!"DP1

5.6.3 Normality

In recounting the issues of disability one service user described his disability as not been able to act normally and continued to say that there is no way that he could cope with normal life.

The concept of normal is one which occurs as a recurrent theme; P1 (DP16) describes her ability to carry out daily activities such as shopping, walking and identifies the following as an important part of her life;

"I like to keep busy, have people round that means there's always stuff to do and things happening. Normal things like conversation and well stuff!!! Makes me feel included." (I1P1)

P6 commented that his sex drive had become normal and that his mood had stabilised allowing him to go out of the house and fulfil normal activities. (DP6), he further goes on to say that 'I'm more or less normal so as to speak on this olanzapine' (IP6), a theme he reiterates when he confirms he now has more choices in his life and describes this as 'normalising things now' because of having the choice to either do something or not. (I2P6). He concludes by saying he now has a better quality of life and believes he now leads a normal life.

P2 identifies that she is now able to carry out activities which others regard as normal, and clarifies this by stating:

P2 "you can talk to shop keepers more and more and be more normal like a normal person…………

Researcher: so it's normalised things for you?

P2 Yeah" (I1P2)

P2 also identifies with aspects of normality that she is now able to carry out such as going to a bank, when asked if there was anything that she wouldn't have been able to do if she were still on the older medication she replied:

"Yeah, I would say so; I wouldn't have gotten this place myself ….. I wouldn't have … I'd be scared to do things that normal people do like banks and building societies, you know, things to do with… I wouldn't have got this flat on my own, cos I did it myself "(I1P2).

This inclusion is an important aspect to coping and getting on with her life and making a difference as she describes

"A year ago I used to cope!!! But now I feel like I am living. Actually enjoying doing stuff, partaking in life. Even if it's pottering around at home. I know people don't really talk about my illness but it would appear that they accept me!!" (DP1)

Bilton et al (1996) identify that within cultural bias there is an accepted shared knowledge about mental illness. Individuals who are diagnosed as mentally ill accept the shared knowledge and internalise the cultural norms and rules. They accept the validity of the diagnosis of schizophrenia, their health status or the need for treatment. They may also accept the negative identity assigned to them, although this may lead to internal stigma.

However P5 describes how her life has altered since the introduction of atypical antipsychotic medication, when asked about being able to go out and if she felt better replied:

P5: Oh it's been marvellous, I'm a different woman altogether with this new medicine they've invented

Researcher: can you give me an example of why you feel a different woman?

P5: well I can knit, I can sew, and I can lead a normal life, not staying in after a tablet, on the Chlorpromazine I was like a zombie….. (I1P5& I2P5)

Further on in interview

P5: it's really good medicine, I can live a fulfilled normal life. (IP5).

P 11 links the concept of normality (DP11) to the use of public transport and how he is able to use buses to carry out activities of daily living such as shopping, something he was unable to do on the older medication. Additionally (I2P11) he talks of his using a mobile phone as a normal event and his ability to top it up himself is seen as an important aspect of his independence, whilst his ability to manage money by going to the post office (I1P11) on his own is also a key concept as he normalizes his life.

P10 reflects on what he calls the positive aspects of his tablets and how he has now returned to normality, claiming that;

"I am back to the capabilities I possessed at the age of fifteen with just different opportunities presenting themselves" (DP10).

P10 repeats how he is able to face interactions nowadays and is able to do lots of things like chair meetings and describes himself as back to normal (I1P10). DP13 describes how he is now on the waiting list for a flat where he can continue his re-integration into society and lead a normal life as he describes it, and he is happy to carry out normal activities such as shopping, catching a bus, cooking and interacting with others (DP13).

Goffman (1963) remarked that the difference between a moral and a stigmatised person was a question of perspective, not of reality.

5.6.4 Summary: Social Networks and how they have impacted on friends, family and an ability to live a 'normal 'life

In this section I have attempted to show how the impact of stigma on an individual is not just restricted to a label and that it has more far reaching aspects in terms of leading a normal life. This section has shown a deeper understanding of the difficulties a person encounters on a daily basis. Things that people do within society on a daily basis that are taken for granted such as socialising, making friends are not as easy for people with schizophrenia, and the social isolation has in many ways been generated by society itself.

Perlick et al (2001) have suggested that stigma has reduced adaptive social functioning in people with schizophrenia whilst service users and their families felt devalued (Streuning et al 2000). Stigma created barriers and was associated with reduced adherence to treatment (Sirey et al 2001). People with schizophrenia were perceived and constructed as disabled. This led to devaluation, social isolation and rejection (Williams and Collins 2002) as has been shown by the participant's within this section. Goffman talks about the face to face interactions having an impact on how we interact with individuals in terms of treating people at face value. However Goffman (1963) would contend that the negative attributes of stigma can be seen to be deeply discrediting whilst Cocker et al (1998) confirm that stigmatised individuals convey a social identity that is devalued in a particular social context. Furthermore Giddens (2001) would suggest that individuals accept and collude in the creation of mental health systems and structures (e.g. hospitals) which in turn create and shape individuals who accept and become dependent on these systems and structures, thereby reducing social contacts, and leading to internal stigma.

It follows then that the concept of normal is a contentious issue but for these participants just being able to carry out the smallest of tasks is an achievement, and has improved or altered their lives immensely

Rose (1994) discusses social constructionism, and proposes that social apparatuses exist which use positivistic knowledge and create knowledge and truths about sanity and insanity. This in turn leads to defining and describing people in medical terms (e.g. mentally ill), and through differentiation and categorization, medicine manages the lives of those deemed to be mentally ill. Those who are not perceived to be useful citizens are perceived to be a social problem and a sickness in the social body.

Goffman (1963) identified that family and friends may endure a stigma by association, what he calls the 'courtesy stigma', whilst Docherty (1997) reports a patients' shame in admitting to mental illness.

Furthermore Schultz (2002) suggests that the experience of schizophrenia is not just limited to the symptoms of the illness, and in conjunction with Finzen (1996) contends that schizophrenia is accompanied by 'second illness': the reactions of the social environment and the stigma associated with the disorder.

Scambler (2004) contends that there are two types of stigma: internal stigma, where shame and expectation of discrimination are likely to inhibit a person from disclosing a mental health problem, and external stigma, which is the experience of unfair treatment by others.

Both internal and external stigma are harmful to people with mental health problems as both types of stigma lead to social withdrawal and loss of social support (Green et al 2003). The fear of stigma and discrimination leads to loss of confidence, or self-stigma.

The impact of stigmatisation upon schizophrenia sufferers has added a new dimension to the illness experience and has led to social isolation, limited life chances and delayed help-seeking behaviour (Link 1982, 1987, Fink and Tasman 1982, Rosenfield 1997, Angermeyer, Matchinger and Riedel-Heller 1999, Sirey et al 1999).

In this chapter I have tried to give an overview of how people live their lives and highlight their individual experiences through extracts from their diaries, interviews and in paintings. What is clear is that this study has only just touched the surface of how people feel, how they live and what they are experiencing on a daily basis.

Chapter 6

Discussion and Conclusion

6.0 Introduction

This chapter presents the summary and conclusions of the findings of the study that have been presented in this thesis. The chapter begins by summarising the findings which have been presented in chapter 5 in section 6.1 incorporating the core concepts and emerging themes. These themes and concepts are discussed in relation to the original outcomes which can be seen below. Section 6.2 then address the limitations of the study. A discussion of the appropriateness of the use of Goffman is entailed and if his work is still valid and reliable in today's society.

Implications of the thesis findings on healthcare policy and practise are then discussed in section 6.3 and a discussion is on how the findings can influence future health care provision is given. Reference is made to relevant literature and existing health policy in order to illustrate the need for greater exploration of the lived experiences of people with schizophrenia.

Finally, recommendations for future research are presented in in section 6.4 paying particular attention to the need for further investigation into how people live their lives with schizophrenia.

6.1 Summary of findings.

The original aims and objectives of the study were to assess the lived experiences of people with Schizophrenia prescribed atypical antipsychotic medication and to look at how people with schizophrenia lived their lives paying particular attention to the following:

- Establish the difference in socialising for patients on atypical antipsychotic medication and to explore how schizophrenia may have an impact upon face to face interactions.
- Assess the nature of the relationships with health care professionals for patients on atypical antipsychotic medication and how patients' relationships with their family and social contacts affect their quality of life.
- Assess how a patients' perceived loss of control and loss of identity has an impact on activities of daily living (e.g. eating patterns, work, sleep and play).
- Investigate how the mood and motivation of a person with schizophrenia may be influenced by choice of medication and how this may impact on self-esteem.

- Explore how the views and opinions of others may affect the daily living of patients with schizophrenia, and to look at the consequences of side effects of atypical antipsychotic medication for patients with a diagnosis of schizophrenia.

The majority of patients included in the study attended either a rehabilitation unit or were in the community and visited by a professional as part of a CMHT. The researcher found the initial recruitment of participants quite difficult to come by, despite spending time with the head of psychiatry in a large local Trust who appeared responsive to the study: there were problems with recruiting participants. Despite having worked in the Trust and knowing a large proportion of the Consultant Psychiatrists, there appeared a reluctance of many to engage in the study. However one Consultant was very keen and invited the researcher to two of his meetings, this was Dr A and he had used diaries himself in working with patients and was keen to help, and information was cascaded down in his team, following this two participants were found. Only one other Consultant met the researcher face to face to discuss the study, other Consultants agreed in principal and agreed that the researcher could attend team meetings and ask staff to discuss. Some Consultants did not respond at all to any requests.

The problem of recruiting suitable participants meant a long delay in collecting data despite following the ethical protocol. However over a period of time and through the use of networking, discussing with previous Mental Health colleagues (Registered Mental Health Nurse (RMN's) and care assistants) the participants began to come forward. It raised the question of control and possible issues of power, do Consultants still hold some kind of power in the relationship with patients? was there some rationale for not complying? It has been suggested by Lupton (1997) that there is an over emphasis on doctors power over patients and that patients are the victims of this power. Lupton(1997) goes on to say that patients willingly participate in and collude in medical dominance and as such they place a positive value on recovery from illness. Furthermore Lupton (1997) implies that in some small degree this power cannot be taken from doctors and that this power is transmitted through all social groups. It can be argued then that medicalisation encourages dependency which lead to social exclusion and disempowerment amongst this group of people, a concept that became apparent as the study progressed.

The researcher met with each participant at least three times, the initial discussing and providing of the dairy, along with the mid and end point interviews. One of the positive aspects of not only being a researcher but also being a RMN is that he had an ability to communicate in a way that may not have been done by a non RMN. In his dual role as a nurse and researcher he was able to convey a calm relaxing manner that encouraged the participant to feel at ease and also have ownership of what they had to say.

Participants were asked to keep their diary for around one month, and most people seemed to manage this relatively easily having said that not everyone made an entry every single day, and typically entries began to tail off toward the end of the one month period. Also, despite giving people quite detailed written instructions, including examples of what to write some people revealed in their diaries that they were uncertain that what they were doing was what was wanted. It became apparent that people did have things to say and write and in many cases wanted to tell their story as they saw it and not under the constraints of a doctor- patient relationship. Upon reflection it was apparent that the researchers relaxed manner and a passion to hear what people had to say was important in gathering this information. P1 had the confidence to paint a description of what she endured with the torment of her voices and by spending time writing her diary it also gave her more confidence to challenge and tackle her fears, and at the same time sending art work to a National Museum for display.

Some people wrote a great deal in their diaries, and they reflected on their day and provided detailed accounts of what they were doing and how they were thinking and feeling and this provided rich data on their lived experiences. A number of the participants were very articulate in their diaries, one participant needing two diaries to tell their story, again thanking me for having the opportunity to tell her life experiences and what she went through on a daily basis. Some participants struggled to write a complete diary, due to poor hand writing caused by a fine tremor, caused by the side effects of medication. Yet despite this they were articulate in their interviews explaining how they lived their lives, giving a valuable insight into how they felt many years were wasted but thankful that they now had the chances to have a life. Goffman's(1982) face to face work has enabled participants to express themselves in a way that would have not been possible if we were to utilise a different theoretical framework. Using face to face interviews has enabled participants to describe and elaborate on their diaries and their lived experiences.

Reading and listening to their experiences it became more apparent to the researcher that this group of people are very rarely listened to and that the media and society does tend to exclude and isolate them.

 During the study there was only one participant who the researcher deemed unwell enough to pass on his concerns to the care co-ordinator. Despite being able to fill in his diary and complete the two interviews, it was apparent that he was struggling with everyday life and this was reflected in some of his diary entries. The researcher therefore took the ethical decision to exclude his data from the final study in the best interest of the individual concerned. During the interviews he did concur with some of the themes that had emerged from other participants, however due to his fluctuating mental health his data was excluded.

It has been clearly shown in section 5 that a person's life has numerous complicated components attached to it and that the impact of the diagnosis of schizophrenia has far reaching consequences.

The inability to carry out such small tasks as eating, cooking washing has had an impact on many of the lives of the participants, the disclosure of loss of relationships is also a great concern to individuals. How we perceive someone with schizophrenia either through the media or public perception is also of great concern as this stigma tends to stay with an individual for the majority of their life. As more and more problematic behaviours (Walton 1985) are blamed on medical conditions and not on the deficiencies of society, it is not hard to see how people with schizophrenia are seen to be suffering from 'a final and irrevocable loss of his mental existence' (Bleuler 1978a: p447, cited in Barham 1992). This loss of existence has been identified as a loss of control and a loss if identity in this study and concurs with the theory of Goffman. Furthermore as we develop this concept of social isolation Baumann (1989) argues that as the responsibility of one social group is eroded, it causes what he terms 'the process of social separation'. Thus as can be seen this is part of the process for each of the participants who have taken part in this study.

This then raises the issue of people becoming a full-time mentally ill patient in self-concept, according to Lally (1989) something that has Goffman allured to himself, and one which has shown to be true for the participants in this study.

Schulze, Matthias & Angermeyer, (2003) and Link & Phelan (2001) have indicated that there exists an imprecise picture of stigma associated with schizophrenia, due to the way in which society perceives the illness. Goffman (1986) argues that those with schizophrenia first and foremost feel that their illness and the stereotypes associated with it often shapes people's perceptions of them, and thus imposes an illness identity upon them. This is regardless of whether or not they are experiencing acute symptoms of the illness, and is perceived as having a negative impact on their quality of life.

Goffman's theoretical concepts where he looks at face to face interactions, stigma and how the impact of institutions affects an individual is clearly still relevant today needs further exploration, for as Goffman has said that in our interactions with others we have certain expectations on how they should behave. We assign them roles - i.e. adults have to behave responsibly. Once people behave differently we stigmatise them. They then have to deal with these stigmas (they can be anything from abuse to just ignoring or looking oddly at them) and that is how the stigmatised cope with their identity. Goffman also states that we behave as social actors; we think that we have scripts that tell us how to behave. If anyone deviates we then stigmatise them.

Furthermore Goffman has suggested that we develop regions - front and back, we behave differently with different people. When mental illnesses occur people can't develop these regions and they behave against the scripts that others think they should be reading. Then they get stigmatised.

One of the major attributes to Goffman is that he is not as deterministic as say Parsons and Durkheim who think structures determine our behaviour. Goffman reiterates that we as a society are about social interaction and how we interact in a face to face situation.

Goffman's work is more relevant in today's society when we consider the impact of social media and how this negates social interaction; more face to face interaction would enable society to become more socially acceptable and could be a way to reduce the stigmatisation that people suffer. The advent of facebook, twitter and other social media. has given society a way of hiding behind a front (as Goffman contends) and therefore reduces the interactions that make society function.

Barham (1992) would suggest that if we are not to exacerbate the demoralisation of people with mental illness and thus stigmatise them further, then society is in need of new psychiatric theories that look at what the service users themselves require, a further rationale to look at the lived experiences of people with schizophrenia and challenge traditional views. Barham (1992) infers that people with enduring mental illness such as schizophrenia were regarded as 'refugees, and who had no viable social place. He further contends that the society in which we function has no social order for them and that it has no place for them in its midst. Furthermore Bonner et al (2002) has suggested that institutional exclusion has now been replaced by social and economic exclusion. It has been shown by Bonner et al (2002) that people with schizophrenia had unmet needs in the following dimensions, psychological distress, day time activities, physical health and the company of others. This concurs largely with what participants have told us. This would suggest then that primary based care within the mental health sector does not reduce social exclusion, and that local mental health services are not adequate. Furthermore it would suggest that policies are not effective in helping to deal with social exclusion for those with schizophrenia. One could postulate then that the focus is more on risk reduction/management than promoting social inclusion and engagement with the services.

What is clear from findings is that schizophrenia is not just a debilitating illness on its own but it is accompanied by a secondary illness which is more socially disabling, that of stigma and its impact on a person's daily living.

6.2 Limitations of the study

There were 19 participants within the sample and many of these have had long periods of hospitalisation, however they were deemed to be well and not in an acute phase of the illness. With the resulting 19 diaries and 38 interviews a large and rich amount of data was gathered which gave a very detailed account into their lived experiences. One of the concerns of the study was a lack of detail from some of the participants, who despite living in the community were quite disabled by the illness itself.

Participant P15 filled in his diary daily but his routine was very much the same and diary entries were limited to 3 or 4 lines, and his responses during the interviews were also limited and lacked the depth of other participants. However one thing that P15 did share was that he now coped better and that he had a better quality of life (I2P15), although he did not have a large social network.

Participant P18 was also very similar in that he had limited entries in his diary and found coping by having a set routine and a close family support network who took him to play football. P18 also had a part time volunteer job in a charity shop and did express that he had more motivation on his newer medication. These two participants illuminate the difficulty in trying to express themselves in great detail, for both had clearly become disabled to some extent by the illness. Although they had social contact (with ex-patients and close family) they had in effect become socially isolated within the community.

There was a relevant ratio of male to female which was proportionate to the prevalence of schizophrenia as discussed in section 2. Within the study there were no participants of an ethnic origin which may have influenced some of the findings. This may have illuminated a different perspective from a different cultural aspect and added to the findings.

There were also some minor problems with some participant's unable to keep a diary for a month due to the chronicity of their illness and some struggled to write due to the side effects of medication. However this was compensated by the use of the interviews which gave a forum for the development of their lived experiences.

The sample selected was small, mainly due to the initial difficulty in recruitment caused in some way by a reluctance of some consultants to engage in the study.

One of the aspects that could be addressed is the apparent lack of enthusiasm by some of the consultants to the study,(this is discussed further in 6.4).

6.3 Implications of the study.

Funding for the newer drug treatments in schizophrenia has become a contentious issue with drug costs rising significantly in recent years. With increasing evidence that new drug treatments can improve clinical functioning sufficiently to allow discharge from hospital in cases where treatment had previously failed, there would seem to be every justification for making such treatments available when appropriate.

Not only can one see the importance of ensuring that the newer atypical neuroleptics are made available but it is also paramount that the views of service users are taken into consideration in order to influence policy making and make informed choices for individuals. These choices are then made to influence their quality of life and not based on a cost effective basis.

It is clear from the findings that people with mental health problems want to be listened to, want to be involved, particularly in decision-making regarding their treatment and care and want to be taken seriously. Improving the style of interaction between professionals and patients does not require new resources or additional expenditure, but does require a change of approach for many people.

Furthermore the issue of choices in relation to medication revolve around a complex relationship between the doctor and the patient where one 'appears' to have a superior role to the other and this creates a conflict and also has a negative impact on an individual's confidence. This conflict has been discussed by a number of the participants in their diaries and is a concept that has been expressed previously as noted in Barham (1992: p48) *"He's superior …..Between you and me, he's superior to me, I'm the patient and he's the doctor".* This conflict manifests itself in the simple assumption that 'patients' feel that there is insufficient opportunity to talk through problems and that some state

"With schizophrenia you are not living, you just exist. There is not a lot of future for you, but you come to terms with the illness. I am labelled for the rest of my life….. I think schizophrenia will always make me a second class citizen." (Barham 1992:p58)

Goffman (1970), Bonner et al (1996) Giddens(2001) have discussed how social relations and power structures are inherent in society and that people with mental illness learn to play roles and conform to the rules of society. Hence people with mental illness are then placed in a role (by people in society) that makes them compliant within a medicalisation process. This medicalisation process can thus be deemed as medical power in a response to perceived social problems. It can then be assumed diseases are created by the medical profession and patients thus become objectified and are seen as less important than the disease, hence individuals lose their individual identity. Rabinow (1991) contends that this medical power creates patients which may then be used to operate in society and maintain the medical imbalance of power. Moorey (1998),contends that with professionalism comes expert status which involves knowledge and skills, a situation which creates inequality between client and health professional and dependency in service users. Moorey (1998 pp. 46-47) discusses the diagnostic relationship, in which the health professional identifies the problem, its cause and delivers the solution to the client. This relationship makes the health professional's power legitimate and disempowers the service user.

It has been suggested by Bentall (2003) that the classification systems (DSM-IV and ICD-10) are flawed and arbitrary, and have their cultural roots in an industrialised and scientific economy. He suggest that a person who has a psychotic symptom, might not experience a behavioural breakdown, can participate and function in social life, and can have a valued role in society and yet receives a label which has far reaching consequences.

Within this study we have looked at Goffman's (1990b) work in relation to stigma and spoiled identity and the impact of a label can have, despite hearing from individuals about the negative impact of schizophrenia it appears that things are not going to improve.

The recent introduction of the new classification DSM-V, (May2013) could have huge impact on people with schizophrenia, far from helping individuals to integrate back into society it appears this will label people further. It has been suggested by The British Psychological Society (2001) that the proposed diagnoses were based *"largely on social norms, with 'symptoms' that all rely on subjective judgments... not value-free, but rather reflecting current normative social expectations"*, noting doubts over the reliability, validity, and value of existing criteria.

6.4 Recommendations for future practise.

What is clear is that further exploration is needed of patients' lived experiences utilising a phenomenological approach, to identify individual incidences of how schizophrenic patients carry out their daily lives. In order to combat the impact of stigma on schizophrenic patients it is essential that first-hand information is gained from the patients, and that they can make a difference to their social integration when faced with negative attributes associated with their illness.

A major concern within health care is that there is little consensus about what constitutes quality of life or how to measure it (Sainfort 1996). Andrews (1976), Campbell (1976) & Ferrans & Powers (1992) would contend that quality of life is defined in terms of subjective perceptions of life satisfaction, happiness, social relations, physical health and psychological well-being whereas Spilker (1990) would argue that more objective indicators such as income, quality of housing and physical function are determinants of quality of life. To compound this view, most of the instruments used to assess quality of life rely upon a single respondent, which is either the patient or the clinician but rarely both, in addition few quality of life instruments cover the broad range of domains that have been shown to be related to quality of life.

Sainfort et al (1996) explains that 'clinicians, clinical investigators and policy makers in the field of mental health have now recognized that quality of life is an important measure of outcomes in patient management, cost-effectiveness evaluations, clinical trials, and treatment outcome studies', whilst Lamb (1979) & Lehman et al (1982) suggest that the major goal in the provision of mental health services is the improvement in quality of life.

It is clear that a way forward must be found in order to develop a better quality of life for service users, consequently Coleman and Smith (2005) assert that service users must cease to be victims and empower themselves. They must redefine themselves as people who have unusual experiences as this shows oneself and one's illness in a more positive light, according to Williams and Collins (1999).

The National Institute for Clinical Excellence guidelines propose that partnership involves building a "supportive and empathetic relationship with users and carers", and involves giving clear information to users and promoting recovery (National Institute for Clinical Excellence 2002 p.6). Treatment and care should be delivered in an atmosphere of hope and optimism. Joint decision-making between the person with schizophrenia and the clinician, in the choice of medication, should take place with the emphasis on choice and not based on cost and symptom reduction.

Nurses should promote wellness and this means working with clients, joint decision making, helping clients to work towards their own development. Nurses should challenge social norms (Barker & Davidson 1998), however this may be difficult as nurses are subject to cultural bias (Bilton et al 1996) and governmentality (Rose 1999) in the same way as service users and may be unable to challenge social norms.

Morrall (1998a) asserted that nurses are disempowered because of the power of medicine and Morrall (1998a) concluded that nursing is a mediated profession, which means medicine has traditionally controlled the knowledge base and roles of nurses, and access to clients is controlled by doctors. The level of nursing autonomy is influenced by medicine, and medicine facilitates the power and roles of nurses. The extended role of the nurse is only possible with the permission of medicine. As a mediated profession, nursing does not define its work processes or outcomes and is therefore not professionally autonomous in the same way as medicine. Therefore for Morrall (1998a), nurses are not in a position to empower patients because they have limited power themselves.

Many health care organisations are beginning to embrace the concept of empowerment but find actualising the concept to be challenging. In order to fully understand the use of empowerment within organisations it is imperative that we have an understanding of what is meant by the concept. One of the advantages of utilising empowerment within health care

organisations is that it enables collaboration with other agencies and it addresses the issues of service providers.

It has become a requirement within the UK since the National Health Service and Community Care Act 1990 that assessment for health is conducted on the basis of need, and that the outcome of an intervention is measured in terms of impact on the person's quality of life (QoL).

Evans & Harwood (1991) and Katschnig (1997) report an increase in the assessment of quality of life in general medicine, which looks at a broadening of treatment goals, aimed at prolonging life and symptom alleviation to maximising an individual's satisfaction with life. This theme has now been taken on within psychiatry, particularly as part of a multidimensional assessment of clinical outcomes in schizophrenia (Meltzer 1992), in evaluation of rehabilitation programmes (Pinkney et al 1991) and as a variable to be assessed in clinical trials of new neuroleptics (Lehman, 1983;Meltzer et al 1989; Awad 1992; Awad 1995).

Barry (1993) suggests that the concept of quality of life normally refers in some way to the sense of well-being and satisfaction experienced by a person with regard to their life and Baker (1982) indicates that this measurement of quality of life may be particularly appropriate for people with long term mental health problems, hence the importance for research linked to quality of life.

Within this study it leads us to conclude that in a clinically stable, mild to moderately ill schizophrenic patient population, symptom severity, neurocognitive deficits and other treatment issues do not impair patients' ability to appraise quality of life.

This then supports the current study suggesting that the patient's own subjective views on quality of life are valid and reliable within the client group selected. Furthermore it follows that atypical neuroleptics such as clozapine, risperidone, olanzapine that improve negative symptoms and quality of life and produce less tardive dyskinesia and will be of advantage in prescribing early in the treatment of schizophrenia.

It is important to the participants within this study not to just measure the direct cost of a particular drug treatment but to balance this against the patient's quality of life, as improvements in quality of life decrease the impact of schizophrenia on patients and family members.

What is clear from this study is that people with schizophrenia experience a wide range of stigmatising both with the public domain and also from within the health care field. I have tried to gain a deeper understanding of peoples lived experiences through the use of a phenomenological perspective, which was the most appropriate in this case.

Further research is needed on a larger scale, perhaps utilising the social media in a more positive way, encouraging participants to keep a blog, by describing their day to day experiences via a supported Facebook page keeping a diary for a longer period, also a larger sample group from a greater cross section of cultures as very little is still known about this group. More work is needed on the methods used to evaluate a person's quality of life which need to take into consideration their lived experiences and not just a rating scale that is not respondent sensitive. People with schizophrenia need to feel that they are being involved in the decisions about their care; they need to know that they are being listened to and that they have valid accounts of their lives to tell.

As P1 described it

"I am in charge of the schizophrenia, it's not in charge of me" (DP1)

Reference List

Aitchison, K. and Kerwin, R. 1997 Cost-effectiveness of clozapine. A UK clinic-based study. *British Journal of Psychiatry*. **171**, pp.125 -130.

Aleman, A. et al 2006. Insight in psychosis and neuropsychological function. Meta-analysis. *British Journal of Psychiatry*. **189**, pp.204-212.

Allebeck, P.1989. Schizophrenia: a life-shortening disease. *Schizophrenia Bulletin.* **15,** pp. 81 – 89.

Almond, S. and O'Donnell, O.2000. Cost analysis of the treatment of schizophrenia in the UK: a simulation model comparing olanzapine, risperidone and haloperidol. *Pharmacoeconomics.* **17**(4), pp. 383-389.

Almond, S. et al.2004. Relapse in schizophrenia: costs, clinical outcomes and quality of life, *British Journal of Psychiatry.* **184**, pp.346-351.

Alpers, G.W. and Tuschen-Caffier, B.2004. Energy and macronutrient intake in bulimia nervosa. *Eating Behaviour*. **5**, pp.241–9.

American Psychiatric Association (APA)1994. Diagnostic and Statistical Manual of Mental Disorders, 4th edn. (DSM-1V). American Psychiatric Association, Washington DC.

Andersen, L.F. et al 2004. Validity and reproducibility of self-reported intake of fruit and vegetable among 6th graders. *European Journal of Clinical Nutrition.* **58**, pp.771–7.

Andreasen, N. C. et al 1995. Symptoms of schizophrenia: methods, meanings and mechanisms. *Archives of General Psychiatry*. **52**, pp 341-351.

Andreasen, N. C. and Olsen, S.1982. Negative v positive schizophrenia: definition and validation. *Archives of General Psychiatry*. **39**,pp 789-794.

Andreasen, N.C. 1995. Symptoms, signs and diagnosis of schizophrenia. *Lancet.* **346**, pp. 477- 481.

Angermeyer, M. C. and Matschinger, H. 1995. Violent attacks on public figures by persons suffering from psychiatric disorders: Their effect on social distance towards the mentally ill. *European Archives of Psychiatry and Clinical Neuroscience*. **245**, pp. 159–164.

Angermeyer, M. et al. 1999 Whom to ask for help in case of mental disorder? Preferences of the lay public. *Social Psychiatry and Psychiatric Epidemiology*. **34**, pp. 202–210.

Appleton, J.V. and King, L. 2002. Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing*. **40**, pp. 641-648.

Armstrong, D. 1994. Bodies of knowledge/knowledge of bodies. In: Reassessing Foucault: Power Medicine and the Body (Eds Jones, C. Porter, and R.) pp. 17–27. Routledge, London.

Arns, P. G. and Linney, J. A. 1993. Work, self, and life satisfaction for persons with severe and persistent mental disorders. *Psychosocial Rehabilitation*. **17**, pp 63-79.

Awad, A.G. 1992. Quality of life of schizophrenic patients on medications and implications for new drug trials. *Hospital and Community Psychiatry*. **43**, pp.262-265.

Awad, A.G. and Voruganti, L.N.P.1999. Quality of life and new antipsychotics in schizophrenia: Are patients better off? *International Journal of Social Psychiatry*. **45,** pp**.**268-275.

Awad, A.G. et al.1995.Patients' subjective experiences on antipsychotic medications: Implications for outcome and quality of life. *International Clinical Psychopharmacology*. **10** (Suppl 3), pp.123-133.

Babbie, E.1979. The practise of social research, 3rd edition Wadsworth, Belmont, California

Bachrach, L. L. (ed.) 1970. Deinstitutionalization: An Analytic Review and Sociological Perspective. Rockville, MD, National Institute of Mental Health.

Baker, F. and Intagliata, J. 1982. Quality of life in the evaluation of community support systems. *Evaluation and Program Planning*. **5**, pp. 69-79.

Barham, P.1992. Closing the Asylum: Mental Patient in Modern Society Penguin Books.

Barham, P. and Hayward, R. 1992. Relocating madness. From the mental patient to the person. Free association books London.

Barham, P. and Hayward, R. 1991. From the Mental Patient to the Person. Routledge, London.

Barham, P. and Hayward, R.1995. Relocating Madness: From the Mental Patient to the Person. Free Association Books, London.

Barker, P. 1999. The Philosophy and Practice of Psychiatric Nursing. Churchill Livingstone, London.

Barker, P.2002. The Tidal Model: The healing potential of metaphor within a patient's narrative. *Psychosocial Nursing and Mental Health Services*. **40**(7), pp. 42-50.

Barker, P. and Davidson, B. 1998. Psychiatric Nursing: Ethical Strife. Arnold, London.

Barry, M. M. and Crosby, C. 1996. Quality of life as an evaluative measure in assessing the impact of community care on people with long-term psychiatric disorders. *British Journal of Psychiatry*. **168**, pp. 210-216.

Barry, M. M. 1997. Well-being and life satisfaction as components of quality of life in mental disorders. In Quality of Life in Mental Disorders (ed. H. Katschnig, H. Freeman and N. Sartorius), pp. 31-42. John Wiley & Sons, Chichester.

Barry, M.J. 1993. Involving patients in treatment decisions for benign prostatic hyperplasia. *Prospectives*. **3**(3), pp.1-4.

Batchelor, J.A. and Briggs, C.M. 1994. Subject, project or self? Thoughts on ethical dilemmas for social and medical researchers. *Social Science & Medicine*. **39**(7), pp.949-954.

Battaglia, J.2001. Compliance with treatment in schizophrenia.http://medscape.com/viewarticle/418612.

Bauman, Z.1989. Modernity and the Holocaust. Cambridge: Polity Press.

Bean, P. 1986. Mental Disorder and Legal Control. Cambridge: Cambridge

Beasley, C.M. et al.1996. Olanzapine versus placebo and haloperidol: acute phase results of the North American double-blind olanzapine trial. *Neuropsychopharmacology*. **14**,pp.111-123.

Becker, H. 1963. Perspectives on Deviance: The Other Side. Macmillan, Toronto.

Becker, H. S. 1963. Outsiders. Studies in the sociology of deviance. New York: Collier-Macmillan.

Bellack, A.S. et al.1990. An analysis of social competence in schizophrenia. *British Journal of Psychiatry*. **156**, pp. 809-818.

Benner, P. 1985. Quality of life: a phenomenological perspective on explanation, prediction and understanding in nursing science. *Advances in Nursing Science*. **8**, pp.1-14.

Benner, P. 1994. Interpretive phenomenology: Embodiment, caring, and ethics in health and illness. Sage,Thousand Oaks CA.

Bentall, R.P. 2003. Madness Explained: Psychosis and Human Nature. Penguin, London.

Bentall, R.P. 1990. (ed.) Reconstructing Schizophrenia, London. Routledge.

Berg, B.1989. Qualitative Research Methods for the Social Sciences. Allyn and Bacon,

Bertram, G. and Stickley, T. 2005. Mental health nurses, promoters of inclusion or perpetrators of inclusion. *Journal of Psychiatric and Mental Health Nursing.* **12**, pp.387–395.

Bilton, T. et al. 1996. Introducing Sociology, 3rd edn. MacMillan Education Press, Basingstoke.

Birchwood, M. and Smith, J. 1987. 'Schizophrenia and the family', in J. Oxford (ed.) Coping with Disorder in the Family, London: Croom Helm.

Blankerz, L. 2001. Cognitive components of self-esteem for individuals with severe mental illness. *American Journal of Orthopsychiatry.* **71**, pp.457–465.

Bleuler, M. 1978. The schizophrenic disorders: Long-term patient and family studies. Yale University Press (New Haven).

Bochner, A. P. 2002. Perspectives on inquiry III: The moral of stories. In M. L. Knapp et al 1994. Antipsychotic medication; is worse? A meta-analysis of the published randomized control trials. *Psychological Medicine*. **24,** pp. 307-316.

Bott, E.1976.Hospital and Society, *British journal of Medical Psychology*. **49**,pp.97-140 Cited in Barham & Hayward, relocating Madness, from the mental patient to the person. Free Association Books, London.

Bowling, A.2002. Research methods in health (second edition). Buckingham: Open University Press.

Bracken, P. and Thomas, P. 1999. Home treatment in Bradford. Openmind **95**, p.17.

Brissett, D. and Edgley, C. 1975. "Introduction" in: Brissett D. and Edgley, C. (eds.) Life as Theatre: A Dramaturgical Sourcebook, Chicago, Aldine Publishing Company.

Brorson, S. et al.2013. Pain Relief at the End of Life: Nurses' Experiences Regarding End-of-Life Pain Relief in Patients with Dementia. *Pain Management Nursing*. Feb **28**. (12) pp. 73-7.

Browne, S. et al.1996. Quality of life in schizophrenia: relationship to sociodemographic factors, symptomatology and tardive dyskinesia. *Acta Psychiatrica Scandinavica.* **84** (2), pp.118-124.

Bruegel, I. and Smith, J. 1999. Taking risks, Safe in the City.

Brugha, T.S. et al.1993. The relationship of social network deficits with deficits in social functioning in long-term psychiatric disorders. *Social Psychiatry and Psychiatric Epidemiology.* **28**,pp. 218–224.

Bruner, J. 1987. Life as narrative. *Social Research.* **54**,pp.11-32.

Bryman, A.1988. Quantity and quality in social research. Unwin Hyman, London.

Bryman, A. 2007. Social Research Methods. OUP Oxford.

Bryman, A. 2006. Integrating quantitative and qualitative research: how is it done? *Qualitative research*. **6,** pp. 97-113.

Buhling, K.J. et al. 2004. No influence of high- and low-carbohydrate diet on the oral glucose tolerance test in pregnancy. *Clinical Biochemistry.* **37,** pp. 323–7.

Burch, R.1989. On phenomenology and its practices. *Phenomenology & Pedagogy*.7, pp.187-217.

Burnard, P. 1991. A method of analysing interview transcripts in qualitative research. Nurse Education Today. **11**, pp461-466

Burnard, P.1995. Unspoken meanings: qualitative research and multi-media analysis. *Nurse Researcher.* **3**(1), pp.55-64.

Bury, M. 1991. The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness.* **13**, pp. 451–468.

Byrne, P.1997. Psychiatric stigma: past, passing and to come. *Journal of the Royal Society of Medicine.* **90**, pp.618–620.

Byrne, P.2000. Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric Treatment.* **6**, pp.65–72.

Byrne, P. 2001. Psychiatric stigma. *British Journal of Psychiatry*. **178**, pp. 281 -284.

Caliguri, M.H.et al. 1997. Incidence and risk factors for severe tardive dyskinesia in older patients. *British Journal of Psychiatry*. **171**,pp.148-153.

Cameron, B. 1998.Understanding nursing and its practises. Unpublished doctoral dissertation. University of Alberta, Edmonton.

Campbell, A. 1976. Subjective measures of well-being. *American Psychologist*. **31**, pp.117-124.

Campbell, P. and Lindow, V. 1997. Changing Practice: Mental Health Nursing and User Empowerment. Royal College of Nursing, London.

Calvin, A.O.et al. 2009.The cardiovascular intensive care unit nurse's experience with end-of-life care: a qualitative descriptive study. *Intensive Crit Care Nurs.* **25**(4),pp. 214-20.

Carr, D.1986. Time, narrative, and history. Bloomington: Indiana University Press.

Charon, J.1979. Symbolic interactionism Prentice-Hall (Englewood Cliffs, N.J.).

Clandinin, D.J. and Connelly, F.M.2001. Narrative Inquiry: Experience and Story in Qualitative Research.

Cohen, M. Z. 1987. A historical overview of the phenomenological movement. Image: *Journal of Nursing Scholarship.* **19**, pp.31-34.

Coleman, L. M. 1997. 'Stigma: An enigma demystified' in Davis, L.J. (ed.)

Coleman, R.1999. Recovery: An Alien Concept. Handsell Publishing, Gloucestershire.

Coleman, R. and Smith, M. 2005. Working with Voices: Victim to Victor 11, 2nd edn. P and P Press, Dundee.

Conley, R. and Kelly, D.2001. Management of treatment resistance in schizophrenia. *Biological Psychiatry*. **58**, pp.898-911

Corin, E.1990. "Facts and Meaning in Psychiatry: An Anthropological Approach to the Lifeworld of Schizophrenics." *Culture, Medicine and Psychiatry.* **14**(2), pp.153–88.

Corin, E. and Gilles, L. 1994. "From Symptoms to Phenomena: The Articulation of Experience in Schizophrenia." *Journal of Phenomenological Psychology.* **25**(1),pp 3–50.

Corrigan, P.W. and Penn, D.L. 1999. Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist.* **54**, pp.765–776.

Corrigan, P. W. and Buican, B. 1995. The construct validity of subjective quality of life for the severely mentally ill. *Journal of Nervous and Mental Disease*. **183**,pp. 281-285.

Cottrell, V. and Shulz, R. 1993. The perspective of the patient with Alzheimer's disease: a neglected dimension of dementia research. *Gerontologist.* **33**(2),pp.205-11

Couchman, W. and Dawson, J.1990. Nursing and health-care research: the use and application of research for nurses and other health care professionals. Scutari, London.

Coxon, A.M. et al.1993. Sex role separation in sexual diaries of homosexual men. *AIDS.* **7,** pp. 877–82.

Crawford, A. 1996. Stigma Associated With AIDS: A Meta-Analysis. *Journal of Applied Social Psychology*. **26**, (5),pp. 398–416.

Creer, C. and Wing, J.K. 1974. Schizophrenia at Home. London, England: Institute of Psychiatry.

Creswell, J. W. 2003. Research design: Qualitative, quantitative, and mixed methods.

Creswell, J. W. and & Tashakkori, A. 2007. Developing publishable mixed methods manuscripts. *Journal of Mixed Methods Research*. **1**, pp.107-111.

Creswell, J.W. and Plano Clark, V.L. 2007. Designing and Conducting Mixed Methods Thousand Oaks, CA: Sage.

Crisp, A. 1998. Changing minds: every family in the land. The coming college campaign to reduce the stigmatisation of those with mental disorders. *Bulletin of the Royal College of Psychiatrists.* **22**, p328.

Davidhizar, R. E.1985. Can clients with schizophrenia describe feelings and beliefs about taking medication? *Journal of Advanced Nursing* **10,** pp.469-573

Day, J.et al.1998. A comparison of patients and prescribers beliefs about neuroleptic side-effects: prevalence, distress and causation. *Acta Psychiatrica Scandinavica*. **97**, pp. 93-97.

Delespaul, P.G. and de Vries, M.W. 1987. The daily life of ambulatory chronic mental patients. *Journal of Nervous and Mental Disease.* **175**, pp. 537–44.

Department of Health. 1998 Modernising mental health services safe, sound and supportive.

Department of Health. 1999. National Service Framework for Mental Health. London: DoH.

Department of Health. 2000. National service framework: our healthier nation. London: DoH

Devaney, S.M.et al. 1998. The clinical skills of community psychiatric nurses working with patients who have severe and enduring mental health problems. An empirical analysis. *Journal of Advanced Nursing.* **27**, pp. 253–260.

Diamond, T.1992. Making Gray Gold: Narratives of Nursing Home Care (Women in Culture and Society). University of Chicago Press.

Dickerson, F.B. et al.2002. Experiences of stigma among patients with schizophrenia. *Schizophrenia Bulletin.* **28**, pp.143–155.

Dickey, B. et al.1981. A follow up of deinstitutionalized chronic patients, four years after discharge. *Hosp Comm Psychiatry.* **32**,pp.326-30.

Diekelmann, N. et al .1989. The National League for Nursing criteria for appraisal of baccalaureate programs: A critical hermeneutic analysis. New York:
Disability Studies Reader, London: Routledge. pp.216-231.

Docherty, J.P. 1997. Barriers to the diagnosis of depression in primary care. *Journal of Clinical Psychiatry.* **58**, pp.5–10.

Donnelly, L. 1999. Schizophrenia patients face denial of new drug treatments. *Health Service Journal.* **109,** p. 8.

Doyle, L. et al. 2009 The Weekly Qualitative Report. *Journal of Advanced Nursing.* **65**(6), pp.1171-1181.

Dresser, R. 1998. Time for new rules on human subject's research? Hastings Centre Report. **28**(6), pp.23-24.

Dunn, G. C. eds. This is madness: a critical look at psychiatry and the future of mental health services. Ross-on-Wye: PCCS Books. pp. 135-148

Durkheim, Emile and Marcel Mauss. [1903] 1963. Primitive Classification. Translated by Rodney Needham. Chicago, University of Chicago Press.

Edwards, E. and Timmons, S. 2005. A qualitative study of stigma among women with post natal mental illness. *Journal of Mental Health.* **14** (5), pp.471-481.

Eisner, E. W. 1991. The enlightened eye: Qualitative inquiry and the enhancement of educational practise. New York, NY: MacMillan Publishing Company.

Estroff, S. et al. 1997. Violence and severe mental disorder in clinical and community populations: The effects of psychotic symptoms, co morbidity, and lack of treatment. *Psychiatry.* **60**(1), pp.1-22.

Estroff, S. E, et al. 2004. From Stigma to Discrimination, an analysis of community efforts to reduce the negative consequences of having a psychiatric disorder and label, *Schizophrenia Bulletin.* **30**(3), pp.493-509.

Estroff, S.E. 1989 Self, identity, and subjective experiences of schizophrenia: In search of the subject *Schizophrenia Bulletin.***15**(2), pp.189-196.

Estroff, S. E. et al. 1997. Pathways to Disability Income among Persons with Severe, Persistent Psychiatric Disorders. *Milbank Quarterly.***75**(4), pp.495-531.

Farina, A. and Felner, R.D. 1973. Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology.* **82**, pp.268-272.

Ferrans, C. and Powers, M.1992. Psychometric assessment of the Quality of Life Index. *Res Nurs Health.* **15,** pp.29-38.

Field, P.A. and Morse, J.M. 1985. Nursing research: the application of qualitative approaches. Croom Helm, London. Chapman & Hall.

Field, P.A. and Morse, J.M. 1992. Nursing research. The application of qualitative approaches. London: Chapman & Hall.

Fink, P. and Tasman, A.1992 Stigma and Mental Illness. American Psychiatric Press, Washington, DC.

Finkelstein, S.M. et al.1992. The impact of home monitoring and daily diary recording on patient status in cystic fibrosis. *Paediatric Pulmonology*. **12**, pp 3–10.

Finzen, A. 1996. Der Verwaltungsrat ist schizophren. Die Krankheit und das Stigma. Bonn: Psychiatrie-Verlag.

Firestone, W. A. 1987. Meaning in method: The rhetoric of quantitative and qualitative research. *Educational Researcher*. **16**(7), pp.16-21.

Flanagan, J.C.1978 A research approach to improving our quality of life. *Am Psychologist*. **33,** pp**.**138-147.

Fortenberry, J.D. et al.1997. Sex under the influence: a diary self-report study of substance use and sexual behaviour among adolescent women. *Sexually Transmitted Diseases*. **24**, pp.313–19.

Foucault, M.1961 Madness and Civilization: A History of Insanity in the Age of Reason Blackwell.

Foucault, M. 1980 Truth and power. In: Power/Knowledge (eds Gordon, C.), pp 166–182.The Harvester Press, Hertfordshire.

Foucault, M. 1995 Madness and Civilization: A History of Insanity in the Age of Reason. Routledge, London.

Foucault, M. 1996 The carceral. In: Criminological Perspectives: A Reader (Eds Muncie, J, Mclaughlin, E. & Langan, M.). pp. 392–396. Sage, London.

Fox, N.J. 1993 Post Modernism, Sociology and Health. Open University Press, Buckingham.

Fox, D. J.1982 Fundamentals of research in nursing, 4th edition Appleton-Century- Crofts, Norwalk, New Jersey.

Franz, M.D. et al.1997 Conventional Versus Atypical neuroleptics: subjective Quality of Life in Schizophrenic Patients. *The British Journal of Psychiatry*. **170**(5), pp. 422-425

Freeman, L.M. and Gil, K.M. 2004. Daily stress, coping, and dietary restraint in binge eating. *The International Journal of Eating Disorders.* **36, pp.** 204–12.

Fryers, T. and Woof, K.1989. A decade of mental health care in an English urban community: patterns and trends in Salford, 1976-87. In: Wing JK, editor. Health services planning and research. London: Gaskell.

Gaebel, W. et al. 2005. Schizophrenia practice guidelines: international survey and comparison. British Journal of Psychiatry. **187**, pp.248–255.

Gallo, K.M. 1994. First person account: Self stigmatization. *Schizophrenia Bulletin.* **20**, pp.407 – 410.

Garber, M.C. 2004. The concordance of self-report with other measures of medication adherence: a summary of the literature. *Medical Care.* 42, pp.649- 652.

Garfinkel, H. 1964. Studies of the Routine Grounds of everyday Activities, in Garfinkel, Studies in Ethnomethodology, Cambridge, Polity Press. pp. 35-76.

Gerlach, J. and Peacock, L. 1995. New antipsychotics: the present status. International *Clinical Psychopharmacology.* **10**(suppl 3), pp. 39-48.

Gibbons, J.S. and Butler, J.P. 1987. Quality of life for "new" long-stay psychiatric in-patients. The effects of moving to a hostel. *Br J Psychiatry.* **151,** pp.347–354.

Gibbons, J. S. and Butler, J. P. 1987. Quality of life for "new" long-stay psychiatric in-patients. The effect of moving to a hostel. *British Journal of Psychiatry.* **151**, pp.347-354.

Giddens, A. 2001. Sociology, 4th edn. Polity Press, Cambridge.

Gil, K.M.et al. 2004. Daily mood and stress predict pain, health care use, and work activity in African American adults with sickle-cell disease. *Health Psychology.* **23**, pp. 267–74.

Gill, A. 2003. An investigation into the distress caused by side-effects of atypical neuroleptic medication and the effects this may have upon the quality of life of patients' Leeds Metropolitan University submitted as part of Msc qualification (unpublished).

Giorgi, A. 1994. A phenomenological perspective on certain qualitative research methods, *Journal of Phenomenological Psychology.* **25**, pp.190-220.

Giorgi, A. 1975. An application of phenomenological method. In A. Giorgi, C. Fischer, & E. Murray (Ed.), Duquesne studies in phenomenological psychology. Vol. II. Pittsburgh: Duquesne University Press.

Giorgi, A. 2008. Concerning a serious misunderstanding of the essence of the phenomenological method in psychology. *Journal of Phenomenological Psychology*. **39**, pp.33-58.

Glaser, B. G. and Strauss, A. L. 1967. The discovery of grounded theory, Aldine, New York.

Goffman, E. 1963. Stigma: Notes on the Management of Spoiled Identity. Penguin Books, London.

Goffman, E. 1959. The presentation of self in everyday life. New York. Anchor Books

Goffman, E. 1968 Stigma. Notes on the Management of Spoiled Identity. Penguin Books, London.

Goffman, E. 1961. Asylums. Penguin, England.

Goffman. E. 1970. Social interaction; Expression, Game theory Blackwell. Oxford.

Goffman, E. 1982. Interaction Ritual: Essays on Face-to-Face Behaviour, New York. Pantheon.

Goffman, E. 1986. Frame Analysis: An Essay on the Organization of Experience, Boston. Northeastern University Press.

Goffman, E. 1986. Stigma. Notes on the management of spoiled identity. New York: Touchstone.

Goffman, E. 1990a. The Presentation of Self in Everyday Life, London, Penguin.

Goffman, E. 1990b. Stigma: Notes on the Management of Spoiled Identity, London, Penguin.

Goldberg, D. et al. 2000. WHO Guide to Mental Health in Primary Care ICD-10. World Health Organisation, Geneva.

Goldner, E. M. 2002. Prevalence and incidence studies of schizophrenic disorders: a systematic review of the literature. *Canadian Journal of Psychiatry*. **47**, pp. 833-843.

Graf, J. et al. 2004. Patients and community perceived stigmatization towards mentally ill people and its consequences on quality of life. *Journal of Nervous and Mental Diseases*. **192**, pp.542–547.

Green, G. et al. 2003. A Mental health service user's perspective of stigmatisation. *Journal of Mental Health*. **12**, (3), pp. 223–234.

Green, D. E. et al 1987. Community attitudes to mental illness in New Zealand twenty-two years on. *Social Science Medicine*. **24**, pp.417–422.

Green, J. and Britten, N. 1998. Qualitative research and evidence based medicine. *British Medical Journal*. **316,** pp. 1230-2.

Green, S.B. et al.2005. Living Stigma: The Impact of Labelling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families. *Sociological Inquiry*. **75**(2), pp.197–215.

Greene, J. C. et al. 1989. Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis*. **11**(3), pp.255–274.

Grimshaw, A. 2001. The Ethnographer's Eye: ways of seeing in modern anthropology. Cambridge University Press. Cambridge, UK.

Grosh, M and Glewwe, P. 2000. Designing household survey questionnaires for developing countries: lessons from 15 years of the Living Standards Measurement Study. Washington, DC: The World Bank.

Gysels, M. et al. 2002. Women who sell sex in a Ugandan trading town: life histories, survival strategies and risk. *Social Science and Medicine*. **54**, pp.179–92.

Hallett, C. 1995. Understanding the phenomenological approach to research. *Nurse Researcher*. **3**, (2), pp.55-65.

Hammond, H. 2008. Critically assess Goffman's analysis of the presentation of self, accessed at http://www.essex.ac.uk/sociology/documents/pdf/ug_journal/vol2/2009SC203_HannahHammond.pdf.

Hammond, M. et al. 1991. Understanding Phenomenology. Blackwell Science, Oxford Hammersmith: Harper Collins.

Hanson, W.E. et al 2005. Mixed Methods Research Designs in Counseling Psychology. *Journal of Counseling Psychology*. **52**(2), pp. 224-235.

Haralambos, M.et al. 1993. Sociology: A New Approach, 2nd edn. Causeway Press Ltd, Lancashire.

Haralambos, M. and Holborn, M. 2000. Sociology Themes and Perspectives, fifth edition.

Harding, C. et al. 1987. The Vermont longitudinal study of persons with severe mental illness, I. Methodology, study sample, and overall status 32 years later. *American Journal of Psychiatry.* **144**, pp.718-728.

Harding, C. M.et al. 1992.Chronicity in schizophrenia: revisited. *British Journal of Psychiatry.* **161** (18), pp.27–37.

Hargreaves, S. 2003. NICE guidelines address social aspect of schizophrenia. *BMJ.* **326** (7391) p.679.

Haupt, D.W. 2006. Differential metabolic effects of antipsychotic treatments. European Psychopharmacology.**16**(3), pp.149–155.

Hayward, P. and Bright, J. 1997. Stigma and mental illness: a review and critique. *Journal of Mental Health.* **6**, pp.345–354.

Healy, D. and McMonagle, T.M. 1997. Enhancement of Social Functioning as a Therapeutic Principle in the Treatment of Depression. *Journal of Psychopharmacology.* **11**, pp.525-531.

Heller, T. et al. 1996. Mental Health Matters: A Reader. Macmillan, London.

Henry, C.J. et al. 2004. Physical activity and levels of inactivity in adolescent females ages 11–16 years in the United Arab Emirates. *American Journal of Human Biology.* **16**, pp. 346–53.

Herz, M.I. et al. 1977. Brief hospitalization: A two-year follow-up. *American Journal of Psychiatry.* **134**, pp.502-507.

Hickey, G. and Kipping, C. 1998. Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing.* **7**, pp. 83–88.

Hoffmann, H. Et al. 1995. Age as a factor in identifying young adult chronic patients who are difficult to treat. *Psychiatric Services.* **46**, pp.404-406.

Hogan, T. P. et al. 1983. A self-report scale predictive of drug compliance in schizophrenics: reliability and discriminative validity. *Psychology of Medicine.* **13**, pp.177-183.

Holmes, C.A. 1990. Alternatives to natural science foundations for nursing. *International Journal of Nursing Studies.* **27**, pp.187-198.

Howe, K. 1985. Two Dogmas of Educational Research. Educational Researcher **14**(8), pp. 10-18.

http://www.nimhe.org.uk/antistigma/whatworks.[accessed 15 October 2007]

http://apps.bps.org.uk/_publicationfiles/consultation-responses/DSM-5%202011%20-%20BPS%20response.pdf (accessed on August 12th 2013).

Hudson, M. 1999. Psychiatric hospitals and patient's councils. In: This is Madness: A Critical Look at Psychiatry and the Future of Mental Health Services. (Eds Newnes, C).Holmes, G. & Dunn, C. pp.135–148. PCCS Books, Ross-on-Wye.

Husserl, E. 1977. Phenomenological psychology (J. Scanlon, Trans.). The Hague: Martinus Nijhoff. (Original work published 1962).

Hutchinson,S.A.et al 1994. Benefits of participating in research interviews. Image: *Journal of Nursing Scholarship*. **26**, pp.161-164.

Huxley, P. 1993. Location and stigma: a survey of community attitudes to mental illness: enlightenment and stigma. *Journal of Mental Health*. **2**, pp.73–80.

J. A. Daly (Eds.), Handbook of interpersonal communication (pp. 73-101). Thousand CA: Sage.

Harrison, J. and Gill, A. 2010. The experience and consequences of people with mental health problems, the impact of stigma upon people with schizophrenia: a way forward' *Journal of Psychiatric and Mental Health Nursing*. **17**, pp.242–250.

Jablesnky, A. et al. 1992. Schizophrenia: Manifestations, incidence and course in different cultures. *Psychological Medicine*. Supplement **20**, pp.1-97.

Jeffries, J. J. 1995. The acute phase. In B. D. Jones (Ed.), Demystifying schizophrenia: Navigating diagnosis, care and recovery (pp. 33-56). Montreal, QC: Grosvenor House Press Inc.

Jeste, D.V and Caligiuri, M. P. 1993. Tardive Dyskinesia. *Schizophrenia Bulletin*. **19** pp. 303-316.

Jeste, D.V. et al. 1999. Incidence of tardive dyskinesia in early stages of low-dose treatment with typical neuroleptics in older patients. *American Journal of Psychiatry*. **156**, pp. 309-311.

Johannsen, W. 1969. Attitudes towards mental patients: A review of empirical research. *Mental Hygiene*. **53**, pp.218- 227.

Johnson, W. S. 1986. 'Appraising Goffman', in *The British Journal of Sociology*. **37** (3) pp. 348-369.

Johnson, R. B. and Onwuegbuzie, A. J. 2004. Mixed methods research: A research paradigm whose time has come. *Educational Researcher*. **33**(7), pp.14-26.

Johnston, M.E. et al .1984. Effects of labelling on income, work and social function among hypertensive employees. *Journal of Chronic Disease*. **37**, pp. 417–423.

Johnstone, L. 1999. Do families cause 'schizophrenia'? Revisiting a taboo subject. In: This is Madness: A Critical Look at Psychiatry and the Future of Mental Health Services (Eds Newnes, C., Holmes, G. & Dunn, C. pp. 119–132. PCCS Books, Ross-on-Wye.

Jorm, A.F. et al. 1997. Helpfulness of interventions for mental disorders: beliefs of health professionals compared with the general public *Br J Psychiatry*. **171**, pp.233-7.

Jorm, A.F. et al.1997. Beliefs about the helpfulness of interventions for mental disorders: a comparison of general practitioners, psychiatrists and clinical psychologists. *Aust N Z J Psychiatry*. **31**(6), pp.844-51.

Kane, J. 1999. Olanzapine in the long-term treatment of schizophrenia. *British Journal of Psychiatry*. – Supplement. **37**, pp.26-9.

Kane, J.M. and Marder, S.R. 1993. Psychopharmacologic treatment of schizophrenia. *Schizophrenia Bulletin*. **19** pp. 287-302.

Kaplan, H.I. and Sadock, B.J. 1992. In: Comprehensive Textbook of Psychiatry. Wilmington, DE: Williams and Wilkins.

Katschnig, H. 1997.How useful is the concept of quality of life in Psychiatry? *Current Opinion in Psychiatry*. **10**(5), pp. 337-345.

Kemmler, G. et al. 1997. General life satisfaction and domain-specific quality of life in chronic schizophrenic patients. *Quality Life Res*. **6**, pp.265-273.

Kenten, C. 2010. Narrating Oneself: Reflections on the use of solicited diaries with diary interviews. *Qualitative Social Research on line*, **11** (2).

Kessler, R. C. 1999. The World Health Organization International Consortium on Psychiatric Epidemiology (ICPE): initial work and future directions. *Acta Psychiatrica Scandinavica*. **99**, pp.2 -9.

King, M. B. 1993. Management of schizophrenia - the general practitioner's role. British *Journal of General Practice*. **42**, pp. 310 - 11.

Kinon, B. J. and Lieberman, J. A. 1996. Mechanisms of atypical antipsychotic drugs: a critical analysis. *Psychopharmacology.* **124,** pp.2-34.

Kirby, A. 1991. Narrative and the self. Bloomington: Indiana University Press.

Kisling, W. 1994. Compliance, quality assurance and standards for relapse prevention in schizophrenia. *Acta Psychiatrica Scandiniavica.* **89**(382), pp.16-24.

Knapp, M.R.J. 1997. Cost of schizophrenia. *British Journal of Psychiatry.* **171,** pp. 509-518.

Knight, M.T.D. et al. 2003. People don't understand: an investigation of stigma in schizophrenia using Interpretative Phenomenological Analysis (IPA*). Journal of Mental Health.* **12**, pp. 209–222.

Koch, T. 1995. Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing.* **21**, pp.827-836.

Kvale, S. 1996. Interviews. An introduction to qualitative research interviewing. CA: Sage.

Lai, Y.M. et al. 2000. Stigma of mental illness. *Singapore Med J*, **42.** Pp. 111-4.

Lally, S. 1989. Does being in here mean there is something wrong with me? *Schizophrenia Bulletin.* **15**, pp. 253-265.

Lamb, H. R. and Goertzel, V. 1977. The long-term patient in the era of community treatment. *Archives of General Psychiatry.* **34**, pp.679-682.

Lamb, R. H. 1979. The new asylums in the community. *Archives of General Psychiatry.* **36**, pp.129 -134.

Landgren, B.M. et al. 2004. Menopause transition: annual changes in serum hormonal patterns over the menstrual cycle in women during a nine-year period prior to menopause. *Journal of Clinical Endocrinology and Metabolism.* **89,** pp.2763–9.

Larsen, E. B. and Gerlach, J. 1996. Subjective experience of treatment, side-effects, mental state and quality of life in chronic schizophrenic out patients treated with depot neuroleptics. *Acta Psychiatrica Scandinavica*, **93**, pp.381-388.

Laurence, J. 2002. Pure Madness: How Fear Drives the Mental Health System. Kings Fund, London.

Lefley, H. 1987. Impact of mental illness in families of mental health professionals. *Journal of Nervous and Mental Disease*.**175**, pp.613 -619.

Lefley, H.P. 1992. `The stigmatized family' in P.J, Fink & A. Tasman (Eds.) Stigma and Mental Illness (pp.127-138). Washington, D.C, American Psychiatric Press.

Lefley, H.P. 1996. Family Caregiving in Mental Illness, London, Sage.

Lehman, A. 1983. The well- being of chronic mental patients: assessing their quality of life. *Archives of General Psychiatry*. **40**, pp. 369-373.

Lehman, A. et al. 1982. Chronic mental patients: The quality of life issue. *American Journal of Psychiatry*. **139**, pp.1271-1276.

Lehman, A.F. et al 1986. The quality of life of chronic patients in a state hospital and in community residences. *Hospital and Community Psychiatry*. **37,** pp**.** 901-907.

Lemert, E. 1962. Human Deviance: Social Problems and Social Control New Jersey: Prentice Hall, Eaglewood Cliffs.

Lemert, E. M. 1951. Social pathology. New York: MacGraw Hill.

Levav, I. et al. 1993. An epidemiological study of mental disorders in a 10-year cohort of young adults in Israel. *Psychological Medicine*. **23**, pp. 691 -707.

Lewis, G. et al. 1998. Socioeconomic status, standard of living and neurotic disorder. *Lancet*. **352**, pp.605 -609.

Lieberman, J.A. 1996. Atypical antipsychotic medication as first line treatment of schizophrenia: a rationale and hypothesis. *Journal of Clinical Psychiatry*. **57**. (11), pp. 68-71.

Lincoln, Y. S. and Guba, E. G. 1985. Naturalistic inquiry. Beverly Hills, CA:Sage

Lindow, V. 1990. Participation and Power. *OpenMind*. **44**, p.10.

Link, B.G. 1987. Understanding labelling effects in the area of mental disorders: an assessment of the effects of expectations of rejection. *American Sociological Review*. **52**, pp.96–112.

Link, B.G. et al. 1991. The effectiveness of stigma coping orientations: can negative consequences of mental illness labelling be avoided? *Journal of Health and Social Behaviour*. **32**, pp.302–320.

Link B.G. et al. 1997. On stigma and its consequences: evidence from a longitudinal study of patients with dual diagnosis of mental illness and substance abuse. *Journal of Health and Social Behaviour*.**38**, pp.117–190.

Link, B. and Phelan, J. 2001. Conceptualizing stigma. *Annual Review of Sociology*. **27**, pp.363 -385.

Link, B. G. 1982. Mental patient status, work, and income: An examination of the effects of a psychiatric label. *American Sociological Review*.**47**, pp.202–215.

Link, B.G. 2001. Adverse effects of perceived stigma on social adaptation of persons diagnosed with bi-polar affective disorder. *Psychiatric Services*. **52**, pp.1627-`1632.

Link, B.G. et al. 1989. A modified theory labelling approach to mental disorders: an empirical assessment. *American Sociological Review*. **54**, pp. 410-423. Cited in: Struening, E.L.et al. 2001. Stigma as a barrier to recovery: the extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services*. **52** (12), p.1634.

Luijpen, W. A. and Koren, H. J. 1969. A first introduction to existential phenomenology. Pittsburgh: Duquesne University Press.

MacIntyre, A. 1981. After virtue. New York: University of Notre Dame Press

Madriz, E. 2000. Focus groups as feminist research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. pp. 835–850. Thousand Oaks, London, New Delhi: Sage Publications.

Manning, C. and White, P.T.D. 1995. Attitudes of employers to the mentally ill. *Psychiatric Bulletin.* **19**, pp.541–543.

Manning, P. 1992. Erving Goffman and Modern Sociology, UK, Polity Press.

Marder, S.R. 1999. An approach to treatment resistance in schizophrenia*: British Journal of Psychiatry*. **37**, pp. 19-22

Mariño, R. et al. 1999. Reporting of events using diaries. In: Minichiello V, Sullivan G, Greenwood K, Axford R (Eds). Handbook for research in health sciences. Sydney, Australia: Addison-Wesley.

Markowitz, F.E. 1998. The effects of stigma on the psychological wellbeing and life satisfaction of persons with mental illness. *Journal of Health and Social Behaviour*. **34,** pp.335–347.

Marland, G. R. 1999. Atypical neuroleptics: autonomy and compliance? *Journal of Advanced Nursing.* **29**(3), pp. 615-622.

Maxcy, S. J. (2003). Pragmatic threads in mixed methods research in the social sciences: the search for multiple modes of inquiry and the end of the philosophy of formalism. In Tashakkori, A. and C. Teddlie, (Eds.), *Handbook of Mixed Methods in Social and Behavioral Research.* Thousand Oaks, CA: Sage Publications.

Maxwell, J. A. 1992. Understanding and validity in qualitative research. *Harvard Educational Review*. **62**(3), p.279.

McCann, T.V. 2004. Advancing self-determination with young adults who have schizophrenia. *Journal of Psychiatric and Mental Health Nursing*. **11**, pp.12–20.

McGuffin, P. and Neilson, M. 1999. Behaviour and genes. *British Medical Journal*. **3,** (19) pp.37–40.

Mead, G. H. 1934. Mind, self, and society: From the standpoint of a social behaviourist. London, University of Chicago Press.

Mechanic, D. 1989. Medical Sociology: Some Tensions Among Theory, Method, and Substance, *Journal of Health and Social Behaviour.* **30**(6), pp.147-160.

Mechanic, D. et al. 1994. Effects of illness attribution and depression on the quality of life among persons with serious mental illness. *Social Science Medicine.* **39**, pp.155–164.

Meltzer, H.Y. et al. 1990. Effects of six months of clozapine treatment on the quality of life of chronic schizophrenic patients. *Hospital and Community Psychiatry*. **41**, pp.892-897.

Mendelson, W. B. et al. 1977. Sexual physiology and schizophrenia. *Acta Scientifica Venezolana.* **28**, pp. 417-425.

Mental Health Act 1983 Law Online (accessed 18th August 2013) available at http://www.mentalhealthlaw.co.uk/Mental_Health_Act_1983_Overview

Mercier, C. and King, S. 1993. A latent variable causal model of the quality of life and community tenure of psychotic patients. *Acta Psychiatrica Scandinavica***. 89** pp.72-77.

Miles, M. and Huberman, A.M. 1994. Qualitative Data Analysis. Thousand Oaks, CA: Sage Publications

Minichiello, V et al. 1999. A review of male to male commercial sex encounters. Venereology: The Interdisciplinary, *International Journal of Sexual Health***. 11**, pp**.**32–41.

Mirowsky, J. 1990. Subjective boundaries and combinations in psychiatric diagnoses. *Journal of Mind and Behaviour*. **11**, pp.407-423.

Moorey, J.1998. The ethics of professionalised care. In: Psychiatric Nursing: Ethical Strife (Eds Barker, P. & Davidson, P.), pp. 39–56. Hodder, London.

Morgan, D. L. 2006. Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*. **1**, pp.48-76.

Morgenstern, H. and Glazer, W.M. 1993. Identifying the risk factors for tardive dyskinesia among long-term outpatients maintained with neuroleptic medications. *Archives of General Psychiatry.* **50**, pp.723-733.

Morrall, P. 1998a. Mental Health Nursing and Social Control. Whurr, London.

Morrall, P. 1998b. Clinical judgment and social empowerment. In: *Psychiatric Nursing, Ethical Strife* (Eds Barker, P. & Davidson, P.) pp. 249–255. Hodder, London.

Morrongiello, B.A. et al. 2004. Understanding toddlers' in-home injuries: I. Context, correlates, and determinants. *Journal of Paediatric Psychology*. **29**, pp. 415–31.

Mueser, K.T. et al. 1990. Social competence in schizophrenia: premorbid adjustment, social skill, and domains of functioning. *Journal of Psychiatric Research*. **24**, pp. 51-63.

Miles, P. 1977. Conditions predisposing to suicide: a review. *Journal of Nervous and Mental Disorders*. **164,** pp**.** 231 - 46.

Murray, C.J. and Lopez, A.D. 1996. Global health statistics. Cambridge, MA, Harvard School of Public Health, (Global Burden of Disease and Injury Series, vol. II).

National Institute for Clinical Excellence. 2002. Schizophrenia: Core Interventions in the Treatment of Schizophrenia in Primary and Secondary Care. Clinical Guideline 1. NICE, London.

National Institute for Clinical Excellence. 2008. NICE implementation uptake report: atypical antipsychotic drugs for the treatment of schizophrenia February.

National Institute for Mental Health in England. 2004. Emerging Best Practice in Mental Health Recovery. NIMHE.

National Institute for Mental Health in England. (NIMHE). 2004a. From Here to Equality: A Strategic Plan to Tackle Stigma and Discrimination on Mental Health Grounds. NIMHE, Leeds.

National Institute for Mental Health in England (NIMHE). 2004b. Scoping Review on Mental Health, Antistigma Discrimination, Current Activities and What Works. NIMHE,

London. Available at: http://www.nimhe.org.uk/antistigma/whatworks (accessed 15 October 2007).

National schizophrenic fellowship. 2002. Just one per cent: The experiences of people using mental health services.

Nieswiadomy, W. L. 1993. Foundations of nursing research (2 nd Ed), Norwalk, Appleton and Lange.

Nightingale, D. J. and Cromby, J. 1999b. Reconstructing social constructionism. In D.J. Nightingale & J. Cromby (Eds.), Social constructionist psychology: A critical analysis of theory and practice. pp. 207–224. Buckingham: Open University Press.

Nightingale, D.J. and Cromby, J. (Eds). 1999a. Social constructionist psychology: A critical analysis of theory and practice. Buckingham: Open University Press.

Norman, I. and Parker, F. 1990. Psychiatric patients' views of their lives before and after moving to a hostel: a qualitative study. *Journal of Advanced Nursing*. **15**(9), pp. 1036-44.

Nunnally, J.C. 1961. Popular Conceptions of Mental Health. Holt, Rinehart and Winston, New York, NY.

ODPM, London. Office of the Deputy Prime Minister (ODPM). 2004b. Factsheet. 'Stigma and discrimination on mental health grounds'. In: Action on Mental Health. A Guide to Promoting Social Inclusion, pp. 1–8. ODPM, London. Available at: http://www.socialinclusion.org.uk/publications/Action On Mental health%20Fact-Sheets.Pdf (accessed 15 October 2007).

Office of the Deputy Prime Minister. 2004a. 'The impact of stigma and discrimination' Mental Health and Social Inclusion. The Social Exclusion Unit Report. London: ODPM, pp. 24-3.

Oiler, C. 1982. The phenomenological approach tin nursing research. *Nursing Research*. **31**, pp.178-181.

Oliver, J.P.J. et al 1997. Measuring the quality of life of severely mentally ill people using the Lancashire Quality of Life Profile. *Social Psychiatry and Psychiatric Epidemiology*. **32,** pp.76-83.

Olshansky, S. et al. 1958. Employers' attitudes and practices in the hiring of ex-mental patients. *Mental Hygiene*. **3,** pp.391-401.

Omery, A. 1983.Phenomenology: a method for nursing research. *Advances in Nursing Science*. **5**, pp.9-63.

Onyett, S. R. and Ford, R. 1996. Community mental health teams- where's the wreckage.

Orb, A. et al. 2001. Ethics in Qualitative Research. *Journal of Nursing Scholarship Volume*. **33**(1), pp. 93–96.

Osborne, J. W. 1994. Some similarities and differences among phenomenological and other methods of psychological qualitative research. *Canadian Psychology*. **35**(2), pp. 167-189.

Parsons, T. 2001. The social system Routledge.

Patel, N. and Fatimilehin, I. 1999. Racism and mental health. In: This Is Madness: A Critical Look at Psychiatry and the Future of Mental Health Services. (Eds Newnes, C., Holmes, G. & Dunn, C.), PCCS Books, Ross-on-Wye.

Patton, M. Q. 2002. Qualitative evaluation and research methods (3rd edition) Thousand Oaks, CA Sage Publications, Inc.

Perlick, D.A. et al. 200. Adverse effects of perceived stigma on social adaptation of persons diagnosed with bi-polar affective disorder. *Psychiatric Services* .**52**, pp.1627–1632.

Perring, C. et al. 1990. Families Caring for People Diagnosed as Mentally Ill: The Literature Examined. HMSO/ Social Research Policy Unit, London.

Phelan, J.C. et al. 1997. On stigma and its consequences: evidence from a longitudinal study of men with dual diagnosis of mental illness and substance abuse. *Journal of Health and Social Behaviour.* **38**, pp.177–190.

Phelan, J. et al. 1998. Psychiatric illness and family stigma. *Schizophrenia Bulletin*. **24**, pp.115-126.

Phelan, J. C. and Link, B. G. 1998. The growing belief that people with mental illnesses are violent: The role of the dangerousness criterion for civil commitment. *Social Psychiatry and Psychiatric Epidemiology*. **33**(1), pp.7–12.

Phelan, J. C. et al. 1997. Public conceptions of mental illness in 1950 and 1996: Has stigma declined? Paper presented at the Annual Meeting of the American Sociological Association, Toronto.

Phillips, M. R. et al. 2000. Causes of schizophrenia reported by patients' family members in China. *British Journal of Psychiatry*. **177**, pp.20-25.

Phillips, M. R. et al. 1990. Issues Involved in the Use of Scales for the Assessment of Negative and Positive Symptoms in Psychiatric Patients (in Chinese). Wuhan, PRC, Hubei Science and Technology Publishing House.

Philo, G. 1996. Media and Mental Distress. Addison Wesley Longman, New York.

Picchioni, M. and Murray, R. 2007. Schizophrenia. *BMJ*. **14** (6)**,** 335(7610) pp.91-5.

Pinikahana, J. et al. 2002. Quality of life in schizophrenia: a review of the literature from 1995 to 2000. *International Journal of Health Nursing*. **11**pp. 103-111.

Pinkney, A .A. et al. 1991. Quality of life after psychiatric rehabilitation: the client's perspective. *Acta Psychiatrica Scandinavica*. **83,** pp. 86-91.

Platt, S. 1985. Measuring the burden of psychiatric illness on the family: an evaluation of sane rating scales. *Psychological Medicine.* **15,** pp**.** 383-93.

Porter, R. 1998. Can the stigma of mental illness be changed? *The Lancet*. **352**, (9133), pp.1049 – 1050.

Porter, R. 2002. Madness, a brief history Oxford University Press.

Punch, M. 1994. Politics and ethics in qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.). Handbook of qualitative research. Newbery Park, CA: Sage.

Rabinow, P.1991. The Foucault Reader: An Introduction to Foucault's Thoughts. Penguin Books, London.

Rabkin, J. G. 1974. Public attitudes toward mental illness: a review of the literature. *Schizophrenia Bulletin*. **10**, pp. 9 -33.

Ramos, M.C. 1989. Some ethical implications of qualitative research. *Research in Nursing and Health.* **12**, pp.57-63.

Ramsay, R. and Fahy, T. 1995. Recent Advances: Psychiatry. *British Medical Journal*. **311**(6998), pp.167-170.

Read, J. and Reynolds, J. 1997. Speaking our minds-An Anthology. London; Macmillan.

Remmington, G. and Kapur, S. 2000. Atypical antipsychotics: are some more atypical than others? *Psychopharmacology***. 148**, pp.3- 15.

Reynolds, L.R. and Anderson, J.W. 2004. Practical office strategies for weight management of the obese diabetic individual. *Endocrine Practice*.**10,** pp.153–9.

Robins and Regier. 1991. Psychiatric disorders in America: The epidemiologic catchment area study Free Press (New York and Toronto and New York).

Robinson, J. A. and Hawpe, L. 1986. Narrative thinking as a heuristic process. In T. R. Sarbin (Ed.), Narrative psychology: The storied nature of human conduct (pp. 111-125). New 400–423.

Robson, C. 2002. Real World research (2nd edition) Blackwell Publishing, Oxford.

Rog, D. J. and Rausch, H. L. 1975. The psychiatric halfway house: how is it measuring up? *Community Mental Health Journal*.**11**, pp. 155-162.

Rose, N. 1994. Medicine, history and the present. In: Reassessing Foucault: Power, Medicine and the Body (Eds Jones, C. & Porter, R.), pp. 48–72. Routledge, London.

Rose, N. 1999. Governing the Soul: The Shaping of the Private Self. Free Association Books, London.

Rosenfield, S. 1997. Labelling mental illness: the effects of received services and perceived stigma on life satisfaction. *American Sociological review*. **62**, pp.660–672.

Roth, M. 1986. The Reality of Mental Illness Cambridge University Press.

Royal College of psychiatrists. 1999. Patient Advocacy. Council report CR74.London: Royal College of Psychiatrists.

Rush, D. et al. 1988b. The National WIC Evaluation: evaluation of the Special Supplemental Food Program for Women, Infants, and VII Children. VII. Study of food expenditures. *American Journal of Clinical Nutrition*. **48**, pp. 512–9.

Ryan, T.E. 1999. Managing Crisis and Risk in Mental Health Nursing. Stanley Thorne's publishers Ltd., Cheltenham.

Saha, S. et al. 2005. A systematic review of the prevalence of schizophrenia. *PLoS Med* **2**(5), pp.141.

Saha, S. et al. 2004. A systematic review of the incidence of schizophrenia: the distribution of rates and the influence of sex, urbanicity, migrant status and methodology. *BMC Med*. **28,** pp. 2-13.

Sainfort, F. et al. 1996. Judgements of quality of life of individuals with severe mental disorders: Patient self-report versus provider perspectives. *American Journal of Psychiatry*. **153**(4), pp. 497-502.

Sale, J. E.et al. 2002. Revisiting the quantitative-qualitative debate: Implications for mixed-methods research. *Quality & Quantity*. **36**, pp. 43-53.

Sandelowski, M. 2001. Real qualitative researchers do not count: The use of numbers in qualitative research. *Research in Nursing and health*. 24(3), pp. 230-240

Sartorius, N. 2002. Iatrogenic stigma of mental illness. *British Medical Journal*. **324**, pp.1470–1471.

Sartorius, N. 2007. Physical illness in people with mental disorders. World Psychiatry. **6**, pp.3–4.

Sayce, L. 2000. From Psychiatric patient to Citizen. London: Macmillan.

Scambler, G. 2004. Reframing stigma: felt and enacted stigma and challenges to the sociology of chronic disabling conditions. *Social Theory and Health*. **2**, pp.29–46.

Scheff, T. 1999. Being Mentally Ill. Hawthorne, New York, Aldine Transaction.

Scheff, T. 2006. Goffman Unbound A New Paradigm For Social Science, London, Paradigm Publishers.

Schlosberg, A. 1993. Psychiatric stigma and mental health professionals (stigmatisers and destigmatisers). *Medicine and Law*. **12**, pp. 409–416.

Schultze, B. et al. 2003. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social science and medicine*. **56**, pp.299-313.

Schwandt, T.A. 2000. Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics and social constructivism. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (2nd ed., pp. 189-214). Thousand Oaks, CA: Sage.

Segal, S. P. and Aviram, U. 1978. The mentally ill in community-based sheltered care. New York: Wiley.

Shapiro, A. and Shapiro, E. 2000. The Powerful Placebo: From Ancient Priest to Modern Physician The John Hopkins University press London.

Sharma, T. 2002. Cited in NICE guidance "a real victory" for people with schizophrenia *BMJ*. **15**, (324) p. 1413.

Shera, W. and Delva-Tauiliili, J. 1996. Changing MSW students' attitudes towards the severely mentally ill. *Community Mental Health Journal*. **32**, pp.159-169.

Sheringham, J. et al. 2002. Neuro imaging in schizophrenia: from theory to practice *Hospital Medicine*. **63**, (6), pp.328-331.

Simpson, C.J. 1989. The chronically mentally ill in community facilities. A study of quality of life. *Br J Psychiatry*. **154**, pp.77-82.

Sirey, J. et al. 1999. Predictors of antidepressant prescription and early use among depressed outpatients. *American Journal of Psychiatry*. **156**, pp.690–696.

Sirey, J.A. et al. 2001. Perceived stigma and patient rated severity of illness as predictors of antidepressant drug adherence. *Psychiatric Services*.**52**, pp.1615–1620.

Sirey, J. A. et al. 1999. Psychological barriers in young and older outpatients with depression: Predictors of treatment discontinuation. Paper presented at the American Association of Geriatric Psychiatry, 12th Annual Meeting, New Orleans, LA. March 14–17, 1999.

Siris, S. 2000. Depression in Schizophrenia: Perspective in the Era of "Atypical" Antipsychotic Agents. *The American Journal of Psychiatry*. **157**(9), pp. 1379-1389.

Skantze, K. et al. 1992. Comparison of quality of life with standard of living in schizophrenic outpatients. *British Journal of Psychiatry*. **162**, pp. 797-801.

Skull, A. 1996. Asylums, Utopias and Realities, Ch 1 Tomlinson D & Carrier, (1996) Asylum in the Community London, Routledge.

Smith, G. 2006. Erving Goffman, London: Routledge.

Sofaer, S (1999) Qualitative methods: What are they and why use them. *Health services research.* **34**(5), pp.1101-1118.

Spiegelberg, H. 1982. The Phenomenological Movement: A historical introduction. 3rd Ed.

Spiegelberg, H. 1965. The Phenomenological Movement: A Historical Introduction, 2nd edition Nijhoff, The Hague.

Spilker, B. 1990. Quality of life assessments in clinical trials Raven Press.

Stein, L. and Test, M. A. 1980. Alternative to mental hospital treatment: conceptual model, treatment program and clinical education. *Archives of General Psychiatry*. **37**, pp.392-397.

Stenbacka, C. 2001. Qualitative research requires quality concepts of its own. *Management Decision*. **39**(7), pp.551-555.

Stevenson, O. 2005. 'Working Together in Cases of Neglect: Key Issues' in J Taylor and B Daniel (Eds) Child Neglect: Practical Issues for Health and Social Care, London: Jessica Kingsley.

Stewart, D. C.et al. 2010. 'It's not my job. I'm the patient not the doctor': Patient perspectives on medicines management in the treatment of schizophrenia, *Patient Education and Counseling Volume*. **78**(2), pp.212-217.

Stopka, T.J. et al. 2004. Writing about risk: use of daily diaries in understanding drug user risk behaviours. *Aids and Behaviour* **8**, pp.73–85.

Strauss, J. 1989. Subjective experiences of schizophrenia: towards a new dynamic psychiatry II. *Schizophrenia bulletin* .**15**(2), pp.179-88.

Striegel-Moore, R.H. et al. 2004. Definitions of night eating in adolescent girls. *Obesity Research.* **12**, pp.1311–21.

Struening, E.L.et al. 2001. Stigma as a barrier to recovery: the extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services*. **52**, pp.1633–1638.

Sullivan, G. et al. 1992. Quality of life of seriously mentally ill persons in Mississippi. *Hospital and Community Psychiatry*. **42**, pp. 752-754.

Szasz, T. S. 1961. The Myth of Mental Illness, Holber-Harper, New York.

Talbott, J. A. 1994. The chronic mental patient. Washington, DC: American Psychiatric Association.

Talbott, J. A. and Linn, L. 1978. Reactions of schizophrenics to life threatening disease. *Psychiatric Quarterly*. **50** (2) pp.18-227.

Tandon, R. 1997. Effects of atypical antipsychotics on polysomnographic measures in Schizophrenia. *Bibliotheca Psychiatrica*. **167**, pp.219-222.

Taylor, A. et al. 2004. Influence of diet on iron, copper, and zinc status in children under24 months of age. *Biological Trace Element Research*. **97,** pp.197–214.

Taylor, S.M. and Dear, M.J. 1981. Scaling community attitudes towards the mentally ill. *Schizophrenia Bulletin*. **7**, pp.225– 240.

Taylor, D. et al, 2000. The Bethlem & Maudsley NHS Trust Prescribing Guidelines (6th edn). London: Martin Dunitz.

Thompson, M. and Thompson, T. 1997. Discrimination against People with Experiences of Mental Illness. Mental Health Commission, Wellington.

Tollefson, G. et al. 1997. Olanzapine versus Haloperidol in the Treatment of Schizophrenia and Schizoaffective and Schizophreniform Disorders: Results of an International Collaborative Trial. *American Journal of Psychiatry*. **154**(4), pp. 457-465.

Tollefson, G. et al. 1999. Controlled double blind investigation of the clozapine discontinuation symptoms with conversion to either Olanzapine or placebo. *Journal of Clinical Psychopharmacology*. **19**(5), pp. 435-443.

Torrey, E.F. 1997. Out of the Shadows: Confronting America's Mental Illness Crisis. John Wiley and Sons, New York, NY.

Tsang, H.W. et al. 2003. Stigmatizing attitudes towards individuals with mental illness in Hong Kong. *Journal of Community Psychology*. **31**, pp.383–396.

Tucker, R. 1999. BTSCS: A Binary Time-Series, Cross-Section Data Analysis Utility. Version 4.0.4. Cambridge, MA: Harvard University.

Twinn, S. 2003. Status of mixed methods research in nursing. In A. Tashakkori, & C. Teddlie (Eds.), Handbook of mixed methods in social and behavioral research (pp. 541-556). Thousand Oaks, CA: Sage.

Ullmann, L. P. and Krasner, L. 1965. Case studies in behaviour modification. New York: Holt, Rinehart & Winston, 1965. 401 Stony Brook, New York.

Van Manen, M. 1978/1979. An experiment in educational theorising: The Utrecht School. Interchange **10**, pp. 48-66.

Van Manen, M. 1983. Invitation to phenomenology and pedagogy. Phenomenology & Pedagogy 1, i-ii.

Van Manen, M. (1997). Researching lived experience: human science for an action sensitive pedagogy.

Van Manen, M. (1999). The pathic nature of inquiry and nursing. In: Madjar, Irena and Walton, Jo (eds.), Nursing and the experience of illness. *Phenomenology in practise*. London Routledge, pp.17-35.

Van Manen, M. (Ed). 2002. Writing in the dark: Phenomenological studies in interpretive inquiry. London, ON. Althouse Press.

Van, O.S. et al. 1997. Tardive Dyskinesia: who is at risk? *Acta Psychiatrica Scandinavica.* **96,** pp. 206-216.

Van Putten, T. and May, P. R. A. 1978. "Akinetic depression" in schizophrenia. *Archives of General Psychiatry.* **35,** pp. 1101-1107.

Van Putten, T. and May, P.R.A. 1978. Subjective response as a predictor of outcome in pharmacotherapy. *Archives of General Psychiatry*. **35**: pp. 477- 80.

Van Putten, T. et al. 1984. Response to antipsychotic medication: The doctor's and the consumer's view. *American Journal of Psychiatry*. **141,** pp.16-19.

Vass, A. 2002. NICE guidance "a real victory" for people with schizophrenia. *BMJ.* **15**,324(7351).p. 1413.

Verbrugge, L.M. 1980. Health diaries. *Medical Care*.**18**, pp.73–95.

Waddington, J. L. et al. 1997. The new antipsychotics and their potential for early intervention in schizophrenia. *Schizophrenic Res*; **28,** pp. 207-222.

Walters, A.J. 1995. The phenomenological movement: implications for nursing research. *Journal of Advanced Nursing*. **22**(4), pp.791-799.

Warner, R. 1989. Deinstitutionalization: How did we get where we are? *Journal of Social Issues*. **45** (3), pp. 17-30.

Weiss, M.F. 1994. Children's attitudes toward the mentally ill: an eight-year longitudinal follow-up. *Psychological Reports*. **74**, pp.51–56.

Wertz, F. J. 1983. From every day to psychological description: analyzing the moments of a qualitative data analysis. *Journal of Phenomenological Psychology* .**14** (2), pp.197–241.

Wertz, F. J. 2005. Phenomenological research methods for counselling psychology, *Journal of Counselling Psychology*. **52**(2), pp.167-177.

Wheeler, L. and Reis, H.T. 1991. Self-recording of everyday life events: origins, types and uses. *Journal of Personality*. 59, pp.339–54.

Whitbourne, S.K. and Sherry, M.1991. Identity processes and perceptions of the life span in chronic mental patients. *Int J Aging Hum Dev*. **33**(1), pp.65-73.

Williams, A.C. 2002. Facial expression of pain: an evolutionary account. *Behav Brain Sci* **25**, pp. 439–88.

Williams, C.C. and Collins, A.A. 1999. Defining new frameworks for psychosocial interventions. *Psychiatry.* **62**, pp.61–68.

Williams, C.C. and Collins, A.A. 2002. The social construction of disability in schizophrenia. *Qualitative Health Research*. **12**, pp.297–309.

Wing, J. K. (ed.) 1989. Health Services Planning and Research. Contributions from Psychiatric Case Registers. London: Gaskell.

Wiseman, V. et al. 2005. Using diaries to collect data in resource-poor settings: questions on design and implementation. *Health policy and planning*. **20**(6), pp. 394-404.

Wolff, G. et al. 1996. Community attitudes to mental illness. *British Journal of Psychiatry*. **168**, pp.183-190.

Wolff, G. 1997. Attitudes of the media and the public. In J. Leff (Ed.), Care in the community: Illusion or reality? (pp. 145–163). London: Wiley.

World Health Organisation. 1992. The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. World Health Organisation, Geneva.

World Health Organisation. 1994. Quality of life assessment: An annotated bibliography. Geneva: Author (MNH/PSF/94.1).

World Health Organization. 1993. The ICD-10 Classification of Mental and Behavioral Disorders: Diagnostic Criteria for Research. Geneva. WHO.

Wright, E.R. et al. 2000. Deinstitutionalisation, social rejection, and the self-esteem of former mental patients. *Journal of Health Soc. Behaviour*. **41**, pp.68-90.

Yin, R.K. 1994. Case Study Research: Design and Methods, 2nd edition. Thousand Oaks California Sage key text on design and analysis of rigorous case studies.

Zimmerman, M.A. 1990. Toward a Theory of Learned Hopelessness: A Structural Model Analysis of Participation and Empowerment" *Journal of Research Personality*. **24**, pp.71-86.

Zimmerman, M.A. and Rappaport, J. 1988. Citizen Participation, Perceived Control, and Psychological Empowerment. *American Journal of Community Psychology*. **16**, (5), pp.725-750.

Appendix A

DSM-IV diagnostic criteria for schizophrenia

A. *Characteristic symptoms:* two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):

    (1) delusions

    (2) hallucinations

    (3) disorganized speech (e.g. frequent derailment or incoherence)

    (4) grossly disorganized or catatonic behaviour

    (5) negative symptoms (i.e. affective flattening, alogia, or avolition)

Note: only one criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other.

B. *Social/occupational dysfunction:* for a significant portion of the time since the onset of the disturbance, one or more major areas of functioning, such as work, interpersonal relations, or self-care, are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).

C. *Duration:* continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet criterion A (i.e. active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in criterion A present in an attenuated form (e.g. odd beliefs, unusual perceptual experiences).

D. *Schizoaffective and mood disorder exclusion:* schizoaffective disorder and mood disorder with psychotic features have been ruled out because either (1) no major depressive, manic or mixed episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

E. *Substance/general medical condition exclusion:* the disturbance is not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition.

F. *Relationship to a pervasive development disorder:* if there is a history of autistic disorder or another pervasive development disorder, the additional diagnosis of schizophrenia is

made only if prominent delusions or hallucinations are also present for at least 1 month (or less if successfully treated).

Appendix B

Diary one

Participant one

3rd April 2008

Tony Gill's just been to see me. Although I felt really nervous about him coming, think I did alright. He explained the study really well, left lots of information and this diary.

Got to go to Sam's birthday party this afternoon. Will be seeing people I haven't seen since my illness became public knowledge last year, last time I was unwell I decided to let family and friends know, it was a hard decision to make, to let people know about my schizophrenia. Theirs such a stigma attached to it!!!!!

Anyway back to this party, I feel a bit nervous, but I will go, why shouldn't I go???

No 1.   Not sure how they're going to react to me.

No 2.   Not sure how I'm going to react to them???

I can do this, I can face them, I think!!

God if I can go down to London and back on my own to submit 2 pieces of artwork to the R.A I can handle a kids party can't I?? Still feel high from doing that, won't find out till 30th May whether they have been accepted though. Feel like I've just sat an exam and have to wait for the results. But I did it. Wouldn't have done that a year ago, must be due to my new medication. Well I know it is!!! For the record I am on Aripiprazole (Abilify) and take 15mgs a day. Brilliant stuff, apart from the constipation, well supposes that varies, depending on what I eat. But at least I don't feel constantly hungry like I was on Olanzapine that was a nightmare.

Better unpack from my London trip and get ready for this party. Handled the party well, felt I mixed in and chatted ok. What with London and stuff feeling pretty good, I went to the party and fitted in ok, even though I'm feeling nervous about doing stuff I push myself and find I can do it, feel my confidence is returning which is brilliant. Although the party might have something to do with the beer I drank while I was there, probably a combination of the two. I find on this medication I don't need to drink a lot before I'm feeling tipsy, but on the whole I don't drink much.

Told Steve about Tony, the study and diary, Steve (my son) said it's a good idea, which is what I thought.

<u>Friday 4th April 2008</u>

Not going to open the curtains this morning, I suppose I'm feeling really good and would be so disappointed and down if they were there, so not going to open them and check. Some days I just feel I can't face it, but that's just me, sometimes scared of spoiling how good I'm feeling.

Mums taking me to the supermarket to do a shop, which doesn't freak me out quite like it used to. When I was unwell in the supermarkets I used to feel someone or something stroke the side of my face, that doesn't happen anymore, thank god!!!!! But it doesn't stop me from thinking about it when I am in one. Anyway she's coming and I'm going; one needs to eat.

But the curtains are staying shut. Before this new medication I lived with them pressing up against the windows for a long time, ages and the fear of them getting in!!!!

It makes me …………………. Oh when I think of them. If I close my eyes I can still picture them even now, even though I am well at the moment I still can. Oh Nikki think of something else quickly maybe if I draw them just one more time I'll get it out of my system once and for all, it's not just picturing them I can still feel the fear they made me feel, constantly hoping and praying that they couldn't get in. might draw them when I get back from the supermarket??????? That's my way of coping I suppose, I'll do that!! I'll draw them one last time!!!!

Went shopping with Mum as planned and I was fine. Told Mum about the study and Tony etc. I was fine that's cool!!!

I just have to keep thinking positively when I do stuff take my medication and Bob's your uncle. I'll draw them ….yes think that's a good idea!!! Oh and by the way the curtains are still closed. I'll see how positive I'm feeling in the morning???? As regards to the opening of the curtains that is.

<u>Saturday 5th April 2008</u>

Meeting my daughter Becky in town this morning, we're window shopping and we always have a good natter when we do that, feeling positive today. Think I'm still on a high from going down to London. Hope the drawings are selected to hang in the summer exhibition; fingers crossed, feeling pretty good. Did artwork last night and yesterday, I know some people won't appreciate the subject matter, "faces at the window" but it's relevant to me!!!!

Image one

"Faces at the window"

And I've decided the curtains will be opened this morning. In fact I'll do it right now!!! I want to know today. No more burying my head in the sand, I'll know where I stand, and it's **clear**. Still haven't been in the back garden yet, well it's where they were isn't it!!!

I walked down the drive, once, really fast. Heart was pounding and I was sweating but I did it. Let me explain; the drive is the road where I was arrested by the police, handcuffed and

pushed into a police car. Then pushed into the back of a van and taken to police station. I was arrested and put in a cell for over11 hours and just the thought of walking down the drive again wasn't appealing. I was scared that it might happen again. I think them knowing I had schizophrenia made them react to me like that. I think I had a cup of tea twice and that was it, I wasn't in control in any shape or form that was the scary bit, if you can imagine it. So now when a police car rushes past with its sirens on I freeze inside. I suppose it's just something I'll have to live with!!!

It's not going to stop me meeting Becky or carrying on with my life. The police or schizophrenia that is. This new medication is fabulous, talking of medication I'll go take it now and get ready. Get ready (LOL) its only 6.45am and I'm not meeting Bex till 11.30am. That's me being able to laugh; it feels like laughing is **GOOD!!!.**

Met Becky earlier today we had lunch and shopped it was good. She's good company and shopping was fun. I can handle crowds alright now. Before when I was unwell I found that crowds', being in them was very very difficult. Wasn't very good at handling them at all, it's like I couldn't quite process all the stuff that went on around me as I concentrated on the stuff I had to deal with, like the voices telling me to say, even shout things out at them, and when they weren't doing that they were calling me names, they wanted me to yell, slag, whore, bitch and so on, very obscene, not very nice at all, so in the end I just kept avoiding those situations.

After town I caught the bus to Mums, everybody was there. It was lovely to see everybody, and chat, I've actually enjoyed yet another day, and so it gets better. That's brilliant but on the other hand I'm so scared that the bubble is going to burst at some point, so I make sure that I keep taking the medication. I don't mind with Aripiprazole as it doesn't have many side effects, when I first started taking it I felt a bit sick but that wore off after a while and the constipation comes and goes. I can put up with that. That's nothing compared to the side effects of Olanzapine, constantly feeling hungry, eating more and more and never feeling satisfied, was the worst side effect, which in turn led to the weight gain. I hated the act that I put on so much weight, hated it. I'd almost forgotten

What it was like to eat a meal and feel satisfied, but now I'm in control of what and how often I eat.

And I've maintained a reasonable weight. Although I would like to drop half a stone for the summer, but that's not undoable!

I can handle lots of people being at Mums now, before I used to have everyone and the voices shouting and it was like listening to a radio on two stations, couldn't quite tune into

them simultaneously, very **<u>confusing!!!!</u>** Wish I could explain it better, but what I'm trying to say is its good being well and I intend to stay that way!!!!! I know I have to take my medication and that's what I do!!!

I think I talk more to Dr A's about my experiences than before because I feel better and I'm not experiencing them anymore. I've just got the memory of them. That can be difficult at times but I feel it's just something I'll have to deal with, I think that's why he keeps sending Debbie my CPN to keep coming to see me, she's been coming to see me now for a year or thereabouts, since I was last in hospital. I don't mind really, but I know she wants to get me in the back garden, which I avoid, well it's where they were. Need I say anymore, mind you I am opening the curtains most days which is something, I don't feel in the least bit tired so I'll do some more drawing, a white horse, strong, proud loyal and yet gentle. That's somewhat comforting, those qualities, yes comforting.

Sunday 6th April 2008

It's the early hours of the morning and I can't get back to sleep. Had a really bad night, not just sleeping well but feeling bloated, haven't been to the loo for 3 days now. I'll have to go to the chemist on Monday, it's not just that though, I'm feeling really tired almost all too tired to sleep, well for any great length of time, feel restless. I know tired and restless seem like a contradiction but that's how I'm feeling; maybe it's the subject matter I went on to draw. "Can you see all of me???? Is the title.

Image two

Can you see all of me?

I went on to draw the image (image 2) I used to see of me in the mirrors when they had parts of me missing. Areas of my face would be just missing. Don't really feel up to talking or should I say writing about it at the moment, can't seem to face it, if you'll excuse the pun!!! Maybe I'll just draw something happy now to try and compensate??? I'll go back to "comforting", the white horse!!! Yes I'll do that, make another cup of tea and then I'll get back to it. Another cup of tea and a cig sounds good. Becky and Steve are still in bed, haven't slept much at all, and might as well stay up now!!!

You know this rooms a tip, I'm going to tidy it up right now, don't feel like I can handle doing anymore artwork at the moment so I'm going to tidy, don't have to think about what I'm doing or why if I just tidy. Will get bath and dressed later on, but one thing I'm going to force myself to open the curtains. Going to make myself do it right now!! Sharp intake of breath. And it's clear the window

Yes!!!!!

Now I can tidy.

It's so quiet with the kids in bed. Gosh it's so nice to be able to say quiet. No voices, just quiet how cool is that. I'm liking this quiet, quiet Quiet!!!!! When I am unwell the voices van be so loud, believe me quiet is good. The amazing thing is that sometimes they just used to whisper, I'd hear my name then whispering and I'd be annoyed that they were talking about me, and feel that they had something to say. They should at least say it to my face. So QUIET!! QUIET !! is oh so good. Going to tidy now before the kids get up. !!!

No thinking just tidy….

Steve went to play football earlier and Becky's just gone to work. Hadn't done much in the way of tidying up, didn't really talk much with Bex, but I did make her and myself some lunch. So I am now doing things. Well now that I've got the house to myself I'll do some more artwork. Sometimes I don't feel like talking much. Sometimes I just like to listen to the other people interact. Still feel part of the group but maybe that's just me. Now artwork.

Steve has been home about half an hour. We've made pizza while Steve chopped up a pepper to put on the top of it, while I put some chips in the oven. I didn't fancy that, I 'm having a small portion of cottage pie with a few chips. Chatted a little, feel more like talking now. Slept on the sofa for just over an hour. Feel refreshed must have needed that sleep. See I'm doing stuff. Today feel like it's a mixed bag of emotions. Can't seem to stay focused on a particular thing, whether it is artwork or tidying up!!!! Its 4.10pm and I'm still in my nightwear and I haven't had my bath etc as yet. Foods ready….

Monday 7th April 2008

Its 4.55am and I've had about 5 hours sleep. Let's see, my plans today are to walk to the shops and go to the bank and have a walk round there and catch the bus home. That's a walk round the shops and not the bank!!!! By the way!!!

Feeling really refreshed for having that sleep. Feeling really positive today so far. I can cope with the shops and all the crowds, I know I can. Yesterday has gone, just going to think about today, focus on that!! I will of course put my makeup. Feel like I can face the world when I put it on. Feel I can face the mirrors today. Which isn't always the case, but today I can!!!!!

Change of plan, need to go to town to get artists supplies; shops, town same difference I think. Can return a couple of items and do bank so that's good. Feel in a talking mood today, Steve still in bed and Becky stayed at her boyfriend's last night. No one around at the moment, and no I am not going to talk to myself, am a patient person I can wait till people are around. Been making cards since I got back from town. Had a very busy day today so far

and it's only 5pm. Steve's in the kitchen making tea. Met Becky in town for lunch, they had both been telling me off for humming again. Don't realize I am humming half of the time. I mean who is it hurting, no-one I think. Haven't been as talkative and I thought I would be today, but don't suppose it matters. I've been very creative instead. After tea I will do some artwork too as well. I'll go help Steve, and guess who will get stuck with the washing up????

Had a really good talk with Steve he's going to look for a job, now he's dropped out of sixth form. Not going to get upset or anything about it. Better tidy up my mess from being creative before bed as it's already 10.30pm. I've had a good day and a very productive day too!!!

Tuesday 8th April 2008

Well its 4.10am and I've had about 5 hours sleep. I've just washed the pots from last night, don't quite feel fully awake and after I've made these cigs I'll lie on the sofa for a bit. Feel good for having that sleep. Today I'm going to do the tidying that I've never quite got round to. I miss my stained glass course it doesn't start again till the 23rd April.

I feel I managed town and the buses ok yesterday, feel I'm doing GOOD!!! It's really nice to be feeling so POSITIVE!!! I might have schizophrenia but I'm just a person, trying to get on with my life, it doesn't make me any less of a person. It's made me appreciate being well, it's so good to be able to get on and do stuff, and that's what I intend to do, I really believe that feeling and being positive helps. Stuff the sofa I'm going to make some more cards.

When I'm drawing or painting or making cards I can get really absorbed into that activity and find that I don't really think about anything else. Which I really like. Some days I don't want to think too much about things or events that are going to happen or have happened, maybe it's my way of escaping from the world for a while, sometimes hours or sometimes depending on the subject matter it's my way of coping like with "faces at the window" or "in the walls" I don't analyse it too much I just do it. Or should I say draw it.

I've opened the curtains today, I want to know!!!!!!! And it's clear!!!! I knew it would be, that's how positive and well I'm feeling…..

Just spent ages drawing "can you see all of me?" don't know why I keep going back to that image and drawing it over and over, but I do!! When I was unwell the image I used to see of

me in the mirrors where parts of me were missing. I was terrified that one day I'd look in the mirror and all of me would be missing, if so would I still exist???? Now that's a thought isn't it!!!!

The kids have gone to their dads to watch Liverpool, so I can spread out my artwork and I won't be disturbed. I've just made the stew Natasha showed me how to make in London. Lovely, first time I've ever coked with red wine or any wine for that matter.

I've been busy all day; I find keeping busy really helps me. Helps me stay positive; don't mind taking this medication (Aripiprazole) Dr A's would be pleased that I take it religiously every morning. I lie Dr A's he straight forward and knows his stuff. Don't like the doctors in B…, questions and questions couldn't handle that then. But now I know it's different, I suppose there just trying to get a clear picture, what's happening with you. Dr A's knew why I behaved in certain ways when I told him stuff, he knows which is reassuring. It took me years before I could feel I could trust him, anyway artwork now.

The kids have come home and gone straight to bed; mind you it's after eleven. I've had a sleep for just over an hour on the sofa. I'm going to make some more cards now I feel inspired!!!

Wednesday 9th April 2008

I've done quite a lot today, food shopping, town, card making etc, and feel drained physically and emotionally. Had a lot on my mind. Kept thinking about stuff that used to happen when I was unwell. Drew "in the walls" early this morning. People that lived in my bed room walls (old bedroom). They were kind of emerging most likely with the intention of grabbing me and pulling me in to the walls. The scary thing is nobody would have looked for me if they had succeeded. Wish I could explain even just to myself why I keep drawing this stuff. I keep going back to the same picture working and reworking it, WHY!!!! That's been nagging me all day. ALL DAY!!!

Thursday 10th April 2008

I've got up in such a good mood today despite yesterday: I'm pleased to say!!! Better do my stuff and put my face on, its coffee morning at Chloe's. Today I've opened the curtains and can face the mirrors ok. Feeling good, good GOOD!!! Don't know what happened yesterday but today is a new day!!! Mind you I've had a good night's sleep maybe that's got something to do with it!!! Walked to Chloe's and back that's about 2 ½ miles in total. Think that's set me up for the day, had a really good natter to Chloe, and been making cards since I

got back. Need to make some more cigs then have something to eat, only had yogurts this morning.

Think Dr A would slap my wrists if he caught me dwelling, which is what happened yesterday, I'm going to ask him what the best thing to do is when I'm feeling that way inclined!! I find that even on a day like yesterday I still took my medication. Because I'm well, **I KNOW** I have to take it, talking or writing about it isn't the same as experiencing it, thank GOD!!!!

Amy's just left, Steve's gone to bed and Becky's staying at her boyfriend's flat.

Feeling tired so I should sleep ok tonight. I find on this medication I sleep a lot better, or is that because I'm being busy all day?? Most days!! I get about 5 or 6 hours and that about does it for me. With the little naps sometimes through the day.

Friday 11th April 2008

5.15am, the alarms set for 7.00am so I'm going to do my nails, on this medication they just grow, I'm sure it's the medication as my nails have never ever grown before. Only had about 5 hours sleep but feel refreshed and ready for the day. Going to local village with Mum and Gary today. I can face people, strangers when I come into contact with them when I'm out. Feel my confidence is really growing, more and more. I feel I could handle any situations if they were to arise which make me feel good.

With Abilify   I find that I go through periods of getting headaches, but taking headache tablets usually sorts that out, that as I say comes and goes. Well I haven't had one in over a week, but it's the best thing Dr A has done putting me on this medication. He should put everybody on it, its brilliant, never thought I'd ever say that about my medication, **EVER** one I was on once (Risperidone)? Can't spell it, was dreadful. I didn't have periods for over a whole year and my boobs used to leak and I used to shake and oh the list is endless of the awful side effects which can be very difficult to live with on a daily basis.

And when you've been unwell and recovering which in turn is bad enough, the added tress of unwanted side effects just adds to the struggle of trying to cope with your illness. I would never go back on any of the other medications. I'll stick with Abilify   every time from now on, which I'll go take right now!!!

All afternoon I've had indigestion terrible, I should never have eaten those fish and chips at lunchtime even though they were nice at the time. On the whole apart from that I've had a really good day, which is a good thing. I wonder if the indigestion has anything to do with

the medication??? The kids go to their Dads tonight for the weekend. I much prefer it when there around but there you go.

Lost Mum in H….., but instead of panicking I just made my way back to Gary's car, see I've got my thinking head on today, which I admit is not always the case. I'm going to chill out for a while and watch the telly box; anything will do not bothered even QVC for a bit. Don't really mind. Don't like it when it's just me and the kids are not here. But I'm a big girl I can cope. Now I'm well I do cope with things, think, well I like to think I'm quite a capable person. With the medication I'm on, feel like I've got a clear head which is unusual with these types of medications. Anyway cup of tea, telly box and a ciggy!!!!

Well it's just me now and I will have to entertain myself. I can do that. Artwork, card making or telly box. Think the indigestion is wearing off now which I'm pleased about, as its lasted hours (9.30pm). Might go to bed really feeling quite exhausted now.

Got really bad headache suddenly, I'll go take something.

Saturday 12th April 2008

8am got another headache will take something for it, silly not to really. I'll take my medication as well. Had a headache before bed last night and then just now. At least that indigestion has gone. Today I've planned to do artwork and card making all day. That's it just that. I've done the curtains but not going to bother getting dressed or putting my make up on. Not going anyway might as well stay comfortable in my pj's going to just concentrate on being creative. Feeling a big URR….

What with this headache, but I suppose the tablets will kick in soon enough. But apart from that feeling good, feeling CREATIVE!!!!!I bet this is the medication you know but I'd rather be WELL!!!! And put up with it.

Being is well is GOOD!!!! I can get on with my life like everyone else. I'll ask Dr A when I next see him about it. Now to be creative!!!!!

2pm just taken another headache tablet, still got one, but other than that been really creative. I suppose that's my thing. I can mingle but I prefer to observe. This time last year I couldn't mingle had too much stuff going on. I was incapable, pre occupied with symptoms I was

suffering with. But a while on my new medication has sorted me out!!! I feel like I have emerged from a deep black fearful existence. Like a huge cloud has been lifted. I think that's there's a few repercussions and problems that need ironing out, hence Dr A's and my CPN Debbie. But on the whole I feel like I am progressing on a daily basis, I have the odd wobbly day but who doesn't???? The symptoms disappeared ages ago it's just, well can't explain myself properly, arhhh…… maybe that's why I do all the artwork. Which I'm going to return to right now!!!!

Bex came home after work and is staying here tonight instead of going to her Dads. She has disappeared to her bedroom, which means you've guessed it more artwork. I've taken another headache tablet hopefully they will do the trick. I now I've said I don't mind too much but it's lasted all day!!!!

Defiantly going to ask Dr A's about these headaches, and in the mean time I'll just have to put up with them and continue to take the headache tablets.

Sunday 13th April 2008

Its 6.15am been up ages, I've had about 4 ½ hr. sleep. Don't really dream anymore or if I do I don't remember them. Used to have awful dreams really bad.

Today my plans are to tidy, bit of card making and artwork I'll go between the three. Bex's working today so I'll have the house to myself can really spread out and won't be interrupted.

Stayed up late last night doing artwork. Once I get involved in a piece of work the time just disappears on me. The headache finally went at some point last night.

Really pleased with the artwork I've done over the past few weeks. I feel like I am getting my life back. It's mine. I make the choices, the decisions. I think for myself and make more positive decisions too. Talking of decisions, I hope that the royal academy selects my pieces to be hung in the summer exhibition; they will be going through the selection process now!!!???? "Fingers crossed" oh its exciting stuff.

Now for the curtains, tablets etc ………

I've been doing artwork and tidying up going between the two. I've been quite emotional today, I actually cried at one point, don't really know why? I was putting the finishing touches on a piece titled "Vulnerability " it represents me at my most vulnerable I had to put up with the voices constantly putting me down, at one point I didn't know how to think for myself. It's like they had observed me, my thoughts were no longer my own. They were constantly bombarding me with their thoughts and instructions.

Image three

"Vulnerability"

Think I cried because I realized I am a proper thinking and feeling individual, I can think and feel for myself, I think crying shows that!!!! Or it might just be a release???? or I'm just so damm pleased to be well !!!!

It's 3.30 in the morning and I've been woken up with indigestion. I've taken some rennie for it. Hope that kicks in soon, so I suppose it's **Monday** and that will be the **14th April** 2008.

Gosh it's so uncomfortable. I think that it is the medication you know. Never suffered with this problem before I started taking Abilify .

Tony might know??? I'll ask him next time I see him, which will be Thursday. Silly me why don't I look on the sheet you get with the medication, watch this space.

Bingo, one of the common side effects is "an uncomfortable feeling in the stomach" I bet I've been thinking that it is indigestion, no wonder the rennie doesn't work!!!! Damm. Well I've taken some now………. And another common side effect is headaches too!!!! Haven't read that sheet since I first started taking it, must be fast approaching a year now……… scary stuff.

It's worn off somewhat now thank God!!!! So I'm feeling pleased about that yet I'm in a bit of crappy mood, probably due to a lack of sleep. I know that's a contradiction but there you go, that's how I'm feeling. I will take my medication again today as I want to stay well regardless of the side effects, the benefits of being well far out way them. Don't want to regress into that dark black existence.

Think the couple of extra hours sleep I had earlier on has cheered me up somewhat, and the indigestion has worn off to, so that's a bonus. I have been chilling in front of the telly for the last couple of hours, and sketching in my sketchbook at the same time. It does get me down from time to time the lack of sleep or the side effects which I now know that there are. But as I say I'm feeling ok now and my mood has lifted.

I've been sketching well let's just say a "new beginning" feel like I've been born again, when I compare me now to a year ago which hasn't been an easy journey but a much needed one. I'm sure Abilify   has made it possible.

I'm going to chill in front of the telly box for the rest of the evening and relax. Just slow the pace down a little bit, no more artwork till the morning, don't quite feel in the mood anymore tonight that is!!!

Tuesday 15th April 2008

Well new day, new mood, I'm feeling in a good mood today. No indigestion or headache. So I'm good on that front too. Now if I could just go to the loo!!!!

Apart from all that feeling in a not too sure what to do mood today. For starters I'll tackle the curtains, take my medication and get a bath. Relax yes I'll have a relaxing bath and ponder what to do!!!

While I was in the bath, realised I haven't left the house since Friday. I've been busy since then though, artwork, card making etc…. just haven't been outside, I haven't decided what I'm going to do today as yet????

I am going to ask Dr A for a mood stabilizer, wonder if one exists. Don't suppose I will though, it's just I've been a bit up and down, really happy one minute then crying the next. I don't think it's the medication!!!! Probably just me!!!

Debbie comes to see me on Friday, going to ask her about this computer course I've got the information on. You need to fill in the details with your CPN. So will do that. If I can manage a stained glass course I can manage that. I know it will mean meeting new people but I can handle that!!!???

Because I'm in a good mood I'm feeling positive about doing stuff again. Still no news from the royal academy, fingers crossed!!! I really do hope that it gets selected, that would make my day, month no year!!! It's just a case of playing the waiting game I'm afraid, ah but to be hung in the ROYAL ACADEMY!!!! All summer, BLISS.

The kids have gone with their dad to a gig, but before they left for about an hour or so they did a practice for their open mid night. At one point they even got me singing, we were joking and laughing it was awesome as they put it. Have really enjoyed myself, that's left me in such a good mood!!!!

I'm going to town with them tomorrow after I've been food shopping. Steve's going to do some busking and Bex and I will shop!!!! So that will get me out of the house.

Haven't done anything today, well not anything creative!!! I mean I've done the usual stuff, cooking, washing up etc, but the rest of the time I've just chilled out and then jamming with the kids, well mainly listening to them, I should say was just fabulous. There're so talented. It was so enjoyable.

They have been gone about an hour, and I've been nearly pacing up and down, feel somewhat deflated. Not sure what to do with myself, not sure at all!!! Telly box maybe????

Wednesday 16th April 2008

Well I've done the curtains nothing to report there, meaning it's clear. Took my medication and then ran my bath. I keep smiling to myself, just jamming with the kids was such fun, and it as I say just brings a smile to my face. I anticipate a busy day today. Feeling on top of things again, which is good!!!???? I was in a peculiar mood last night after the kids went out, but at the moment feeling good!!!! No headache, no "uncomfortable feel in the stomach" as they put it and I've been to the loo so how good is that, 3 out of 3, now for my bath.

Its only 7.15 am and mum won't be picking me up till 9.00ish. All I have left to do is put my make up on; don't think that will take nearly two hours. I've looked in every mirror in the house, why??? I suppose its "just in case" Don't know why I do that???? **I'm well!!!!**

Looking forward to the day, I feel I can tackle anything it throws at me; I'm in such a good mood. Bright and breezy.

Been shopping with mum, put everything away. Showed mum the information Tony left. Will be seeing him tomorrow, will show him this diary check that the stuff I'm writing about is relevant etc….

Can't believe the kids are in bed still. Can't moan at Bex, it's her day off, but wish they'd hurry up and get up!!!!!

Eventually went to town with Bex, Steve stayed at home. I got a few crafting items. Becky got what she wanted, it's really late now 12.15 am and I only made one card tonight. Just think I'm feeling more tired than creative tonight. Think I'll go to bed and write tomorrow!!!!

Thursday 17th April2008

Well it's another day!!!! Had a very good night's sleep last night which has put me in a very cheerful mood. Better get ready bath etc as its coffee morning at mine today.

Curtains well I've drawn them again today and the mirrors are ok. I knew they would be, well I'm well aren't I!!!! Feeling refreshed from that sleep and looking forward to the day. Better grab some breakfast before Chloe arrives.

Tony's just gone; he taped what was said etc on a tape. It's just got me thinking I'm not going to let schizophrenia rule me, I'm in control of my life, me!!!!

Amy's just left, see I talked and chatted ok, despite everything else. All of the time she was here kept thinking about other stuff. I read this diary after Tony left earlier; I was surprised that I do all checks and drawings over and over and then some.

I don't know if talking about it with him has brought it all to the front of my mind more, feeling Aah again, can't quite explain it.

Friday 18th April 2008

Debbie's been today she filled in the referral forms for Day centre house. Then we chatted, somehow I found it quite difficult. Questions etc….. She got me talking somewhat too like Tony, and thinking again. People don't talk about my schizophrenia; it isn't mentioned much at all. Told Debbie that I don't want to keep doing these drawings and paintings and that it's the same thing over and over!!! Or all the checks I mean should I still be doing them. Talked about being arrested by the police and put in a police cell. Why the hell did that happen, I mean over 11 hours. Well let's face it, it's because they knew I had schizophrenia I know it is, I was on the verge of bursting into tears and Bex turned up, so I didn't of course.

Went to Harrogate with Mum and Gary this morning again. See I'm doing stuff I can cope. I manage ok, I am coping.

Saturday 19th April 2008

Will be going to mum's today, it's Gary's and Faiths birthdays, so I will be having a drink. Might walk by Asda and buy Gary a cheese cake or something. Not sure see what the weathers doing. See I can think about other stuff too. Actually slept well last night which in turn is good isn't it???? No dream not that I can remember anyway.

Becky came home after work yesterday but went to Dean later on. I miss having her around so much. But she's growing up, it's good that she gets on well with stuff etc……… I've got Steve at home still full time. Like to think I get on ok with my children despite everything else. They seem to accept me for who I am which is good. They're great kids!!!

Got to tidy the kitchen this weekend too, the council are putting in a new kitchen and bathroom. They start in a couple of weeks and someone is coming from the council to see me on Monday. So I'd better tidy up before they come. Haven't done any artwork since Tony came. Only card making, but card making is good, been doing a lot of thinking, more than usual, if that's possible: I know one thing don't want to keep doing the same pictures over and over anymore. I need to move on, but how do I stop myself. How do I????

Haven't dealt with the curtain as yet this morning might tackle them later on. I'll see how I'm feeling later on. Now to tidy up a bit.

Just got in, went to see Steve do a number or two, the band got Steve up front, it was very good, so proud. Had rather a lot to drink but actually enjoyed myself. It was a good evening out, now for bed.

Sunday 20th April 2008

Really pleased for Steve, how well it went last night, music is his thing, like arts and crafts is mine. He is very good at what he does. Just taken some headache tablets with my medication, but I'm sure that's just a slight hangover. Nothing to do with the medication on this occasion. As I did drink a lot earlier, let's see today I plan to just clean and tidy the bathroom. Not sure what my mood is today, not sure at all.

I mixed in and mingled last night, mind you Steve was the only person there who knew about my illness. So I felt relaxed.

Monday 21st April 2008

Feel more relaxed today. I wonder if tidying up is therapeutic or not??? Also feel a lot more positive!!! Dr A once said I'd be on my medication indefinitely, scary thought, because no-one can know what sort of effects it's going to have years down the line!!!! Hopefully none but who knows???

Have to wait in today for the council but I don't mind, as long as a new kitchen and bathroom will be brilliant.

I'm going to tackle the curtains and mirrors today, feeling positive as I say. I suppose everyone has their wobbly days. Don't see why I shouldn't too!!!

Done nothing but tidy today, the man from the council came eventually, two weeks or thereabouts till they start. Believe it or not that's cheered me up, it's a big job the kitchen and bathroom but I'm sure I'll cope. There slots to do and stuff needs packing away, ornaments and stuff, but a new kitchen!!!

Tuesday 22 April 2008

Have been waiting for the post man every day, but I suppose that the longer I don't hear anything the more chance I have that the pictures are going through the selection process more. I hope that they do get selected (Touch wood)!!!!

Roman and Bev, well everyone was at mums on Saturday. What with Gary and Faiths birthdays we had a few drinks and cake, it was good I chatted etc and then having to go to

see Steve stopped me dwelling more. Think I've snapped out of it now, feeling more positive. I have to accept that it is a long well lifetime illness and that I will be on medication indefinitely. It's just something I have to live with. I think it just gets to me, because there's nothing you can do. I mean if you break a leg they put a pot on and it's fixed and that's mended. But you can't fix this, it's never going away. The medication can relieve the symptoms but it's still there, ready to rear its ugly head at any time. Guess what, more tidying to do today, lots to do. Bex stayed at home last night and were going to shops to collect boxes to pack stuff in today. It's her day off and her boyfriend's Dean today as well and he's calling round later on too. I like to keep busy have people round that means there's always stuff to do and things happening. Normal things like conversation and well stuff!!!! Makes me feel included.

The kids are at their Dads watching the Liverpool match; I'm going to have a lie on the sofa till they get back. Been to Asda and done a food shop, just feeling tired at the moment as I got up way too early this morning. Might make some more cards after my nap.

Walked about 4 miles today it's been a lovely day today. Nice to think things can be lovely again!!!!

Got really bad indigestion, I've taken some rennie for it, it woke me up!!! So I'll just potter about till it wears off!!!

Steve's home, got a gig on Thursday night at the pub, I'm going to the pub on Saturday as he'll be doing a song or two there as well. I'm really pleased for him

I dreamt about spiders just now, don't like them but I deal with them. Strange thing to dream about!!!

It's nearly midnight and the start of a new day. Think I'll make some cards as the indigestion has worn off somewhat.

Wednesday 23rd April 2008

Feeling in a good mood today yes raring to go!!!!

Its only 7.30am and I've washed my hair and put on my make up on and done the curtains. Feel I can tackle anything today, yes anything!!!!

After I went shopping this morning I went and stood outside and I looked into the back garden. Not for very long but I did it, I'll stand a little closer to it tomorrow. Think I'll have to do it in stages like opening the room curtains; inch by inch I tackled them. That's what I'll have to do with the back garden.

I sat by the front door for a while this afternoon and ignored the people that went past outside. Last year I used fake tan and didn't use any of the gardens, but this year it's different.

Haven't done much today I've had a lazy day.

Thursday 24th April 2008

Just rang Becky I'm meting her for lunch in the shops at 2.00pm so I'll walk there and catch the bus home (2 ½ miles). Decided I'm going to try drop that ½ stone for summer. Going to go stand and look in the back garden for a few minutes again. My mouth went really dry and I was clenching my fists but I did it again. Slowly does it I suppose. But I am determined to tackle that problem. I mean I open the curtains and face the mirrors. I've just got to persevere.

Feeling pleased with myself. I've stood at the back garden 3 times today, which is oh so good for me think I have to face my fears head on.

Amy's just been, it was just her and me, Steve was out as was Becky.

Keep smiling to myself; I think I've made a big step standing just looking into the back garden. Yes I've just got to keep thinking positively about it.

Friday 25th April 2008

It's early, I've to get ready for my hospital appointment this morning, and it's just a check up on my knees. I've had a couple of Bakers cysts drained so he'll just be looking at them.

Had the right knee drained again, just taken a couple of painkillers, it's not really painful just sore. But he has put rather large bandage on it; apparently pressure has more chance of making it not return again.

Bex's gone out and Steve's gone to his Dads, so I'm going to do some artwork. Stood at the foot of the garden twice since I got back from the hospital. I suppose the next step is to actually stand in the garden, it's scary though as that's where they were!!!!

Feeling really pleased with myself for standing there.

Saturday 26th April 2008

Let's see my plans today are to go to mums this afternoon and then on to the wise owl to see Steve perform etc, so I'm going to chill before I have to get ready, chill, it's good to chill and feel relaxed. Not tensed up constantly worrying about stuff that's happening when I'm not well, I'm completely tense, worried about stuff that happens or is happening; now I really do feel relaxed!!!

They didn't get Steve up for some reason, but nevertheless it was an enjoyable evening, now bed.

Sunday 27th April 2008

Still haven't heard anything from the Royal Academy as yet (touch wood), but will see!!!

No headaches or indigestion so that's good.

The council said it will take about a month to do the kitchen and bathroom. Not keen on the idea of having all the men working in the home but Steve will be around most of the time. I'll cope!!!!

A year ago I used to COPE!!! But now I feel like I'm living. Actually enjoying doing stuff, partaking in life. Even if it's pottering around at home. I know people don't really talk about my illness but it would appear that they accept me!!!!!

Amy & Yvonne are already talking about the 3 of us going down to London again if my pictures are selected to hang in the summer exhibition at the Royal Academy. Oh I do hope they get through!!!!

The kids will be home from their dads soon, I like having them around. Haven't really done much in the way of artwork today.

Really enjoyed myself at mums yesterday we all sat out at one point in the garden, summer is on its way .Yeh!!!

Monday 28th April 2008

It's really early 4.00am but I went to bed at 9.30pm last night. Had about 6 hour's sleep which is really good form. my leg is feeling a lot better now, not as sore which is good.

This morning I'm feeling really good!!!!

Bex went to Dean after her tea last night and obviously Steve is still in bed. I've put the telly on really low its very QUIET!!! Well I suppose it would be this time of the morning. QUIET!!! Yeh!!!

Well today I plan to make cards and tidy. Haven't got any plans to go anywhere today.

Ended up meeting Becky in the shops for lunch today. Caught the bus there and back, she didn't give me enough warning to walk, she said I wasn't as talkative today but well we window shopped afterwards till she had to return back to work.

It's 9.30pm again and I'm off to bed, really tired but I was up really early and I haven't had a nap in the sofa which I sometimes do, after getting up so early.

Had indigestion for a while this evening but it's worn off now thankfully.

I've been in a good mood all day today. Didn't tidy much but there's always tomorrow!!

Tuesday 29th April 2008

It's very early again!!! 5.15am but I did go to bed early too!! Bit early to do the curtains even though it's getting quite light outside.

Today I'm going to walk round to mums and back and I'm going to walk down the drive!!! Nothing bad happened, the last time I walked down it, so I'll just do it, that will be about 2 ½ mile in total if I do, got to keep thinking good things not focus on the negative. I'm just going to make myself do it!!!

Got on the scales this morning 8st 13 lbs., so just under the 9st mark, so only 6lbs to go. At 5ft 2inches 8st 7lbs isn't an unrealistic weight to aim for.

Feeling VERY positive about stuff this morning. Raring to go!!! Just a bit early yet!!

Walked round to mums down the drive, Guess what? Nothing happened; feel like I'm getting on top of this now, really pleased with myself for doing it. Walked home as well, so that's about 2 ½ miles walking as well today. Which in itself is quite good. So when I have to tell myself that I can walk down the drive and nothing will happen, think positively about it. And not avoid it anymore, although I walked really fast past the point where I was arrested and my mouth went dry but I did it.

Haven't heard anything back from Day centre House yet about the computing course as yet!! But there time yet, hope I get on it? I know nothing about computers and using them will be interesting to learn and to do graphics on them etc what with the art work.

Made some cards today, this morning before I went to mums. So I've been quite busy today. I should sleep well tonight.

<u>Wednesday 30th April 2008</u>

Its 1.00am so it's Wednesday now, I've fallen asleep on the sofa for an hour or so. So will just chill and watch the telly box for a while till I get tired again.

Let's see today I'll be doing a food shop and then my stained glass course in the afternoon. They don't know about my illness, no point in telling them now, dove house do though, but that one's run by "mind" so that shouldn't be a problem. Seem to be waiting for the postman every day. News from the R.A. news from Day centre house but it's all positive stuff (Hopefully)!!!

Feeling positive is very good when I'm not well everything is negative: the voices are negative; all the other stuff is oh so negative. Don't feel driven by anything when I'm unwell, just fearful. But now I want to get on and do stuff whether it is artwork, or making cards or stained glass. I want to be productive in all those areas. Don't mind meeting new people, learning new things, hence the stained glass and hopefully the computer course.

It's getting late and I've had a busy day. I'm doing a tiffany panel on my stained glass course and I started to beat the copper foil round the cut out pieces of glass. Good stuff!!!

Before I left I stood next to the back garden and later on I stood when I got back too!!! I'm determined to conquer that problem so I can use the garden this summer. Although it's grossly overgrown that can be sorted.

Bex's home tonight she said she is going to move out in September. I miss her a lot but she's grown up.

I've had a very hectic but enjoyable day today, this evening the kids were practicing and I was singing along again, hound dog and blue suede shoes. Don't you just love 12 bar blues is it?? And not to mention Elvis… Yeh!!! I'm really glad they get on so well. Steve will miss Bex when she moves out too!!!

<u>Thursday 1st may 2008</u>

Been up a while, wish the postman would hurry up. Then I can get on with the rest of the day. The sooner I hear the sooner Amy, Yvonne and me can book and arrange our weekend in London. That's if they have been selected, and yes I will say it again "touch wood"!!!!

See I'm thinking about other things, doing other things, when I'm not well I'm stuck in the moment scared and fearful not able to see beyond that. But here I am making plans, living not only today but looking forward to the future. `

Appendix C

Interview one Participant P1

T	Have you found it easy filling in the diaries?
N	Yes
T	Yep………
N	It does go on a bit
T	Doesn't matter It's your diary…
T	Do you have a particular time of the day that you fill it in?
N	Nope Just now and the usually when I come back from somewhere or in the morning when I get up and then on a night when I go to bed… or if I wake up in the night sometimes I write in it.
T	That's fantastic.
T	What about, you know your family. You're on about your family and friends and you said you'd let them know, is that the first time you've really been to see them all?
N	No I've seen the family and friends since they've known but there were some people that were going to be at the party that I've haven't seen since it became public knowledge and I wasn't sure how they were going to be with me it, but they've were fine.
T	How did your family take it when you told them about learnt about your illness?
N	Well Paul my brother came up to me and went "you all right" and I said "yes" and he said "no" and then he said (with meaning) "no you're all right aren't you" and I said "yes" and he went "all right then", and we don't talk about it or anything, it's not something that's discussed or anything like that.
T	Is your brother younger or older than you?
N	There's only 10 months between us.
T	Why does he not want to talk about it then?
N	It never… we just don't talk about it.
T	How does that make you feel then? Does it bother you?
N	I don't know. No not really, I talk like with my mum, cos she comes with me when I go see Dr A and stuff. I'm quite close to my mum and stuff but other than that it's not sort of generally talked about and stuff.
T	Who's Seb?
N	My son.
T	Oh right. What does he say then?
N	He just said that it seems like a good idea.
T	Does he mind?
N	No.
T	So he's alright about it then?
N	Yeah, I've told him to always talk with other children about it, how I've been and how I've been and stuff like that. He's 16 nearly 17 and my other's 20.
T	Right.

N	So grown up children
T	You've got two children then?
N	Yes I have.
T	What do they do?
N	Just left 6th form, just dropped out so he's looking for a job, well he says he's looking for a job but he's in bed now.
T	Is he
N	I said if you come down… He said I'll go to my bedroom.
T	He could have come down …
T	Have you ever had any instances whilst you've been out in the last couple of weeks where you've been somewhere and you've thought "can't be doing with being here?"
N	I don't like supermarkets very much
T	Just come to the supermarket bit here, that's why I'm asking so
N	I only go to the super market once, my mum takes me. Which I know … she's been taking me for a year cos when I came out of hospital she said I'll take you to the supermarket, stock up on food…. And she took me the next week and it's sort have fallen into a routine where she takes me on a Wednesday morning. There are certain things I don't do… I don't walk down the drive… and my mum says I should walk down the drive because that's … what did she say … it's not, it's just a thing that's happened on the drive and it's not to do like with like with me.
T	What do you mean the drive, the street our here?
N	Yeah, the drive
T	Oh so you call that the drive then
N	No it's the street that's called the drive and I got arrested on it and handcuffed and taken away and stuff on it
T	Is that when you were quite unwell?
N	Yeah
T	Yeah
N	So I don't walk down the drive now. I walked down once and I was … I didn't like it so I just avoid it which is an easy option I suppose but it doesn't hurt anyone though me not walking down the drive
T	No it doesn't no
N	Is that what you mean with the diary though
T	Yeah, this is fantastic, it's fantastic
T	The medication you're on now I know we briefly touched on it last time I was here do you think it's made a big difference
N	It has yeah
T	In what way, I'm getting a flavour …
N	I feel more like it's me and I've got a clear head, like the other stuff you were a bit felt a bit like doped up on them
T	You've been on the olanzapine before and did you say you've been with the risperidone as well?

N	Yeah, I didn't like that at all
T	You didn't like any of them though did you?
N	No not at all.
T	What's the difference with this one then, you say it gives you a clearer head
N	Yeah, clearer head and I'm more myself, I think I'm more myself now than I have been for years
T	Does your family, does your son, do other people appreciate that as well?
N	Oh my mum thinks there's a huge difference with me on this
T	Does that make your mum feel better?
N	Yeah
T	Do you get on better with your mum that way then?
N	Yeah
T	And this new medication does it help you get on better with other people
N	Yeah, yeah
T	Well obviously it's given you the confidence to go to London, I can't get over that. I was telling my partner that you've been to London to present a poster and she was chuffed to bits
T	I'll tell you a little bit about my story in a minute about a poster but I'll come back to that.
T	When you were on the other medication did you not do any artwork or anything?
N	No, not much at all
T	Why was that then?
N	I just wasn't motivated or anything and I just didn't really do much at all, it was well not a struggle… it makes you feel like doped up if you know what I mean
T	I do know what you mean, yeah and I understand what you're saying.
T	Did you keep yourself away from everybody else then?
N	Yeah, I used to stay in the house a lot, but now I go out and stuff, there are certain things I don't do but I do go out
T	And obviously your confidence has come back, you say you are more yourself. What was it like before you were like this, when you used to stop in the house?
N	Well I just used to avoid people, I wasn't very good at communicating, I used to sit in a room and just listen, well not even listen I used to just exist if you know what I mean… now I partake and do stuff and do my artwork again
T	There's a whole new life, it's almost like starting again really isn't it then?
N	Yeah
T	And again, you've put something here that's being able to laugh. That's something that we take for granted but I suppose when you were quite unwell you wouldn't have been able to do that
N	No, I get very withdrawn
T	Yeah
N	Completely withdrawn

T	And when you were prior to this medication would you actually lose contact with all your friends and people and just not
N	Well Louisa who you saw last week I've always stayed in contact with her but I fizzled out with Gaynor and I fizzled out with Mandy and stuff and I don't know, Louisa is a very good friend, I've known her for about 14 years but we don't talk about me you know not being well or anything like that
T	Do you talk about you as you are now?
N	Yeah, we just talk about things that are happening and about things we might do and stuff like that
T	That's good though isn't it, cos it's better to make plans going forward than always reflecting on what's happened back and I think you could actually look back now and see how you've actually moved through that dark years and that stuff you were going through
T	Obviously these names in here I'll obviously change all these names
N	**Becky** is my daughter and sometimes I call her Bex
T	Right. I'll make a note of who's who on this so that at least I know
T	**Becky** is your daughter?
N	Yeah, sometimes she's referred to as Bex in there.
T	Seb is your son isn't he?
N	Yeah
T	Is she the older one? 20?
N	Yeah, she's 20 and he's 16.
T	What I'll do is just make a note so that
T	Where does your daughter live then
N	She lives at home but she's at work
T	Oh they both live at home then, right
T	You're scared that the bubble might burst? Is that about the medication?
N	Well, it's too good to be true almost, do you know what I mean?
T	Yeah
T	Well I think the most important thing for you, and this is me talking as a nurse now, not a researcher, is that you know what triggers off the bad times so that you're aware of your triggers and you're aware you speak to Debbie and just keep being positive about stuff
N	I think being positive helps and active helps
N	I never used to feel positive before but I do now
T	The Olanzapine, did you put much weight on with Olanzapine
N	Oh yeah
T	Did you?
N	Yeah.
T	This newer drug what kind of side effects do you have from that

N	I've got constipation comes and goes, I used to feel dreadfully sick when I went on it a bit but that wore of quite quickly, but I'm left with constipation and I've figured out that my headaches and the indigestion is due to that as well
T	Right and can you cope with them?
N	Well I just take Rennie, I don't know if it works or not but I'd rather put up with them and be well. It's weighing it up isn't it really?
T	Yeah, it is, it is, and I think just reading some of the stuff you've put in here speaks volumes for the fact that it's done the world of good for you and I think that it says that you'd rather be on that and put up with a few minor ailments than go back to the way it was before
N	Mmm
T	Yeah? And again, I think with the fact that you are obviously able to control what you eat and do some exercise will obviously balance up the fact that, you know
T	How often do you see Dr A?
N	About every three months
T	Every three months, he's good isn't he? I like Dr A.
N	I do too, he knows his stuff
T	He does and I think at the bottom line as well is he's very genuine and he cares about people,
N	He is yeah
T	I think very highly of Dr A. And again I think the other thing is as well he's always trying to move forward and think of things to help people, which is one of the reasons why he's helped me today, to help me to help you to help other people who might suffer the same things
T	The back garden? Is that the back garden out there?
N	Yeah, that's the back garden
T	Don't you go out there then?
N	No
T	Why's that then?
N	Cos that's where they were.
T	Where?
N	Where they were
T	Who are they?
N	The people that were pressing up against the window
T	Is that when you were poorly?
N	Yeah
T	Right. Do you think you'll ever get the confidence to go out there and confront it?
N	Well, I think Debbie's going to make me. Not make me but, you know. She said we'll tackle that, sort of thing
T	And I think now's the time to tackle it when you've got the confidence and you've got the support and the guidance to do it.
T	Examples of questions

T What has changed for you after you first developed schizophrenia? What sort of things changed for you?

N Well, I lost my job

T Right. When you lost your job did they hold it open for you or did they get rid of you straight away

N Well what they did was I was in hospital, you know in Highroyds

T Right

N And when I came out obviously I couldn't go straight back to work and I had a conversation with the manager I suppose. She says "well do you want to just leave then?" and I said "yes" and that was it, but if she'd have asked me a few weeks later maybe I would have said no, hold it open for me, I don't know. That was the turn in events.

T Did you not want to go back because of the illness?

N Well I was… no I didn't actually, that's probably why I said yes.

T And again I think that maybe that's something to do with some of the stigma that's attached to it. Do you think there is a bit of a stigma attached to it?

N Oh there is, yeah

T Do people treat you differently?

N Well sometimes I get the feeling that they're being wary about what they say to me, they don't want to trigger me off or something maybe, I don't know. I don't know, on the whole they're alright, but apart from Louisa it's mainly family that I see anyway

T Right

N And like people outside don't know do they cos it's not stamped on your forehead or anything

T It's not but sometimes I think you walk around and sometimes you think it is. It's like when I've got my psoriasis I sometimes think

N Everyone can see it

T Yeah, and I'm conscious now that I'm fiddling about with it now I know I shouldn't do and I often think people look at me cos I've got scabby arms but I haven't got scabby arms, it's just a little bit of skin that's loose.

N One thing I do is that if I'm out and people are laughing, I think they're laughing at me

T Right

N I don't know why

T Right. And again I think that probably stems from when you've been ill previously isn't it yeah and having and saying now when you're well that they're not laughing at me. You can laugh at it yourself then and say well it's not really me is it?

T What you've got in this diary is spot in, it's perfect, and again it comes out as you're reading it, yes I can tidy, it's doing the little things

N I didn't do anything like that before the other medication and stuff

T It comes out as you go through it and its

T The voices have gone?

N Yeah

T	Totally?
N	Yeah
T	When you were unwell, how many voices did you have?
N	Four/Five
T	All horrible at you?
N	Yeah
T	Yeah, I can't imagine what it's like for one minute and people say to me and I acknowledge what you're saying and sometimes they say they've gone quiet, sometimes they say they're loud and
N	The thing that used to annoy me was, not annoy me but sort of not perplex me but I used to want them to go away and then if they were whispering and I heard my name I'd be thinking well why don't you say it to my face instead of just whispering about me. Bizarre isn't it?
T	But its good that they've gone
N	Oh yeah
T	And it's nice to know
T	Plays football? Where does he play football?
N	At the fields on a Saturday
T	I run a girls football team
N	Do you?
T	Yeah and we're at the cup final in May
N	Oh, that's good
T	And again, doing little things like cooking
N	Yeah
T	Yeah?
N	I don't like going to banks
T	Putting your make up on, is that something you didn't used to do either?
N	No
T	So again.
T	Is there an artist supplies in the shops? An artist's shop?
N	No in town there is
T	Is there one in town?
N	Yeah,
N	There's a few in town.
T	It's surprising that when you consider there's a big university up there and everything else.
N	I know, there isn't, not in the shops
T	No
T	Been making cards as well?
N	Yeah

T	Tons of stuff
N	I sell them as well
T	You sell them as well?
N	Yeah
N	Not many, just enough to buy more supplies to make more
T	But again that's something that you wouldn't have done previously isn't it?
N	No, I'd never have done it before
T	Gone on the buses, that's something you wouldn't do.
N	No didn't like the buses
T	But confident enough to go on the buses now
N	Yeah I am a person exactly trying to get on with my life. I think that's fantastic it's important that you're aware of it and that everyone else is aware of it as well and I think that's true.
T	This is really really good this, I can't say any more.
N	Is it alright if I carry on in that vein?
T	Everything that's in there is fine and as I'm going through it there's bits that are coming out that stand out to me like going back here, when I'm drawing or painting or making cards I can get really absorbed in that activity, I bet that's something you thought you'd never be able to do.
N	No, not for a long time
T	Just looking at the stuff you've been doing, it's fantastic
T	Kids are going to their dad's to watch Liverpool, are they Liverpool fans?
N	Yeah

Lady laughs (18.07 mins in)

T	Since you've done the diary have you seen Dr A since you started doing the diary?
N	No, I don't see him till May
T	You don't see him till May and Debbie's coming tomorrow?
N	Yeah
T	What time do you normally go to bed, do you normally go to bed late?
N	Quite late, but I have little naps on the sofa sometimes
T	I'm a night person as well, I like to stop up late but when I have to get up for work next morning I think urgh I shouldn't have stopped up late last night and I don't do anything when I'm sitting up, I just sit there and potter
N	I'm not tied to a clock so I can just, I know if I get up at some ungodly hour like 4 o'clock and think I'll do this that or the other I know I can have a little sleep on the sofa
N	See last time I saw Dr A, I said I did all these
T	Right
N	And that's what I do in the sketch book and stuff and I said I don't want to do that no more but I'm still doing it, I don't know why, I just keep doing the same image over and over again. Working, reworking them and stuff, it must just to get it out of my system or something I don't know.

T	Were those images the ones that you'd relate to when you were unwell?
N	Yeah
T	Right. When you did them when you were unwell what did you think? What did you think about them? How did you relate to them?
N	Cos I didn't know how to deal with them I thought well, that's my thing art so I just used to draw, draw how I was feeling or you know
T	Did you think about them as a positive thing or negative?
N	Negative
T	What about looking at them now?
N	Oh, I don't know, it's just something I've kept doing
T	Again, I can't draw for love nor money, they look really fascinating to me but do they cause you bother when you do them or not or
N	It depends, it depends what mood I'm in
T	Right
N	It's like at one point I was crying the other night and I don't know why and I thought maybe it's the subject matter so I changed what I was doing
T	Right
N	Or it might have just been I was so happy to be you know not in that position any more, I don't know.
T	Yeah, I think the positive thing is the fact that you can actually do it and that you can look back and think yeah I'm still doing them but I can also do other things as evidenced by what you've got here and I think, that for me, in a way it's good that you can actually look at them and just think yeah and sometimes it happens and then it's changing the subject matter and being positive about where you're going from now on.
N	Some days I don't do anything. Some days I don't even get dressed or anything
T	We're all entitled to do that aren't we?
N	We all have days like that, well I suppose not everybody.
T	You've been to a local town?
T	Confidence is really growing, so again there are lots of things coming out of here. I think this is fantastic this Janet, it really is.
T	You lost your mum in the local town?
N	Yeah
T	I lost her, we went to the toilets and we just lost each other and I thought "Oh go to the car where Peter's parked" and she was coming up as I was going down near the car but before I would just have sort of wandered around and I don't know what I would have thought.
T	You've put in here that instead of panicking you've made your way to Peter's car, I've got my thinking head on today, which again is another positive thing that you're able to cope and that you're able to go out there and like you said previously, you're a normal person, you can get on with the rest of your life and that just shows that you can do it, you know, and all these things. You know you should be proud of the fact that you've written all these positive things in here.
N	Yeah

T	Yeah
T	Is Peter your mum's partner?
N	Yeah
T	Again, I'll change all these names when I do it, I'll put Dr A
N	I don't mind who you show cos if it helps anybody.
T	I take on board what you're saying there but again we're bound by some sort of contractual agreement between us. I won't pass this onto anybody at all. What I will do is I'll keep it and obviously put a number on the front, number 1 or number 3 or whatever but again, it won't be passed around to people. And again, that's the confidentiality between the two of us. If there's bits of it that I take out to type up and it might mention your mum or Harrogate then it might be went with mum to Harrogate and her partner, or whatever.
T	But all the names will be changed again, like Josh's name will be changed and like I agreed with you when I first did it
N	Yeah, yeah
T	It's alright you saying that now but in a couple of months' time you might say I don't want him mentioning anything, but again, be reassured that it's confidential and it won't be shown around
T	Feeling creative. Bex, I've noticed when you've put Bex now
N	It's like sometimes I put Josh and sometimes I put Seb
T	Fingers crossed, exciting stuff, aw I do hope you get in.
N	I know, it'll be brilliant
T	Yeah, you've mentioned here about you nearly cried about a piece of artwork you've been doing
T	What sort of places do you go now that you wouldn't have gone too previously?
N	Art gallery,
T	Art gallery?
N	Town, call in there sometimes, not been in for years
T	The one in the local town?
N	The one down near the town hall.
T	I once went in there and they had an exhibition of a student's lying in a sleeping bag, couldn't understand this.
N	I can do my stained glass course, but it doesn't start until the 23rd. I'd never have done that.
T	So there's lots of things that you're doing now that you wouldn't do.
T	Did you ever feel lonely previously?
N	Don't know if lonely is the right way to describe it, isolated.
T	Isolated. Do you still feel that now?
N	No
T	Why's that, what's different?
N	Cos I'm doing stuff, that I like to do as well, that interests me and mixing and things
T	50 pages, absolutely impressive, I'll give you that back,

N   Right

T   10 out of 10 for that

N   Shall I just keep carrying on like that?

T   Just keep going on the way you've been going there, it's absolutely brilliant, I've no, there's nothing I can say really that's superb. It's exactly the sort of stuff I'm looking for and it's also

N   That's why I just write it when I feel I want to

T   Yeah, it's when you want to write it, there's no hard and fast rules it doesn't have to say you have to write it at 9 o'clock, 10 o'clock whatever, doesn't have to say much, don't have to write in it every day. What you're putting in there is great, I've got a flavour and a feel for how your life has changed so much, even in the last two weeks when I've seen you, your confidence is growing and the fact that you can go places and do things that you never used to do. Speaks volumes for what's happening to you.

T   That's it really, I don't think there's anything else I've got to say. Have you got any questions? Any concerns or anything about the diary keeping.

T   Do you feel OK filling the diary in?

N   Yeah,

T   Yeah? Do you share that with anybody?

N   No, I haven't shown it to anybody.

T   What about the children, do they see it or

N   They see me writing in it but they haven't seen it, they haven't read it or anything

T   How would you feel if they asked to read it? Would you let them?

N   I'd let them if they wanted to.

T   Just curiosity, turn this off now

N   Has it been recording?

T   Yeah

Appendix D

Interview two Participant P1

N   Show you, they're the two pictures I sent in

T   Oh right, for the erm ….. Exhibition

N   Yeah

T   Right

N   Well, they're just photos; they were in the frame so they got light reflection

T   Oh right, I've told you I've been selected to do a poster competition, so I've got to design my own poster now, I don't know what I'm going to do, so

T   I've got my camera to take a picture of the things, is that alright still?

N   Yeah

T   You've nearly filled the whole book in haven't you?

T   Tony's just gone…… Again, I'd like to reiterate what I've put on there

N   Yeah

T   All the names and everything will be taken out, it'll be confidential, it'll go into the back of my study but nobody sees it, but now, if, when I submit my thesis, I've got to go in front of an exam board, and it's just to make sure I've done everything properly. Now it might be that they ask for a selection of diaries, and I'm going to take all the diaries in with me, but they're not entitled to look at them unless they get my permission for it, and it'll be just a case of looking at it and just checking up. So it's not as if it's going to be published, or anything else like that, these will be destroyed in a couple of years' time

N   Yeah

T   So, it'll all be gone. And again, it's what you said in here, you're in control of your life, not the schizophrenia

N   Yeah

T   Yeah, so that's good

T   So, how's things been since I last saw you then?

N   OK, yeah

T   Yeah, any situations you've been in where……………..

N   Well, I've read that diary a few times back to myself, you know sort of started like
         and I've pushed myself and I've stood by the back garden, and I've walked down
         the drive a couple of times and nothing's happened.. So, there you go

N   That's got to reaffirm it in my mind that I can walk down the drive

T   And it reaffirms what you've put in here that you're in control, and you are in
         control of your life and you do what you want to do, yeah

N   Yeah

T   Have you spoken to Debbie since you've seen me?

N   Yeah, yeah, I saw her and I was telling her like with the drawings that it's the same
         thing over and over again and I'm not going to do that now, I'm going to move onto
         the next phase and stuff

T   There's lots of positive things coming out and I think for me, I've sung your praises
         to people, I've never mentioned your name to anybody but I've said "I've got
         someone who's done a diary and she's doing absolutely brilliant" and I've said
         "she's even submitted work to an exhibition in London" and all the positive things
         that's come out and I'll feed that back to Debbie when I speak to her to say thank
         you for letting you take part in the study, and I'll speak to Dr A and say that I
         appreciate the help that you've given. I'm really, really pleased that you're actually
         very positive about things

N   I am yeah

T   Yeah

N   I've had a few wobbly days, cos I was annoyed at myself for letting it go on for so
         long

T   Letting what go on for so long?

N   Like not walking down the drive and

T   Right

N   Avoiding the back garden, cos there's no reason to really

T   Well there isn't now is there cos you know and I think that's the positive thing is
         that you know that the medication that you're on, plus the help and support you've
         got, and your own self-confidence and your own self-belief it's amazing. I've seen
         a difference in you and I've only seen you twice, three times maybe, so

Pause while T reads diary ………………

T   Day centre House, what's Day centre House?

N They do computer course and things like that so you have to get referred by Debbie, so she filled in the forms when she came

T It rang a bell in my head and I thought is that

N It's in a place down road

T Right, so what things are you going to do then?

N I want to do computing, learn about computers and do graphics and things like that, tying it in with the artwork

T That's fantastic. Have you ever thought about publishing all your artwork in a book and writing about your experiences and stuff?

N No, no I've never thought about that, I don't think I'd be able to do it, I don't know.

T I'm sure somebody like yourself, to me, the stuff you've got there, even just describing the drawings and the paintings, to me that's something that you'd be able to do, you're talented enough to do it

T reading diary ………………………

T Does it bother you now talking about the things you've got in your diary, about when you were arrested and stuff, does that bother you or can you see

N I've never really talked about me being arrested, no-one mentions it so when I talk about it, it shouldn't have happened, so I get a bit wound up it I think

T Does it help avoiding not talking about it or does it help talking about it or

N I think it's best to isn't it, cos you just end up bottling it all up, don't you?

T Well, I think, again, it's not for me to interfere with what's going on, I can offer my opinion but I think if you look at the way you've challenged the back window and walking down the drive it says that you can take steps forward by doing that and I think what you've done is you've challenged those things and you've actually moved forward

N I have put it off though, like walking down the drive

T Hopefully it wasn't me that triggered it, don't be telling Debbie , I'll be getting into bother

T How's your son? Is he in bed?

N He's awake, he's just upstairs on the computer, and I said you'd be here soon so he stayed up there

T And how's your sleep pattern? Is your sleep pattern good, bad?

N   I get up really early but sometimes I go to bed early so that's not surprising that I get up early but I do go back to bed again

T   Right, do you normally get a good night's sleep?

N   I get about 5/6 hours

T   Right

N   Five hours

T   Solid sleep?

N   Well, sort of sometimes I get up and have a cup of tea then go back to bed again, it varies

T   Right

N   It depends how busy I've been through the day

T   Right

N   If I've been really busy I sleep better, which is

T   The same for everybody, yeah

N   Yeah, but sometimes I stay up late, like when the kids have gone to bed and I start making cards again, or something, cos I'm not tied to a timetable I can please myself

T   Yeah, you've put in here that you've not done any artwork since I've been, is there any reason for that or is it just

N   I've been making cards more

T   Right

N   I thought, I won't do any more, I've got plenty, so I'll just leave it, and you know, I took Johnny out and did a bit more work on Johnny Depp and put him back again and I've been pottering…..just doing little things like that but nothing sort of

T   And you've managed to occupy your time during the day with stuff that you do, and again you've obviously got the computing, things are obviously moving forward a lot

N   Stained glass started again yesterday so that takes up Wednesday afternoon

T reading diary…………..

T   How was the band? Did you go see them?

N   It's not a band. It's Becky and Josh on base, Josh on guitar and they play together but sometimes they get him up to sing a song with the band so it's really good to hear them with like percussion and everything

T   And you went to the? Where was it

N   The Pub l I went to, the pub, and I've been to The other pub as well, local is it?

T   Yeah, yeah

N   down the Road

T   And were there lots of people there?

N   No, it's not a very big place

T   No, was it crowded though?

N   In the little room where they do the performance it is, yeah it's really good

T   And how did you feel when you were in there with all those people?

N   All right

T   Did you?

N   No one knows anyway so

T   Again, that's another positive thing that you can take forward that you can actually… I'm glad you enjoyed it, I'd forgotten about that… and you said you felt relaxed and felt quite good about it so again it's very positive things again

N   I just move things around a bit

T   It's like my office at work, I move things around and think I've got to tidy up today

T   Does it bother you about being on your medication a long, long time, indefinitely maybe?

N   It's new medication isn't it so they don't really know the side effects, what long term effects they have, that's a bit… but

T   But would you rather have the quality of life you've got now

N   Yeah

T   I needn't bother finishing the question, had I?

T   Is there anything that you feel your illness stops you from doing?

N   Well, when I'm not well I don't think about tomorrow or the next day, I'm just living the here and now and worrying about like them and the voices and stuff so it's moment to moment, you don't focus on anything like if someone says oh next

week we're going to, whatever, you don't even think about anything like that, you're just living in the now thing

T But at the minute you can plan things ahead

N Yeah

T That's good. Who's Peter again?

N My mum's boyfriend of 30 odd years, partner

T You've got in here that you like to keep yourself busy and do things, obviously that's something that you like to do now, when you were unwell would you put that off?

N Yeah

T Prefer to be on your own?

N Yeah, I wasn't very communicative or anything like that, I just used to keep myself to myself and stay in a lot, I didn't go out much at all only if I really needed to

T And do the kids see a big difference in you?

N Oh yeah

T And do they comment on it?

N Yeah they do, I mean like we were singing last night and I was singing the second verse of Blue Suede Shoes cos they didn't know it

T Don't think I know it either

T So again, the whole thing for me is a very positive experience for you and I mean even when you say you have you're up and down days you can always look forward to thinking about

N But everybody does anyway, we all have wobbly days, you know what I mean

T Yeah, we do, nobody can be good every single day

N No

T You've been up, you've washed your hair and you've put your make up on, how does that make you feel when you put your make up on?

N I can face the day, you know what I mean?

T And did you not used to do that, did you

N No, never used to do like make up or stuff like that, didn't think to, and didn't face the mirrors

T Did you tell Debbie that you've tackled the back door, the back garden?

N Once I threw a box in there and I run and got it and came back out again, you know where the window is and where they were, I've told her stuff like that but she's coming next week so I've got loads to tell her

T I would think so yeah from what you're saying in here, a lot of positive stuff's come out of that there, it might be that we've triggered it off when we've had our little conversation, I don't know but that's really, really good

N But I haven't seen her since

T No, I was just wondering, so again yeah, do you want a copy of this diary making or not or, it's up to you, I can photocopy it if you want to and give you it back and send it to you if you want or are you happy just to leave it with me?

N Just leave it with you

T That's fine, that's alright yeah

T I think to have taken my fears head on; I think you're right, I think you have done

N Yeah

T Keep smiling at myself, it's like winning the lottery isn't it?

T Have you had something wrong with your knee?

N Yeah, I've had some cysts, so they've drained it again

T And do you have a good social network of friends?

N It's mainly family

T Yeah

N And Louisa, who comes for the coffee mornings and that but I don't see Mandy anymore and I don't see Gaynor any more

T Right

N So I don't know why that is, but they sort of didn't come as often as Louisa, but Louisa's stayed true, she's a really good friend

T So you do things with Louisa, you go out with Louisa?

N Yeah, we go out on girl's nights out well everybody and husbands and everything and that lot

T Right. Is there anything in the diary that you want to mention to me or discuss with me?

N No

T No, I'll just take this. I've got to type all this up now.

T   When do you find out about your posters?

N   Up until 30th May you might have to wait

T   You'll have to let Debbie to let me know. I might be in London sometime in June or July I think so I'll go and have a look.

N   Well it's at the Royal Academy

T   You've mentioned it in here somewhere; I've seen the Royal Academy in here

T   Do you think you get enough support?

N   Yeah I do, Debbie comes and I see Dr A

T   When do you see Dr A next?

N   End of May

T   End of May. When was the last time you saw him?

N   About three months before then, I see him about every three months

T   He might well ask you about this then when you see him

T   Well there's nothing else for me to ask you really, you've done really, really well, I'm really pleased, I'm really chuffed that you've taken part in the study, and again, if there's a point in the next 6 or 7 months where you feel like you want to withdraw from the study then I'll quite happily get rid of everything, obviously it'll be a shame but that is your choice, and again I mean I'll just reiterate what I said on the confidentiality, nothing will be mentioned, nothing will be.. if I do use any quotations or anything from the diary or anything then your name won't be mentioned, it'll be like participant number 1 or number 2 or whatever, so there'll be no way anybody can actually trace anything back to you anyway. So it'll all be confident, you'll be anonymous. If Dr A asks to see the diary or the tape recordings the answer will be a polite 'no'. There's only me that get to see these and keep these. Somebody will look through them, my supervisor, just to make sure I've transcribed them properly but even they won't listen to everything, so there's only me really that's going to listen to the whole thing, so I hope that reassures you about everything and I hope I've been professional enough with you.

N   Yeah you have

T   And I hope I've done everything right

N   Yeah

T   I think I have, and I hope I haven't intruded too much on your personal life or whatever

N   I think it's helped me actually

Appendix E

Participant P14

10th Sept

Diary of Graham

Woke up early spot of cleaning, had game of chess with Kevin Lost, bugger felt in fairly good mood. Spot of cooking trying to be health conscious grilled sausage, bacon, mashed carrots and a spud, sugar snap peas and gravy. Mooched till about 3pm went to see Tony (RMN) doing PhD. Seemed a reasonable bloke. Got back to cottage buoyant mood. Billy Idol on CD player. Good vibe. Can't be arsed going to shop. On a bit of a roll this week after passing Maths, Art and Calico qualifications. Looking forward to watching bit of TV tonight.

Had a good chat with Gerry about his day prior to Tony turning up at Community Room, bit peed off at Tony been late. Apologetic though so no prob. Watched a bit of TV with Richard. Had a take away CRAP! All in all had a good day finished off with shower bed Bon Nuit!

Diary Day 2 11th Sept

Got up fairly early couple of cups of coffee. Plan to go shopping today went to town. Rob and Kev were on bus so had someone to chat to, got back quite bored after shopping as it was mainly foodstuff. Trying to keep weekly budget down to £75 as an exercise in budgeting. But at mo spending about £25 on top of that. Quite disappointing. Also started crusade of cutting down on smoking and initiating healthy eating. Quite a lot to take on altogether. But do not get too down if I feel I am selling myself short. What I try to do these days is to measure success against failure so in terms of success. Been out of hosp 18 months of more. Packed in drinking, haven't gambled excessively managed to save. Got a decent looking place into which I have invested a lot of money into. I pursue my hobbies with a view to making Art. Been able to buy presents for families and friends at special occasions keep myself fairly active. Mentally as opposed to physically. Passed 2 courses and 2 exams in the last couple of years.

Determination to achieve goals in my life steadily working towards them. I'm not even going to list my failures as I want to remain positive and forward thinking. After completing said list got warm glow and was able to pat myself on the back. Spent bit of time this aft

watching commitments know you did not want this type of Diary. But moods often reflect on how one spends ones time. Because I was in a sense active I ended up feeling better than if I had spent the day afternoon sleeping. In terms of structure I am not particularly busy at the moment so measure my mood by how I spend my day. Therefore this step by step approach to how I spend my time. In terms of function ability most of the things I do I now tend to take for granted things I do on a day to day basis. Such as taking the bus, shopping, cooking, cleaning, and going to my various courses, such as Art and Maths. Although have nothing organised to do until the 22nd of this month. So in terms of a mood diary it is very difficult to be able to say I particularly enjoy either one thing over the other. In terms of meds I tend to take and tolerate whereas in the past (in hosp) I have refused meds and ended up relapsing time after time.

Diary Day 3 12th Sept

Got up early went to see if Kevin (staff) was available for game of chess. Busy. Felt a bit annoyed try to rationalise. If he had been busy with me would not have entered my mind to be "annoyed" so no prob. As we had not really arranged anything. Kev came down at 10am for chess. Had the best game since staring to play each other 1 ½ hours of concentration and deep thought. Had him on back foot. Resulted in stalemate. Bugger! Really enjoyed exercising the grey matter though. Well worth waiting for scores stand at 3-2 to Kevin now! Bloody enjoyed every minute of it! Went straight to town, did some shopping for CD's and a graphic novel felt comfortable both on bus and in town. Got back enjoyed novel and listening to Burning Spear. Went to sleep at 3pm.

Day 4 Sept 13th

Woke up at 6:30am chatted to Anthony for 1 ½ or so.

Pleasant chat that whiled away a bit of time. Went to town did bit of shopping, won £48 on scratch card. Bonus. Went back to discovery. Bought a couple of magazines watched a bit of TV when I got back. Tried doing some painting unmitigated disaster.

Day 5 Sept 14th

Got up about 12:30pm went back to bed at 2pm Richard called round, had a good chat. Then Lorraine came. Then Anthony. Bit bored, watched a bit of TV. Bit of non-event. Totally boring day. Felt I had achieved nothing at all.

Day 6 Sept 15ᵗʰ

 Got up fairly early invited Beth in had a general chat. Felt a bit flat, first thing in the morning. Although chatting for an hour or so. Boring day so far, felt I could have achieved something. Have felt fairly flat and unmotivated for the last few days. This is unusual for me. Put it down to having nothing scheduled. i.e. Maths and Art. To be honest though could have done some reading, drawing or painting etc. this tends to make my day worthwhile. Went to town. Did a bit of retail therapy. Quite enjoyed it. While there I went into town bank with a view to opening an account. Gave me a bit of a lift to do something for myself. Came back. Interviewed by leisure fella. Received £5 voucher to make it worthwhile. Seemed nice bloke. Had mammoth game of chess with Kevin. Really enjoyed it I won. Did not enjoy it just cos I won. Excellent game. Gave me a bit of a lift. I've had a really positive day today.

Day 7 Sept 16ᵗʰ

Again got u quite early. Going to sisters for tea. Also going to town to <u>try</u> opening a bank account. Feel quite good about this as I usually do things like that with other people. So in a sense a boost to my ego. Good also to be going to Belinda's for tea. Haven't been for a while so be good to see her Bobby and Talia. Hope there no arguing fat chance of that. Went to town at 11:30am got bank account sorted, and then did bit of shopping felt alright. Went to Belinda's for tea only her and Bobby at home so quite enjoyable came home. Had a bit of chat with staff. All in all a pretty good day.

Day 8 Sept 17ᵗʰ

Woke up at 9am. Couple of fags, coffee and meds. Think I'll finally do washing today. Started washing at 10am. Bit boring really, but it has to be done, I suppose. Beth came in to say hello, actually I invited her in. had a nice chat which passed the time. Finished washing about 1:45pm. Glad to have finally got it done. In terms of mood I could probably say I have had very much an average day. Played Kev at chess later on in day. Feels good to do something with my day rather than sleeping, must admit over the last month have done quite a bit of that as a result of my week being generally unplanned. Get quite negative feeling when I waste my day. So today felt fairly good in that I got main chores done and for an hour or so (of playing chess) I felt I had passed my time quite productively. Also felt quite good about my chat for the day. Beth has told me recently that she can tell I am losing weight. Again this tends to help my general mood. So much achieved today was far from negative.

Day 9 Sept 18th

Rose fairly early during passage of morning felt at quite a loose end. Lazy morning also. Feeling a little low (not clinically I might add) gonna have to motivate myself and think about having a shower. Should help make me feel a bit better about myself had a shower, felt quite perked up, it's amazing how having a shower and feeling in profane shape can change ones mood.

Went down to co-op, bit of shopping, Richard bought back his Xbox £50 bonus. Had game of chess with Kevin. I won. Yup – hee! 4 – 4 at moment. Quite like playing chess as it gets your brain working and, to be honest is the only brain training I do. Saying that I have been reading quite a bit lately "**Garm Enghast**" quite a good read, Paul said "one of few who will have read Lord of the Rings, The Chronicles of Thomas Covenant, The Unbelievers and The Gorrienghast Trilogy. Watched a bit of TV.

Day 10 Sept 19th

Got up at 7am appointment with Dave today 9:30am saw Dave had quite pleasant chat. Decided to go to town. Got back about 12pm went to sleep about 1pm or 2pm?

Day 11 20th Sept

Got up about 8am, did washing, had cup of tea with Lorraine in staff room, had nice chat collected meds. Bit of a boring day so far. Feel at a loose end. Not achieved anything at all, can't even be bothered doing chores yet to be perfectly frank! Feel kinda empty listening to music. Not lifting my mood. Could go to town but feel as if it would be waste of time. With a bit of luck my mood will lift. Certainly do not want to spend the best part of the day in bed as I did yesterday. Get the impression that would be total waste of time. Also very negative. Stayed up all day today. Watched DVD of Garth Brookes first time I have played it since I have had it. Went to bed feeling slightly better than if I had spent all day in bed.

Day 12 20th Sept

Woke up at 8am had a shower set off for Greg's at approx 10:45am, walked into town quite a pleasant day. Swelteringly hot. I was sweating like a tap. Felt good to be walking tho rather than catching bus, got to interchange at about 11:30am. Caught bus at 11:45am. When I got to brothers felt quite good that I had walked there. At brothers for a while. Then went for another walk. Had fairly pleasant time at brothers (had tea) came back. Good chat with Beth. Really knackered. Plan on walking to town tomorrow; have to see tho, as my legs

are really tired. Maybe have to walk through pain barrier to get my muscles to tear and build up strength. Playing bit of music fairly early to bed I think.

Day 13 22nd Sept

Got up early, had shower, feeling good looking forward to going to Maths today. Gonna continue fitness regime and walk to town. Bit of a dull day so won't sweat as much as yesterday. Walked into town. It was knackering. But when I arrived in town I felt that I had achieved something positive. Went to Maths struggled. But managed to get approx 60 out of 100. Again felt sense of achievement listening to music at moment to pass the time. After hard day at "office" shall probably watch soaps although storyline of Eastenders at moment is a bit torturous. 30 something's man having so called "relationship" with 15 year old girl. *Watched with a sense of unease and discomfort*. Watched bit of tele and went to bed about 10pm.

Day 14 23rd Sept

Woke up about 7am. Got washed and stuff. Has cereal for breakfast. Went for meds. Quite looking forward to today as I am starting new Art course. Set off about 9:30am. Went to P.O. got to Cathedral centre felt quite good. Lost 10 fags bit of a bummer. Enjoyed Art. Did still life. Came back. Watched bit of TV although fairly busy quite a stale and uneventful sort of day. About 10pm now, bed soon, quite an average, unexciting day, as I say, pretty much an uneventful sort of day. No real highs or lows.

Day 15 24th Sept

Got up about 8am plan on walking to town today, although I am not really feeling up to it. Not looking forward to Maths. I did not walk to town after all. I laid down for a while and dozed off. As a result I did not feel up to walking got into town by bus. Found Maths class very difficult. Was quite happy when it came to an end.

Day 16 25th Sept

Woke up about 8am, couldn't have drink, no milk. Plan to ring DLA today with a view to getting it paid into my Halifax account. Listening to a bit of music Neil Young and Crazy Horse. Also rang Income Support and Incapacity. Arranged to get said benefits into new Halifax Account felt good to be dealing with authorities on my own. One of the people I spoke to was quite annoying seemed to think I was a bit thick. I don't know it that was

associated with "Mental Ill Health" Got the impression it was. Tony is late that makes me a little peeved to be honest. I tend to be patient when it comes to time keeping. I hope that he arrives soon. He is already approx 20 mins late. To some that might not be much but when I am due to meet someone in town, for instance I will probably arrive a good 30 minutes before the time I am due to meet them. When this kind of thing happens I often get the feeling that the other person does not really hold me in any esteem. Tony finally arrived about 3:15pm when he arrived he immediately apologised saying he had rung the office, but there was no answer. Find that hard to believe as there is always someone in the office. He recorded our chat. Asked about stigma etc surrounding mental illness. Had quite a good time talking to him, had tea. Then watched TV until about 8pm. Then put some music on. Thought about reading or drawing. Did bit of reading "**Govg Gomenghast**" went to bed at 9pm.

Day 17 26th Sept

Got up about 8:15am felt quite tired but decided not to go back to bed. Plan on walking to town today but will have to see if I do. Listening to some reggae whilst waiting for post to arrive. Expecting letters from DLA and other benefits, although to be honest it is unlikely that they will arrive today. Went to bed about 11am and woke up finally at 5pm, felt that I had wasted major part of day. Then watched bit of tele, mainly soaps. Up until about 9pm. I hope I don't waste too much time tomorrow. As I say (or as I have done in the past in this diary) I feel very negative when I waste a major part of my day. But I still do it!!

Day 18 27th Sept

Got up about 8:30am had a couple of ciggies and a cup of coffee. Did washing up from last night feel reasonably good. Went to town about 9:20am. Felt I have already achieved more than yesterday. Also did a spot of cleaning. Then I started washing my clothes. Still haven't had anything to eat and it's already 12:30pm. Listening to Runrig a Scottish band who I got into at least 15 years ago. As well as going into town today I have done my washing and have also done bits and pieces of cleaning.

As a result of being quite busy I am fairly pleased with myself. Might walk down to co-op later with a view to getting a couple of things I forgot whilst I was in town started some cooking (if one can call it that) at 1:30pm. Mashed potatoes and carrots, steak and kidney pie, chips and gravy. To be honest one can hardly call it cooking but at least it's not a take away or crisps and chocolate. Listening to reggae whilst I am waiting for my dinner to be ready, had dinner washed up then had nap from approx 3pm to 5pm. Watched bit of tele (inc Merlin) watched Lord of the Rings "Return of the King" on TV until it finished at 11pm had a couple of fags and then went to bed.

Day 19 28ᵗʰ Sept

Got up late today, about 10:45am. Beth came down about 11:15am. Made a cuppa then did a bit of tidying, put washing up away vacuumed. Did bit of polishing, felt alright. Needed the lie in as I did not go to bed until about 1am in the morning. Had a good chat with Beth had cereal to eat about 1pm, plan on going to co-op a little later. Then I am going to do some more cleaning, mopping and cleaning surfaces in kitchen and bathroom. Went to bed about 2pm and woke about 6:30pm. As a result of this did not do the cleaning I had set out to do. Watched bit of tele. Then took a look at film "Pans Labyrinth" from 9pm.

Day 20 29ᵗʰ Sept

Woke up at 06:45 and decided not to go back to bed as I am going to Maths today. Feel alright although a little tired. Have to go and collect meds from office. Collected meds about 8am. Watching news on tele. Hovered at 8:45am waiting for mail to arrive. With a bit of luck I shall receive some letters from the benefits agencies. Went to town about 10:30am bought graphic novel from Discovery Terry Pratchetts "Guards" quite good only £2.

Then had dinner, cheeseburger. Started bloody raining and I only had a t-shirt and waistcoat on, then I went to Oxfam. Bought Dahlia book. Went to Maths. Doing some formula work not too hard really I got some wrong by not being careful plus trying to divide numbers with decimal points into whole numbers, i.e. 18 into 18 what you have to do is change decimal place to whole number from 1.8 to 18 then go to next decimal place to whole number, that being 180. Then you add the sum. 18 divided 180 = 10. Think I've got that particular thing pinned down. Then did fractions, found the work I was doing this week much easier than last weeks. Got home about 5:15pm dull day (weather wise) teach me to listen and take notice of weather report. Had game of chess with Kevin. I played bloody rubbish. He won taking score to 6-4. Whooped my arse. I challenged him again and played a lot better. I managed to check-mate him. He still had a few major pieces, Queen and (I think) two rooks and a bishop and a knight. Played reasonably well. The game went on for quite some time. He left (defeated) about 8:45pm score stands 6-5 to Kevin. Managed to pull back a bit of (wounded) pride. Then rang for take away. Donner and fries. About 9pm had a shower after "secret millionaire" then settled down to watch "the croupier" at approx 10:15. I had a reasonable day today all in all.

Day 21 30ᵗʰ Sept

Woke up about 7:15am was really tired considered going back to sleep. Then I thought about my commitment to go to all of my lessons so did not think it would be such a good

idea. Set off for town at 9am got to Cathedral Centre about 9:45am. Went straight into Art, more or less. In the morning we were working on the project we started last week. I quite enjoyed it. Then in the afternoon we did some brain storming on the brief we received. I think I've got some decent ideas to work on. Really enjoyed my day. On the way back cashed in winning lottery ticket (£4) and bought 2 more. Won "18 so that's a bonus isn't it. Had something to eat, jacket spud, beans, cheese and tomato. Had game of chess with Kevin. Only two pieces taken a pawn each. Then I check-mated him. Quick game ½ hour, 6-6 the score now. Went round to Richards watched bit of TV. Then came back watched the Skeleton Key (film) quite strange, went to bed about 11:30pm not a bad day, all in all.

Day 22 1st Oct

Got up about 8am started game of chess with Kevin. Stalemate scores stand at 6 ½ each now. Whilst I was quite pleased not to lose feel I should have won as I had the upper hand for biggest part of the game. Never mind though as it filled an hour of my time. Figured out (later on) that the game was not a stalemate. Although Kevin could not move his King without putting his King in check he could have moved quite a few of his other pieces. So we will have to call the game a null and void. Not a bad day, so far. I am not particularly looking forward to Maths. Although the whole process has become slightly easier it is still not something I look forward to. It is essentially a means towards an end. Went to town, bought a couple of books from Oxfam, quite good, struggled with Math fractions. Left about 3:40pm, went into another charity shop, bought another book, and got "2 worth of scratch cards won £10. Not a bad result. Not done badly for food today cereal with skimmed milk and 1 sugar. Dinner was bowl of weight watchers soup with 2 rolls and Muller light yoghurt. Watched bit of TV found out that Beth was pregnant, pleased for her. Did bit of drawing, sheep skulls.

Day 23 2nd Oct

Woke up by phone. Brother wanted me to put money into his bank to avoid charges. Said I was not confident. He said did not matter. Someone rang for Pam. Rearranged appointment, 3:30pm next Thursday, said okay. Then remembered I had appointment with you. Too late to do anything about it now. Sort it out later. Rang brother back. Change of mind, said I'd sort it. Pleased I changed my mind. Another "normal" thing I am dealing with. Went to town about 11:30 am went to Morrison's and bought some cigs. Then I went to post office. Took £100 out. Paid money in for Greg (bit of normality, glad I changed my mind) bought book from Oxfam "The Atlas of Tolkien's Middle Earth" £2.99, and then went shopping for food. Then went to discovery bought Graphic novel and junior murryn CD. Came back home. Before I set off for town did bit of cleaning, mopping, vacuuming, polishing and

wiping kitchen and bathroom surfaces and tops. When I got up noticed difference. Smelled like a hospital nice and fresh and clean. Feel good about today.

Although I slept in a bit I have still had a productive day. Richard and Beth came round, we spent most of the evening chatting, Richard feeling slightly insecure about the course/job etc. he was in a bit of a mood to begin with, good straight talking. Came round. One of the best evenings I have had for a long while.

Day 24 3rd Oct

Got up about 9:15am had shower feeling reasonable, had something to eat about 11am. Pork pie and pork dripping sandwiches. Went to bed about 11:30am Richard woke me up about 1:45, wasn't going to go to town but changed my mind. Went to town and did bit of shopping with Beth and Richard. Quite enjoyed myself bought DVD, CD and Music mag and watched bit of TV with Richard and Beth. Then watched Film "Underworld Evolution" had a really good day, all in all.

Day 25 4th Oct

Got up about 9:15am went to Greg's about 11am. Got there had a sausage and bacon sandwich. Stayed until about 5pm collected money I had put into his bank £50. Gave him £10 to treat himself. Not a bad day.

Day 26 5th Oct

Woke up at 10:30am went to bed late last night, had shower about 11am. Felt much better, Sue picked me up at 1:00pm went for dinner. Came back at 5pm. Went round to Richard. Bit of chat. Came home about 7pm watched Harry Potter until 9pm before it finished went to bed. Very average day.

Day 27 6th Oct

Woke up at 8:15am did washing up from yesterday. Put washing in about 9am. Did not really feel like going into Maths today. Considered ringing in sick lazy thoughts. Went in about 11am did a bit of shopping at Smiths for Art materials went to Cathedral Centre Maths was not so bad, quite enjoyed it really. Glad I didn't skive off, came back on bus was home for about 5pm. Had Kevin game of chess. He missed the chance to take my Queen. Went on to promote 2 of my pawns to queens. Check mated him after that relatively easily.

That takes the score to 7-6 to me. Did a bit of scanning and printing on computer. The colours are not coming out properly. Will have to have a look at it. She is coming to see me at 11am on Thursday, time now 10:12pm. Have set alarm for 7am. Will get to bed soon I think. Have not had too bad a day really. Although I have not really done anything out of the ordinary today. Went to bed at approx 10:15. Hope to wake up early.

Day 28 7th Oct

Woke up at 7am, quite tired, did bit of drawing not very successful. Had a shower and shave by 8:30am. Went to town today in a taxi, could not be bothered messing about. Got there about 9:30am went straight into Art. Had a very good day today. I really enjoyed it came home via shop (Tesco) bought bits and pieces for tea. Got home by about 5pm. Long day so far, put tea on, Quiche (cheese and onion) chips and I think I'll probably have it with some beans, and a bit of bread and butter. Changed mind decided to have it with macaroni cheese rather than beans. Did vacuuming and washing up, also did a bit of polishing while waiting for my tea. Had a game of chess with Kevin. I won again! That means I have won 4 on the trot. Score now stands at 8-6 to me. Had a shower about 9pm felt smashing. Went to bed about 10pm.

Day 29 8th Oct

Got up at 9am did vacuuming about 9:30 after taking meds. Ironed top for maths session at Cathedral Centre. Cleaned away the washing up. Brushed my teeth, had wash and general brush up. Felt great afterwards. Smoking after brushing ones teeth feels quite good although it really defeats the object to be honest. Thinking about going to town early today to do bit of shopping. Did bit of shopping in town. Went to River Island and bought a watch. Then I went to CBGB's and bought a silver ring. Both items came to £29. Then I went to maths. Got there about 11:30am. Had dinner about 12:15pm Heinz mushroom soup and a roll. Also wild cherry low fat yoghurt. Enjoyed my maths session was doing decimals and percentages of whole numbers, relatively easy left early (3:30pm) went to Primark spent £16, a white top a zip up jumper and a pair of grey trousers. Then from there went to Morrison's spent approximately £10. So all in all today I have spent £55 I wanted the toilet quite badly, Market was closed so I thought I would get to The Star, felt not bad at asking normally I do not go to the toilet in a pub unless I am drinking there. Got back home put tea on, pepperoni pizza. Put CD on. Bob Dylan's "Bootleg" really good music. Had tea. Did washing up. It's been a fairly busy active day today. Listened to music. Had game of chess with Kevin. I won again. That's 5 on the trot. The score stands at 9-6 to me. Later on I went round to Richards for a bit. Came back about 9pm. Listened to music, went to bed about 10 pm. Good days in all.

Day 30 9th Oct

Got up about 8:15am, rang Halifax enquiring about a paying in book. I was told they no longer do them. Another thing I've done that's "normal". See Pam at 11am. Might go to town today. We'll just have to see. Pam arrived at 11am. We had a really good chat. She helped me with my benefits. Getting income support paid into my Halifax account. Pam seemed very pleased with my progress. Quite good to get positive feedback. Went to town about 12:15pm. Did bit of shopping. Underworld, the Dubliners and a blues CD by John Lee Hooker. I also bought a fantasy art book from Discovery. And an ornament from CBGB's. In all I spent approximately £30, I also paid my rent (16.38) and put a tenner of credit on my phone.

So today I have spent £57 or there abouts. Put Underworld CD on when I came home. The time is now 2:05pm, not a bad day so far. I was also working on a drawing of Winnie the Pooh and friends this morning for Beth. Showed Pam my sketchbook. She seems really pleased with what I am doing in Art and life in general.

Appendix F

Interview P14

T   Right we're up and running now then Graham, so how have you felt filling the diary in then? OK?

S   To be honest I thought it'd be a bit more of a problem than it was to be honest, because I've been asked in the past to actually do quite a few diaries, about mood etc, but I've never really reacted very well to them so to do one continually and not really forget is a bonus from what I usually do

T   And is there any particular time of the day when you fill it in?

S   I'll get up and have a cuppa, get a shower maybe, depending how busy I am, and basically that's what I've been doing say, whether I got up early or not

T   Yeah

S   How I tended to feel in a morning, rather than just, you know, go through this or, went to town, did this, did that or did the other, it's all about how I feel, well generally about how I feel about what I've been doing

T   Yeah

S   About whether I've felt bored or whether I've felt listless, you know, that sort of thing

T   And how long… and what medication are you on again?

S   I'm on the Clozapine

T   Clozapine

S   And also on **sodium valporate**

T   And how long have you been on that for then?

S   The er…

T   Clozapine

S   Clozapine, only about a year and … no probably about two years

T   Right, and what were you on before you were on the Clozapine?

S   Modicate

T   Right, did that agree with you?

S   Well it did and it didn't you know, I mean, initially when I was first on modicate, I was on a massive dose, I was on you know like 400mg a week which as far as I can

tell is sort of like 200mg above the recommended highest dose, you know what I mean?

T   Did you have bad side effects with that or…?

S   I did get quite a lot of side effects but I can remember approaching my doctor at one time, well it wasn't actually my doctor, my doctor was on holiday so the other doctor would help with relief and he basically asked me to walk up and down, asked me about all my symptoms, basically he knocked it down from 400 overnight to 200

T   Yeah

S   You know what I mean, so, as far as he knew there was something major up with me so

T   Did that … when you were on that modicate did that stop you from doing stuff, did that stop you from doing things that you normally do?

S   Well I was in hospital at the time, in a secure hospital, you know, so really it's hard to measure really

T   Right

S   You know, because very much there it was sort of like more or less a routine, you get up at a certain time, you go to bed at a certain time, you go to work at a certain time

T   Right

S   You know all them sort of things, so in that respect it's very hard to gauge, but in terms of when I was certainly at you know, the secure unit in local hospital.

T   Yeah

S   When I was on the modicate there I felt a little bit worse than now

T   Right, I mean you're doing things here, I've only got the first page and you've talked about having a game of chess

S   Yeah

T   Is that something you would have done on the other medication?

S   Well yeah because I used to play chess when I was in secure unit so

T   Right, so that's something you've continued. Do you still get as much enjoyment out of it now?

S   Yeah, I'd say so, well some days I play like… I had a game last night; I just wasn't really into it

T   Yeah

S   I'd been to maths, yesterday and my head was cabbage and I had a game of chess, I'm not making excuses but you know it was a bit much for me after that to be honest

T   Yeah, and what about your cooking and stuff, you're good at cooking? You do a lot of stuff for yourself?

S   Well in the past I've cooked a lot, you know, basically I've been taught as well

T   Right

S   Basically I've been brought up to cook by my mother from a fairly early age and stuff, but you know when I was in secure unit again, they sort of had excellent facilities, basically because they have to have them you know, because of the people they contain getting bored and stuff it could lead to certain problems, but whilst I was there, you know, I sort of like learned to cook pies from scratch, made my own pastry, you know

T   Yeah

S   All them sort of things so I could probably go back to that but now I cook more convenience foods

T   Right

S   I mean, there will still be times when I might get **in** a couple of lamb chops do some veg with it and stuff

T   Yeah

S   But a lot of the time I take a pie out of the oven, some oven chips or something so it's not really cooking as such

T   But again, it's something that you probably wouldn't have done when you were on the other medication when you were quite unwell

S   Well no I was doing, doing that, well; you see it's hard to judge because I spent 10 years in Ashworth

T   Right

S   So basically for a lot of that time I was reasonably well, maintained on the medication

T   Right

S   So motivation wasn't that much of a problem to be honest

T   Right, do you feel better on this medication than the other medication or…?

S	It's hard to judge really I mean sometimes I get really tired and I don't know whether that's the meds or not to be honest

T	Right

S	A lot of people say "oh, the meds are responsible for this, that and the other" you know they'll say it affects their motivation and that's true to a certain extent but it depends on how you apply yourself as well, you know over the years I've been told by certain people whether it be doctors, nurses, people like that, that you know it depends on how you treat the medication, you know whether you give into it or whether you fight it you know what I mean

T	Yeah

S	Whereas you think, right I'm tired now so I'll go to bed or I'm tired now I'll think sod it, I'm going to do something, I'm going to go out or I'm going to do some drawing or whatever you know so a lot of it's about self-motivation rather than the meds to be honest I think

T	Yeah, and do you think, I mean, I suppose again it'll be difficult to gauge, do you think you've got a better quality of life now than what you had before?

S	Well, obviously, because I'm out of hospital now so it's obviously better

T	Yeah

S	But yeah, the meds, I was in the secure centre as well for quite some time

T	Right

S	But I don't know if it was the medication then, I think it was, and I can't remember exactly what I was on, but I used to have terrible trouble in a morning, if I didn't go to the toilet straight away, say for instance I lit up a fag, I'd be basically running to the toilet

T	Yeah

S	On a number of occasions I basically filled my trousers

T	Right

S	Because I hadn't got there quick enough and certainly that was a very distressing time

T	Yeah

S	You know, basically I'd had a shit in a sink once because I'd got undressed in my room you know to go to bed, and I'd nothing on and I thought well I can't … and I got this overwhelming urge to go to the toilet and I thought I can't get dressed in

time because I'll crap myself anyway so then I ended up doing it in the sink you know, so obviously things like that

T   Yeah

S   They are very negative and if it was the meds causing that I'm very glad I've changed really, you know what I mean, so

T   Right, you talk about your art

S   Yeah

T   What is it you enjoy about your art? What kind of art do you enjoy?

S   Well it's all sorts of things, mainly fantasy to be honest

T   Right

S   But I also do stuff like that up there. That's something I did when I was in the secure **Centre**, a lot of its I don't know, it's er, from your imagination

T   Yeah, yeah

S   Quite a lot of it you know, so…

T   And do you enjoy that then? Do you enjoy doing stuff like that?

S   Yeah but I'm also doing it as a course now, at the moment, you know so basically, that's being, I've just recently passed a course which is NCFE Level 3

T   Right

S   And that's equivalent to A Level, the next course I'm doing which I start in about a week, well I started this week actually, that's basically equivalent to 4 'O' Levels over 2 years so, I'm hoping eventually to get to the point where I could either get a job with my artwork or get a job and have my artwork to fall back on, make little bits of extras you know what I mean

T   Right

S   It's something I enjoy doing, but whether or not I could stand it as a full time job you know under deadlines and stuff like that you know I might not be able to do it because, you know

T   Yeah

S   In the past when I've been doing really too much I've become stressed and ended up becoming poorly again so I've got to really balance it so it just doesn't happen

T   And do you find that you've got the concentration levels to do that then?

S   Not compared with when I was younger

T   Right

S   I mean when I was younger I was unemployed for a quite some time and often I'd spend 8 to 10 hours a day drawing, you know what I mean, so there's nowhere near that amount of concentration, I can concentrate for a good couple of hours at least you know what I mean

T   Yeah

S   But as I say it's no comparison with myself as a youngster

T   You play chess a lot with Kevin, the score's 3-2

S   Yeah

T   It might be further on as we go through the diary

S   Yeah it's 4 now

T   Is it?

S   Yeah,

T   Is he one of the people from around here?

S   Yeah, he's one of the staff

T   Right and do you have a…

S   To be honest I don't have very … I have very little if any contact with other people around here

T   Right

S   Except Richard

T   Right

S   Who's a friend who I got to know both in hospital and on the Calico Project?

T   I was just going to say do you go on the Calico project?

S   Not anymore no

T   No

S   To be honest, it used to be good because you could have a bit of a laugh, a bit of a joke and

T   Yeah

S   But now there's too many people too politically correct you know, you can't step over boundaries and it's more like a chore to be honest, and that's why I packed it in, well plus getting the coursework as well

T Yeah

S But I couldn't see myself sort of like working outdoors in all-weather you know, and struggling as it were with carrying big lumps of wood and stuff and just uncomfortable you know what I mean

T Yeah

S And it wouldn't have bothered me as I say when I was younger I had a job when I was younger as a milk man well not as a… a part time job, and that was like getting up at 5.00 in the morning, working for four hours and getting a couple of quid a morning for it, so at that point I wasn't shy about hard work but over the years I think I have become a little bit to be honest.

T Do you think you mix well with people? Do you have any problem mixing with people?

S No not really, no

T Do you think people treat you any differently because of your illness? When you meet somebody new do you let them know that you've got schizophrenia or not?

S I don't ever speak about my schizophrenia because it's only ever … you know I don't really agree with it to be honest,

T Right

S You know, I wouldn't… I might not say I've got schizophrenia or a mood disorder, I'd probably say I've got existing mental health problems and I have had for some time

T Right

S To be honest, when people hear the word schizophrenia even other people with mental illness, because I've been in a position where I've been in hospital visiting the main hospital, you know, the main hospitals have like little

T Yeah

S Drop in centre

T Yeah

S You can have a cup of tea and that and the actual people on the main wards, the main open wards, if they heard the word schizophrenic they'd go "oo" they're all axe murderers and nasty, nasty people, so it's not just your public who viewed it but it's also to a certain extent your peers you know what I mean

T So you do think there's some kind of stigma attached to the label

S Course there is, yeah

T Yeah, and it's obviously from your perceptions the negative

S A lot of the time yeah, it's almost, say for instance now, I'll do my artwork now and people will say "oh that's amazing" but compared when I was younger and was at it 8 hours a day, I'm nowhere near as good. I often get the feeling, I wouldn't say it's quite patronisation because like obviously a skill like painting and drawing not everybody has it but I think sometimes people think because he's got a mental illness he shouldn't be able to achieve this, that and the other you know what I mean

T Right

S Because on one occasion I remember a psychiatric doctor, you know a psychiatrist, asking me what way I my future, what did I see myself doing. I told him I'd like to live in an hostel and work towards a degree and get my degree, and when I read the report written about me afterwards he'd put this is the man's grandiose ideas and that was regarding degree, etc, so even the clinicians and the people that so call look after you, they have very negative views a lot of them and you know, they think that just because this person has a mental illness he must be thick, you know what I mean?

T Yeah

S He must not be capable of functioning, you know

T And do you think that these people in a position of power/authority, do you think they treat you differently and make decisions for you based on the fact that you've got an illness?

S Yeah they do and very much so, because I must admit I was getting poorly towards the end, but when I went on K…. Unit, you know I ended up getting my meds reduced, I think it was from 100mg a week on Modicate to 17 ½ a week, you know, which to me is very much a maintenance dose now when, when I, the doctor came to see me the second opinion doctor I was told it was the most difficult decision they'd ever had to make regarding a second opinion, but he still believed I needed the anti-psychotics, now I personally think I didn't needed the anti-psychotics, the problem being, as well as stopping the anti-psychotics I also stopped the tablets for my mood disorder, and it's that reason I believe that I became ill, you know, not schizophrenia

T Right

S So, even though I disagree with the diagnosis, etc, I still take the medication with all its side effects because I just daren't risk really becoming ill again

T Right

S Because like what I've made the decision now is to get well, sort myself out, get a normal life, a normal job, a normal, you know, just normal

T And there's the issue there, what is normal?

S Well a lot of people say that

T Yeah

S And you hear it a hell of a lot in psychiatry

T Yeah

S From psychiatric nurses from doctors and you know, it's very blasé I think, to be able to say, you know when you are normal or whatever normal is, and somebody says well I'm not normal, what's normal

T Mm

S You know, people in a position maybe where they've got a career, they've got a house, they've got a wife, they've got children, you know for a 46 year old to have none of that

T Mm

S You know what I mean, that's not normal is it really by any means

T Yeah, I see what you're saying, do you think, I mean it's an interesting topic this and it's an interesting conversation and interesting slant to it, do you think people give you a label and expect you to fit into certain expectations?

S Basically yeah, as I say a lot of people… you know I write occasionally, you know, creative writing, I mean, I've got my art, I'm reasonably bright

T Yeah

S I'm by no means silly or stupid you know what I mean, but I mean, in the past certain reactions I have had you know, whether it be becoming annoyed or that could perhaps give people the indication that I've less control over my emotions and that could be to a certain extent due to a lack of maturity

T Yeah

S And I do, I tend to agree with that because like when you're in hospital you don't have any of the life changing decisions to make, you know, very often, and you're cosseted from so called normal life don't you

T Yeah

S   So then when you react in a childlike way or a childish way you assume it's not so much the er the circumstances, it's the illness, you know what I mean and I've done some very silly things, I've even had, I've said and done some very nasty things

T   Right

S   I mean I can remember being in hospital and knowing that the staff would just put me in secluded and knowing how they'd react I basically punched the door, and it had sort of Perspex glass in it, you know Perspex

T   Yeah

S   And my knuckles would be bleeding, basically suck the blood out of my knuckles, spat it at the door when they were looking in and said you'd better not effing come in here because I've got aids you know what I mean, and I'll spit at you and I'll kill you. I also said as well because I knew what I was doing, I also said to a couple of the staff I'm going to fucking rape and kill your children

T   Right

S   So you know, how people view you then obviously becomes tainted doesn't it, because you might be, I'm not saying its all mental illness, you know what I mean

T   Yeah

S   But sometimes you're nasty, just because you're nasty, but like by the same token they would then back as very negative, it won't be oh this is mental illness or whatever

T   Yeah

S   You know when you're being nice and you're mentally ill, it's fine, but when you're being nasty and you're mentally ill it's a different thing, and certainly I've suffered very much abuse at the hands of staff, you know, I've been restrained to.. You know, for some time, I couldn't lift my arm above my shoulder height, you know what I mean

T   Right

S   I found it very difficult to... and basically, it wasn't a case of oh we'll restrain this person as carefully as we can, it was done to hurt you basically because they knew a lot of things you'd said and done to them were nasty and they were basically getting their own back, you know what I mean so..

T   Mm, do you feel good about opening a bank account yourself?

S   To a certain extent yes because it's... I mean I suppose it's a bit daft really but for a long time I've had people helping me out and helping me do certain things and like

today when I rang up the disability people and stuff and got my post office account transferred to my Halifax account, I wouldn't say it makes me warm and happy all over but it's good to do something for yourself than relying on other people, and the reason I'm doing these sort of things on my own for is eventually I want to be out and you know. I mean I've discussed it with my doctor and my social worker and they think you know I'm ready to apply for an absolute discharge and I've only been out two years in January so that's quite an achievement

T   It is

S   There's people on the 37, 41 or 41 it becomes

T   Mm

S   Very rarely get out less than 5 years you know what I mean and stay and get that absolute discharge

T   And it's about making progress and making steps forward isn't it?

S   Yes of course it is, yeah, I mean sometimes it might be really, really difficult doing simple things but as time goes on but even so you've got to push yourself each step and some people think I don't want to push myself, I'm frightened and stuff like that but you have to face them fears and meet up to them or else you never progress

T   No

S   I mean, and that's true of anybody whether they have a mental illness or not, you know if... you know for the first time you go on holiday abroad you know, oh I don't know about flying or what, but everybody has a little

T   Anxiety about it doesn't them. OK I've nothing else that I'd need to ask you really

S   No

T   There's a lot of stuff in this diary which is really good erm, is there anything else you'd want to ask me or say to me or

S   No I'm fine, it's alright

T   Right

Appendix G

Tony Gill

3 Merrall Close

Haworth

1st September 2007

Dear Chair

<u>Ref: 07/H1302/66</u>

Please find enclosed the amended ethics forms that you require in order for you to consider my research proposal further.

I have addressed the points raised at the initial ethics meeting on the 17th July and would also like to make the following points:

- No participants will be excluded who are unable to speak or write English, any participants who wish to complete the diaries in another language will be encouraged to do so and these will be translated at a later date.

- Each participant will be given a notebook to use as their own personal diary and participants will be encouraged to write down their perceptions of issues that they feel are important to them, e.g. how they interact with others, how they feel people perceive them on a daily basis, how they cope with life on a daily basis, and what they actually do and feel during a day. A copy of the instructions for the keeping of the diaries is enclosed.

- A consent form and information leaflet for the focus group has been included.

- An amended information leaflet has been included for the diary keeping and interviews (original copy and changes highlighted).

- Instructions for diary keeping also enclosed.

- The draft letter to patients from consultants is enclosed.

Yours sincerely

Tony Gill

Appendix H

<u>Procedure for research</u>

People eligible for the study will be identified following initial discussion with the consultant in charge of their care.

The consultant will make initial contact with the people identified via a letter we have agreed upon.

Once permission has been sought from the consultant responsible for their care, I will then approach the individual, by sending them a letter inviting them to participate in the study.

The individual's key worker will also be contacted so that they are aware of what is happening and also to enable myself to be introduced to the participant.

Once initial contact has been made, I will talk through the information leaflet and consent form with the participant and allow them 48 hours to decide whether to take part in the study.

I will answer any questions at an initial meeting and once the participants have had their queries answered, then they will sign and date the consent form with the principal researcher present.

A phone number of the principal researcher will be given to each participant which will enable them contact him.

A further telephone number and contact details of my research supervisors from the University of Leeds will also be available to each participant.

Confidentiality is also of great importance. The participant's identity will not be revealed, and any personal details will be kept separate from the data collected and written study itself.

Each participant will remain anonymous and will be allocated an arbitrary number, such as 001 or 002 etc, and no one other than the principal researcher will know which participant corresponds to which number.

The data collected within this study will be in three distinct formats: the diaries, interviews and a focus group.

The interviews and focus group will be tape recorded and transcribed verbatim.

All of the data collected will then be read through and notes made throughout the transcript on general themes. This will enable the author to become immersed in the data, by doing

this it will enable him to become more aware of the life world of the patients in the research. The data will be analysed using Burnard's content analysis.

The analysis will look for consistent and contrasting themes among the 20 participants. What aspects are common to all or many participants? What aspects vary greatly, and is the variation idiosyncratic or is it associated with characteristics such as age, gender, care received, etc?

Ensuring that any distress caused by the interviews to participants is addressed. In order to reduce this, each participant will be given a phone number to contact the researcher, so that they can discuss any issues.

Participants will be aware that, if the researcher feels that there are issues that may significantly affect their care, or adversely affect their health, then he will discuss these with their CPN or equivalent person in charge of their care.

When conducting a visit, the principal researcher will always ensure that someone is aware of where and when he is conducting the visit. This is to ensure his safety.

Each participant will be involved in giving data for 4−5 weeks.

The period of data collection will last 11 months in all. Some participants will be invited to participate in a focus group at the end of the data collection period which, for some participants, will be several months after their period of diary keeping.

Once the data collection has been completed and written up, it is hoped that the principal researcher will be able to feed his findings back to those involved by way of seminars, written articles and by speaking at local health centres to service users.

Appendix I

Tony Gill

3 Merrall close

Haworth

Keighley

BD22 8QG

Dear John

Please find enclosed details of amendments that you require as part of the R & D approval for my PhD study.

1. Please find enclosed a summary of the procedure for carrying out the research.
2. The data will now be stored at the University of Leeds in a securely locked filing cabinet/safe once the data has been collected and analysed. This will be either in the PhD research suite or the research office.
3. Please find enclosed two copies of the relevant consent forms.
4. I agree to offer each participant a summary of the research findings in addition to the offer of a full paper.
5. the sponsorship form has been sent to Andrea nelson at Leeds University who will contact you direct with the form, I have asked her to fax it to you on 0113 295 2412.

I also agree to abide by all the rules and regulations/conditions set out in the research Governance Framework for health and social care.

Could you let me know as soon as I have full approval so that I can begin my study

Yours sincerely

Tony Gill

Appendix J

Letter from consultant to Patient

Please reply to:

Dr …………………..

Leeds

Tel: ……………………

Date:

Dear

I would like to invite you to take part in a research study. I have agreed to work with researchers from the University of Leeds on a study looking at

The Lived Experiences of People with Schizophrenia Prescribed 'Atypical Neuroleptic' Medication.

I am writing to you because you get this type of medicine. Are you willing to help them with their study?

If you would like to take part, could you please complete the tear off slip at the bottom and either return it to me at the address above or give it to your care co-ordinator the next time you are in clinic.

If you agree to take part in the study then one of the researchers (Tony Gill) will contact you shortly.

You can meet with the researcher, Tony Gill, and change your mind, no-one will mind.

Whatever you decide to do, it will not affect the healthcare or medicine you receive.
Yours sincerely

Dr ……………………..

Name:_____

I agree to participate in the study and give my permission

for the researchers to contact me.

I do not agree to participate in the study and do not want

the researchers to contact me.

Please tick the appropriate box and return to your care co-ordinator the next time you are in clinic.

Thank you

Appendix K

Letter to Participants

Please reply to:

Tony Gill PhD student

School of Healthcare,

University of Leeds, LS2 9UT

Tel: 07919834348

E-mail: hcsagi@leeds.ac.uk

«Address_1»

«Address_1»   Our Ref:

«Address_2»

«Address_3»   DATE

Dear

We would like to invite you to take part in a research study. Your Consultant has agreed to work with researchers from the University of Leeds on a study looking at

The Lived Experiences of People with Schizophrenia Prescribed 'Atypical Neuroleptic' Medication.

We are writing to you because your consultant has indicated that you get this type of medicine. Can you help us with this study?

If would like to take part, Tony Gill (a research student) will contact you to arrange a convenient time and place to talk with you about your experiences and how you can take part in the study. This should take about 30-45 minutes and can be arranged at the hospital or in your own home, or at a day care centre depending on your preference.

If you would like more information about the study, please contact Tony Gill on 07919834348, and he will send you more details.

- **You can meet with the researcher, Tony Gill, and change your mind, no-one will mind.**
- **Whatever you decide to do, it will not affect the healthcare or medicine you receive.**

Yours sincerely

Tony Gill, Peter Knapp and Peter Morrall

Appendix L

Consent Form for diary keeping and interviews (3)

Study title: **The Lived Experiences of People with Schizophrenia Prescribed**
                     Atypical Neuroleptic Medication

The purpose of this form is to make sure that you are happy to take part in the research and that you know what is involved.

Please tick to confirm

I have read and understood the information leaflet given to me.

☐

I have had the opportunity to ask questions and discuss the study with my family and friends.

☐

I have had the opportunity to ask questions about the study and have had

my questions answered..

☐

I understand the purpose of the study and how I will be involved.

☐

I understand and accept that by taking part in the study I will/may

not gain any direct, personal benefit from it.

☐

I understand that I will be taking part in this study of my

own free will, and I understand that I may withdraw from

 it at any time and for any reason, without my medical care

or legal rights being affected.

☐

I have given my permission for parts of the data collected to be

used in reports of the research on the understanding

that my identity will not be revealed.

I agree to take part in the study

I agree to the interviews and focus group to be

tape recorded.

Thank you very much for agreeing to take part in keeping a daily diary and agreeing to take part in an interview for my research.

Signed   _____

Name in Block Letters_____

Date   _____

Appendix M

Patient Information Leaflet (2)

Date:

STUDY TITLE: The Lived Experiences of People with Schizophrenia Prescribed Atypical Neuroleptic Medication

<u>A diary study and interviews</u>

Introduction

I invite you to take part in a research project.

- You do not have to say yes.

- If you decide to say no, then you do not need to give me a reason.

- Please ask me if there is anything you do not understand.

Please read this information carefully before you decide what to do. I will give you time to think about taking part and to ask other people for advice.

<u>What is the purpose of this study?</u>

I want to find out more about what people do on a daily basis; to find out what they spend their time doing and to see what kind of social networks they have. I want to see what their quality of life is like and to see if this is influenced by the type of medication they are on.

<u>Why have you been chosen?</u>

You are receiving medication which belongs to a group called atypical neuroleptics, and the symptoms of your illness are well controlled at the moment.

<u>Do you have to take part?</u>

It is up to you to decide whether or not to take part: if you do agree, I will give you this information sheet and ask you to sign a consent form saying that you agree to take part in the study.
If you decide to take part, you are still free to change your mind at any time and without giving a reason, and this will not affect your care in any way.

<u>What will happen if you agree to take part?</u>

After you have signed the consent form I will issue you with a notebook that you can use as a diary and you will then be asked to keep a daily diary for a period of 4 weeks describing how you live your life each day.

You will have an interview with me after 2 and 4 weeks whilst keeping your diary. This is to enable you to discuss anything that you think is important and to describe what you have done each day, and these interviews will last between 30-45mins

During the interview we will talk about how you have being living your life, what social contacts have you made, how your illness affects how you do things and what you feel is important to you. All information which is collected about you during the research will be kept private and confidential. It will be stored in a locked filing cabinet in a secure office. If you mention something you would not like to be shared with your consultant during the diaries or interviews, you may ask for it to be omitted or for the interview to be kept confidential.
I will not discuss what you say during the interviews with your consultant without your permission.

What are the possible disadvantages and risks of taking part?
Interviews and diaries have very few risks. However, during the interviews we may discuss issues that are uncomfortable and distressing. I will try not to upset you in any way. You can also stop our interview at any time. I will tape the interview to make sure my record of what you say is accurate.
You may be concerned about describing things to do with your life and how you live it which you are not happy about. We will not pass on what you say to your doctor without your permission.

What are the possible benefits of taking part?

You will not get any personal medical benefits from agreeing to take part. However, the study may highlight how people's quality of life can be influenced by the choice of medication. This could help people in the future.

What will happen to the results of the study?

The diaries and interview tape will be looked at to identify common themes that have emerged and after a period of time the diaries and tape will be destroyed.

It will not be possible to identify you in any way from the publications, reports and guidelines that are produced.

Who is organising and funding the research?

The University of Leeds

Contacts for further information

Tony Gill PhD student, School of Healthcare, University of Leeds, LS2 9UT

Tel: 07919834348

E-mail: hcsagi@leeds.ac.uk.

Dr Peter Knapp, Lecturer, School of Healthcare, University of Leeds, LS2 9UT
Tel: 0113 343 1237 or 0113 343 1251.

E-mail: p.r.knapp@leeds.ac.uk

Thank you for reading this information and thinking about taking part in this study. If you agree to take part, then you will be given a copy of this information leaflet and a signed consent form to keep.

Appendix N

How to fill in your daily diary.

Thank you for agreeing to take part in this study. Here are some points to bear in mind when filling in your diary.

- I am interested in your account of things that you do day by day and how you feel about them.

- Please remember that this is your diary and I am interested in what you do, how you feel and what your thoughts are. If you are unsure about including something, please do, I would rather have too much information than too little.

- Please don't worry about spelling, grammar or 'best' handwriting, but do try to write as clearly as you can.

- Try to fill in the diary each day; we can discuss the best time for you when we meet. If you cannot make an entry for a particular day, then you can fill it in the following day. Try not to fill in the diary more than one day after the entry was due. For example, don't try to fill in Wednesday's entry on a Friday.

- Please try to make a note of the date for each entry in your diary.

- Try and write a paragraph about what you did each day and explain your thoughts on events. For example, you might put
    - "What I did today was…",
    - "How I felt today was…",
    - "My medication today caused me to feel…"
    - "People I met today were …"
    - "Today I felt good because…"
    - "My plans today include …"

- I will arrange to meet you after 2 weeks and again after 4 weeks. This is to discuss in more detail some of what you have written and discuss any concerns you may have.

- If you have any questions about the health diary, please phone or text Tony Gill on 07919834348 . Tony will get back to you, so you don't have to pay for the call.

Thank you

Appendix O

Atypical antipsychotic medications

- Clozapine (Clozaril) Available in oral tablets and dissolving tablets.
- Risperidone (Risperdal) Available in oral tablets, dissolving tablets, liquid form, and extended release intramuscular injection.
- Olanzapine (Zyprexa) Available in oral tablets, dissolving tablets, and intramuscular injection.
- Quetiapine (Seroquel) Available only in oral tablets.
- Aripiprazole (Abilify) Available in oral tablets and dissolving tablets.
- Amisulpride (Solian) Available only in oral tablets.