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'MANAGING PRECONCEIVED EXPECTATIONS' - MENTAL HEALTH SERVICE USERS EXPERIENCES OF GOING HOME FROM HOSPITAL: A GROUNDED THEORY STUDY

A Thesis Presented to the University of Dublin, Trinity College for the Degree of Doctor in Philosophy

by

Brian Keogh

June 2011

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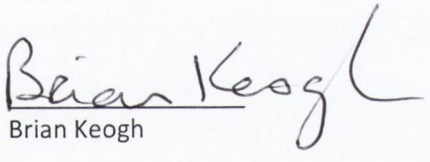
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'MANAGING PRECONCEIVED EXPECTATIONS' - MENTAL HEALTH SERVICE USERS EXPERIENCES OF GOING HOME FROM HOSPITAL: A GROUNDED THEORY STUDY

SUMMARY

Background: The experience of mental distress and subsequent admission to hospital can be a difficult and challenging event in a persons' life. Following a period of hospitalisation, going home and re-entering the community can also result in increased vulnerability for mental health service users. Furthermore, relapse and subsequent readmission to hospital are a major source of stress for service users. Readmission rates have been suggested as one indicator of the success of the transition from hospital to community care. In 2009, there were 20,195 admissions to psychiatric hospitals in Ireland. Seventy percent (n=14,223) of these admissions were readmissions suggesting an unsuccessful transition for a high number of people.

Aim: The aim of this study was to develop a grounded theory that explored mental health service users' experiences of going home from hospital.

Methodology: This qualitative study used classic grounded theory techniques as described by Glaser. Participants were recruited from community mental health services, vocational and voluntary organisations in one large urban area. A total of thirty five interviews were conducted with thirty one mental health service users who had been discharged from hospital. Theoretical sampling was used and data was collected and analysed simultaneously using the constant comparative method. The analytic processes were documented in theoretical memos as advocated by Glaser and Strauss.

Findings: Central to classic grounded theory development is the articulation of the participants' main concern following their discharge from hospital. Once this emerged, the social and psychological processes that the participants used to resolve this main concern form the components of the substantive theory. In this study the participants' main concern was related to their desire to manage the negative assumptions that their social audience had about them once they were discharged from a psychiatric hospital. The participants resolved this concern with a process conceptualised as *'Managing Preconceived Expectations'* which had seven related subcategories.

The first category, *'Absorbing Preconceived Expectations'* describes how prior to the participants' contact with the mental health services they had already formed a negative conceptualisation of mental distress and psychiatric hospitalisation. They perceived mental distress as something to be ashamed of and something to be feared. In addition they generally had a poor knowledge of issues pertaining to mental health and mental distress. The second category *'Acquiring Preconceived Expectations'* describes how, when the participants were admitted to hospital, they acquired additional conceptualisations of mental distress which impacted negatively on their experience and reinforced the conceptualisations that they already had. For example, the participants were indoctrinated into the bio-medical interpretation of mental distress and they received messages that the course of their 'illness' was lifelong and chronic.

The third and fourth categories '*Validating Preconceived Expectations*' and '*Maintaining Preconceived expectations*' describe how, when the participants were discharged from hospital, the negative perceptions of mental distress that they had absorbed were validated and maintained through their interactions with their social audience. For example they were made to feel ashamed for having a 'mental illness' thus validating their belief that it was something to be ashamed of. The fifth category, 'Avoiding Preconceived Expectations' describes the many avoidance techniques the participants used to avert being stigmatised because of their mental health problem. Central to the avoidance techniques was the participants' desire to manage disclosure about their experiences and their mental health problem. In addition they socially disengaged, avoiding contact with their peers which led to further exclusion. When they did disclose, they often encountered negative reactions and discrimination, which further perpetuated their desire to avoid preconceived expectations.

The final two categories '*Reassessing Preconceived Expectations*' and '*Defying Preconceived Expectations*' describe how the participants moved along a more positive trajectory and developed a more meaningful and positive relationship with their mental health and their experiences of mental distress. Firstly, the participants' re-examined their experiences and this provided them with a greater understanding of mental health and recovery. This re-examination was influenced by a number of factors which are described as '*recovery catalysts*'. In addition, the participants also made an irrevocable decision not to allow their mental distress to override the other facets of their identities. In '*Defying Preconceived Expectations*', the final category of this grounded theory, the participants actively defied the preconceptions that were made about them because they had a mental health problem. They did this in two ways: through '*being a success*' and '*maintaining mental health*' both of which challenge the conception that mental health problems are chronic and unremitting.

Conclusion: The substantive theory that emerged from the data and presented in this thesis demonstrates that the persistence of mental distress based stigma is not only prevalent but it also has a negative effect on mental health services users. The negative stereotypes held about people with mental health problems were not only applied to them by the participants' social audience, but were applied to themselves by themselves. The participants' experience of mental distress based stigma following their discharge from the mental health services had a negative impact on their perceptions of themselves. Furthermore, the stigma they encountered negatively influenced their ability to recover and to adapt to the difficult feelings and experiences that accompanied their need for admission to hospital. This theory adds to the extensive literature which explores mental distress based stigma. In addition it presents a conceptual framework which aids our understanding of the participants' experiences at a difficult and vulnerable time.

ACKNOWLEDGEMENTS

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I would like to thank the Health Research Board for their financial support in the completion of this study.

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A special note of gratitude to my partner PK even though I was accused of not having a job when I was working on the research full time.

Finally, I would like to dedicate this thesis to my Parents who have always supported me, not just in my career but in every aspect of my life.

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CHAPTER ONE: AN OVERVIEW OF THIS THESIS

> 'Supporting and assisting clients who have a mental health issue to transition from hospital to community are critical for improving care and health outcomes' (Forchuk et al., 2007:85)

Introduction

This classic grounded theory study explored mental health service user's experiences of going home from hospital. A substantive theory was developed which articulated the participants' main concern and the processes they used to resolve this concern. The theory, entitled *'Managing Preconceived Expectations'* demonstrates that the central concern for the participants following discharge was other peoples perceptions of them now that they had been officially declared as having a mental health problem. This concern was based on the participants' negative conceptualisations of mental distress, which were validated and maintained through their interactions with the mental health services and their social audience when they came home from hospital. The participants managed these concerns through the processes of *'Avoiding Preconceived Expectations'* and *'Defying Preconceived Expectations'*, which will be discussed in more detail later on in this thesis. The aim of this introductory chapter is to provide a brief description of the background, rationale and aims of this study. In addition it will provide a succinct overview of the contents of this thesis.

Background and Significance

Although mental health services in the community have developed considerably in the last number of years, psychiatric hospitalisation remains a prominent feature of the Irish mental health services. Within this service, the high number of readmissions to hospital for service users has been commented on (Daly et al., 2007). This high number of readmissions has remained constant at around 70% of total admissions[1] since the 1980s despite a progressive and consistent expansion of the community services during that time. Incongruently, the lack of suitable mental health community services have often been blamed for the demand on acute care beds and the high number of readmissions to hospital. Despite this, our understanding of the transition from hospital to home and the reasons that people

---

[1] Even though the number of total admission to hospital has decreased, readmissions rates have remained high. For example 72% of total admissions in 1989 were readmission (n=19,720). In 2009, the percentage of readmissions remains at 70% even thought the total number of admissions has fallen considerably (Daly & Walsh, 2010).

become frequent users of the hospital services is poor. Despite a review of the literature, no Irish studies could be located that explored this phenomenon from a service user or service provider perspective. Furthermore descriptions of the discharge experiences of mental health service users were limited to anecdotal information or as an aspect of studies exploring other experiences such as acute care. It was within this context that this study was conceived, and a research proposal was designed which sought to explore the discharge experiences of mental health service users in Ireland.

Prior to starting this study, I did have some knowledge of the research area, albeit anecdotal. I trained in the United Kingdom and when I returned to Ireland in 1995 I found that my role as a staff nurse was different to what I had been used to in the UK. In the UK, systems had been put in place to assist mental health service users to cope effectively in the community. Despite this my role in preparing people for their discharge regardless of where I worked was not much more than cleaning the 'patients' bed area and organising a prescription. Equally in Ireland, I felt that little or no thought was given to planning or preparing service users' for discharge. However, I thought that where I worked may have been atypical of the wider mental health services as it took referrals from all over the country. Furthermore, the rates of readmission where I worked appeared quite high and it was not unusual to pick up a service user's medical notes to reveal that they had twenty or thirty admissions to this particular hospital[2]. These readmissions were a source of stress and frustration for the nursing staff who worked there and service users were often negatively perceived for not coping effectively at home. This is corroborated by McBennett (2005) who suggests that the psychiatric nurses in his study viewed 'revolving door' admissions in a negative way and believed that service users who were frequently re-admitted represented a failure to achieve positive outcomes by mental health staff. In addition, from personal experience, readmissions were often explained by staff using a non compliance/adherence discourse which I now believe is overly simplistic.

It was no surprise to me when I started to collect the data that the participants stated that they had no preparation for discharge from hospital apart from being

[2] This assumption is not reflected in the statistics: in 2009 there were 2,744 re-admissions to private hospitals, 65% of total admissions (Daly & Walsh, 2010).

allowed to go home on weekend or day leave. As the simultaneous processes of data collection and data analysis progressed, it emerged that the participants were not really concerned about this lack of preparation for discharge, even though they all reported that they were petrified about the prospect of going home. Their fear was driven by theirs and their social audience's negative interpretations of mental distress and the participants' devalued status following their discharge from hospital. A conceptual framework which explains the origins of these negative perceptions and how the participants managed them is therefore the focus of this dissertation.

Selecting the Research Topic

When I moved to this University in 2003 I instantly became cognisant of my role as a researcher. Prior to this I had never really considered completing a PhD, but it seemed a natural progression now that I was within the academy. When I made the decision to register on the PhD programme I began the search for a research topic. What I was clear on from the start was my desire to complete research that was steeped in my background as a psychiatric nurse and on something that I believed was relevant to the people who used the psychiatric services. My interest in the area of discharge from hospital emerged in response to literature I came across as part of my teaching that focused on relapse prevention. Although this was not really the area that was investigated it was influential in the design of the project. This initial reading led me to examine the area more closely to reveal that 70% of admissions to hospital were readmissions (Daly & Walsh, 2010) and that this figure had remained relatively constant since the advent of community care, which began in Ireland during the 1980s. Although I completed a research proposal as part of the registration process that focused on relapse prevention, the area of interest became more focused on the transition from hospital to home as it seemed to be an under researched topic. Many people told me that this research had already been completed; however as stated, I was unable to locate literature that supported this claim.

Aim of the Research

Developing aims and objectives for a grounded theory study is sometimes viewed with extreme negativity by classic grounded theorists. However, I believed that it was important to have at least one overall aim which would help to focus the research. Later on in the project when I was applying for Health Research Board

funding[3], specific objectives were developed. By the second time I applied for the funding I was more familiar with the subtle nuances of grounded theory and was a little more in opposition to the notion of aims and objectives for this type of study. However, I still was of the view that the ones developed were sufficiently broad to allow for the participants' main concern to emerge as is required of a grounded theory study. The final aims and objectives are outlined below.

The overall aim of this study was to generate a substantive theory of service users' experiences of going home from a psychiatric hospital. The following were the research objectives:

1. To explore the social and psychological processes that occur when mental health service users are discharged from hospital.
2. To develop a theoretical framework that provides an explanation of the processes used by service users following discharge from a psychiatric hospital.
3. To situate this theoretical framework in the context of current understanding of the experiences of mental health services users when they are discharged from hospital.

Choosing Grounded Theory as the Research Methodology

The broad aims and objectives of this study dictated that qualitative research was the most suitable approach to explore the experiences I wanted to capture. Way before this research was conceived, I had made a decision that this research would capture the voice of mental health service users regardless of the subject area. This decision was immersed in a rather naïve aspiration that I should stay close to my own roots as a psychiatric nurse rather than as an academic or teacher. It was for this reason that grounded theory became interesting to me as it matched with my aspirations (naïve or not) of allowing the participants experiences and concerns to guide the data collection and analytic approaches. Furthermore, developing a theory that could be utilised in clinical practice appealed to me, because it provided a concrete outcome and something that had not been done before within this context. In hindsight, using classic grounded theory has not just provided the

[3] This project was awarded a one year research fellowship (2009 – 2010) from the Health Research Board.

substantive theory contained in this thesis; it has also allowed me to reflect on the practice of psychiatric nursing, specifically my practice which has impacted both on my attitudes to psychiatric nursing and how I teach as a member of faculty staff.

A Note on the Language Used in this Thesis

Although the participants in this study referred to themselves as 'patients' and referred to their mental health problems as 'mental illness', it Is not my intention to subscribe exclusively to the medical model. I will refer to them as mental health service users or people with mental health problems rather than 'patient' or 'client'. In addition, I will use the term 'mental distress' to describe the range of mental health problems that the participants were hospitalised for. Later in the findings chapters (chapters six to eight) I refer to the participants' social audience and by this I mean those individuals who are active onlookers and who provide feedback to the participants. This is in direct contrast to the common perception of an audience as passive and non-responding. The term 'audience' is taken from Goffman's (1959) work 'The Presentation of Self in Everyday Life' and is used widely throughout his work to describe the many social relationships that individual's may have.

Format of the Thesis

This thesis is divided into ten chapters including this introductory chapter. The next chapter presents an overview of mental health service development and delivery in Ireland. In addition it presents contextual information about the nature of the services where this study took place. The third chapter examines information about the substantive area which was mental health service users' experiences of going home from hospital. Chapters four and five discuss the philosophical and methodological issues that pertain to this study. This includes an overview of the methodological approach which was classic grounded theory. The substantive theory that emerged from the data analysis approach is presented in chapters six, seven and eight and this is followed by a discussion of the emergent theory (chapter nine). The final chapter (chapter ten) explores the implications of this piece of research and will present recommendations for research, education and for mental health professionals working with mental health service users. In addition it will describe the concept of rigor as applied to this study.

CHAPTER TWO: MENTAL HEALTH SERVICE DEVELOPMENT AND DELEVERY IN IRELAND

Introduction

The experience of a mental health problem and admission to a mental health service can be one of the most distressing, frightening and disempowering events in a person's life (The Sainsbury Centre for Mental Health, 1998; Kovisto et al., 2003; Foster, 2007; Walsh & Boyle, 2009; Nolan et al., 2011). In 2009 there were 20,195 people admitted to psychiatric hospitals and units in Ireland[1] (Daly & Walsh, 2010). For these people, coming home from hospital and re-entering the community can be a challenging experience. Re-adapting to community living is often hampered by the enduring and unpredictable trajectory of mental distress (Beebe, 2009). Issues such as social exclusion, loneliness, stigma and unemployment can negatively impact on services users' recovery, resulting in a high number of people being readmitted (Montgomery & Johnson, 1998; Johnson & Montgomery, 1999; Lamaire & Mallik, 2005; National Economic & Social Forum, 2007a; Nolan et al., 2011). Readmission rates have been suggested as one indicator of the success of the transition from hospital to community care (Lien, 2002). In 2009, 70% (n=14,223) of admissions in Ireland, were classified as readmissions (Daly & Walsh, 2010), suggesting unsuccessful transitions to community and home living for a high number of individuals. Relapse and subsequent readmission is a major source of distress for service users and their family members (Brosnan, 2006). Dukkers et al. (1999) and Greenberg and Rosenheck (2005) suggest that in the transition from hospital to community care mental health service users are often subject to increased vulnerability. In addition, relapse and readmission has been shown to result in decreased quality of life for service users, acceleration of social disablement, as well as the economic burden on the health services (Shepherd et al., 1989; Hogarty et al., 1991; Chang et al., 2003).

In 2001, the Health Research Board announced that the high number of readmissions to hospital provides evidence of the enduring and recurrent nature of many mental health problems and the need for expansion of the community care services (Health Research Board, 2001). Mental health services have undergone

[1] Unless otherwise stated Ireland refers to the Republic of Ireland

substantial changes since the initial drive for community care in Ireland started in the early nineteen eighties. Despite these changes, research has suggested that adapting to community living following a period of hospitalisation is difficult (Lemaire & Mallik, 2005). Furthermore, there is little evidence to suggest that the alterations in mental health care provision over the past number of years have positively impacted on the lives of service users. There is also acknowledgement that there is a lack of 'step down' facilities for service users who use the mental health services, which subsequently results in service users being discharged too early from hospital, thus worsening their chances of remaining well in the community (Department of Health & Children, 2003)[2]. In summary, achieving a positive outcome from hospital discharge is something that mental health professionals find challenging (Simons & Petch, 2002). Despite this, there is a paucity of research in Ireland, which examines the transition of mental health service users from acute inpatient services to community living. The overall aim of this chapter is to place the current study in context by discussing the policy and legal developments that have impacted on the provision of mental health care in Ireland. However, it will begin by briefly discussing the rather contentious issue of literature reviewing and grounded theory, the chosen methodology for this study.

Reviewing Literature prior to Grounded Theory Development

Central to the concept of grounded theory is the suspension of preconceived ideas about the nature of the theory that will emerge once data collection and analysis begins. One of the ways that researchers are advised to do this is by not completing an in-depth literature review in the substantive area prior to starting the study. Of all that is written about grounded theory, the absence of a literature review is possibly the most consistent and well known 'fact'. However what is less described is the difficulty that this poses for students who have been educated using more traditional scientific models of research. It was virtually impossible for me to ignore the literature as applications for research funding were made on a number of occasions and these required that I present some rationale or justification for doing this research now. Moreover, my interest in the area of hospital discharge had emerged from teaching on undergraduate and postgraduate educational programmes in the context of relapse prevention which required a considerable knowledge of the issues concerned. Glaser's (1978; 1998) advice to

[2] Hereafter referred to DoH&C

leave the literature review until the theory is developed is well justified and became clearer to me as the *'Managing Preconceived Expectations'* theory developed. However, there is no suggestion in Glaser's work that grounded theory researchers become like empty vessels approaching the substantive area with blank sheets and empty minds. My personal and professional experiences were important ways of developing theoretical sensitivity (Glaser, 1978). Glaser (1998) suggests that the literature can be sourced when the researcher's theory has emerged and that the emergent theory will direct the researcher to what literature to sample and in what area[3]. Then the literature can be integrated as additional data that can be used to support the emerging theory. I did complete a literature review but as Glaser (1978) suggested it was conceptually different from the theory that emerged and although part of it is presented here as background information most of it was redundant. Within this written work, it was easy for me to omit from the review the sections that were written and subsequently deemed not relevant to the emerging theory. However, it was more difficult to 'ignore' the influence they had on my preconceptions about the nature of the research problem and the shape and direction of the emerging theory. Therefore the body of literature presented here relates to the substantive area that was the focus of my interest at the time.

Mental Health Care Provision in Ireland

The provision of mental health services internationally have undergone a number of transformations resulting in the current preoccupation with normalisation and care in the community (Jones, 2004). These transformations have stemmed from a range of interrelated historical events, altered philosophical beliefs about mental health problems and modifications in 'treatment' and 'care' paradigms. Ultimately, these developments have shaped social policy in Ireland and current practices in the care of people with mental distress are a direct result of a number of legal and policy documents that have been published since the foundation of the state in 1922. The history of Ireland's care and treatment of people who have mental health problems, at least since the 1980s, appears to correspond with international contexts in that there has been a gradual decline in the amount of psychiatric in-patient beds and an increasing emphasis on community care. Both of these approaches to care were heavily influenced by the biomedical paradigm and often

[3] In his own words he argues that libraries and the books within them will still be there when the theory is developed!

maintained that the absence of symptoms was the key to successful treatment (DoH&C, 2006). Although biomedical approaches remain influential, current approaches to care in Ireland have seen an increase in interest in the recovery movement and this reflects an attitudinal change in the perception of mental health problems as a chronic debilitating process (Mental Health Commission, 2005). This section will attempt to look at the key concepts that have influenced mental health care provision in Ireland.

Historical Development of the Mental Health Services in Ireland

Prior to the introduction of the asylum system in Ireland, the countries' 'mentally ill' were cared for by charitable organisations in poorhouses, houses of industry or in the nation's jails (Reuber, 1999). The apparent increase in the number of people with mental health problems from the 1800s on, according to Malcolm (2003), prompted the British government to establish a number of state funded asylums throughout the country. The reasons for this unprecedented increase in admissions to asylums are unclear in what at that time was a mainly rural population and where the industrialisation process had limited impact (Malcolm, 1999). Reuber (1999) suggests that many people were admitted to hospital for social reasons, such as poverty, or the lack of an adequate support network. While Brennan (2007) argues that the perpetuation of the asylum system was maintained because these institutions not only offered employment to local communities, but were also integral to the social lives of the individuals who lived and worked there. The first of these publically funded asylums was The Richmond Asylum, later known as St. Brendan's Hospital which was built in 1815[4] (Malcolm, 2003). The use of mental hospitals or asylums as the primary location for the provision of mental heath care has been generally well described in the Irish and international literature (Finnane, 1981; Robins, 1986; Malcolm, 1999, 2003; Walsh, 1997; Reuber, 1999). In addition, the functions and practices of these asylums were documented annually from 1843 onwards initially by the Inspector of Lunatic Asylums, then by the Inspector of Mental Hospitals and more recently by the Inspector of Mental Health Services (Brennan, 2007). These reports not only provide empirical data on the number of people admitted and discharged to these numerous institutions but also provide information on the changing nomenclature used to describe mental ill health over time (Brennan, 2007).

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[4] St Patrick's Hospital, a private hospital for people with mental health problems and intellectual disabilities was opened in 1745.

Institutional and custodial care persisted up until the mid 1980s and reached its peak in 1958 when the Republic of Ireland had the highest number of psychiatric hospital residents in the world, with approximately 0.5% of the population being accommodated in institutions around the country (Walsh, 1997). The poor living conditions of the thousands of inmates was exacerbated by the frugal finances ring fenced for mental health services which resulted in shoddily built asylums that were under resourced and badly maintained (Malcolm, 2003). The inspector of mental hospitals in his annual reports for the years 1956 and 1957 identified overcrowding as one of the principle issues impacting on the quality of services in mental hospitals in Ireland (Inspector of Mental Hospitals, 1956, 1957), prompting the suggestion that admissions to asylums should be more rigorously screened to prevent social admissions from occurring (Ryan, 1999). Social admissions continue to cause controversy in modern mental health service with Keogh et al. (1999) suggesting that 'inappropriate' admissions[5] to hospital and delayed discharge from hospital stem from inadequacies in the community mental health system.

Policy Frameworks and the Mental Health Services in Ireland: The Commission of Inquiry into Mental Illness, Planning for the Future and Vision for Change.

In 1961, the Minister for Health established a commission of inquiry on mental health problems whose remit was to examine and report on the services available for the mentally ill and the changes thought necessary for legislation. The Commission issued the report in 1966 and recommended that mental hospitals should not be seen as places of custodial care, but rather centres of rehabilitation with an emphasis on short-term treatment, and a subsequent return of service users to the community. The Commission of Inquiry (Govt. of Ireland, 1966) specifically commented on the high number of people housed in psychiatric hospitals around the country stating that:

> 'At any given time, about one in every seventy of our people above the age of 24 years is in a mental hospital' (Govt. of Ireland, 1966: xiii).

[5] By inappropriate the authors mean admissions that might have been prevented had other community services been available. For example, service users were admitted to hospital often because community services were not in place or they were in acute beds for longer periods than necessary because residential arrangements were unavailable.

The report also advocated a greater role for the General Practitioner in psychiatry and a stronger emphasis on mental health promotion by public health personal. It also recommended a move away from traditional mental hospitals situated at the periphery of towns and cities, and the establishment of small units in general hospitals. This perhaps suggested an attempt at narrowing the divide between physical and mental health problems (Govt. of Ireland, 1966). Despite these recommendations, little progress was made in implementing change and little government money was spent to achieve these goals (Webb et al., 2002). Although the report was timely given the large numbers of people housed in mental hospitals around the country, there was no plan of action which meant that recommendations were unevenly implemented throughout the country (Walsh, 1997). However, the number of in-patients did decrease following the publication of the Commission of Inquiry on Mental health problems in 1966 (Govt. of Ireland, 1966). However, in comparison to International standards they did remain high with about 13,000 (363 per 100,000 total population) people being looked after in Irish mental hospitals in 1984 (Malcolm, 2003).

The publication of the policy document Planning for the Future (Dept of Health[6], 1984), advocated a wholesale reconfiguration of the psychiatric services in Ireland, resulting in a process of strategic deinstitutionalisation and a reduction in the number of inpatient beds. This document placed an emphasis on ensuring that the various Health Boards[7] throughout the country took action to reduce the number of people in long stay facilities and the establishment of a more community orientated service. However progress was slow and subsequent Governments have been criticised for failing to implement the full range of recommendations suggested in the document (Amnesty International, 2003; DoH&C, 2006). Following the publication of Planning for the Future (Dept of Health, 1984), people continued to be admitted to hospital, albeit for shorter periods. Bed numbers were dramatically slashed. For example, in 1984 there were 12,484 psychiatric beds in Ireland, in 2004 there were 4,121 (HRB, 2004). Part of this reduction included the relocation of 'long stay' service users to smaller residences in the community. This

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[6] Prior to 1997 the Department of Health & Children was known as the Department of Health.

[7] The Health Act 1970 (Government of Ireland, 1970) established a number of health boards throughout Ireland who were charged with the administration of the public health services. These were disbanded in 2004 and replaced with The Health Service Executive (Health Act, 2004). There were eight Health Boards and there are now four HSE areas.

included the relocation of people with intellectual disability who were also housed in psychiatric hospitals around the country. In addition, hospital personnel were also moved to the community but there is no evidence to suggest that they were equipped with skills to make this transition, suggesting that institutional practices and institutional care continued regardless that the location of care had changed. Planning for the Future (Dept. of Health, 1984) explicitly directed the health boards across the country to make provisions for individuals with mental health problems based on catchment areas which were based on the size of the population. This factor may have contributed to the somewhat uneven distribution and the diversity of services throughout the country. For example, according to The Department of Health and Children (DoH&C, 2006) only a low number of areas have introduced home care teams for looking after people who would typically have been admitted to hospital. The policy also suggested that hospital care would be necessary for a long time to come and made recommendations for improving existing hospital services. Planning for the Future (Dept of Health, 1984) built on The Commission of Inquiry on Mental Illness (Govt. of Ireland, 1966), by arguing that hospital admissions should not only be therapeutic but also rehabilitative as well.

Planning for the Future (1984) has been described as both a set of recommendations and a philosophy of service provision (Kelly, 2004). It is credited with decreasing the number of long stay beds in hospital and starting the processes associated with deinstitutionalisation in Ireland. However, it did little if anything to challenge the general populations understanding of mental health problems or to tackle the problem of stigma. Its primary goal of relocating the services physically into the community was generally successful, although people with acute needs continue to be somewhat dependent on hospital care. A major failing was the assumption that people who were moved from psychiatric hospitals would naturally integrate with the community and those within it (DoH&C, 2006). This seemingly obtuse oversight may have stemmed from a lack of insight into the experiences of living with a mental health problems in Ireland. Consequently, problems such as stigma and social exclusion were overlooked. Planning for the Future (Dept of Health, 1984) failed to consult with mental health service users arguably reinforcing their already passive role. This reflects the perception at the time of mental health service users as 'sick' and in need of care as well as the overall paternalism of the mental health services at the time. Although the authors of the document did want to improve and modernise mental health services in

Ireland, they failed to consider the wider context of mental health as more than a series of signs and symptoms. Moreover, it failed to prepare mental health professionals and users of the service for this change in direction which may have resulted in confusion about the role and remit of the community service. This view is supported by The Department of Health and Children who suggest that the 'spirit' of the community philosophy as envisaged in Planning for the Future (Dept. of Health, 1984) was never fully realised (DoH&C, 2006:56). This may have impacted on people's perception of the value of community care resulting in hospital admission being seen as the 'gold standard' of psychiatric care and a lack of faith in the services provided in the community.

Amnesty International (2003) were also critical of the work in this area and describe it as being uncoordinated, piecemeal and ad hoc rather than well coordinated and methodical. Other documents such as the Health Strategy (Dept of Health, 1994) and the Health Promotion Strategy (Dept of Health, 1995) sought to refocus the entire health services by improving the quality of life for people through health and social gain. The seven key lifestyle areas targeted for improvement placed an emphasis on physical health despite having no baseline information on basic lifestyle and health practices at that time (Friel et al., 1999). Quality and Fairness: A Health System for You (DoH&C, 2001) offered little in terms of developments of the mental health services apart from hinting at the future direction of the services in terms of the forthcoming establishment of the Mental Health Commission and the changes in legislation stemming from the enactment of the Mental Health Act (Govt. of Ireland, 2001).

The Expert Group on Mental Health Policy published their report 'A Vision for Change' in 2006 (DoH&C, 2006) which outlined the recommendations for the future of the mental health services in Ireland. Following extensive consultation with key stakeholders including service users, a comprehensive plan for the development of the mental health services in Ireland was introduced. This contained a ten year target for complete implementation and the development of a monitoring group to ensure that the recommendations are implemented. The document built on its predecessor 'Planning for the Future' (Dept of Health, 1984) by firmly situating mental health care in the community. However it tackled some of the shortcomings of 'Planning for the Future' (Dept of Health, 1984) by attempting to alter the philosophy of community care and challenging the

assumption that mental health problems are generally debilitating and chronic. Firstly it used extensive consultation with service users to underpin some of the recommendations and secondly, it made a commitment to include service users at every level of service provision. The underpinning philosophy of 'Vision for Change' (DoH&C, 2006) is centred on the notion of recovery, participation with users of the service and their families, and integration into life in the community. It focuses on these issues and offers guidance to service providers on how to develop a culture of partnership between providers and users. Furthermore a national service user executive was established which interfaces with service providers and policy developers. Vision for Change (DoH&C, 2006) also made recommendations to challenge social exclusion and stigma and called for the introduction of evidence based programmes to combat stigma although these have yet to be introduced. In addition, it was critical of the dominant biomedical approach to mental health problems and emphasised greater use of psychosocial interventions.

Legal Framework and Mental Health Provision

The enactment of the Mental Treatment Act in 1945 (Govt. of Ireland, 1945) replaced earlier outdated legislation and introduced the procedures for voluntary and involuntary (temporary) admissions. In addition, part II of the Act launched the role of the Inspector of Mental Hospitals (replacing the Inspector of Lunatic Asylums) with a remit to visit all mental hospitals at least once a year and produce an annual report. The remainder of the act outlined standards of care in mental hospitals and safeguards to protect people with mental health problems from wrongful detention. The Act did little to reduce the admission rates in Ireland (Kelly, 2008) despite its explicit rule of admitting service users that were examined by a medical practitioner and considered likely to benefit from admission to hospital. However, the act stated that service users should be discharged once they had recovered.

Despite some attempts to update mental heath legislation in Ireland during the 1980s and early 1990s, the Mental Health Act 1945 continued to be used despite growing recognition of its antiquated rules and outdated emphasis on voluntary and temporary admission orders. The Mental Health Act, introduced in 2001, replaced the 1945 Act and became fully operational in 2006 (Govt. of Ireland, 2001). The Mental Treatment Act (Govt. of Ireland, 1945), in comparison to the later Mental Health Act (Govt. of Ireland, 2001), was typical of the international

discourse on mental health problems at the time, which sought to treat mental health problems as well as producing standards of care within the dominant care environment, namely the asylum. The Mental Health Act (Govt. of Ireland, 2001) was concerned with more than just the treatment of mental distress. It strived to alter the philosophical underpinnings of the psychiatric services in Ireland as well as modernising of the processes for voluntary and involuntary admissions. In addition to the introduction of stringent processes to monitor involuntary admissions procedures, the new Act resulted in the establishment of the Mental Health Commission. The Mental Health Commission is an independent statutory body, whose main function is to promote and foster high standards and good practices in the delivery of mental health services as well as ensuring that the interests of detained persons are protected (Mental Health Commission, 2008). The first aspect of the commission's role has over recent years, sought to refocus the direction of the mental health services in a manner congruent with international discourse on human rights and the care of people with mental distress. This refocusing has also placed the emphasis of care on a recovery based model as well as involvement of service users in the planning, delivery and evaluation of services. In it's publication 'Quality in mental health – your views' (Mental Health Commission, 2005:44) one of the central themes at the crux of this comprehensive document is that quality in mental health care should include a

> '..holistic seamless service and the full continuum of care, provided by a multi disciplinary team'.

In addition, the processes of establishing this continuum of mental health care, following consultation with key stakeholders, including mental health service users, was a shift away from a dominant paradigm of paternalism and practitioner oriented service led developments. Building on the Quality in Mental Health Care document, the Mental Health Commission published a quality framework providing comprehensive measurable standards and criteria for what mental health service users and their families/carers can expect from a modern mental health service. Standard 1.3 and 1.4 situates the location of this service firmly in the community with the provision of needs based services and programmes targeting prevention, early detection, early intervention and mental health promotion as key strategies (Mental Health Commission, 2006). In addition to the quality documents, the Mental Health Commission also published a discussion document on a Recovery model for Irish mental health services (Mental Health Commission, 2005). This

document was subsequently accompanied by a framework to assist practitioners implement a recovery orientated model of practice (Mental Health Commission, 2008).

Current Focus of the Mental Health Services in Ireland

The drive to locate care in the community in Ireland is emphasised by social policy where every government publication about mental health, since the 1945 Mental Treatment Act, has called for the location of care to be shifted away from the institution. In addition, the Mental Health Commission and the Department of Health and Children has sought to refocus the underlying philosophy of the services by advocating for a recovery orientated model of practice and through strategies to improve the social integration of people with mental health problems in Ireland. Although there has been a general winding down of the number of inpatient hospital beds and closure of most large psychiatric hospitals, there are still some acute units situated in traditional asylums. There is somewhat uneven distribution of community services throughout the county and this is dependent on geographic location and the size of the local population. Generally, services fall within the tertiary domain with management of symptoms and readmission prevention being one of the indicators of success. Traditional forms of treatment locations dominate, with day centres, day hospitals, outpatient appointments and domiciliary visits from community mental health nursing staff being the primary contexts for community care. Some sectors, for example the North Kildare Mental Health Service, have introduced a home based service which runs in tandem to the traditional services (Gibbons & Cocoman, 2006). This service, introduced to ease the pressure on acute admission wards and to assist in breaking the 'discharge/relapse' cycle, provides intensive care at home to people who would normally have been admitted to hospital. A recent evaluation of one of these services in the North Kildare area found that providing acute care at home afforded a greater sense of involvement for clients and their families. Furthermore, it provided the home care team with a better understanding of what it is like for people to live with mental health problems (Gibbons & Cocoman, 2006). In other sectors approaches such as assertive outreach, are beginning to emerge albeit in a rather sporadic fashion (DoH&C, 2006).

Recovery Orientated Services

Traditionally the success of mental health care has been judged primarily on the absence of symptoms, quality of life for service users or global functioning, all of which tend to be quantitative measures. Internationally (DoH&C, 2006), and more recently nationally (Mental Health Commission, 2005), a growing preoccupation with the notion of Recovery has begun to emerge. Recovery is a complex phenomenon and reflects a move away from traditional forms of treatment as being dominant, although it does not disregard them as unimportant. The recovery philosophy is subjective and reflects a way of living as opposed to a treatment or management prescription. Anthony (1993:12) defines recovery as

> 'A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness. Recovery, involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of 'mental illness''.

In this context it is clear that Recovery is more than just the reduction or remission of symptoms but is wider in terms of the individuals' ability to adjust to these symptoms and lead a life that is full and complete (Mental Health Commission, 2005). In line with this assertion, Anthony (1993) argues that Recovery can occur even if symptoms are present. Although recently the Irish Mental Health Services have consistently advocated for a recovery orientated model of practice, Kartalova – O'Doherty & Doherty (2010) argue, that prior to the publication of their grounded theory on Recovery, there was no explicit theoretical framework of Recovery within Ireland to guide mental health professionals. The lack of empirical evidence or conceptual understanding of the nature of Recovery as a philosophy or indeed a process may be down to the lack of understanding that exists about the concept. This is supported by Higgins and McBennett (2007) who argue that Recovery is a nebulous concept with numerous definitions and often means different things to people at different times. Despite the multiplicity of definitions, a number of assumptions exist. Possibly the most consistent aspect of Recovery among the various definitions and interpretations is the notion of Recovery as being more than just the absence of symptoms. Moreover, the idea of Recovery as purely the absence of disease appears to trivialise what Anthony (1993: 3) describes as a 'truly unifying human experience'. Although diagnostic classifications and symptomatology provide labels for the myriad of experiences that mental health

problems present, it does not provide an understanding of the impact on or experience of these symptoms for people who experience them (Repper & Perkins, 2003). Furthermore, diagnostic labels can in themselves be damaging and perpetuate the sense of difference that individuals with mental health problems experience. The concept of recovery seeks to realign the biomedical dominance and paternalism of traditionally run mental heath services in favour of a more user centred approach to care.

Possibly the first step in the implementation of a recovery orientated service is the repositioning of the mental health service user as an active participant in the care provision equation rather than passive recipient of services. Secondly, it attempts to shift the locus of expertise away from mental health professionals and recognise the expertise that mental health service users have by experience. In the past the views of recipients of care from the mental health services have received little attention (Graham et al., 2005). As with people with physical disabilities and people who have serious physical conditions, contact with the mental health services can be prolonged. However this attachment with the service can be made more difficult for people with mental health problems due to the stigma attached to mental health problems and the use of mental health services (Davies, 2005). Conner (1999) suggests that there is an increasing acceptance among mental health professionals of the valuable contribution that consumers are in a position to give. This is furthered by the suggestion that involving mental health service users is not as she describes a luxury item, but an essential component of high quality mental health services.

Another aspect of Recovery is the concept of self determination where individuals with mental health problems are empowered and confident to create and determine their own identities, lifestyles and cultures (O'Hagen 1995; Roberts & Wolfson, 2006). This essentially means that the goals of Recovery are determined by the individuals who use the mental health services rather than being imposed by those providing the services (Mental Health Commission, 2008). In addition the concept of hope is central to the recovery philosophy and key to helping individuals to assimilate their experiences, and to regain the ability to live a meaningful existence often in the face of adversity (Mental Health Commission, 2005; Higgins & McBennett, 2007; Kartalova – O'Doherty & Doherty, 2010).

Kartalova – O'Doherty & Doherty (2010) in their Irish grounded theory of Recovery, from the perspective of those who are recovering, present a conceptual framework which describes the participants passage through a process called 'reconnecting with life'. It describes the negative interpretations of mental health problems and the participants' general disconnection with life following their contact with the mental health services. The processes that propel the journey from 'disconnection' to 'reconnection' describe strategies that individual services users adopt to suit their individual needs. These were both traditional (medication, talking therapies) and non traditional (deep breathing, positive self talk) which can be incorporated into current mental health services. This theory is useful in articulating the range of helpful interventions that service users adopt as strategies to manage their mental health problems. It does little to explain what recovery is apart from further reinforcing the nebulous nature of the concept and the diversity of interpretations that exist. Furthermore, it is not clear if the participants' conceptualisation of recovery was the same as the authors i.e. Recovery as a personal philosophy or Recovery as the process of recovering from symptoms.

Higgins et al. (2010) conducted an evaluation of a wellness and recovery education programme conducted across three sites in the Republic of Ireland. The overall aim of the programme was to introduce the concept of Recovery and WRAP to a range of people with an interest in mental health including service users, carers and mental health professionals. It also aimed to introduce the principles of the Wellness Recovery Action Plan (WRAP) an internationally recognised action plan for managing mental health developed in the United States by Mary Ellen Copeland. The results of the evaluations were generally positive and the findings suggest that one of the most valuable things that the participants reported was the emphasis on wellness and *mental health* rather than *mental illness*. Furthermore, the concepts associated with recovery in particular hope and self determination was perceived as particularity refreshing to the participants when juxtaposed with traditional view of illness as being life long and unremitting.

The findings from both of these studies highlight an affective or emotional component to Recovery. This requires a change in attitude for both mental health service users and professionals that possibly makes the implementation of a recovery orientated service very difficult as existing attitudes are difficult to change. Furthermore, labelling Recovery as a philosophy or theoretical framework

arguably overcomplicates something that is essentially very simple and runs the risk of alienating both service users and practitioners. Interestingly, adopting the concept of Recovery as a personal philosophy or affective state creates an awareness of the range of stressful situations and triggers that individuals are exposed to. In addition Recovery introduces individuals to the helping strategies that they can utilise themselves. Most of these are resourced internally or from their immediate social and support network arguably making Recovery cost effective. This is because the strategies tend to compliment existing therapies such as medication and are generally free (e.g. taking some exercise to combat feelings of stress, listening to music to distract from troubling thoughts, building an extensive support network etc). What these strategies highlight is the potential of traditional mental health services to deskill service users and create a dependence on professional help and prescribed therapies such as medication rather than fostering and optimising skills and resources that are already available to the individual in question.

The process of Recovery can not be addressed without considering social inclusion or social integration. According to Granerud and Severinsson (2007) social integration for users of the mental health services forms part of the overall goal underpinning the decision to decentralise the psychiatric services. However, there is evidence to suggest that people with mental health problems often have difficulty integrating into the community and social opportunities such as employment are more difficult for them than for the general population (Social Exclusion Unit, 2004). In Ireland, mental health policy has attempted to address the problem of social integration over the past forty years but this has mainly centred on moving the physical location of care into the community. Although this has had reasonable success in terms of decentralising the psychiatric services and shifting the focus of care away from the psychiatric hospital, it failed to address the psychosocial needs of service users whose primary motivations on discharge from hospital may not have been just to be symptom free. Consequently, issues surrounding the general publics' understanding and attitudes towards mental health problems were not addressed resulting in social exclusion of people who had a history of using psychiatric services. A recent survey completed by Milward Brown (2010) using a nationally representative sample of Irish adults (n=977) attempted to capture the public's attitudes towards mental health problems and people who use the mental health services. They found that six out of ten people

had no experience of people with mental health problems and that over half of the respondents believe that mental health issues are common but not well understood. The respondents were better able to recognise depression but less able to recognise the symptoms of schizophrenia. There was also some evidence of discrimination with respondents reporting that generally people with mental health problems should have the same rights as others, however, 38% would not feel comfortable working with someone diagnosed with schizophrenia and 36% would not be comfortable living next door to someone diagnosed with schizophrenia. The survey also suggested that the lack of understanding about the nature of mental health problems resulted in the high number of people who would not voluntarily disclose their experiences to work colleagues (48%). Moreover, 50% of the respondents would hide if they had mental health problem from friends and 34% believed that their family would also hide the fact that they had a relative with a mental health problem. Public attitudes like these lead to stigma and resultant social exclusion.

Yang (2007) defines stigma as a process whereby individual differences are labelled and stereotyped. The stigmatised are then relegated to a separate social group where discrimination and status loss result in a reduced quality of life. Underpinning this process is a power imbalance between those who use the services and those who don't, which facilitates stigma to exist. Although research examining stigma has produced a voluminous body of work, stigma continues to be a pervasive and unremitting experience for people who use the mental health services. According to Corrigan and Penn (1999) the impact of stigma on affected individuals can be as bad as the symptoms of the mental health problem and that diminishing stigma is imperative to improving the quality of life for people who use the mental health services. Hinshaw and Stier (2008) suggest that the evidence to support the existence of mental health stigma is plentiful and since the 1940's there is consistent evidence that the public stigmatise those with mental health problems. Although recently there has been an increased understanding of mental health and metal illness, this has not seen a commensurate reduction in stigmatising attitudes (Hinshaw & Stier, 2008). The biological model of mental distress supports the view that the symptoms of mental health problems perpetuate social dysfunction. However, it is not just the symptoms of mental health problems that have a negative impact. The general public's reaction to people who use mental health services is in part due to the negative assumptions

that people hold against these people. These stereotypical assumptions are enacted in the form of discrimination (Corrigan, 1998). This discrimination does not just impact on the persons' sense of self but on other societal roles and norms. For example, this discrimination leads to poorer housing, poorer employment and generally poorer opportunities for people with mental health problems (Corrigan, 1998).

Despite a consistent drive to reduce stigma, examples of stigma remain prevalent and society's insensitivity to people with mental health problems continues to be pervasive and enduring (Corrigan, 1998). Hinshaw (2007) suggests that the vast majority of literature about stigma has emerged from the literature on racism and prejudice and although there have been attempts to link some of these concepts with mental health stigma these ideas have not been systematically applied. However, there is a multitude of papers and research articles discussing mental health problems based stigma which has emerged possibly in response to the social integration difficulties that have arisen for people who use the mental health services. These mainly centre on the experience of stigma (enacted stigma) and the internalisation of these negative aspirations (felt stigma) (Hinshaw, 2007). To a lesser extent, courtesy stigma which results from contact with a stigmatised individual has also garnered some interest in the literature (Angermeyer et al., 2004). In summary, stigma and discrimination have been cited as the greatest impediment to recovery, quality of life and social inclusion (Social Exclusion Unit, 2004)

The problems associated with stigma, discrimination and social exclusion for people with mental health problems have led to a greater emphasis on models of social inclusion for people who use the mental health services. The Department of Health and Children (2006) describe social exclusion in this context as something that occurs when people with mental health problems become unable to access the range of social opportunities available to other people. For example, repeated hospitalisation may lead to unemployment which may subsequently lead to poverty and loss of the social networks traditionally associated with work. Research has consistently demonstrated the vulnerability of mental health service users to social exclusion and other research anecdotally demonstrates their experience of social exclusion (e.g. the high number of people with mental health problems who are unemployed or the high number of people who are single or who live alone).

Strategies introduced to tackle social exclusion usually start attempting to redress attitudes towards mental health problems and the people who use the mental health services. However the pervasive nature of mental health problems based stigma is difficult to shift and although strategies such as community care and promoting a biological basis[8] to mental health problems have been introduced they have not altered the generally disparaging attitudes towards people who use the mental health services. Vision for Change (DoH&C, 2006) recommended a number of strategies to tackle social exclusion such as increasing the contact between those who use the mental health services and those who don't, educational strategies and strategies that challenge discrimination. In addition strategies to reduce other features of social exclusion such as poverty, unemployment and poor housing have also been recommended by Vision for Change (DoH&C, 2006) although these have yet to be implemented.

In line with the Governments desire for social inclusion for people with mental health problems, the National Economic and Social Forum (NESF, 2007a) published their manifesto aimed at improving social inclusion for people with mental health problems and improving the mental health of Irish people generally. They commissioned research, examining mental health within the workplace (NESF, 2007b). This piece of research suggested that although employers (n=306) think that people with mental health problems should be supported and given equal opportunities in the workplace, about a quarter (23%, n=70) of the employers surveyed would be reluctant to employ someone with a mental health problem. There was also a perceived expectation that employing people with mental health problems would coincide with increased absenteeism (39%), reduced work capacity (25%) and interpersonal difficulties (26%). Furthermore a high number of the employers within the survey (69% n=211) would not tell their own employer if they themselves had a mental health problem. This decision not to disclose is somewhat justified given that two thirds of the employers surveyed would give the individual in question less responsibility and only about 35% would consider it likely that a person with mental health problems would get a promotion. These negative attitudes towards people with mental health problems may possibly stem from age old perceptions that people with mental health problems never make a full

[8] The promotion of mental distress as a biological entity has not gone unquestioned and remains a contentious issue.

recovery. Regardless they provide evidence of the many difficulties that people with mental health problems have to face.

The National Economic and Social Forum's (2007a) outline a comprehensive set of strategies that firmly situate mental health within the wider socio-cultural context. This reflects the Recovery movement which sees mental health problems as being beyond the individual and their medical diagnosis. Consequently the strategies are multi-layered which aim to strengthen society, organisations within that society, the community and finally individuals. These strategies include health promotion campaigns, mental health services that are integrated with mainstream services, service user involvement and media campaigns. In addition, it outlines specific strategies to target employees with mental health problems. These are particularly concerned with ensuring employees are supported to return to work after sick leave. Strategies such as flexible working arrangements and a staggered return to full time work following a period of absence have been suggested among others. Furthermore, creating a working environment which is sensitive to the needs of people with mental health problems is paramount (NESF, 2007b). In tandem with this policy the Government has recently launched its anti-stigma campaign called 'See Change' which aims to reduce the stigma attached to people with mental health problems and to challenge and reduce discrimination. However this innovation has only been launched and its impact has yet to be evaluated.

Summary and Conclusion of Chapter Two

This chapter has attempted to place the current study which focused on mental health service users experience of going home from hospital in context. It did this by describing the policy and legal frameworks that have influenced the development of the mental health services in Ireland. Like other western countries, Ireland has sought to shift the focus of care for people with mental health problems away from the dominant asylum and to introduce community orientated care. This process has not been uncomplicated and despite persistent attempts to make this happen, community care has not been fully realised. The publication of the Mental Health Act (2001), the establishment of the Mental Heath Commission and the publication of Vision for Change (DoH&C, 2006) sees a new impetus for change in the Irish Mental Health Services. These have advocated for a recovery oriented model of service and strategies to tackle problems such as stigma and social exclusion which earlier policies had overlooked.

CHAPTER THREE: GOING HOME FROM HOSPITAL

Introduction

Despite the developments in community care since the publication of Planning for the Future (Dept of Health, 1984) inpatient hospital treatment continues to be a dominant feature of the mental health services in Ireland (Daly et al., 2007). This is reflected in a recent survey completed by Schizophrenia Ireland (2007). They found that despite the developments in community care, 87% (n=3480) of respondents still were hospitalised at some stage because of their mental health problem. This highlights the dependence on hospitalisation and perhaps its perceived inevitability for people with mental health problems. The purpose of this chapter is to discuss the literature which describes mental health service users' experiences of going home from hospital. It will begin by examining the concepts of readmission, relapse prevention and discharge from hospital. It will then discuss concepts related to discharge from hospital namely discharge planning and models of discharge. Following this there is a discussion on the international literature exploring the transition from hospital to home, followed by a discussion on mental health service users' experiences of discharge from hospital in Ireland. Although no study was located that specifically examined the experience of discharge from the acute mental health services in Ireland, many of the studies reviewed alluded to the experience and this will be presented in this chapter.

Readmission to Psychiatric Inpatient Facilities

According to Montgomery and Kirkpatrick (2002) the success of treatment programmes is often based on whether the individual concerned has been re-admitted to hospital. In addition, Mgutshini (2010) suggests that readmission to hospital has become a quality indicator and is often interpreted as the failure of the earlier admission. The term 'revolving door' has been used to describe a population of individuals who are frequently readmitted (Daly et al. 2007). Details of the situation in Ireland are available from the Health Research Board (Daly et al., 2007) who note that the Irish mental health services are based on a revolving door process. Daly et al. (2007) define revolving door patients or 'frequent users' as those individuals who had four or more admissions over a five year period. They found that in the period from 2001 – 2005, almost 37% (n=3473) of the study group were readmitted at least once with just over 7% (n=246) identified as frequent users/revolving door patients. They suggested that individuals who were male, who

had a primary diagnosis of either schizophrenia or drug dependence and who were under the age of 20 were most likely to be readmitted. Other predictors of readmission included those who had a dual diagnosis as well as those individuals who had spent longer in hospital when they were first admitted. Daly et al. (2007) suggest that there is a need to examine the reasons for the high number of readmissions in the Irish context as no data is available. However, they state that the high number of readmissions and frequent users of the service seem incongruent with the emphasis on community care and the resources dedicated to caring for people in the community. Furthermore, the study concluded that hospitalisation is almost inevitable for some people with serious and enduring mental 'disorders'. Although this study articulated the demographic variables that increase risk for relapse and subsequent readmission, the reason why the readmission rates remain high is unanswered. One possible explanation offered is the inability of the community services to meet the needs of people with mental health problems (Daly et al., 2007). This is echoed by the Department of Health and Children (2004a) who suggests that some of the service users they interviewed stated that they had no community support following discharge resulting in re-admission. However this overtly simplistic deduction does not adequately illuminate the complexities involved for people living in the community with mental health problems. Furthermore the report presents a rather negative outlook for those with mental health problems, suggesting that relapse and subsequent admission is almost inevitable. This is in contrast with the recovery movement who present a more positive and hopeful message to those with mental health problems (Mental Health Commission, 2008).

Keogh et al.'s (1999) study examining bed occupancy in the then Eastern Health Board, found that there was an adequate number of hospital beds to cater for the catchment area but the use of these beds was not optimised. This meant that sometimes people who were seriously acutely ill could not avail of hospital admission even though the services in the community were inadequate to deal with their presenting difficulties. This situation has been described by Amnesty International (2003) as being unfortunate for the quality of service user care. Keogh et al. (1999) found that not all hospitals in the area under scrutiny had written admission or discharge policies and for those which did, there was little evidence that regular audit of implementation occurred. They also suggested that a high number of individuals were admitted by non consultant staff and that just

under half (47% n=106) did not have a psychiatric assessment prior to admission to hospital by a health professional. This may have offset the need for admission by the utilisation of available community resources.

The high number of voluntary admissions in Ireland suggests that individuals rely on hospitals as an effective means of therapeutic intervention and may not see community care as adequate during times of crisis[1]. This is heightened by Mechanic's (1996) assertion that we still do not have a clear understanding of what actually is beneficial for people who are living in the community with mental health problems. George and Howell (1996) conducted a phenomenological study to examine the lived experience of rehospitalisation for a small group (n=5) of service users and care givers in the United States. To them, rehospitalisation was not seen as a negative event but rather a viable treatment option that afforded them safety, stabilisation and renewal of hope. Although being readmitted to hospital did cause a level of frustration to the participants, this was mainly due to being repeatedly discharged into an environment that was not conducive to their individual needs. This made the participants feel powerless as they often had little say in their discharge plans or their choice of treatments. Although this study was conducted in 1996 and the sample size was relatively small, it does concur with the arguments for greater service user involvement in care planning and delivery as well as providing individual choice in treatment and aftercare regimes.

Irmiter et al. (2007) looked at a total of 37,527 admissions to veteran hospitals in the United States over a seven year period. In that time 86% were re-admitted to a range of facilities including non-psychiatric facilities (20% of the total readmissions). On average those that were readmitted to psychiatric facilities were admitted within a year. Individuals were at greater risk of re-hospitalisation if they had a dual diagnosis, had a substance use disorder or were homeless. Individuals who were readmitted to hospital were also more likely to have a diagnosis of schizophrenia rather than bipolar affective disorder. Individuals who were married were less likely to be readmitted.

Langdon et al. (2001) conducted a study in the United Kingdom which examined readmission rates of service users who had been admitted over the course of a

[1] In 2009, there were 20,195 admissions to hospital 91.9% of these were voluntary (n=18,562) according to the Daly & Walsh (2010).

year (n=128). They differentiated between revolving door (a total of three or more admissions) and non revolving door (less than 3 admissions). The study found that just over half of the people admitted (51%) were classified as being revolving door. Although there were no significant differences between the two groups in terms of age, marital status or gender, the revolving door group were more likely to be living alone. Similar to the Irish study completed by the HRB (Daly et al., 2007), Langdon et al. (2001) found that individuals who were in the revolving door group were more likely to have a diagnosis of schizophrenia or psychoactive substance abuse, and to be taking prescribed medication. The revolving door group were more likely to be discharged to supported hostels in the community with the non revolving door being discharged to supported housing. It should be noted that even though differentiations were made between the two groups, a high number of the total admissions for the year matched the criteria for revolving door service users and it is not clear how many of the remaining 49% had more than one admission.

Korkeila et al. (1998) found that service users with a diagnosis of psychosis or personality disorder were more than twice as likely to be readmitted to hospital when compared to people with organic disorders. Furthermore those who spent longer than 30 days in hospital were also at risk of readmission. However this does not explain the high readmission rates in Ireland where average length of stay in hospital has been relatively short[2]. Furthermore the importance of diagnosis perhaps is overstated given that the likelihood of readmission is multi-factorial and not purely related to diagnosis alone. This view is supported by Mgutshni (2010) who completed a comprehensive review of risk factors for psychiatric re-hospitalisation. He examined the multi disciplinary case notes of 59 service users over a two year period as well as interviewing mental health professionals (n=12) and services users (n=23) who were frequent users of the service. He found that clinical staff and service users differed in their opinion to the reasons why re-admission to hospital occurred. Clinicians cited non adherence to medication and other difficulties with prescribed medications as the major reason for re-admission. On the other hand service users described external and situational problems such as breakdown in personal relationships, poor access to services and financial problems as being the influential precursors to re-admission to hospital. Social

[2] According to the Health Research Board, 49% of service users admitted to hospital in 2009 were discharged within two weeks (Daly & Walsh, 2010).

isolation and social exclusion were seen as the most important factors that were given the highest priority within service user accounts.

Relapse Prevention

Conner (1999) advocates that mental health service users are on a particular journey through life. This journey, is often one which can be painful and the route to wellness and recovery is often difficult and can often not be completed alone (Conner, 1999). Setbacks such as readmission to hospital have come to be known as a 'relapse' which continues to link mental health problems to the disease and biomedical paradigm. Despite the wide usage of the term 'relapse', Simonelli-Collen (2005) suggests that relapse is a complex concept that is not uniformly defined in the research literature. She suggests that the concept of relapse cannot be considered in isolation, but must be seen more as a process comprised of multiple dimensions rather that just the re-emergence of symptoms. As mentioned, there is a tendency to see relapse and resultant readmission to hospital as a natural part of the mental health problem trajectory and this has led to the practice of relapse prevention. This generally consists of monitoring early warning signs (re-emergence of symptoms) and the enactment of an action plan which sets in motion a chain of events or interventions that offset the emergence of what has come to be known as frank or full blown psychosis (Birchwood & Spencer, 2001). Although most of the literature describes relapse prevention in terms of people with a diagnosis of schizophrenia, the interventions can be generalised to a wide range of individuals. The theoretical models associated with relapse prevention tend to be based on the stress vulnerability model as proposed by Zubin and Spring (1977). These propose that intrinsic and extrinsic factors trigger stress, which in turn trigger the re-emergence of symptoms. Relapse prevention occurs firstly to manage the resultant symptoms that arise in response to stress, and secondly to manage stress generally. The emphasis within relapse prevention programmes is on early warning signs and early intervention, consequently, arresting the progression of the symptoms and possible readmission to hospital.

Research internationally has reported on the effects of medication and psychosocial interventions in relation to the reoccurrence of mental health problems with a decrease in hospital admission being the measure of positive outcome (Van Meijel et al., 2004). Ayuso- Gutierrez and Rio Vega (1997) suggest that adequate medication therapy significantly reduces the risk of relapse and that

psychosocial interventions such as psycho-education, problem solving and stress reduction provide supportive assistance to the service user and their family (Van Meijel et al., 2004). Relapse prevention tends to prioritise clinical symptoms and the reduction of stress. It concentrates on early warning signs and presents a linear progression that arguably disallows people to have a bad day, set against the backdrop that sees relapse as inevitable. This is in contrast to the Recovery model which suggests that bad days are a part of everyone's existence and promotes a positive philosophy imbued with hope (Mental Health Commission, 2008). For example the Wellness Recovery Action Plan (WRAP) advocated by Mary Ellen Copeland also advises service users to make an action plan, list their early warning signs and to practice stress reduction techniques (Copeland Centre for Wellness & Recovery, 2009). However it is the message of empowerment, self belief, self determination and hope that make the difference between the two approaches (relapse prevention and WRAP) and shifts the balance from paternalism to egalitarianism.

Discharge Planning

Houghton et al. (1996:89) describes good quality hospital discharge as:

> 'Patient satisfaction with involvement in the process of discharge, the absence of problems after discharge and the assessment, documentation and meeting of the need for community care after discharge'.

In examining the discharge literature from an international context, much of the published research and discourse is centred on discharge of people with physical health problems from the acute medical services and is skewed towards examining discharge among the older population with physical health problems, who are perceived as being highly vulnerable to readmission (Naylor et al., 1994; Houghton et al., 1996 & McKeown 2007). A Cochrane systematic review conducted by Shepperd et al (2010) following a systematic review of mainly medical and surgical randomised controlled trials found that the effectiveness of discharge planning on health outcomes was inconclusive. Despite this a number of factors have been highlighted as integral to the process. Most importantly is the notion that the planning that occurs for discharge begins on admission and that effective discharge involves communication between the many professionals involved with service users and their significant others (Parkes et al., 2010). Steffen et al. (2009) completed another systematic review on discharge planning specifically in mental

health care. They included 11 studies in their review and found that most of the planning centred on discharge preparation (for example education and the appointment of an aftercare coordinator while the individual was still in hospital). They suggested that there was some difficulty in determining what constituted discharge and where discharge ended and aftercare began. They also suggested that the heterogeneity of peoples' needs on discharge for people and the lack of an effective definition of continuity of care made discharge planning difficult. This is supported by Atwal (2002) who acknowledges the complexity of discharge from hospital and how this complexity is heightened by the multiple needs of the individuals being discharged.

Simons and Petch (2002) suggest that an assessment of patient needs could assist in the planning of the individuals discharge from hospital. In their study they used the Camberwell Assessment of Need to measure the met and unmet needs of service users who were recently discharged from hospital in Scotland from the perspectives of staff and patients. The results of the study suggest that the physical and psychosocial needs of people post discharge were high. In addition, the perceived needs of those with a non psychotic diagnosis were rated lower by mental health professionals. The findings generally correlate with the other studies mentioned earlier, with psychosocial needs such as daytime activities and company rated as being important. These unmet psychosocial needs were associated with increased risk of re-admission to hospital. In support of the present study, Simons and Petch (2002: 443) argue that their:

> 'study has shown that the needs of patients after discharge are sufficiently high to warrant more focused attention'.

Atwal (2002) also notes the absence of a social history when assessments are being completed. She suggests that if an accurate social history is collected from the service user and significant others, problems that arise post discharge might be avoided. The issues of assessment was also raised by Cleary et al. (2003) who are of the view that asking service users what they would prefer following discharge is a positive step in closing the gap between their expectations of the mental health services and what they actually receive. Participants (n=84) in the study valued contact with other service users and receiving information from health professionals about how other people manage their problems as well as contact from a staff member in the hospital. Other issues were practical and dealt with

things such as alcohol use, what they would do if they began to feel unwell and medication management (Cleary et al., 2003).

Models of Discharge

In the United States, Canada and the United Kingdom a number of different models have been implemented to ease the transition from hospital to community. These have emerged in response to the high number of readmissions experienced on acute wards or to assist service users in transitioning from long term care in the context of deinstitutionalisation. In the United Kingdom and elsewhere a number of health care personnel have been introduced to the ease the transition from the acute medical services to home. Two differing approaches have been used, either the use of a discharge planner or a liaison nurse (Dukkers et al., 1999). Discharge planners are generally health care professionals who work in a hospital and who plan and coordinate after care services prior to the service users' discharge. On the other hand, the liaison nurse tends to work as an intermediate or link between hospital and community services, helping to smooth the transition as well as enhancing communication between professionals. These innovations have not been mirrored in the mental health services possibly due to the decentralisation of the mental health services but also given the volume and expansion of community services, they may have been deemed an unnecessary addition. However, in some areas a role designated as a 'link nurse' has emerged (Armitage et al., 2004).

Some of these protocols have been evaluated within the acute medical care context. For example Naylor et al. (1994) completed a randomised controlled study of their discharge planning protocol for older adults on medical wards. The intervention group (n=140) received continual assessment and an individualised discharge plan which was drawn up in conjunction with the older person, family, and the multi disciplinary team, including the older person's primary nurse. In addition, a nurse specialising in gerontological nursing visited the discharged person within 48 hours of discharge and every two days thereafter as well as being available by phone. The results indicated that three times more people in the control group were re-hospitalised when compared the intervention group. The authors in this study argue that comprehensive protocols are needed to maximise positive outcomes for recently discharged older patients. Moreover, these protocols need to be targeted and specific to the needs of patient groups and implemented by nurses with specialist education.

In mental health care, the rate of readmission to hospital sparked the introduction of the Care Programme Approach (CPA) by the Department of Health in the United Kingdom (Department of Health, 1990). The focus of the CPA was to improve the coordination of services for people with mental health problems living in the community. The CPA specifically instructed health and social services to come together to plan the needs of individuals through the appointment of a key worker, effective assessment, care planning and regular review of individual needs. The CPA was updated in 1999 which saw the merging of CPA with care management in an attempt to provide a more streamlined approach and to provide services with a single operational policy (Department of Health, 1999). For those individuals who are admitted to hospital, the CPA instructs clinicians to organise an aftercare meeting early in the admission and to appoint an aftercare coordinator to manage the needs of the individual on discharge. Despite the CPA's good intentions, Simpson et al. (2003) suggests that the CPA has not been successful in reaching it true potential and remains unpopular, overly bureaucratic and unevenly implemented.

A survey of consultant psychiatrists in the United Kingdom (n=200) found that 58% of the participants suggested that the CPA was a problem and was not person centred. In addition 36% believed that they CPA could not help service users to get help in a crisis situation (Hampson, 2005). Evaluations like this prompted a further review of the CPA in 2006 (Department of Health, 2006) leading to the publication of 'Refocusing the Care Programme Approach: Policy and Positive Practice Guidance' (Department of Health, 2008). This refocusing sought to diminish the amount of bureaucracy associated with the CPA by creating guidance only for service users deemed to have complex and multiple needs.

While the CPA mainly centred on voluntary users of the services, the Government in the UK introduced Supervised Community Treatment (SCT) for those individuals who had been receiving care and services under the Mental Health Act (2007). The central focus of SCT is the establishment of an unambiguous contract between service users and health care providers for treatment in the community. Failure of the service user to comply can result in their recall to hospital (involuntarily) for treatment (Haspel, 2008). In Ireland the Mental Health Act (2001) has introduced standards for planned admission and discharge from hospital, for example the

provision of continuity of care and follow up for all people discharged from the services. However the Mental Health Commission are currently engaged in developing a code of practice on admission, transfer and discharge which is presently in the consultation phase.

Forchuk et al. (1998) describe a transitional discharge model called 'Bridge to discharge' which was introduced on a ward with people who had received inpatient care for at least five years in Canada. This model consists of peer support, with inpatient staff providing care following discharge which focused on the development of a therapeutic relationship. However a large scale evaluation of the approach using post discharge interviews (n=390) which measured quality of life, heath care utilisation and levels of functioning found that post discharge quality of life did not improve significantly when compared to the control group (Forchuk et al., 2005). However, the study did reveal that participants in the intervention group were discharged earlier than the control group. Reynolds et al. (2004) applied the transitional discharge model to a group of people discharged from the acute psychiatric services in Scotland. Inpatients were randomly assigned to a control (n=11) and experimental group with the experimental group receiving support from inpatient staff in the post discharge period as well as support form other service users. The authors concluded that the number of readmissions was reduced for the participants assigned to the experimental group (n=14). In addition there were improved scores in terms of functioning and quality of life for these people. The authors acknowledged the small numbers as a limitation to this study and suggested larger multi site replications to measure the potential benefits of the intervention are necessary.

Similarly Cameron et al. (2007) describe a hospital to community transition programme referred to as 'the bridge'. This Canadian innovation utilises a community liaison nurse who 'bridges' the transition experience for the adolescences involved in the study. An evaluation using a standardised questionnaire (n=17), semi structured interviews with service users (n=4) who had completed the programme and staff working at the facility (n=3) was completed. In this study the participants were discharged to a high support, short term residential facility where they and their families receive structured therapy and psycho-education aimed at assisting their reintegration into the community. Central to the success of this programme was the role of the clinical liaison nurse

who assessed the adolescents' mental state, the individuals and their families' motivation as well as formulating short term achievable goals that the young person and their family could work towards. The study claimed that the innovation has reduced the number of readmissions and reduced the inpatient stay. The high level of professional and peer support injected into the innovation appears to be a precursor to its success. In addition, a thorough assessment prior to the individuals discharge appears to ensure that individuals are ready to move on to the next stage of treatment and that they are motivated to participate. The latter variable would suggest that motivated individuals may be more prone to success regardless of the innovation.

Dixon et al. (2009) conducted a study in the United States to evaluate the effectiveness of a brief three month critical time intervention. This intervention targeted 135 individuals discharged from an acute unit and involved a specialised clinician who met with the individual and identified possible areas of concern that might arise following discharge. The clinician developed a plan of action to target areas of concern, as well as developing a therapeutic relationship with the individual. Following discharge the clinician visited the individuals and maintained a high level of support. The evaluation suggests that individuals assigned to the brief three month critical time intervention had better discharge outcomes as measured by the Brief Psychiatric Rating Scale (Overall & Gorham, 1962) and the Quality of Life Interview (Lehman, 1988).

Discharge from Hospital and Suicide

A number of studies have looked at suicide following discharge or within the immediate post discharge period (Ho, 2006, Kan et al., 2007, Desai et al., 2008 & Karvonen et al., 2009). Karvonen et al. (2009) examined database information about the timing of completed suicide for older and middle aged people (people over the age of 50) following their most recent period of hospitalisation. They examined the database from 1988 – 2003 in one region in Finland, and found that approximately 30% of all suicides of people who were 50 years and over (n=240), were completed within the first month of discharge. Furthermore they concluded that elderly women were more likely to die by suicide following hospitalisation, possibly reinforcing the concept that older adults are more vulnerable in the post charge period regardless of their physical or psychosocial needs. Desai et al. (2008) completed a similar study but examined all people discharged from the Veterans

Affairs Heath Care system in the United States over a four year period. From a total of 119,159 individuals, 0.89% (n=1,057) died by suicide with almost 47% using a firearm to kill themselves. The authors conclude that individuals living in communities where there is poor social support or where the individuals feel sensitive to a range of community stressors may be a suicide risk. They suggest that reducing the availability of means through stricter gun control may reduce completed suicides among individuals at risk.

Kan et al. (2007) attempted to identify risk factors for recently discharged individuals who had died by suicide by using a matched case control study (n=97). Findings indicated that within the immediate discharge period, suicide was associated with previous suicide attempts, a history of deliberate self harm, living alone, compulsory admission and loss of contact with the mental health services following discharge. This research called for further study in this area and argued that both diagnostic and psychosocial factors are not just important to suicide risk, but change over time. Ho (2006) retrospectively examined duration of stay in hospital and post discharge suicide. He found that a shorter hospital stay (those less than 15 days) were associated with a lower rate of completed suicide. He concluded that those individuals that have prolonged hospital stays need to be carefully monitored in the presence of other risk factors such as previous suicide attempts.

Exploring the Transition from Hospital to Home

There has been a range of studies that examined mental health service users' experiences of the transition from hospital to home. Lorencz (1991) conducted a small grounded theory study where she examined the pre discharge perceptions of people with schizophrenia (n=4). Although details surrounding the methodology are sketchy, the data analysis process culminated in the production of a core explanatory variable 'becoming ordinary'. This variable describes the participants' aspirations 'to become self supporting and independent' following discharge (Lorencz 1991: 198).

Beebe (2002) in the United States outlined the problems that people with schizophrenia identified on their return to the community, following hospitalisation. In her study the participants (n=37) identified side effects from medication, problems managing the symptoms of their illness, environmental

stress and financial concerns as being the prevalent problems that people experienced in the weeks after their discharge. Montgomery and Johnson (1998) conducted a phenomenological study in Canada examining the lived experiences of ten 'chronically ill patients'. The essential themes that emerged described the participants' initial optimism when leaving hospital coupled with their growing recognition of the problems that they had to face on re-entering the community. Relationships with other people played a role in either providing positive support or in some cases were a source of stress. Other factors such as employment or engagement in activities were also helpful in promoting positive experiences. The authors of the paper concluded that leaving hospital and returning home involved adjusting or change. This adjustment is required even though the participants hospital stays were relatively short (between two and seven weeks). Interestingly, the authors' ultimate statements (Montgomery & Johnson, 1998: 502) sum up the present study's intentions:

> 'In order to help chronically ill patients prepare to resume their lives in the community after being hospitalised, nurses must be aware of the kinds of hurdles and pleasures each one expects to face. Only the patients themselves can tell us what these are'.

In a later study, the same authors (Johnson & Montgomery, 1999) interviewed eight individuals about their experience of living in the community after they had been discharged again using a phenomenological approach. They found that the participants in this study did not make major changes to their lives following discharge and that being discharged was not a catalyst that paved the way for an alternative way of life. Social problems such as unemployment and isolation impacted negatively on the participant's life in the community. This coupled with living with a chronic illness made attempts to improve their lives e.g. getting a job, difficult (Johnson & Montgomery, 1999). The authors suggest further research that examines the experience of re-entering the community following a period of hospitalisation (Johnson & Montgomery, 1999).

The findings of Johnson and Montgomery's (1999) research are supported by Lemaire and Mallik's (2005) study which suggested that people with a severe mental health problem have numerous difficulties when trying to integrate into community living. Their quantitative study involved service users (n=135) who were attending rehabilitation centres in Baltimore, USA. One hundred and thirty five participants completed a self report demographic and diagnostic survey as well as a

'Barriers to Community Integration Scale' designed in an earlier study (Mallik et al., 1998). They found that barriers to integration such as employment and financial resources were rated highly. Their study concluded by suggesting that future research should 'clarify the meaning of community integration from the perspectives of individuals with severe mental illness' (Lamaire & Mallik, 2005:131).

Honkonen et al. (2003) using a specifically designed structured interview investigated the psychosocial and clinical characteristics of service users diagnosed with schizophrenia (n=3257) three years following their discharge from hospital. They noted that people who had been discharged from hospital in the 1990s were in 'poorer condition' at the point of discharge than their previous counterparts in the 1980s (Honkonen et al., 2003:164). This they believed put community services under additional pressures. The reasons this happened may be down to high demand on beds resulting in earlier discharge for service users. In addition, community services are believed to manage people with higher levels of acuity resulting in them presenting to hospital with greater psychosocial problems. In addition, service users who utilised the services provided by the community care services were less disabled then those who did not. Furthermore, individuals who were socially isolated were more likely not to attend the community care programmes resulting in relapse and subsequent re-admission.

Similarly, an Australian study conducted by Hobbs et al. (2000) measured a group of long term service users with mental health problems (n=40) who were moved from long term wards into smaller residences in the community. Although this study spoke about service users being 'discharged' from hospital, the participants were afforded community psychiatric services and twenty four hour supervision. Despite this support, seven of the forty service users originally discharged were readmitted permanently and 37% of the remaining individuals required temporary readmission. However, over the two year period when the data was collected, the service users did show improvement in a range of life skills and importantly their life satisfaction. In this study all of the participants who were discharged to the community residences had a diagnosis of serious mental health problems and had spent a minimum of two years in hospital. However it does demonstrate the complexity of mental health problems and its variable trajectory regardless of health or social interventions. It is heartening to note that a follow up study on the same group, conducted six years after the initial transfer demonstrated that the

service users had an increased level of life satisfaction as measured by a quality of life index designed by the authors (Hobbs et al., 2002). This occurred despite a reduction in medication and in the level of supervision (Hobbs et al., 2002). Despite the success of the transition, residents still remained socially isolated and depended on the staff for most of their social contact.

Roe (2005) interviewed 43 service users who were considered to have severe and enduring mental health problems in relation to the effect of their illness on their sense of self. The findings of the study suggest that severe mental health problems and the social consequences of severe mental health problems had a negative impact on how participants viewed themselves and that this influenced the course of their recovery. However, rediscovering their sense of self through exercising a talent or skill or through interpersonal communication with others also influenced the capricious trajectory of 'mental illness'. The study also suggested that changes in the participants' sense of self influenced how they integrated into the community and acquired fulfilling community roles. The study concluded that the course of severe mental health problems in not easily measured through demographic and objective tests but is dependent on the subjective experience and the impact that has on the individuals' sense of self. Therefore a holistic approach to policies and interventions is advocated for service users integrating into the community (Roe, 2005).

Service Users' Experiences of Discharge from the Mental Health Services in Ireland

In Ireland, a literature search revealed a number of studies examining services users' experiences of the metal health services. However no study could be located that specifically examined service user experiences of going home from hospital. The studies located tended to look at the broad experience of mental health care and found that service users were critical of the overuse of medication as an intervention (Farrelly, 1999; DoH&C, 2004a, 2004b; Dunne, 2006). In addition many of the studies suggested that there was nothing for service users to do while in hospital and the groups and activities provided did not take into consideration the specific needs of the service users attending (Pathways, 2002; DoH&C, 2004b). This is supported by O'Donovan and O'Mahony (2009) who suggest that the service users in their study (n=8) found some of the group activities on the ward basic, repetitive and non applicable to their specific situations. Service users in the

Department of Health and Children (2004b) consultation document 'What we heard' described a good experience of inpatient care occurred when staff on the unit were kind, helpful and took an interest in their welfare. Conversely, bad experiences occurred when service users were not included in their care, were not given enough information about their care and when staff displayed negative and authoritative attitudes towards them. In addition, bad experiences occurred when services users were forced to comply with treatments or when there was an over emphasis on medication (DoH&C, 2004b). This is supported by Barry (2007) who states that the service users in her study (n=7) perceived consistent expert relationships with professionals as being invaluable to positive outcomes and experiences. In addition information about care and choice of service were seen as pivotal to best practice in mental health care (Barry, 2007). The importance of having someone to talk to and to feel listened too was also reiterated in Farrelly's (1999), Dunne's (2006) and Kartalova-O' Doherty and Tedstone-Doherty (2010) studies. Participant in Dunne's (2006) study felt that the structure of the service and its underpinning philosophy mitigated against nurses having more therapeutic interactions with service users. In Dunne's (2006) study service users' day to day life on the wards was described as:

> 'Dreary, deskilling and anti-therapeutic and likely to promote institutionalisation when admissions were lengthy or frequent' (Dunne 2006: 39).

Although discharge planning, procedure and experience was not the primary focus of any of the studies located, discharge from hospital was mentioned. Pathways (2002), a voluntary organisation for mental health service users, in conjunction with Schizophrenia Ireland, conducted a study examining service users' experiences of using mental health services in the west of Ireland. Eighty questionnaires and 35 interviews were completed on a wide range of activities associated with their experience. With regard to discharge, 65% (n=52) of participants were anxious about going home, but only 52% (n=41) had been involved in the decision process around their own discharge. Of those involved in their discharge planning (n=41) 92% (n=38) found it helpful. Based on the findings the authors suggested that there should be a mediator or an advocate appointed to help prepare the service users for their impending discharge and that the service users' involvement in their discharge should be given special attention (Pathways Report, 2002). The authors of the report raise the question:

> 'If users are placed in a passive role with regard to discharge does this not greatly increase their dependency on the services rather that facilitating the recovery process?' (Pathways Report, 2002: 59).

Dunne (2006) suggests that discharge from hospital was mainly an administrative process e.g. organising transport home or ensuring that service users had enough medication. There was no evidence to suggest that the service users were aware of any discharge or aftercare plan or that they had any specific preparation. An earlier study completed by Keogh et al. (1999) found that 79% (n=185) of the medical notes they examined retrospectively had a discharge plan for the service user. It may be that the discharge plan existed but it was not communicated to the service users when they were discharged. Dunne (2006) recommends that service users should be prepared for discharge and should be supported by a multi-disciplinary team sensitive to the needs of the individuals. One of the key recommendations states that:

> 'The transition to home would be made easier and the likelihood of relapse would be reduced if the concerns of service users were addressed before discharge...' (Dunne, 2006:97).

Central to consultation documents completed by the Mental Health Commission (2005) and the Department of Health and Children (2004a; 2004b), was service users desire for the mental health services to be community orientated. Some service users were of the view that being admitted to hospital made community reintegration more difficult (DoH&C, 2004). When the participants were asked about community care following discharge in the Pathway's (2002) study, they suggested that the facilities did not always cater for their specific needs. For example participants attended the day hospital or centre for a specific time rather than to attend a specific programme. In addition, participants found that programmes to assist them going back to work or college were very helpful. In addition, many people used alternative or herbal remedies to cope with mental health problems in the community, strategies that could be provided by mental health services for individuals as an adjunct to pharmacological treatments. In Dunne's (2006) study, the service users complained about the lack of continuity of services (for example the doctor working with the service users changing every six months). As with the Pathway's (2002) study, activities that were geared towards individual needs were seen as most helpful (Dunne, 2006). Assistance with retraining and returning to work was valued by the service users in Dunne's study,

but this was not always available (Dunne, 2006). Gibbons and Cocoman (2006) in their evaluation of a home based service found that issues such as availability of service, relationships with staff and having someone to talk to were perceived as important components of a community mental service for service users.

Doherty et al. (2007) examined what it was like for people living in community based mental health residences in Ireland. They found that although the mental health service users who lived in these residences were generally happy with their living arrangements, there appeared to be a lack of involvement in care despite the high levels of functioning demonstrated by the individuals. The residences were compared to mini institutions which mirrors Bergin and Clarke's (2005) assertion that institutional practice and philosophy was dominant in the community. In addition, many of the individuals were unemployed and appeared not to integrate into community living relying on other residents, their families and the staff for social support (Doherty et al., 2007). The researchers recommended a need for integration in the community beyond the residence and that policies within the residences should allow greater freedom and control for the residents. Furthermore, staff should be trained in the principles of recovery and encourage residents to raise their levels of expectations in terms of their capabilities to achieve greater independence.

Brosnan's (2006) qualitative investigation on the perspectives of service users (n=33) on partnership within mental health services in one mental health service in Ireland found that one of the most worrying things that the participants spoke about was their fear of becoming mentally unwell again. There is some evidence to suggest that the outcomes for service users following discharge from hospital in Ireland are poor (Finnerty et al., 2002). This occurs even though research completed by Keogh et al. (2003) argued that there was a high level of service use (attendance at outpatient appointments and day hospitals) among the service users they interviewed (n=64). However what the service users did at the community services provided was not recorded and emphasis was placed on the quantity (number of attendances) rather than the quality. Furthermore the number of readmissions to hospital in Ireland has been used as an indicator of the success of the community services and a lack of development in the community services have often been blamed for the high number of readmissions in Ireland (Amnesty International, 2003; Daly et al., 2007).

Summary and Conclusion of Chapter Three

The mental health services in Ireland have undergone substantial change since the foundation of the state. These changes have been in response to international trends in mental healthcare delivery, most notably the shift from hospital to community care. Despite the emphasis on community care there is still a major focus on admission to hospital and preventing admission or readmission seems to be the indicator of community care's success. Much of the focus of community care appears to be the prevention of hospitalisation and this trend continues with the introduction of innovations such as home care whose primary aim is to prevent hospitalisation. Fundamentally, the emphasis on preventing readmission to hospital by the mental health services fails to recognise the extensive needs of people who use the mental health services. In addition it creates a negative impression of a psychiatric hospital reinforcing the notion that to be admitted to hospital is a negative rather than a therapeutic experience. Recently and again influenced by international trends, there has been a desire to refocus the mental health services towards a Recovery model of practice. This aims to alter the philosophy of the mental health services through recognising the role of service users as experts in their care. The success of this paradigm shift is yet to be seen across the entire services.

The Health Research Board (Daly et al., 2007) suggests that admission to psychiatric hospital plays an important role in the overall management of people with 'mental illness'. The difficulties facing people when they are discharged have often been centred on biomedical and disease based models suggesting that preventing the re-emergence of clinical symptoms (relapse) are key to successful community tenure. Furthermore these studies are often couched in the belief that relapse and readmission to hospital are often inevitable for users of the services. The experiences of people leaving hospital and returning to the community have been investigated using quantitative, experimental and phenomenological methodologies. The transition of 'long stay patients' into the community has also been well documented. Although these studies go some way to explaining the participants' experiences and the challenges encountered they fail to provide data, which explains the social and psychological transition process for service users discharged from the acute mental health services. In addition, no coherent model or theoretical framework was located in the literature which explains or aides an in depth understanding of the transition from hospital to community for this group of

individuals. Hence, the aim of this study is to generate a theory using grounded theory methodology that explains service users' experiences of going home from a psychiatric hospital. The next chapter examines the philosophical and methodological considerations underpinning this study.

CHAPTER FOUR: PHILOSOPHICAL AND METHODOLOGICAL CONSIDERATIONS

Introduction

In order to choose a research design the researcher must first decide which research paradigm is congruent with their beliefs about the nature of reality (Mills et al., 2006). The chosen methodology for this research study is grounded theory which has emerged from both an objectivist and constructivist paradigm (Glaser & Strauss, 1967; Glaser, 1992; Charmaz, 2003a). However, Glaser argues that traditional or classic grounded theory does not sit comfortably among any research paradigm and this standpoint is subject to great debate in the literature resulting in confusion for the novice researcher. Mills et al. (2006) suggests that researchers using grounded theory as a form of enquiry must be able to identify their epistemological and ontological positions in order to align themselves with one of three main versions of the method[1]. Furthermore, Coyne and Williams (2000) argue that researchers must be explicit about how they locate and position the research that they complete. This they suggest will demonstrate their sensitivity to the multitude of epistemological interpretations available while making other differently positioned researchers more responsive to the findings. The aim of this chapter is to examine the research paradigms that have emerged in response to Glaser's consistent reluctance to pigeon hole grounded theory as a particular 'type' of research. In addition, an overview of classic grounded theory will be given as well as an overview of some of the differences between classic and other forms of grounded theory. Finally, the researcher will discuss his understanding of the epistemological underpinnings of this research study.

Philosophy of Science

According to Seaman (1987) science involves the conversion of theory to propositions and the transformation of these propositions into facts. Crotty (2003:8) defines epistemology as 'how we know what we know'. Definitions of epistemology generally speak of it as a branch of philosophy that seeks to explain the roots, characteristics, methods and limits of knowledge. The empiricist epistemology often referred to as the scientific or objectivist approach was established in the 17th century by scholars such as Descartes and Bacon. They

[1] These are classic grounded theory, evolved grounded theory and constructivist grounded theory. For further elaboration see Mills et al (2006).

strived for the development of knowledge through investigation and experiment (Turner, 1995) and this remains for some the dominant philosophy and the gold star approach to developing and verifying knowledge today. However, epistemology has developed over time as other scholars became interested in moving away from the dominant objectivist philosophy. These scholars denied the dictum that reality exists separate from our consciousness (Crotty, 2003) and that there is in fact several 'realities' that are shaped by numerous biological, psychological and socio-cultural factors. For example, Freud's psychoanalytic theory discusses the power of the unconscious mind and its impact on individuals through complex mental processes such as denial and repression (May, 2006). The notion of a theory developed around something as intangible as the unconscious mind is in stark contrast with Descartes, whose position was arguably based on the notion of conscious rationality (May, 2006). On the other hand the structuralist perspectives' acceptance of diagnosis and classifications of 'mental illnesses' may be in stark contrast with other perspectives, which see 'mental illness' as a being constructed by divergent cultural and historical influences and beliefs which have infiltrated society's consciousness and become the norm (Hyde et al., 2004).

Foucault was concerned not only with the development of knowledge, but also with what keeps knowledge and facts in circulation. According to Mills (2003), Foucault believed that what was viewed as knowledge changed in each historical period (Mills 2003); a process he called 'episteme'. For example, medicine has sought to classify and cure illnesses and biomedical knowledge has been considered by many as the 'truth'. However, this 'knowledge' is developed within a specific historical and socio-cultural construct with a language and nomenclature that is steeped in objectivist philosophy. It virtually ignores other ways of knowing about illness (such as cultural interpretations of health and illness) and has pushed this knowledge aside as a non truth. In the development of knowledge, Foucault (2002) believes that power plays a crucial role in determining what constitutes knowledge. Those with power are able to keep their version of knowledge in circulation whereas other knowledge remains unknown because of this power imbalance. According to Kearney, (1994) Foucault was sceptical about knowledge's alliance with innocence and neutrality; rather he believed that the 'truth' is often exclusively held by certain powerful institutions. Consequently, knowledge and truth were delimited or defined and those that fell beyond these limits were deemed to be deviant. Foucault's attempts at challenging our traditional worldview

of what constitutes knowledge and the processes that keep knowledge in circulation are down to a 'hidden history of power' and serve to maintain social control (Kearney, 1994: 291). Foucault's ideas about power/knowledge are only one perspective among many, and provide evidence that deciding on how we know what we know is not straightforward. Furthermore aligning ourselves with particular epistemologies often requires us to adopt a particular philosophy. This coupled with the emerging view that epistemological debates are futile as researchers strive to answer questions using varied methodological approaches (Gordon, 1998) make the pursuit of epistemological clarity difficult.

In contrast to epistemology, ontology refers to the study of being (Crotty, 2003) and asks the question, what is existence? Crotty (2003) believes that epistemology and ontology sit alongside each other. Where ontology poses the questions what is a particular phenomenon, epistemology poses the question how do we know? Guba and Lincoln (1994) suggest that ontology seeks to establish the form and nature of reality and what can be understood about reality. Put simply, Sarantakos (2005:30) suggests that ontology informs research methodologies as to 'what social research is supposed to study'. On the other hand, paradigms are thought patterns contained in any discipline or epistemology. Kuhn (1996) describes paradigms as sets of practices that are unique to a scientific discipline and articulate or define those practices during a particular period of time. The term paradigm has, in recent years, added to the confusion surrounding knowledge and the development of knowledge as it has been used interchangeably with epistemology. According to Sarantakos (2005:30) a paradigm is a 'set of propositions that explain how the world is perceived'. Paradigms assist the researcher in establishing the importance and legitimacy of a particular systematic investigation and assist us in ascertaining what is reasonable given the parameters of a given paradigm (Sarantakos, 2005; Annells, 1996). Crotty (2003: 35) summarises their purpose within research: 'Thus the paradigm establishes the parameters and sets the boundaries for scientific research and, in the ordinary course of events, scientific enquiry is carried out strictly in line with it.' Paradigms, according to Sarantakos (2005) are packages that contain the ontology, epistemology and methodology of a given discipline and thus guide the practice of everyday research.

To summarise, the language of epistemology and ontology is confusing and sometimes misleading. Different authors use conflicting definitions of the key

concepts and disagree over what constitute the various components of a research paradigm or epistemology. Consequently, deciphering my personal view has been challenged by the lack of a consensus on the nature of knowledge and the nature of reality. This is compounded further by Glaser's continual reluctance to align grounded theory within an overarching research paradigm. What follows is a discussion on my understanding of objectivism and constructionism which has ultimately aided my understanding of grounded theory, the methodology that has guided this study.

Objectivism

According to Sarantakos (2005) objectivism stems from an empiricist epistemology and has the following key features:

- Truth and reality are objective and can be measured.
- Reality exists separate to our awareness and has its own identity.
- Reality has the same meaning for everybody.
- Reality is discovered by researchers.
- Researchers remain objective and neutral.

According to Benton and Craib (2001), empiricists argue that scientific statements are only those statements that are testable by experiment or observation. Objectivism emerged from the physical sciences which, according to Glashow (1992:28) are 'eternal, objective, a-historical, socially neutral, external and universal truths'. Benton and Craib (2001: 14) provide a doctrine of seven basic principles of the empiricist approach. Most important in this dictum is the view that 'the individual human mind starts out as a blank sheet. We acquire our knowledge from our sensory experience of the world and our interactions with it' and 'scientific objectivity rests on a clear separation of (testable) factual statements from (subjective) value judgements'.

Two research paradigms have stemmed from the epistemological movement of objectivism: positivism and post positivism. Auguste Comte, according to Benton and Craib (2001) is widely attributed as the originator of positivism. Since then, the concepts affiliated with positivism have been expanded on, challenged, re-examined and re-described over time (Crossan, 2003). Crotty (2003:20) summarises the positivist movement as being 'what is observed, the observation in

question being scientific observation carried out by way of scientific method'. According to Parahoo (2006), positivists believe that it is possible to reduce complex events into more simple laws and that these laws strive to explain and to predict with statistical precision. Objectivity in research therefore is a sought after and realistic goal (Harrington, 2005). According to Crossan (2003) the main aim of the positivist movement is to remove subjective and speculative opinions through the use of mathematics and induction. He suggests that a major criticism of this approach is that the focus on value free objectivity and the independence of the researcher among other factors does not allow this approach to study the complex behaviours of human beings. Although there has been a move away from this originally dominant approach to knowledge generation, it still remains influential in healthcare research where randomized controlled trials remain the leading forms of investigation. In fact, Rockmore (2005) suggests that the belief that knowing is about finding, uncovering or discovering 'truth' is still a very common belief and has strong support. However, according to Clark (1998), positivism's reductionist view of the person conflicts with nursing's humanistic and holistic view of the individual and the world they inhabit.

With the emergence of psychology and sociology as distinct and recognisable branches of science, the dominant positivist approach compromised and softened its beliefs towards the nature of knowledge and the generation of facts. Positivism segued into what is known as post-positivism which challenged the formers rather dictatorial grasp on what constitutes evidence and truth (Crossan, 2003). Although positivism and post positivism are seen as an extension of philosophical belief on a particular continuum, Clark (1998) suggests that the post-positivists offered an alternative understanding of truth. This epistemological debate centres on the notion that researchers' no longer accept the view that there is a single truth that is visible through observation and scientific measurement. Conversely, the researcher influences the process and the findings generated are 'contextually based' and not automatically open to generalisations and replication (Coyle & Williams, 2000: 1238). This does not mean that the logical reasoning and precision advocated by positivism is redundant, it means that what constitutes evidence alters and that research becomes more open to other forms of inquiry particularly qualitative methods (Clark, 1998). Crotty (2003) describes this form of positivism as a humbler version of scientific inquiry, one where the objectivity and influence of the researcher is questioned and acknowledged and where research findings are

approached with caution rather than certitude. Post-positivism to me suggests that even though a broader interpretation of evidence and truth is acknowledged, the emphasis is still strongly placed on the positivist aspect and that these other forms of knowledge or truth are really just an addendum to positivist dominance. In mental health nursing, supporters of the objectivist approach argue for greater quantifiable support for nursing interventions (for example Gordon, 1998). It is argued that a lack of reliability and validity (Burnard & Hannigan, 2000) and what Gourney and Ritter (1997) suggest are no more than unreliable accounts of nurses' and patients' experiences, impact negatively on research. Objectivism in the form of quantitative research has come under considerable criticism for its lack of relevance to the practice of psychiatric nursing (Gordon, 1998). Quantitative measurement of peoples' experiences, through statistical analyses may not locate their experiences in a manner that is congruent with their contextual situation or in a language that is harmonious with theirs (Coyle & Williams, 2000).

Constructionism

Constructionism has emerged in apparent opposition to objectivism and in some cases has replaced it as the dominant approach to understanding knowledge (Crotty, 2003). The overarching premise of constructionism as a concept is that meaning is not created, it is constructed (Crotty, 2003). According to Sarantakos (2005) constructionism suggests that there is neither an objective reality nor truth. Rather, reality is constructed through our impressions and interpretations of phenomena that are culturally and historically defined. Consequently, multiple realities exist as interpreted by multiple viewpoints and these realities are subject to refinement over time (Berger & Luckman, 1966; Schwandt, 2003; Sarantakos, 2005) Constructionism has emerged as an alternative to positivist and post-positivist thought as researchers tried to explore the subjective context of human emotion and experience (Schwandt, 2003). However, like all things epistemological, a simple definition will not illuminate the complexity of this concept and this basic idea has evolved and diversified over time. Broadly, constructionism can be classified into two major world views – constructivism and social constructionism. These world views however, are often used interchangeably and many different versions exist, ultimately having different meanings to different disciplines (Rockmore, 2005). The language of constructionism is confusing and it is worth at this point elaborating briefly on these two concepts.

Social constructionism according to Burr (2003) consists of a number of key assumptions which are underpinned by the view that a critical stance is taken against knowledge which is taken for granted. The way that we understand is culturally and historically specific. Consequently knowledge is not a static concept and what we know and how we understand is dependent on where and when we are in the world at a given time. The knowledge of the world is constructed between people; therefore, social action and knowledge goes together (Burr, 2003). According to Hyde et al. (2004) social constructionism is not concerned with knowledge that describes a particular phenomenon, it is concerned with how this knowledge has permeated the public consciousness and become fact. Anderson (1995:8) suggests that:

> 'seeing reality as socially constructed – doesn't mean that there is nothing out there. It means understanding that all our stories and what's out there – all our scientific facts, our religious teachings, our societies beliefs, even our person perceptions – are the products of a highly creative interaction between human minds and the cosmos'.

Koch and Harrington (1998) support this stance, suggesting that the end result of something like qualitative research has not one voice, but many voices. According to Charmaz (2003a) this approach to grounded theory places an emphasis on the shared process of data collection and data analysis. The end product, she contends, reflects not only the participants but the researcher's thinking (Charmaz, 2003a). Social constructionism places an emphasis on the collective generation of knowledge through socialisation, therefore knowledge is readily available, sustained and reconstructed when we are interacting with each other. There is considerable support in the sociological literature for the social construction of 'mental illness' as a concept. According to Horwitz (2002) Durkheim established these viewpoints by moving the object of sociological critique from individuals within society to cultural classifications of meaning offering a different perspective of characterising 'mental illness'. These, Horwitz (2002) suggests, are not better ways of understanding mental health and illness but merely alternative ways of understanding, situated among many other ways. Foucault (1989) also supported the social construction of 'mental illness' and his historical work suggests the birth of 'madness' following the eradication of leprosy in Europe (Foucault, 1989). Scheff (1999) gives us another example of this by not speaking about signs and symptoms of illness but of residual rule breaking in his sociological theory on being mentally ill. Kutchins and Kirk (1997) also cite the case of the removal of homosexuality from

the Diagnostic and Statistical Manual of mental disorders (DSM) and the inclusion of borderline personality disorder as evidence of the construction of 'mental illness' in the face of limited empirical evidence to support these decisions. They argue that the removal of homosexuality as an illness from the DSM stemmed from objection by the increasingly powerful gay rights movement rather than from the results of rigorous research. Conversely, the inclusion of borderline personality disorder as a unique phenomenon attempts to group together a cluster of diverse and heterogeneous behaviours that they believe is unhelpful to the person in dealing with their real problem. What has occurred is the inclusion of a diagnosis that groups together people, mainly women, who present with difficult and challenging problems. Furthermore the evidence to support its inclusion in their opinion is flimsy and unlike homosexuality, there is no lobbying group for 'difficult and angry women' (p. 199) preventing the inclusion of this diagnosis (Kutchins & Kirk, 1997).

Constructivism (sometimes referred to as 'cognitive constructionism' (Heap, 1995) on the other hand is a term reserved for 'epistemological considerations focusing exclusively on the meaning making activity of the individual mind' (Crotty 2003: 58), or how we as individuals make sense of the world and refers to the unique experience of each of us (Crotty 2003). To paraphrase Heap (1995), social constructionism is concerned with collective construction whereas cognitive constructionism (constructivism) concerns itself with objects cognitively constructed. However according to Heap (1995) these concepts are not diametrically opposed. On the contrary, they are related or entangled. Constructivism is a consequence of social constructionism (Heap 1995) so arguably the two cannot function in isolation. This is reminiscent of Berger and Luckmann's (1966: 96) assertion that 'Society exists only as individuals are conscious of it' and their alternative suggestion that 'individual consciousness is socially constructed'. However, definitions and explanations aside, it is difficult for the researcher to practically apply these complex concepts into research projects and to interweave the philosophical assumptions into data and research findings. Bury (1986) suggests that even though constructionism has some common core concepts it still remains a loose trend in social thought which is confused by conceptual ambiguity. Mills et al. (2006) offers some guidance on how researchers can adopt a constructivist approach in grounded theory research; however the advice mainly stems around the reciprocity of the researcher and participant relationship which does not really

inform us on how to 'construct' grounded theory. Furthermore Charmaz's (2003a; 2006) numerous attempts at framing grounded theory within the constructivist paradigm do not really offer any real philosophical debate that situates the methodology within this worldview.

Grounded theory

Grounded theory has been described by its founders as 'the discovery of theory from data systematically obtained from social research' (Glaser & Strauss, 1967:2). Developed by Glaser and Strauss during the 1960s, grounded theory in simple terms, according to Charmaz (2006), is a methodical yet pliable framework for collecting and analysing data. Since its creation, grounded theory has become a popular approach for nurse researchers with over 3000 published papers reporting research findings or discussing the methodology itself (Mills et al., 2006). Holloway and Wheeler (2002) suggest that grounded theory is a popular method for nurse researchers because of the ordered and structured way that the data is collected and analysed. Despite the extent of its use in nursing research, some confusion exists as to its theoretical underpinnings as a methodology. This is confounded by the branching of the method over time, which has seen a move away from the traditional or classic approach advocated by Glaser and Strauss in the 1960s. Regardless of the epistemological debates surrounding grounded theory as a method, the focus of the approach is to discover key events in an individual's life and to unravel the processes that contextualise or shape these events (Charmaz, 2003a). This aim of this section is to examine the core concepts associated with classic grounded theory which is the methodology underpinning this particular study. In exploring the classic approach to grounded theory, attempts will be made to highlight the contrasting features of Glaser's approach when compared to the other accepted variations in the method, namely Strauss and Corbin (1990, 1998) and Charmaz (2003a; 2006).

Nomenclature and Language of Grounded Theory

Before commencing a discussion on the origins and practicalities of grounded theory, it is important to examine briefly the nomenclature and the language associated with the method. Mills et al. (2006) classifies three accepted variations in the method (classic, evolved and constructivist). Although others exist, for example Clarke's (2005) version based on situational analysis, each of the variations have common characteristics and share similarities across a range of key

stages in the process. However differences are related to the epistemological assumptions that each variation takes (McCann & Clark 2003) which can lead to confusion. What is required is a thorough understanding of each of the variations and a clear articulation at the beginning of a research project of which strand is being used (McCann & Clark 2003). Using the various strands interchangeably or as a methodological cookbook may damage the credibility of the research findings and the subsequent grounded theory. Several authors have written extensive accounts of the differences and similarities between the various schools of grounded theory method, most notably Glaser himself (Glaser 1992; Glaser 2002). This section of the chapter will also shed some light on the debate.

Another feature of grounded theory which causes confusion is the type of language used to describe the processes underpinning the method. Initially Glaser and Strauss (1967) were criticised for using language that seemed to align the method with more quantitative paradigms. The decision to use such terms to explain the method, Charmaz (2003a) believes, is because the authors of the method were attempting to break into the dominant positivist approach to data collection at the time. Nonetheless, students new to grounded theory method will be met with a plethora of terms that sometimes are used interchangeably. With the arrival of Strauss and Corbin's (1990; 1998) version of the method new directions were taken with the introduction of new and sometimes complex terminologies. This section will explore the method and its terminologies while later in chapter 5, the author will attempt to apply these methods to the current research problem.

Historical Perspectives Underpinning Grounded Theory Method

Grounded theory is both a research methodology and the end product of a grounded theory research study (Charmaz, 2003a). Most students of the method automatically begin their search for meaning behind this complex methodology in Glaser and Strauss's (1967) seminal work 'The discovery of grounded theory'. However, Glaser had written about the constant comparative method in 1965 predating the more familiar work published in 1967. This book, based on the authors' experiences of developing theory on the social processes of dying patients, revolutionised the scientific perception of qualitative research which at the time was seen as a method for purely substantiating quantitative data or for verifying existing theory. The authors pooled their experiences together from

different schools of scientific thought. Glaser studied at Columbia University and had training and experience in quantitative methodologies whereas Strauss studied at the University of Chicago which was known for it critical qualitative leanings (Goulding, 2005). Their collaborative work on dying in hospital culminated in the development of thorough analytical procedures that could be used to develop theory across many diverse disciplines (Charmaz, 2006).

Although grounded theory is almost always cited as a qualitative research method, its flexibility cannot be underestimated. Its founders do maintain that the method is most suited to qualitative and ethnographic investigations, however it can be utilised for quantitative investigations such as experiments or surveys (Glaser & Strauss, 1967; Glaser, 1978). Indeed a chapter dedicated to quantitative data is contained in the Glaser and Strauss's (1967) original text. Although Glaser and Strauss's (1967) original argument at the time was to defy methodological assumptions about the nature of qualitative investigations, it went further by providing systematic guidelines for handling data and producing theory (Charmaz, 2006). At that time, the positivist approach dominated all research and the development of new theories was supplanted by the testing and refinement of existing theories using mainly quantitative procedures (Charmaz, 2006). Glaser and Strauss (1967) defied this belief and suggested that the process of theory development and verification could occur simultaneously. Grounded theory differs from other qualitative methods in that they generally provide a detailed description of the phenomena of interest as an outcome of the research, whereas grounded theory guides the researcher through a number of key stages to arrive at abstract theorising (Goulding, 2005).

Philosophical underpinnings of Classic Grounded Theory

Although classic grounded theory has emerged from an objectivist epistemology, Glaser (1998) is reluctant to pigeon hole grounded theory into any one overarching paradigm. This standpoint puts classic grounded theory at odds with other methodologies that are keen to make explicit the theoretical frameworks that underpin and guide their research. Classic grounded theory's reluctance to do this has resulted in other researchers attempting to squeeze grounded theory into various research paradigms, most consistently symbolic interactionism (Blumer, 1969). According to Christiansen (2008), other approaches to grounded theory, apart from their name, are fundamentally different from the classic version. The

rationale behind this is clear and is based on the basic premise of grounded theory to allow theory to emerge from data. Christiansen (2008) argues that if the researcher aligns themselves with a particular research paradigm, then they must view the data through this research paradigm. Accordingly, the researcher will attempt to fit the theory into a preconceived theoretical framework, which forces the data, subsequently stifling the emergence process. Glaser (2001:199) makes this stance very clear in the following quotation:

> 'It is only a question of applying a rigorous and systematic method for discovering and explaining these patterns. No preoccupation is necessary regarding questions of ontology and epistemology or interpretation: Generation of concepts that are abstract of time, place and people, will transcend these issues'.

Thus the data becomes the theoretical framework and any decisions or directions taken by the researcher are based purely on the data and the emerging core variable (Christiansen, 2008). Applying preconceived theoretical concepts to the research process is therefore antithetical to classic grounded theory as described by Glaser and Straus and Glaser (1967; 1978) (Hernandez, 2008). What other authors have presented as versions of grounded theory (such as Charmaz and Strauss and Corbin) are in fact diametrically opposed to the classic version and although these are sometimes cited as having evolved from the original method (Mills et al., 2006) which suggests an improvement on the original method, they are essentially different. In addition, the language and nomenclature of these versions, although generally consistent with the original method mean different things, further alienating them from the classic version (Christiansen, 2008). It is not clear why these other versions of grounded theory methodology have emerged but one can speculate on a number of factors. Firstly, classic grounded theory is difficult to learn and time consuming. The processes associated with the method are complex and require the researcher to stay close to the data and to suspend apriori beliefs about the nature of the research problem, insisting that the concerns of the research participants are paramount. This is difficult for researchers who have formulated specific research questions or who have limited time to dedicate to the completion of the research. This may be the reason why many researchers utilise grounded theory in an eclectic fashion, dipping into the methodology to guide various aspects of their research project. This may have implications for the credibility of their studies and further impact on the credibility of qualitative research in general. In addition, classic grounded theory requires that the

researcher move from description of the data to conceptual abstraction which theoretically explains behaviour conceptually rather than descriptively (Glaser, 2001; Holton, 2008). There is a tendency for researchers to describe their data because conceptual abstraction is difficult (Glaser, 2008, personal communication) further distancing them from the classic method. Another explanation that may account for this fragmentation of the method may lie in its lack of ties to philosophical beliefs regarding the nature of knowledge. As stated previously, grounded theory is thought of as a qualitative method. Inherent to most qualitative research is the belief that the researcher is inextricably tied to the researched and that researcher objectivity cannot be achieved (Clark, 1998). Grounded theory, staying true to its objective leanings, believes that researcher objectivity can be enhanced through the processes of constant comparative analysis and through having faith in the mantra of 'trust in emergence'. However, any allegiances with positivism or post-positivism are denied by Glaser (2008, personal communication).

Grounded theory – Glasarian Style

The goal of grounded theory according to Glaser (1978:93) 'is to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved'. It does not attempt to provide a perfect picture of a particular area; instead it develops a theory that accounts for most of the relevant area (Glaser & Straus, 1967). Glaser's approach to grounded theory has come to be known as the traditional or classic approach to the method (Glaser, 1992; Mills et al., 2006). At the core of Glaser's approach (Glaser & Strauss 1967; 1978) is '...emergence, discovery and inductive theory generation' (Glaser 1992: 122) and guidelines for the collection and analysis of data are provided in Glaser's many books. In addition, Glaser advocates that the research problem will also emerge as a core category and that researcher should have few if any preconceived ideas about the phenomena under investigation (Glaser, 1978). McCann and Clark (2003) suggest that grounded theory has a number of key characteristics and differs from other forms of qualitative research in terms of sampling, data collection, data analysis and the presentation of the research findings. These key characteristics assist the researcher to collate the important issues that arise for the research participants during the data collection process (Mills et al., 2006). According to Charmaz (2003a:256) 'grounded theory offers a set of flexible strategies, not rigid prescriptions'. She further elaborates on the flexibility of grounded theory by

suggesting that the method gives the researcher strategies for analysing the data and does not specify data collection measures (Charmaz, 2003a). These key characteristics will be discussed in greater detail later in this section.

Although the steps of grounded theory appear to flow in an apparent linear process, in fact many steps can occur at the same time making grounded theory a complex and challenging research methodology. Grounded theory is both inductive and deductive (Glaser & Strauss, 1967; Glaser, 1978). Researchers, during the data collection and analysis of data are advised to ask questions of the data and to follow gut feelings about what to look at and where to go with the data (Charmaz, 2003a). Induction in grounded theory according to Goulding (2005) refers to the development of theory from the data rather than commencing the study with preconceived ideas. During the development of inductive theory, the analyst moves from description of the data to more abstract generalisations and the development of theory (Morse & Field, 2002). Researchers' then use logical deduction to decide where to go next in the data collection process, and this is known as theoretical sampling. In exploring the logic of grounded theory method it is difficult to separate the key stages and talk about them as independent entities. The stages of the method are closely interrelated and directly influence each other. For example, the process of constant comparative analysis (discussed later) is directly influenced by theoretical sampling and the level of conceptual abstraction that the researcher applies to the data. Grounded theory studies are generally presented as a core category and a number of related sub categories. Each of these categories contain a number of properties which serve to describe the range of experiences attached to the categories.

Theoretical Sensitivity

Theoretical sensitivity is defined by Glaser and Straus (1967:46) as the researchers' ability to 'have theoretical insight into the area of research, combined with an ability to make something of his insights'. To achieve this complex phenomenon, Glaser (1978) advises the researcher to commence the study with few, if any, preconceived ideas about the area under investigation. This, Glaser (1978) believes, assists the researcher in examining the data though a lens that is untrammelled by predetermined theories or ideas. This can be done by not completing a detailed literature review prior to the study and by explicitly suppressing the urge to formulate aims and objectives at the onset of the enquiry. The latter idea appears

to be the very antithesis of a traditional approach to research and poses problems when funding authorities require aims and objectives for research monies. Theoretical sensitivity, according to Glaser (1978) requires creativity while Charmaz (2006) describes this phenomenon as akin to wonder and whimsy. Researchers must demonstrate the ability, built up over time, to extricate the nuances and subtle differences in the generated data and to be insightful and sensitive to the hidden meanings behind the experiences of the research participants (Holloway & Wheeler, 2002; Glaser, 1978). Wilson and Hutchinson (1996) further emphasise the importance of creativity during the grounded theory process and although flexible guidelines for the collection and analysis of data are offered, the final theory 'stands on its own as diverse, parsimonious, conceptual, and relevant to the data' (Wilson & Hutchinson, 1996: 124). Although this could be perceived as a reductionist approach, Glaser (1978) argues that parsimony is necessary for theoretical abstraction. Furthermore, researchers are not looking for descriptive coverage, rather conceptual clarity related to *one* core concept.

The processes associated with grounded theory method also enhance the researchers' ability to become theoretically sensitive to the data. Glaser and Strauss (1967) and Glaser (1978) also offers some strategies that may assist the researcher to become theoretically sensitive. Firstly the researchers' personal experiences that have occurred separate to the present research study will influence the researcher's ability to conceptualise the data. In addition, other people involved in the research study may influence the analyst's thinking and the direction the emergent categories take. As the theory 'emerges' from the data, researchers will be able to use the literature to attempt to integrate the new theory into existing theories, thus assisting the researcher to further conceptualise their emergent theory. As with data collection, Glaser advises researchers to theoretically sample the literature in order to flesh out and elaborate the categories and sub-categories (Glaser, 2010 personal communication). Finally, researchers are advised to be sensitive to new categories and insights that emerge late in the research process. These new insights should be included until they either become integrated into the grounded theory or are refuted by the constant comparative process. Theoretical sensitivity requires the researcher to remain open minded and flexible throughout the data collection, analysis and theory writing process (McCann & Clark, 2003).

Theoretical sampling

Sampling in grounded theory is described as theoretical rather than purposeful in that it is driven by the emerging theory (Cutliffe, 2000). This is where the researcher jointly collects and analyses the data in order to decide 'what data to collect next and where to find them' (Glaser, 1978: 36). Theoretical sampling according to Glaser (1978) controls the data collection process. Because of the inductive nature of grounded theory, sampling cannot be predetermined. However, theoretical sampling does involve the purposeful selection of a sample in the initial stages of the study and participants are recruited based on the general subject or problem area (Cutliffe, 2000) with sampling procedures becoming more refined as the grounded theory emerges. Theoretical sampling differs from purposive sampling in that the latter makes a preconceived judgement about who and where to sample based on the substantive area or area of interest (Cutliffe, 2000). Conversely, sampling in grounded theory is based on the analysis of the data, which means that further sample selection is not based on the continual selection of participants from a homogenous group, but on the emerging theory. Although sampling strategies employed in quantitative and qualitative research differ on a fundamental level, researchers must be careful not to confuse theoretical sampling with other forms of qualitative sampling whose purpose is generally to describe and explain the data. What is important in grounded theory is the richness of the data (as decided by the emerging theory) and not the frequency that it occurs (McCann & Clark, 2003).

The gold standard for data collection is saturation of data, a complex phenomenon whereby no 'new' data emerges from the data collection/analysis procedures. According to Charmaz (2006:101) theoretical sampling 'pertains only to conceptual and theoretical development' and its purpose is to assist researchers in the construction of categories that inform and provide robustness to the generated theory. As categories emerge from the data, the researcher must ask himself 'what groups or subgroups does one turn to next in data collection, and for what theoretical purpose?' (Glaser & Strauss, 1967: 47). The answer to this question lies in the categories that have been generated which have emerged from the data. The theoretical sample must have theoretical purpose and relevance to these categories (Glaser & Strauss, 1967). Chenitz and Swanson (1986:9) neatly summarise the purpose of theoretical sampling by stating that

> 'Sampling to test, elaborate and refine a category is done for verification or to test the validity of a category. Further sampling is done to develop the categories and their relationships and interrelationships'.

Charmaz (1990) explicates the processes involved in theoretical sampling. Firstly data is analysed to determine categories, then further data is collected to fill out these categories and to check if these categories are repeated in subsequent data collection and analysis.

It is difficult initially to definitively state the number of potential participants in any grounded theory study as data analysis procedures directly affect the sampling procedures. In addition, it may also be difficult to state categorically who the research participants will be as only the broad area of interest stimulates initial sampling procedures. This concept relates to the flexibility of the method which was originally intended to be useful regardless of the direction the analysis and subsequent theoretical sampling takes. Charmaz (2006: 97) suggests that engaging in theoretical sampling assists the researcher 'from becoming stuck in unfocused analyses'. As mentioned earlier, theoretical sampling continues until saturation of categories is achieved. Data saturation in grounded theory happens when 'categories are saturated, elaborated and integrated into the emerging theory' (Coyne & Cowley, 2006: 513). Charmaz (2003a) writes about gaps in the researchers' data and holes in the researchers' theories. The purpose of theoretical sampling, she explains, is to try to fill these conceptual holes and gaps by collecting 'delimited' or precise information that will elucidate the emerging theory. Another warning that Glaser (1978) provides is to avoid the usual trappings of assuming that age, gender and other 'face sheet variables' are relevant to the emergent theory unless they earn their way into the emergent categories.

Constant Comparative Analysis

Glaser and Strauss (1967) advocate for the use of constant comparative methods in the analysis of the data. Constant comparative analysis occurs when the data collection and data analysis occur simultaneously, is underpinned by theoretical sensitivity and is refined by theoretical sampling. This, according to Charmaz (2006) assists the researcher to compare and contrast data within data and from other data at different points or stages. Initially the researcher will code the data and

from these codes they will develop more succinct categories which highlight important considerations in the data. Concepts according to Goulding (2005) are more advanced than codes and their purpose is to explain the relationship between and across incidents. Although not an original concept at the time, constant comparative analysis was used in different ways in both quantitative and qualitative research. However, according to Glaser and Strauss (1967), constant comparative analysis is useful in both the generation of grounded theory and in the verification of the theory. The latter purpose provides the method with an inbuilt technique for demonstrating robustness to the research findings. Throughout the grounded theory process, researchers are encouraged to compare the codes with other codes, codes with categories and categories with categories. Finally categories are compared to the emerging concepts. According to Charmaz (2006) constant comparison assists the researcher in demonstrating the analytic development of the grounded theory.

Glaser and Strauss (1967:106) describe the first fundamental rule in constant comparison analysis – 'while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category'. Coding requires the researcher to think inductively and in order to tap the freshness of the researcher's thoughts. This requires the researcher to continually stop the coding process and write a memo which captures their thoughts about the situation at hand, the decisions they are taking and the reasons they are taking them. As the initial coding develops, researchers are advised to commence integrating the categories from an early stage in the data analysis process. Delimiting the theory according to Glaser and Strauss (1967) occurs at two levels, the theory and the categories. As the constant comparative process persists, the categories and the properties that describe them, will reduce with a subsequent reduction in terminology. This assists in the development of the two major requirements of grounded theory – parsimony of variables and scope in how the theory can be applied (Glaser & Strauss, 1967). Parsimony refers to the adoption of the simplest assumptions in the formulation of the theory. In line with this parsimony of variable there is a reduction in the number of categories that can explain the theory. Closely tied to this concept is category saturation, which will be discussed in more detail later in the section. Finally, Glaser and Strauss (1967) describe the ultimate step in the constant comparative analysis, the writing of the theory using the categories and a series of memos articulating the conceptual

journey. In summary, Glaser and Strauss (1967:23) briefly outline the purpose of comparative analysis:

> 'In discovering theory, one generates conceptual categories or their properties from evidence; then the evidence from which the category emerged is used to illustrate the concept'.

Coding and Categorising the Data

Coding in grounded theory presents the researcher with many challenges and those using the method must have a clear understanding of the process. In Glasarian grounded theory, guidelines are provided for the coding of the data and a thorough overview of the process is provided in Glaser's (1978) publication on the method. There are two phases to the coding process and these will be discussed in some detail.

1. Substantive coding
    a) Open Coding
    b) Selective Coding
2. Theoretical Coding

Table 4.1: Coding in Classic Grounded Theory (Glaser 1978)

Again the process of coding does not occur in isolation and is inextricably linked to the other phases of the method. This initial analysis generates open codes which tend to be a description of what is happening in the data. As the data pours in, the analysts continues this open coding until commonalities appear in the data and what Glaser (1978) describes as concepts begin to emerge. Concepts, basically, are units of data grouped together that have limited explanatory power but they pave the way for theory generation. Once codes begin to develop, using constant comparative analysis and theoretical sampling the analyst attempts to build on these concepts and flesh out their properties. Categories are then developed and these group together the relevant concepts that articulate the phenomena of interest. Glaser (1992:38) defines categories as 'a type of concept...used for a higher level of abstraction'. Repeated data collection and constant comparative analysis is performed and this attempts to either refute these categories as being irrelevant or they become saturated and form part of the emerging theory.

Substantive Coding - Open Coding

Goulding (2005) describes open coding as the initial phase of the constant comparative approach to data analysis where the researcher codes the data for every possible meaning. Glaser (1978) suggests that open coding helps the

researcher to determine which direction the research is heading and informs the theoretical selection of future sources of data. Glaser (1978) provides the analyst with several rules to help them achieve open coding:

1. Ask a set of questions of the data –
    a. What is this data a study of?
    b. What data does this incident indicate?
    c. What is actually happening in the data?

2. Constantly code using line by line coding.
3. The analysis must be completed by the analyst.
4. As coding is a constant source of ideas, analysts should stop coding when ideas or haunches arise and complete a theoretical memo.

(Glaser, 1978)

Open coding it the process of fracturing the data into discrete units of meaning (Goulding, 2005). Both Glaser (1978) and Charmaz (2006) advocate the use of line by line coding which ensures adequate coverage of the data and assists in the development of categories that are grounded in the data. However the type of data collected will influence the way that the open coding takes place. Regardless, open coding should be completed quickly and with spontaneity (Charmaz, 2006) and using gerunds, that is words that reflect action, will help the analyst to stick to the data and to explain the processes that are occurring (Charmaz, 2006; Glaser 1978). Charmaz (2006: 49) provides us with a code for coding:

1. Remain open
2. Stay close to the data
3. Keep your codes simple and precise
4. Construct short actions
5. Preserve actions
6. Compare data with data

The process of open coding allows the researcher to verify, correct and saturate codes. The process of constant comparison and theoretical sampling ensures that codes that initially seemed relevant but are not, are not subsumed into the emerging categories (Glaser, 1978).

Substantive Coding – Selective Coding

Glaser (1978:61) states that 'to selectively code means to cease open coding and to delimit coding to only those concepts that relate to the core variable, in sufficiently significant ways to be used in a parsimonious theory'. Once the analyst has made some connections in the data at the open coding level, they can begin selective or focused coding which help pull together and elucidate larger chunks of data (Charmaz, 2006). Again with constant comparative analysis, the process of selective coding is not linear and analysts will find themselves revisiting earlier data to look afresh at ideas and concepts that might have been missed (Charmaz, 2006). Substantive coding occurs at the open and focused level and serve to describe the data as perceived by the researcher. Substantive coding culminates in the emergence of categories which are conceptually thick descriptions of the data. Glaser (1978) outlines two different types of categories: Sociological codes and in vivo codes. Sociological codes are codes that add sociological meaning to the analysis, are derived from the researchers in depth knowledge of the data and add clarity to the analysis (Glaser, 1978). In vivo codes on the other hand, are derived directly from the data and are formulated using the language of the participants. These according to Glaser (1978) are explanations of behaviours or processes that account for how the basic social processes are resolved and both of these codes must demonstrate analytic ability and imagery.

Theoretical Coding

Theoretical codes, on the other hand, are more complex and represent the relationships between the categories and symbolise the whole theory (Glaser, 1998). Their purpose is to 'weave the fractured story back together again' (Glaser, 1978:72). To emphasise the inductive nature of grounded theory, theoretical codes emerge in a conceptual and abstract manner and serve to add 'precision and clarity' to the emerging theory (Charmaz, 2006:63). Theoretical coding requires the analyst to move from describing the data to looking at in more theoretical and abstract ways. To assist us in this task, Glaser (1978) provided us initially with 18 coding families. He builds on these coding families in his 1998 publication, 'Doing grounded theory' (Glaser, 1998). However, Glaser is adamant that these coding families act a guide for the researcher and must earn their way into the emerging theory. This is in contrast with Strauss (1987) and Strauss and Corbin (1990; 1998) who emphasised the use of one coding family (commonly known as the 6 Cs: context, condition, cause, consequence, covariance and contingent).

Coding and categorising in grounded theory is complex and clouded by subtle nuance which requires a thorough understanding of the variety of grounded theory being utilised. Obfuscating this issue further is the introduction of another type of coding called axial coding (Strauss & Corbin, 1990, 1998). Axial coding occurs following open or initial coding and its purpose is to bring the codes back together in an attempt to provide clarity and direction to the data albeit at an early stage. Glaser (1992) was highly critical of this development on the original method, which he deemed as being unnecessary. Furthermore he believed that it contributed to the forcing the data into a preconceived hypothesis rather than letting the issues of concern emerge.

Saturation

Saturation is closely related to sampling and is the goal of category development. Generally, saturation in qualitative research, according to Streubert and Carpenter (2003:364) refers to the 'repetition of data obtained during the course of a qualitative study'. In grounded theory, saturation refers to each of the categories reaching a level of completeness through the constant comparison of data and the theoretical sampling of future sources of data. Consequently, saturation occurs at a number of levels and at different stages of the analytic process. Using deductive measures the researcher seeks to saturate certain codes that appear to have strong explanatory power. For example, the analyst will deduct where to collect data from next based on the analysis of data and the emerging concepts. Other qualitative approaches arrive at saturation after an extended period of collecting data and no new data emerges. According to Glaser (1992) theoretical sampling continues on each category until it is developed and integrated into the theory, saturation is achieved at this point.

The core category

According to Streubert and Carpenter (2003) the goal of grounded theory is to discover theoretically comprehensive descriptions about a particular area of interest. This discovery is articulated though the core category or variable (Streubert & Carpenter, 2003). Glaser (1978:93) states that a core category will 'account for most of the variations in a pattern of behaviour' and that the other categories will be related to the core category. He further elaborates on the description of the core category later in 2004 by suggesting that it will explain how

the main concern of the participants is persistently resolved (Glaser, 2004). The core variable emerges gradually through the constant comparative process and analysts should attempt to saturate categories that appear to have strong descriptive and explanatory ability (Glaser, 2004). Core categories are similar to theoretical codes and their purpose is to explain and pull together the other related categories and their properties (Glaser, 2004). Core categories are always present in a grounded theory study and they can be basic social process but not necessarily so (Glaser, 1978). In order for the analyst to assess whether to adopt an emerging category as a core category, Glaser (1978:95) offers criteria to guide their decision.

Once the concept has emerged researchers continue to modify and integrate the concept through constant comparison and theoretical sampling (Streubert & Carpenter, 2003). Examples of core categories can be found in the literature, a selection are presented in table 4.2.

Author	Substantive area	Core Category
Fallon (2003)	Borderline personality disorder	Travelling through the system
Higgins et al. (2008)	Sexuality	Veiling sexualities
Law (2009)	Needs of dying patients	Bridging worlds

Table 4.2: Examples of core categories

According to Glaser and Strauss (1967:31) grounded theory can be presented as 'either a well codified set of propositions or in a running theoretical discussion using conceptual categories and their properties'.

Basic social processes

Basic social processes are a type of theoretical code and Glaser (1978) suggests that the primary difference between basic social processes is that they describe a process and have two or more stages. Like other theoretical codes, basic social processes emerge from the data and researchers should not enter the grounded theory process attempting to articulate a process as this may contribute to the forcing of the data. In Glaser and Strauss' (1967) original text the pursuit of basic social processes was the key to the grounded theory process, however this was later refuted by Glaser in subsequent texts (Glaser 1978). Although common in grounded theory research, basic social processes are not the only way to present the emergent theory or to explain the processes that are evident in the data.

Theoretical Memos

Glaser (1978) describes memos as being a core process in the development of grounded theory. Memos articulate the grounded theory journey from the initial coding to the development of the emergent theory. They capture every idea that the researcher might have in relation to the data and the decisions that they make in terms of categorising, sampling and theory generation. Theoretical memos connect the stages of the analytical process with the generated theory and lead naturally to abstraction or ideation (Glaser, 1978). Without memos Glaser (1998) warns that the generated theory will be conceptual description and will lack the theoretical density required of substantive grounded theory. Without memos the researcher will not be able to engage in theoretical sampling nor will they be able to advance their skills in theoretical sensitivity. Memos are basic to begin with but as the research progresses, they become complex, dense, clear and accurate (Corbin & Strauss, 2008).

Given the importance of theoretical memos, Glaser (1978; 1998) gives considerable guidance on their relevance and usage as well as providing information on how to keep and sort the memos. Glaser (1978) presents us with four goals of memos these being:

1. To theoretically develop ideas
2. To complete the first goal with freedom
3. To maintain a memo fund
4. This memo fund must be highly sortible.

Memos will originate from the analysis process and are in constant development throughout the life of the research. Constant comparative analysis spurs the memoing process on as the analyst articulates the decisions he makes regarding the data. As the codes and categories are either refuted or continued to saturation, memos spawn more memos and the rewriting of previous memos (Glaser, 1978). By using memos throughout the constant comparison analysis process, preconceived biases that the researcher might hold are disproved as only those categories that are emerging from the data will remain. The memoing process is well suited to the capricious nature of grounded theory method as all the decisions that the researcher makes about the data will be clearly articulated with rationales within the memos.

Literature as a Source of Data

Charmaz (2006) suggests that the role of the literature in grounded theory research has been misinterpreted and disputed. The original founders of the method are clear in their position of delaying the return to the literature until the data has been analysed (Glaser & Strauss, 1967). Glaser (1978) reiterates this stance in subsequent texts. The purpose of this is to remove or at least limit any preconceived ideas that the researcher may have. Looking at the data through the lens of an extant theory may result in the forcing of the data and thus stifle the emergent process. As the methodology evolved, Strauss and Corbin (1990; 1998) altered their stance on the role of the literature and advocated a preliminary review to provide justification for the study and to assist in the development of theoretical sensitivity (McCann & Clark, 2003). Glaser (1978) on the other hand, supports the use of the literature to support the emerging theory and suggests that the role of the researcher when returning to the literature is to find a place for their theory with existing bodies of work. Although reviewing the literature within the substantive area is frowned upon in traditional grounded theory research, Glaser (1978) suggests that reading other theories will help the analyst to become theoretically sensitive. For example, in this study, reading about mental health services users experiences of inpatient care helped me to attune to the participants experiences.

Rigor in Grounded Theory Research

In classic grounded theory the relevance of the theory is based on the theory's ability to fit, grab and work (Glaser & Strauss 1967). Later, Glaser (1978) introduced a fourth dimension to these criteria: the theory should be modifiable. Within the grounded theory method the strategies of constant comparative analysis, theoretical sampling and theoretical sensitivity assist the researcher in verifying the emerging data. These processes will be described in more detail and applied to this study in chapter ten.

Grounded Theory - Straus and Corbin

Glaser (1992) was highly critical of Strauss' (1987) and Strauss and Corbin's (1990; 1998) development of the grounded theory methodology. Charmaz (2003a) suggests that the differences lie in their differing epistemological philosophies although both have objectivist leanings. Glaser and Strauss' (1967) and Glaser's (1978) approach to the methodology advocates for the researcher to remain independent from the research. However, through the constant comparison

analysis process, any preconceived ideas or experiences that the researcher brings within him into the research will not be forced onto the emergent theory as they will not be in the data. Strauss (1987) and Strauss and Corbin (1990; 1998) on the other hand, recognise the experiences and personal philosophies of the researcher and their impact on the grounded theory process, arguably placing it within the constructivist paradigm. However, Mills et al. (2006) state that Strauss and Corbin (1990; 1998) are never clear about the underpinning epistemological or ontological thoughts that drive their research method. This is further complicated by their use of language such as 'bias' and 'objectivity' which situates evolved grounded theory in objectivism, although this was later rejected (Mills et al., 2006). This presumption has a major impact on the data collection process. For example, in the later version, researchers are allowed to conduct a preliminary review of the literature in order to justify the study and develop a research problem. This is in stark contrast to the traditional approach which advocates for researchers to look for the problem within the data. Glaser's (1992) distaste at the development of the method is apparent in his 1992 text, the title of which provides the reader with a summary of the major difference of opinion: emergence versus forcing.

Glaser's (1978) view of grounded theory comprises of a data collection and data analysis process to assist the analysis in the development of a theory that emerges from the data. The key to this appears to be in the management of the data that ensures that the theory is not forced to fit any preconceived theoretical frameworks. Evolved grounded theory incorporates additional processes which Glaser (1992) believes ultimately force the early closure of the theoretical sampling and constant comparative process and results in what he terms as full conceptual description. Glaser was also critical of Strauss and Corbin's (1990; 1998) over emphasis on one coding family (the 6 C's) which he believed aided the forcing of the data into predetermined frameworks.

Another major difference between the classic approach to grounded theory and Strauss and Corbin's version lies in the methods of ensuring the robustness of the emerging theory. Strauss and Corbin (1990; 1998) moved away from the principles of fit, grab, work and modifiability and returned to the more traditional methods of ensuring rigor in quantitative research for example ensuring validity and reliability.

Glaser (1992) suggests that these methods are fine for full conceptual description but not for grounded theory.

Constructivist Grounded Theory- Charmaz

In constructivist grounded theory, Charmas (2003; 2006) rejects the positivist approach that she believes Glaser and Strauss (1967) and Glaser (1978) developed for managing and interpreting the data. The original intention of grounded theory was to develop theory where the analyst remained objective to the data presenting theories that did not adopt individual subjectivities of the research participants. Some qualitative researchers were critical of this stance as it does not allow the participants stories to be adequately displayed in the research findings. In constructivist grounded theory Charmaz (2006) believes that researchers as individuals do not exist in a social vacuum and are influenced by the relationships they have with other individuals and social occurrences both as part and external to the research. She ascertains that 'a constructivist approach places priority on the phenomena of study and sees both the data and analysis as created from shared experiences and relationships with participants and other sources of data' (Charmaz, 2006: 130). In short, constructivist grounded theory acknowledges that researchers are not presenting an independent view of a phenomenon; conversely they present an interpretation of phenomenon, an interpretation that is tinged with the researchers contextual situation (Charmaz, 2006). Constructivist grounded theory according to Charmaz (2003a) moves the method away from the positivist position it holds, a transition that she believes liberates it from its quantitative underpinnings and places grounded theory firmly within the qualitative interpretative tradition (Charmaz, 2003a; 2006). Although the stages of the grounded theory methodology are mostly adhered to in Charmaz's version, the end product is not a core category or a basic social process. Instead the grounded theory accepts the complexity of individuals and their unique experiences as impacting on the generation of the emerging theory (Charmaz, 2003a; 2006). Constructivist grounded theorists are encouraged to keep the data alive by using analytical procedures, such as coding, that are true to the experiences of the participants (Mills et al., 2006). This Charmaz (2003a; 2006) believes, will assist the analyst in producing findings that reflect the experiences of the participants' and reveals the analyst and the participants as co-authors of grounded theory research (Charmaz, 2003a; 2006; Mills et al., 2006).

Glaser (2002) was undeniably critical of Charmaz's (2000; 2003a) constructivist approach to grounded theory and described it as a 'misnomer'. This criticism is harboured on the relationship between the researcher and the research participant. This he believes produces theory that looks for thorough description of the data rather than conceptual abstraction. Glaser (2002) is adamant that the analyst does not compose a story about the participants; rather they generate theory through the constant comparison, conceptualisation and theoretical sampling procedures. Basically, Glaser believes, that regardless of the researchers epistemological and ontological dictums, preconceived hypotheses about the area of interest and the nature of reality, to a certain extent, are irrelevant as the grounded theory method searches for meaning within the data and not from a socially constructed world (Glaser, 2002).

Philosophical Underpinnings of this Study

Coyne and Williams (2000) suggest that the epistemological foundations of qualitative research are open to significant deliberations and that in order to explore the complex experience of services users, methodologies must be equally complex. Nursing, traditionally has 'embraced multiple and diverse epistemologies' (Tarlier, 2005: 126). However as a consequence of this, ontological and epistemological debates in nursing are set against the prevailing backdrop of scholars who are loyal to their own philosophies and directions (Pitre & Myrick, 2007). In nursing, according to Glaser (2005:1), there is a preoccupation with theoretical perspectives - 'Researchers, especially nurses, just want a theoretical perspective'. The alignment of grounded theory with symbolic interaction has to some degree appeased researchers who are unable to accept it as a general research method. For novice researchers, symbolic interaction offers both an ontology and epistemology to guide their research (Glaser, 2005) arguably making it easier to shape and pigeon hole the emerging theory even though this is the very antithesis of classic grounded theory. Moreover, it is relatively simple to drift into this frame of mind given the range of authors and scholars who are unyielding in their opinions of grounded theory as emerging from symbolic interactionism.

In attempting to articulate the underpinning philosophical approach to this piece of research, it is important to be critical of a number of factors. Firstly, the reluctance

of Glaser to allow researchers to choose a particular theoretical perspective at the onset of the research leaves researchers in theoretical limbo and open to criticism from academics for 'ignoring' this important aspect of their study. The theory that has emerged from the description of the participants experiences describes their reactions to being labelled as a 'psychiatric patient' and their subsequent responses to stigma. Both of these concepts have been cited as socially constructed and arguably it would be easy for me to fit my study within that overarching framework. In addition, the categories and the processes that they describe articulate the participants' encounters with their social world following their discharge from hospital. This is in line with Blumer's (1969) assumptions about the nature of symbolic interaction. According to Blumer (1969:4) symbolic interaction 'sees meaning as arising in the process of interaction between people' and that this occurs through a process of interpretation'. However, this was not the framework that was applied to the analytic processes at the beginning of the study. It might have been easier to make these assumptions prior to writing the theory contained in this thesis, but I reluctantly tried to stick to Glaser's instructions and not 'force' the data into a preconceived perspective.

I cannot say that I am objective; however I have strived for a level of objectivity by trying to stay close to the data and by staying as open as possible. However, I am a product of this social world and in that sense have been influenced considerably by my education and indeed my professional socialisation among other things. The emergence of a core category that is conceptually distant from my initial reasons for completing the study goes some way to highlighting the success of my ability to stay close to the data. The processes that were utilised to achieve robustness within this theory development will be further discussed and elaborated in chapter 10. Once the core category had been articulated, it became the lens that the rest of the data was viewed through. In this sense, the core category became equivalent to a theoretical perspective which emerged from the data. All subsequent data analysis, collection and theory generation was guided by the core category. A level of objectively was achievable as only those codes and categories that were relevant to the core category were subsequently included in the final theory. I don't believe that striving for objectivity makes my perspective positivist or even post-positivist. It merely represents my attempts to suspend preconceived beliefs about the data and to attempt to listen to the true concerns of the participants rather than tainting the data with my beliefs or assumed explanations

Although I believe that the data collected in this study is a shared experience between the researcher and the researched, the subsequent analyses and emergent theory is a construction of my interaction with the data rather than a joint construction between me and the participants. The purpose of this research is not to tell the 'individual' participants story, rather to present a grounded theory that is both conceptual and relevant. In other words it is a conceptual rendering of all the participants' stories. Grounded theory was selected as a methodology mainly because I wanted to develop a theory using a methodology that allowed the issues of concern for the participants to emerge, rather than constructing a theory based on my apriori beliefs. However as a collector and developer of these concerns and processes, I acknowledge the socially constructed worldview that has shaped this process. However, rigorously adhering to the grounded theory methods has assisted in minimising preconceived biases that might have occurred.

The Generation of Theory in this Study

Silverman and Marvasti (2008) describe theory as a number of interrelated concepts that aid our understanding of, define or explain a particular phenomenon. Grounded theory according to Glaser and Strauss (1967) can be used to develop or generate two types of theory, namely substantive and formal. Substantive theory according to Glaser and Strauss (1967) is theory developed within a particular area of interest whereas formal theory is developed in a wider area and has a greater application and generalisability. Both of these theories may be thought of as middle range theories as described by Merton (1968). The purpose of this study was to generate a substantive theory that was rooted in the data. As theory, this substantive theory explains how the participants managed a particular concern and presents a range of interrelated concepts within that substantive area. The substantive area in this study was the participants' experiences of going home from hospital. It this sense the theory developed has limited generalisability when viewed in this way. However, it does have greater practical application as it helps to clarify what the concerns of those who are discharged from hospital may be and is relevant to service users and mental health practitioners. It was not my intention to develop a theory with great and far reaching application as to do so was beyond the scope of this project.

Summary and Conclusion of Chapter four

This chapter presented an introduction to the philosophical influences on grounded theory methodology. Central to this discussion is Glaser's reluctance to pigeon hole grounded theory into any one overarching theoretical framework, preferring instead to see grounded theory as a general research method. Although, generally thought of as a qualitative approach, this was not the intention of its founders who believed it could be used with any type of data in any circumstance (Glaser & Strauss, 1967). This has undeniably confused researchers and scholars alike which has culminated in a branching of the methodology over time much to Glaser's dismay. This chapter also described in detail the processes associated with grounded theory as well as a brief overview of to dominant alternatives (evolved and constructivist grounded theory). The chapter concludes with my interpretation of the philosophical underpinnings of this particular study as well my views on the generation of theory. The next chapter describes how I operationalised grounded theory methodology and developed the 'Managing Preconceived Expectations' theory.

CHAPTER FIVE: OPERATIONALISING GROUNDED THEORY METHODOLOGY

Introduction

The aim of this chapter is to describe how I as a researcher carried out this piece of research. The chapter begins with a reiteration of the aims and objectives of the study. The complexities of access to the research participants are presented and data collection and the analytic processes used are discussed. Finally, the ethical issues involved in this study and how I dealt with these issues are discussed in detail. Although, for ease of presentation, the data collection and analysis is presented as a systematic and straightforward process, in practice it did not occur this way. There were also many barriers to reaching the potential research participants and these will be discussed in their relevant sections. Moreover the practice of grounded theory is not linear and challenges the researcher to continually revisit the sampling, data collection and data analysis processes.

Aims and Objectives

The overall aim of this study was to generate a substantive theory of service users' experiences of going home from a psychiatric hospital. The following were the research objectives:

1. To explore the social and psychological process that occur when mental health service users are discharged from hospital.
2. To develop a theoretical framework that provides an explanation of the processes used by service users following discharge from a psychiatric hospital.
3. To situate this theoretical framework in the context of current understanding of the experiences of mental health services users when they are discharged from hospital.

Recruitment and Sampling

Access and Recruitment of Participants

Bearing in mind Woods and Roberts (2003) assertion that planned and diplomatic negotiation is essential to access research sites and potential participants, careful consideration was given to the recruitment of the participants in this study. Initially, I planned to recruit the participants from the Mental Health Service administered by the Health Service Executive (HSE) linked to the University where I work. This allowed me to utilise the Community Mental Health Nursing Service offered by the HSE as well as covering a large and diverse geographical area (this service caters for about 250,000 people). The management of this service is divided with two separate management teams overseeing the administration of the

inpatient and community services in two distinct locations. Burton (2000) suggests that it is necessary to make contact with the participants through the approved research processes in place within organisations. Following ethical approval to conduct the research, permission was sought from the Managing team (the Medical Director, Director of Nursing and the Chief Executive Officer) in each facility to access the potential participants. Permission was also sought from the Director of Nursing in each facility to involve Community Mental Health Nurses (CMHNs) in the recruitment of participants. The CMHNs were to act as gatekeepers to the potential participants. Generally, gatekeepers in qualitative research act as links between the researcher and the participants to ensure that no excessive demands are placed on participants (Mander, 1992). It is often the gatekeeper who informs the participants of the research and in many cases select them based on stringent inclusion/exclusion criteria. Although gaining permission to recruit from these areas was relatively easy, subsequent recruitment of participants proved much more difficult than anticipated. Contact was made with the CMHNs through the Director of Nursing and they were asked to give an information brochure, which included a cover letter, an information sheet and a statement of interest form, to the people who met the inclusion criteria seeking their support (table 5.1).

Inclusion criteria:
• All service users who have been discharged from an inpatient psychiatric facility in the chosen mental health service at least three months ago and who are currently attending a community day hospital, hostel or other community based service.
• The service users must have a nominated community mental health nurse or nominated mental health support worker.
• The service users must be objectively and subjectively well enough to participate in the research (i.e. the participants themselves feel well enough to complete the research and their CMHN also feels that they are well enough to participate).
• Between the ages of 18 and 65 and must be able to provide informed written consent.
• Able to understand and speak English (no access to an interpreter)
Exclusion criteria:
• All service users who have not been discharged from an inpatient psychiatric facility in the chosen mental health service over six months ago and who are not currently attending a community day hospital, hostel or other community based service
• Service users who are not under the care of a community mental health nurse.
• Service users who are unable to provide informed consent.
• Service users who are cognitively impaired due to dementia or intellectual disability.
• Service users who are part of the care of the older person team or who are currently an inpatient
• Service users, who are, subjectively or objectively, not well enough to complete the research (i.e. the participants themselves do not feel well enough to complete the research or their CMHN feels that they are not well enough to participate).

Table 5.1: Inclusion and exclusion criteria

The potential participants were asked to read the information and return the statement of interest form, which indicated their willingness to be contacted about the research study. The researcher then contacted the potential participant to further ascertain their willingness to be interviewed for the research and to arrange a suitable time for the interview. Any queries the participant had were also answered at this stage. At the time of the interview the informed consent form was to be signed following reiteration of the research details. Although I assumed this was relatively straightforward and did not place too much additional work on the already busy CMHNs, there seemed to be an overall reluctance to assist me with the recruitment. I was and still am unable to discover why this occurred, and I endeavoured not to take this too personally (although this was hard at times). I accepted that being an outsider to the hospital and community environments may have had a negative influence on my ability to 'break into' the system. Nevertheless, the gatekeepers' unwillingness to inform potential participants about the research resulted in this study practically grinding to a halt necessitating the development of an alternative recruitment strategy. Later in the research, when recruitment was more successful, it became apparent that many of the participants had contact with CMHNs and they could have been recruited by the earlier method. This made me think that a rich and valuable source of data was left untapped because of the reluctance of the CMHNs to assist in the recruitment process. In an attempt to increase the number of potential participants, I decided to include additional mental health services and although this did not impact on the ethical approval that I originally received, it meant negotiating with additional management teams, which invariably was time consuming and once again was generally unproductive.

Because of the difficulties recruiting participants using the above strategies, permission was sought from the Director of Nursing in one of the areas to allow me visit one of the day centres under their jurisdiction. There, I met with the nurse in charge who was most facilitative and helpful in recruiting some participants. Using similar recruitment strategies as outlined above ten participants were recruited to the research. The main difference was that I administered the research information to the potential participants and was available to answer any questions that they might have. I then visited the day centre a week later and further ascertained the participants' willingness to take part. I was concerned initially that my presence might influence the participants' decision to take part and might be seen as a

coercive force. I attempted to minimise this by ensuring that a gatekeeper continued to be utilised and I approached only those that were interested in talking to me about the research. In practice, many people refused to complete the research and those that did, the voluntary nature of participating was constantly reiterated. Although attending this day centre was particularly helpful in the recruitment of participants, I found that because of the 'drop in' nature of the centre, there was no guarantee who (if anybody) would be there. Furthermore, plans were made to interview several participants and on my return to the centre, the individual in question would not turn up. Many of the people who were attending the centre, had no mobile phones or land lines which meant that reminding them of the interview was impossible. Although I was happy to continue with this arrangement in the interim and I often spent hours at the centre waiting for people to show up or to see if anybody 'new' was interested in taking part in the research, it was unsatisfactory in terms of completing the research within a suitable timeframe. Recruitment of participants was thoroughly anxiety provoking and for some reason became a barrier in terms of completing other aspects of the research. Because of my difficulties in recruiting participants, I was in some way psychologically prevented or unable to proceed with the research, even though there was other work that could have been completed. Furthermore, in grounded theory the data collection, data analysis and theory development are inextricably intertwined. The progression of the research was ultimately dependent on having participants to generate the theoretical sample. Although recruitment of participants would eventually resolve itself after much perseverance, it seemed at times to me that the research would never be completed.

The breakthrough in the recruitment of participants came when I approached a number of voluntary and vocational organisations in the Dublin area. Although negotiating access and gaining additional ethical approval was still time consuming it proved worthwhile and the remainder of participants were recruited in this way. Furthermore, these participants allowed me to contact them again for re-interview, which allowed me to re-examine their experiences in light of the emerging theory if required. In reality, only a small number were re-interviewed. In summary, recruitment of participants proved the most difficult aspect of completing this study and for me this problem was unforeseen. I think I was naïve to think that recruitment would be straightforward and I have learned a number of valuable lessons from this experience, most notably that recruitment should involve a multi

faceted approach. In addition, an adequate timeframe should be given to this aspect of the study as well as the researcher having infinite patience and determination to break through the multiple barriers that exist for researchers conducting qualitative research with mental health service users.

Developing the Theoretical Sample

Sampling in grounded theory is described as theoretical rather than purposeful in that it is driven by the emerging theory (Cutliffe, 2000). This is where the researcher jointly collects and analyses the data in order to decide 'what data to collect next and where to find them' (Glaser, 1978: 36). Theoretical sampling according to Glaser (1978) controls the data collection process. However, theoretical sampling does involve the purposeful selection of a sample in the initial stages of the study (Coyne, 1997). Initial sampling procedures in this present study were based on the general subject or problem area (Cutliffe, 2000) and used inclusion and exclusion criteria. Originally I believed that the sample might change based on the emerging theory, however it was not the sample that changed; it was the data that was collected and the purpose and scope of the interviews. Initially the interviews were quite broad and examined a multitude of different experiences, sometimes in quite a superficial manner. Although I was not really aware of it at the time, theoretical sampling began quite early, albeit in a rather unintentional way. Each interview was informed by its predecessor until the main concern was eventually articulated. In terms of developing a theoretical approach to sampling, it was not until the main concern emerged that I truly began sampling for the social and psychological processes that the participants' used to resolve this concern. This also allowed me to revisit earlier data which confirmed my emerging hypothesis and provided fresh insights about the nature of the participant's experiences. For me the main concern became a crucible and I was continually reluctant to settle on one thing. This continued until there was no doubt in my mind (or in the data) that this was the issue that concerned the participants most. I underestimated the power of the main concern in terms of guiding the research and understanding the participants' experiences. I think I was obsessed with articulating categories in the search for the elusive core code. Although I had many categories, they meant little in terms of explaining the data. This is in contrast to some authors who suggest that the core category is omnipotent and must be articulated early in the data analysis process (Christenson, 2008).

Profile of the Participants

The participants of this research study were all people who used the mental health services in one city in Ireland. Although all have been hospitalised at least once they were living independently i.e. not living in residential or supervised accommodation. Despite this, most were taking psychotropic medications and under the care of a consultant psychiatrist. They were recruited in a number of ways. Some were recruited through their community nurse or day hospital and a large number were recruited through a voluntary organisation and a training and vocational service. The philosophical differences between these organisations were, I believe, reflected not only in successful recruitment but also in the participants' stories and their interpretation of their experiences of psychiatric hospitalisation. A brief profile of the research participants is presented in appendix 1.

Thirty five interviews with 31 participants were conducted. Early in the interview process one of the participants approached me and asked me to conduct the interview again as he felt that he did not get the points he wanted across. Although I thought that his interview was informative, I granted his request. Another female participant was initially interviewed early in the data collection process and because she was an excellent historian and communicator I decided that I would ask if she would be interviewed again. After meeting her again I asked her if she would meet me again (in about a year's time) which she agreed to. During my difficulties in recruiting I interviewed another participant twice, as I was considering re-interviewing as a possible solution. Once the main concern and the core category had emerged theoretical sampling, data collection and data analysis became easier as I knew what I was looking for in terms of category refinement.

Data Collection Methods

Interviews as a Data Collection Method

In general, qualitative interviewing is utilised when the researcher wishes to derive an understanding of the participants' experiences rather than to examine facts or figures (Warren, 2003). Data in this study was collected initially using unstructured interviews. However, in line with ground theory procedures, as the interviews progressed, the interviews became more focused in order to saturate the emerging codes and categories. In conducting the interviews, the emphasis was on openness and inclusiveness. I did not presume to 'know' the participants or their experiences.

Consequently, the opening part of the interview attempted to set the scene by allowing the participants to create a picture of their hospital experiences to date which contextualised their experiences since they have been discharged. Following this I attempted to identify the issues that concerned the participants and how the participants continually resolved these issues. The key to grounded theory research is avoiding forcing of the data which might lead to early closure of the data collection and data analysis process. Consequently the interviewer must be careful not to influence the content of the participants responses by asking ill informed questions which may taint the entire study with the researchers concerns and preconceived ideas (Chamaz, 2003b). Early foreclosure in this study was prevented by using theoretical sampling and the concept of theoretical saturation which advises researchers to continue data collection until no new categories or properties are emerging from the data.

Interview setting

Initially, the plan was to undertake the interviews in the day hospital or mental health facility that the participants attended. This was to ensure that participants were not unduly inconvenienced and that if the interview was upsetting the participant would be in a familiar place with people who knew him or her. When negotiating access to one of the mental health services it was suggested to me to that I complete the interviews in a named location. This prompted me to review the location of the interview as I felt that ensuring people attended a particular centre may firstly be inconveniencing for the participants. Secondly, and more importantly, having the participants 'come to me' seemed to be incongruent with the general philosophy underpinning the research. This I felt would infringe on the autonomy of the individual and create a power imbalance between the me and the participant. Consequently, a change in the location of the interview to a place of convenience for the participant was deemed necessary. Generally the interviews were conducted at either a mental health service day centre or at a voluntary organisation. Two of the interviews took place at the person's place of residence and two of the interviews were conducted in an office at the School of Nursing and Midwifery. One of the interviews was conducted in a public place at the request of the participant. Although, I felt initially that this might not be suitable for reasons of confidentiality, it transpired that this was in fact a relaxed and conductive atmosphere for conversing about the person's experience. In my opinion, this

presented the most equalitarian location as both the participant and I were on neutral ground.

Interviewer Preparation

Although an interview maybe described as unstructured, it is not 'haphazard' (Angrosino, 2007: 42). Fontana and Frey (2005) suggest that the process of asking questions and getting answers is a harder than it looks. According to Horsfall et al. (2007), researchers engaged in qualitative research involving unstructured interviews should be adequately prepared for this role. In addition, Minichiello et al. (1995) argues that interviewing is not something that comes naturally to all people and successful interviewing takes experience and knowledge. In addition, Moyle (2002) suggests that interviewers should also be trained to manage the subsequent complications that may stem from interviewing vulnerable individuals about sensitive topics. Apart from reading the literature, I had no formal training to enable me to qualitatively interview people. Although I am a qualified psychiatric nurse and have worked in clinical practice for several years, there is a fundamental difference between interviewing as part of a nurses role and interviewing for research purposes. When interviewing in clinical practice the function of the interview is primarily symptom based and rarely deviated beyond the individuals' experience of illness and the problems it brings to daily life at that point. These interviews are generally very structured and do not stray from a preset convention based on the documentation that is being used within that particular area. However, I am a product of my training and my experience is set against a medical backdrop which differs to the recovery model now being emphasised (DoH&C, 2006). Research interviewing on the other hand in this project was unstructured and the scope of the interviews was very broad, particularly in the early stages. Although my experience as a psychiatric nurse was probably helpful, I feel that my experience as a teacher was more helpful in preparing me for this role as an interviewer. I have conducted some qualitative research in the past but this has been relatively small scale and utilised semi-structured interviews which are inherently more straightforward and easy to use and analyse. As the interviews progressed I felt that my confidence was building and that my skills as an interviewer did improve. Certainly, discussing the issues with my supervisors was helpful and allowed me to reflect on strategies that I could use during the interview process.

The process of conducting qualitative interviewing is unpredictable (Warren, 2003). Price (2001) argues that securing access, managing power, space, communication, making records and managing the emergent revelations and discomforts are common problems that are associated with unstructured interviews. In addition, Warren (2003) notes the emotional cost of interviews in terms of examining difficult experiences as being stressful for all concerned. Another problem observed by Warren (2003) is the possibility of actually having no participants which she suggests can occur when the topic is stigmatising. Moyle (2002) suggests that one of the difficulties of conducting unstructured interviews with the depressed individuals in her study was finding a way for them to narrate their experiences given that the symptoms of depression may prevent them from telling their story in a logical and coherent manner. Initially the issues of concern stemmed from my lack of experience in conducting qualitative in depth interviews which produced two distinct problems:

1) Sustaining the longevity and profoundness of the interview in order for them to be 'in depth'
2) Facilitating the participants to describe their experience in an attempt to understand what they mean.

McCann and Clark (2005) suggest that if possible the interviewer should pursue the participant's narrative in terms of guiding the interview and avoid a specific line of questioning. In starting the interview I made attempts to develop a rapport with individuals which was assisted by the fact that I had met the potential participants prior to the interview and they had a chance to decide if I was in fact worth speaking to. It was reassuring that when the potential participants eventually heard about this study they were generally happy to share their experiences. Two participants initially said that they would take part in the research but subsequently withdrew. One of these gave no explanation to why she made this decision and the other decided against participating as she felt it would 'open a can of worms' and be too upsetting.

Brink and Wood (1998) describe grand tour questions where the opening question sets the tone for the remainder of the interview and allows for the phenomenon under scrutiny to be discussed. This allows for open and unstructured responses. Although the purpose of the present study is to investigate the social and psychological processes that occur in the transition from inpatient acute services to home, this was not the starting point for the data collection process. The reasons

for this are twofold, firstly narrowing the participants responses to this substantive area prevented the exploration of the antecedents to this event thus framing the experience in isolation to other variables that may (or may not) be crucial to understanding the participants' perceptions. Secondly, in congruence with grounded theory methodology entering the research arena with a preconceived set of questions and a preconceived problem may contribute to forcing the data resulting in a theory that lacks conceptual density. Consequently a narrative approach was adopted which allowed the participant to tell their story in their own words. In addition this process allowed them to place the emphasis on the areas that were of concern to them. This also helped any power imbalance as Wright and Flemons (2002) suggest that data collection should involve the discussion of issues that are important to both the researcher and the participant.

Although the approach was unstructured, the mental health service users in this study often found it difficult to elaborate on their answers resulting in long pauses. When participants were probed about their responses, they often seemed unable to describe what they meant exactly, responding with questions like 'you know what I mean?' or they often looked for reassurance through non verbal cues as if to say 'am I saying the right thing?' Rubin and Rubin (2005) suggest that qualitative researchers use three types of questions that aim firstly to guide the conversation, secondly to seek clarification from previous responses, and finally questions whose purpose is to follow up answers from the main questions. Although my second line of questioning endeavoured to seek clarification as Rubin and Rubin (2005) suggest, some of the participants in this study may have lacked the communicative fluency required to articulate their experiences. This contributed to interviews that may not be as in depth as required for the purposes of the study. The reasons for this are unclear but may be attributed to the fact that the mental health service users interviewed thus far did not have a chance to tell their story and consequently had difficulty finding the words to capture their emotional distress and pain. Alternatively it may be that some of the pain is beyond the persons' everyday language. In addition, many people with mental health problems have difficult concentrating which sometimes impacts on the length of the interview. In one instance the participant seemed to drift off into his own world and when prompted appeared to forget what we were talking about.

On occasions I had to make a conscious decision to resist probing and to remain quiet during an interview, in an effort not be turn the interview into an interrogation. Price (2001) describes a questioning process referred to as laddered questioning. Here the type and depth of the questions are based on the researchers' intuitive decisions about the level of intrusiveness/discomfort experienced by the participant. This approach assists the researcher to avoid turning the interview into an interrogation. In doing so, this may lessen the stress experienced during the interview which is advantageous given that stress may exacerbate existing mental health problems. However, utilising this skill requires practice and becoming intuitively sensitive to the participants reaction to questions is difficult. Consequently the emphasis during these interviews was to allow the participants to tell their story in their own way with a conscious decision made by the researcher to minimise the number of direct questions asked. However this was not always successful because often the participants did not expand on their answers. Moyle (2002) suggests that allowing vulnerable participants additional time to complete the interviews is a strategy that will assist the individual to tell their story. In her study, she found that the interview process was not the end point of contact with the participants' experiences. She felt that the analytic process kept her close to the feelings and perceptions of the individuals concerned and this assisted her in 'truly living the experience' (Moyle 2002: 271). In addition, McCann and Clark (2005) suggest consideration should also be given to the length of the interviews allowing the participant to take breaks if necessary. These strategies were also utilised to some success; however, as mentioned some of the participants had difficulty with concentration span which did impact on the quality and length of the interviews. Short breaks were rarely necessary.

In grounded theory research interviews, according to Chamaz (2003), the researcher has the task of piecing together a process from multiple shared contexts. This provides a 'conceptual analysis' of the data, rather than a description of individuals experiences (Charmaz, 2003b: 691). As the data collection and analysis progressed and once the main concern had been articulated the interview process became easier for me as I was able to ask specific questions based on the main concern and the emerging processes that the participants used to resolve it. I developed an interview schedule with numerous open ended questions that were based on the previous interviews. This interview schedule underwent continuous augmentation in line with memo writing and coding and categorisation. However, I

was cognisant of ensuring that I did not just fulfil my interview needs and continued to encourage the participant to tell their stories and give their particular viewpoints. This was beneficial in terms of ensuring that I was not narrowing my field of enquiry or forcing the early closure of the data collection/analysis process. It was also beneficial to have an aid memoire for interviews where I felt it was difficult to get the participant to 'open up' or to explore beyond the 'yes' or 'no' responses.

The interviews generally came to a natural conclusion and was prompted by the participants' declaring that they had no further information to add or that they were satisfied that they had told as much of their story as they wanted to. At the end of the interview I asked the participants' if they wanted to ask me any questions and generally they did not. Some participants' asked me what was going to happen now with the data that I had collected and I reiterated the information that had been given in written and verbal form at the beginning of the interview. Throughout the interview I made a point of continually asking the participant how they were doing and ensuring that they were not under too much stress. Prior to them leaving I thanked them for their time and pointed out my contact details should anyone wish to contact me.

Participant/Researcher Relationship

Moyle (2002) suggests that qualitative research necessitates a level of personal commitment from the researcher and the person being interviewed. According to Flynn (1986), interviewers require significant interpersonal skills that can aid engagement with the participant while fostering a trusting relationship. Lee–Murray (2003) suggests that the participants in her research, by engaging with the interviewer, took the first step in understanding their experiences. She believes that engaging with research participants is essential not only to developing a therapeutic relationship, but also to elicit data that is rich. However, both warn against the role of the interviewer as a therapist and even though talking about problems may be in itself be therapeutic, advising or educating the participant should be avoided (Moyle, 2002; Lee–Murray, 2003). Although attempts were made to put the individual at ease and to develop a rapport with them, I think that this conflicted with my desire to remain objective and to present myself as non involved and non reactive to their stories. In order to encourage their stories I used verbal prompts and often summarised and paraphrased what the participant was

saying. Although this was done in order to ensure clarity for both me and the participant, I felt that this was misinterpreted sometimes as a therapeutic strategy. On a number of occasions when I paraphrased the participant's point, they suggested that they had not thought about that particular point in that way before. This also happened sometimes when I asked direct questions, for example they might reply 'I never thought of it before but now that you mention it that has happened to me'. Many of the participants in this study commented on the therapeutic value of the interview and many suggested that they never had a chance to tell their story in this way. This I believe stemmed from their constant desire to hide or deny their problems except with health professionals. Even then, they felt that the limited time they spent with their doctor or nurse often meant that there was little scope for exploring their feelings beyond getting their prescription or dealing with something urgent. Furthermore interviews with heath care professionals were generally structured to meet the needs of the services rather than the issues that concerned the participants. For example, a specific mental health assessment needed to be completed etc. Time with new doctors on rotation was also often confined to treatment regimes. Although the interviews with the participants in my opinion, were a far cry from therapy, I was glad that they had some benefit. However, I was keen not to let my role as a researcher impact on the treatment or care that the participants were receiving.

In short, I tried to remain impartial but this was difficult especially if they participants directly looked for advice or asked me questions about their care. On a number of occasions I did provide advice but this was never beyond pointing the participant to a more appropriate source of advice or help such as the people within the centre where the interview was being conducted or their doctor or community nurse. I did not want to present myself as some expert that could provide a commentary on their experiences. I did harbour opinions which I kept in check and occasionally I reacted in a way that did not promote objectivity and these reactions had to be checked for in subsequent interviews. For example, one of the participants described an incident where a staff nurse in hospital stood over her and made her tear a letter up she had written to her doctor. I think my mouth hit the floor, more as a reaction to her upset from recalling the story as well as the actual details of the story itself.

Charmaz (2003b) suggests that power in the researcher/participant relationship can be minimised through the development of trust in the relationship. To achieve this, researchers must not set their own agenda in terms of collecting data and allow participants to tell their story regardless of the time it takes or shape it forms (Charmaz 2003b). This was adhered to throughout the data collection process through allowing the participants enough time to articulate their experiences and through creating an environment that was relaxed and unhurried. Other issues related to power within the research study itself were more difficult to minimise. Firstly, the research agenda and the design of the study were researcher driven although there was an emphasis from the start that this piece of research would at least include mental health service users as research participants. As suggested by Sixsmith et al. (2003) a non hierarchical approach was adopted and during visits to research sites I made an emphasis that everybody who wanted information about the research received it in a manner that was congruent with their educational needs. Furthermore, even though gate keepers were utilised, the decision to impart information either by agreeing to participate or subsequently during the interview was held exclusively by the participant as advocated by Shaw (2003). This was reiterated at the beginning of the interview where the participants were advised that if they did not want to answer a particular question or talk about a particular issue then they were free to do so.

The philosophy underpinning two of the research sites was one of partnership between the staff and the members. This was evident in how the research participants spoke about how they were treated as equals and this was valued. As an outsider, this egalitarian approach was impressive and refreshing given my biomedical enculturation. Being and perceived as an outsider for me I think was beneficial in this instant, as it redressed the power imbalance that may have been problematic given an alternative philosophy. During the interview I attempted to minimise power issues through verbal and non verbal communication and through reducing the power structures within the environment. For example for those interviews that took place in my office, I made sure that I was seated beside the participant and not behind my desk. I also considered what I was wearing during the interviews and made sure that I was dressed casually and not wearing a shirt and tie or a suit. I was keen to show the participants that I was a researcher and not a psychiatric nurse although philosophically this was extremely difficult for me to do.

Data Analysis: Generating the Grounded Theory

Tape Recording and Transcribing the Interview

Glaser (personal communication, 2010) consistently advocates not recording or transcribing the interviews. The rationale for this is that firstly the researcher collects too much data and that secondly the abundance of data obfuscates the central analysis which focuses on the main concern. I was worried that if I didn't record the interviews that perhaps something essential would be missed that would totally destroy the data analysis process. It was reassuring as well to have the recorded interview as well as the transcript as evidence that firstly I actually completed the interview and secondly that I was actually getting somewhere with the data collection and data analysis process. In retrospect, recording the interviews was useful as the transcript obtained allowed me not just to examine the answers the participants provided, but it also allowed me to critically appraise the questions that I asked. Being able to listen to the interview also proved valuable to help my interviewing skills including the tone and volume of my voice. For example, listening to early interviews, I discovered that often I did things like finish the participants' sentences and offer my opinion on certain aspects of the conversation which were beyond my scope and role as a researcher. Even though I made a conscious effort not to do these things, I found that as the interview progressed I then reverted to my old ways.

Listening to the interviews and reading and rereading the transcript helped me to stop this and also to come to terms with long pauses which often peppered the interviews. In terms of analysing the interview, having the transcript gave the illusion that the analysis was easier as I didn't have a blank sheet in front of me, I had a conversation which made writing in vivo codes easier initially. As the interviews progressed, recording the interview was inappropriate on a number of occasions. Either because the participant did not want me to record it or the interview location prevented me from recording the interview. On these occasions I took extensive notes during and immediately after the interview. I was pleased that I could remember a lot of information, and writing only field notes, gave me a different perspective on the nature of qualitative data. On a cognitive level, it appeared that I was somehow able to think in a different way about the direction of the analysis on the data that I had collected. Although this is difficult to explain, I feel that a combination of initially having the transcripts and then not having them was more beneficial to me than not having them at all. The only disadvantage to

this I feel, is that the field notes were primarily based on the emerging theory at that time and that superfluous information may have been unconsciously omitted as it did not add to the theory at that time. It may have been useful at a later date, however as it was not written it was lost. The transcripts had the added advantage of being able to revisit data that was maybe initially viewed as being irrelevant.

Computer Technology

I purchased NVivo a computer package exclusively designed to assist researchers in the management and analysis of qualitative data, specifically grounded theory. However early in the data analysis process I attended my first grounded theory seminar where the overall advice was to refrain from using technology such as this as it forced the data into a linear analysis rather than allowing the researcher to fracture the data and raise it to a conceptual level. Although initially this was difficult for me to understand – the constant talk of conceptualisation and abstraction – it eventually started to make sense. Inputting the data into a computer programme was a futile exercise as it could not compensate for the cognitive abilities that had to be applied to the data. Making sense of the data did not occur sitting at my computer, it occurred following hours and days and even weeks of thinking about the data and applying the rigorous analytic procedures that are advocated by grounded theory methods. I utilised many word documents to analyse the data and I took Glaser and Strauss's (1967) advice to stay close to the data.

Open Coding, Initial Memos and Fracturing the Data

Once the interview was conducted, field notes were written. These tried to capture the feel of the interview and other information that would not be apparent either in the transcript or the audio recording. The recording was listened to a number of times and initial codes were written down. The data was coded using in vivo codes which attempted to conceptualise what was happening in the data. Initially, line by line coding was utilised and this produced a voluminous amount of codes. These codes really didn't progress the analysis and in hindsight it is clear that I didn't really know what I was doing. I tried to complete memos at this stage, but because the analysis was superficial description, there was little depth to the memos and it was very difficult for me to see their relevance. The specific rules that Glaser (1978) outlines were easier said then done. The data was fractured and taken in many different directions. At this point I was influenced by *a-priori* beliefs about the

nature of the participants' experiences and I think that these influenced my initial analysis. For example, because of the high number of readmissions to hospital, I thought that trying to prevent the relapse of the individuals' illness would emerge as the main concern. This was also influenced by the general research area which was related to the participants' experiences of going home from hospital. My initial codes were also very descriptive of the data, rather than looking at the processes that were occurring. As mentioned, I had difficulties trying to raise the analysis from a descriptive to a conceptual level. This difficulty revolved around my comprehension of grounded theory methods and indeed my understanding of what conceptualisation actually required. My analytic abilities were often naïve and akin to my early days as a student psychiatric nurse when I often spent time with service users but had no idea what to say. I tortured the data and had hundreds of codes which meant nothing. I continually became obsessed with leads that I thought were innovative, constantly searching for the core category. However this was to remain elusive at least initially. It was only later after attending one of the grounded theory seminars that I got to grips with coding for incidents rather than line by line coding. This was an important step as it allowed me to code for an event, or description of an event, and this aided the constant comparative process. Once I understood that I was looking at the data and trying to answer the question 'what are the participants doing?' rather than 'what are the participants saying?' that processes and the latent behaviours related to the main concern began to become clearer to me. I must stress here that this process was fuzzy and really quite confusing up until the main concern was clearly articulated. It is difficult to say now which came first as this was not a linear process. Many main concerns and redundant concepts were written and abandoned (although not forgotten) because they did not pattern in subsequent or completed interviews. However they were important as they were part of the analytical process.

Memos also proved an initial hurdle for me and I found that it took a considerable amount of time to reframe my cognitive abilities and to understand the importance that these had in terms of analysing the data and informing and developing the emerging theory. I would often sit at my computer and find that my mind was totally blank and even though I would have spent a considerable amount of time thinking about the data it seemed my thoughts seemed to disappear once I began typing. Glaser (1978) suggests that writing memos and conceptualisation will come easily during the analytic process. However, this was not the case for me and I

seemed to waste a considerable amount of time trying to force the analytic process. As the analysis progressed and I began to utilise the processes of constant comparison the data began to make a little more sense. Although I was reluctant to stick to one line of analysis early, the main concern began to become more and more obvious. Utilising the process of theoretical sampling, the data analysis became more focused and specific. This also had an impact on the data collection process and the entire analysis was conducted through the lens of the main concern. Once the main concern had been articulated the data analysis process became a little easier although there was a continual doubt in my mind that perhaps my line of enquiry was erroneous. However, I was confident that the emerging theory was rooted in the data and that the worries that I had regarding my theorising abilities were nagging doubts that are experienced by even the most ardent researchers. The length of the interviews ranged from 35 minutes up to one hour and forty minutes. Although I felt at the time that the shorter interviews might not be as rich in terms of data, they still provided important information that related to the emerging theory. Interviews that I had felt yielded little new or exciting data often provided interesting ideas or concepts that supported later categories when they were revisited as part of the constant comparison process.

In hindsight, it is clear that my problems with analysis existed through a lack of understanding of grounded theory methodology and my desire to create a grounded theory in a linear, systematic way. This is not possible with grounded theory and requires the researcher to think and act in a fashion that is unusual to traditional research methods. The processes associated with developing a classic grounded theory are abstract and unique to each researcher; consequently a preset formula cannot be followed. Although there are many books and articles written to help the researcher, these are not really rules, rather they are guidelines that can be interpreted differently by different researchers. The key, I think, is the data. Every decision and direction that is taken, the researcher must be able to justify their decisions about future data collection and the concepts that are utilised in the emerging theory as been rooted in the data that they have already. If concepts do not appear consistently in the constant comparative process then they must be looked at cautiously.

When I began writing up the theory, I found that when I revisited a lot of the memos that were written early in the data, I found that they needed to be altered,

developed or rewritten. Although they explained the concept in question, I felt they were not conceptually dense enough or they didn't really make the points that I wanted them to make. In short I felt that they didn't really explain what was going on in the data although in my head, I believed that they did. This again is part of the abstract nature of grounded theory where it is difficult, I think, to put the cognitive processes involved and write what is truly happening on paper. This meant that at the memo sorting phase of the research study when I thought that I should really just have to cut and paste the memos together, it really meant that the theory although sufficiently constructed in my mind was insufficiently articulated on paper. The rewrite of the memos at this stage was hugely helpful not only to make the theory conceptually dense but also to provide a conceptual clarity that was sometimes missing from earlier versions of the theory. Memo sorting was like piecing together a jigsaw puzzle except there are too many pieces and some of the pieces should fit but don't seem to.

Selective Coding, the Main Concern and Identifying the Core Category

According to Glaser (1978) selective coding occurs once the core category has been stated and existing and future data is delimited to that which informs the core category or elaborates it's properties. As mentioned, open coding produced a large number of codes and these codes along with my pre conceived ideas about the nature of the data and the problem obfuscated my ability to see the core category or indeed the participants' main concern. It was only by following the constant comparative procedures and by writing memos that I began to see processes within the data. Selective coding for me I think was a multi layered process in that I had to 'selectively' code from the mass of open codes which ones, I felt were important. Initially, this was very difficult as I had no idea what I was doing or what direction I was going. Attending a grounded theory seminar early in the data analysis process helped me to understand what exactly I was trying to achieve. Even though I had read some of Glaser's many books at that time it was still not that clear to me what the end product of a grounded theory study was. Furthermore the many different approaches taken by other researchers and the multitude of different interpretations of the method did little to assist me in the analytic process.

As mentioned the main concern for me was far more important initially than the core category although I am not attempting to underestimate the core category's

importance. I found it remarkably difficult to come up with a term that had the power to describe conceptually the data I had. At the beginning of the study I searched for the core category as if it were something that was tangible and hidden beneath a stack of crumpled articles on my desk. Early in the process I knew the parameters of the main concern but had difficulties phrasing it. I constantly questioned my abilities as a theorist and was hypercritical of the modicum of talent and intelligence that I possessed. Conceptual explanations of my data seemed impossible to grasp and mantras like 'trust in emergence' did little to nurture the fledgling theory that only barely existed within me and the data. Emergence did not occur like I expected it to. It was not the 'eureka' moment that I had imagined and I was no Archimedes. Emergence for me was more of a 'dawning' experience, the main concern and the core category dawned on me rather than emerged, they dawned on me in a way that I felt that they had been there all the time and I had not given them the analytical attention that maybe they deserved. They dawned because I persevered at the constant comparative analysis and used theoretical sampling to flesh out the concepts that had been written at the start of the analytic process although this had developed over time.

As stated previously, many grounded theory researchers place an overwhelming emphasis on the core category and I attempted to follow suit. The core category caused me a lot of anxiety as I felt that the data collection and analysis phase and my grounded theory would all fall into place once the core category had emerged. However, I seemed to have a lot of difficulty in coming up with one category that conceptually explained the masses of codes that I had. Like everything in grounded theory, perseverance and a lot of time thinking about the data resulted in the eventual emergence of the core category. Even though at this stage I did have the concept in my mind, I still found it difficult to articulate it – that is putting it into words that were meaningful. I toyed with many concepts that I believed were core at the time, however they never seemed to 'fit' or have the 'grab' that Glaser was adamant that the core category should have. I did come up with some interesting concepts but again felt that they were too like some of the concepts that already existed. Eventually the core category that emerged as most appropriate was an ordinary concept that originally was being used as a property of another category, however with the constant comparative process and with memo writing; I felt that it had stronger explanatory powers than originally conceived.

The main concern and the core category in this grounded theory have been given the same name: *'Managing Preconceived Expectations'*. As the main concern it describes the participant's concerns at being treated differently, being labelled as a 'psychiatric patient' and the stereotypical assumptions that are attached to this label. As a core category *'Managing Preconceived Expectations'* describes the processes that the participants use to continually resolve this main concern. Both the main concern and the core category and related categories are discussed in greater detail over the next three chapters.

Theoretical Coding

The grounded theory analytic process creates a number of related categories which are conceptually labelled. Within these categories a number of properties are also articulated – each property explains different aspects of the category it is attached to. Ultimately, each category stems from the core category and explains the ways that the main concern is resolved. Once this is done, the researcher is left with a number of categories and needs to put them together in a particular order which provides a thorough description of the main concern and how the participants resolve it. This is achieved through theoretical coding and according to Glaser, theoretical codes (1978:72) 'weave the fractured story back together again'. In this study the theoretical code is a basic social process as the participants latent behaviours changed over time and were influenced by turning points or what Glaser (1978) describes as critical junctures. Although the beginning and the end of the basic social process were easy to articulate, the other categories were difficult to integrate into the process and required several redrafts before the required fit was achieved. This was completed though the use of mind maps which in this case were handwritten diagrams that continually changed until an emergent fit was reached. McCallion (2008: personal communication) states that in order to achieve an emergent fit, researchers need to think critically about the processes that have emerged as well as being playful and inventive with the data. Even though a basic social process was easily apparent, getting the important categories to congruently flow and identifying the connections was difficult and time consuming.

Theoretical Saturation

As mentioned a total of 35 interviews were completed with 31 participants. Saturation occurred on a continuum and was achieved for different categories at different times. I was reluctant to stop interviewing and in hindsight, data

collection could have ceased a little earlier. On the other hand a number of participants had volunteered to be interviewed and I felt that it would be unethical not to complete them. Although the latter interviews did not introduce any new categories or properties, they gave me a sense of satisfaction and reassurance that the processes I was writing about were being continually repeated. Given the nature of this study and the diversity of people that use the psychiatric services in Ireland, it is likely that at some point, had I continued interviewing, that new information might have emerged. However, I had to put this into a context where there was limited time and resources to continually interview and analyse data based on a possibility of generating new categories. The decision to stop interviewing at that particular point was also discussed with my supervisors.

Ethical Considerations

Ethical Approval

The Irish Council for Bioethics (2004) states that all research involving human participants requires ethical review and approval by a research ethics committee. This study was underpinned by the ethical principles of beneficence, non-maleficience, fidelity, justice, confidentiality and veracity as described by Keogh and Daly (2009) and has undergone rigorous ethical review. It has been presented to the Trinity College, Faculty of Health Sciences' Research Ethics Committee where it was granted approval in April 2006. It has also been approved by the research ethics committee at one of the hospitals involved at the request of the management team governing the area where some of the participants where recruited. Although this was not anticipated by the researcher in the design of the study, ethical approval became a dynamic entity that constantly required amendment and subsequent re-approval from the relevant committees. This occurred in response to problems with recruitment which will be discussed later in this section.

In designing the methodology, I gave considerable time to the potential ethical issues that may arise from undertaking this study. The participants in this study could be considered a vulnerable group. It is generally accepted that vulnerable groups, are made up of people with mental or emotional problems or people with cognitive impairment, among others. Moore and Miller (1999:1034) describe a vulnerable person as:

> 'An individual who is diagnosed with an illness and due to that illness lacks the ability to maintain autonomy, personal independence and self determination'.

Consequently, these people are open to exploitation if the illness impacts on their ability to make an informed decision about understanding and participating in the proposed research (Tee & Lathlean, 2004). Although I accept that some individuals with mental health problems may be described as vulnerable in the research participant sense, it is my experience as a psychiatric nurse that most individuals' 'illness' does not interfere with their ability to make decisions or to understand the consequences of their participation in research (this generalisation does not extend to people with a cognitive impairment such as one of the dementias). This notion of vulnerability, for me, was problematic as it somehow perpetuated the belief that all people with mental health problems continually need paternalistic care and protection throughout their lives. This, for me, created a tension between the philosophy underpinning the study and what were, in my opinion, unreasonable and overtly stringent ethical sanctions. For example, I was required to get permission from all the potential participants' consultant psychiatrists to allow community mental health nurses to approach 'their patients' with information about the study. This was despite the fact that all of the individuals were living independently in the community. Furthermore, it also meant that the access and recruitment of participants was restrictive as it necessitated the use of gatekeepers attached to particular voluntary and mental health services. Subsequently those individuals not attached to these organisations may have missed the opportunity to participate and share their experiences. These paternalistic practices with regards to ethics and the involvement of mental health service users in research are, I believe, reflective of a mental health service that is grappling with emerging changes at a philosophical level where research of this nature is relatively new. This results in a heightened caution when reviewing ethical applications that involve research with mental health service users. Ensuring that this research was completed was, for me, paramount despite the obvious constraints on recruitment and access procedures. Advice received from Professor Barker (2007: Personal communication) was to set aside these issues for the time being and to complete this study. Completion of this study would allow me to challenge these anomalies during future research.

Davies (2005) suggests that the key to achieving ethical approval is to be transparent about the research process and to ensure that the ethics committee are satisfied that the participants have enough information to decide if they wish to participate or not. In developing this research proposal, three main ethical principles arose in line with the guidance provided by the Irish Council for Bioethics (2004). These are discussed the following sections.

Informed Consent

Informed consent implies that the participant fully understands the information they are given about the study and the implication of participation (Polit et al. 2001). Wallace (1995) describes three elements of informed consent; it must be voluntary, it must be specific and it must come from a competent person. These elements underpinned the informed consent process in this study. The Irish Council for Bioethics (2004) state that people's beliefs and opinions must be respected and they must be allowed to make the decision for themselves that they want to be involved in any piece of research. In order to achieve this, all potential research potentials were given all the information about the study including the benefits and the possible risks. Careful consideration was given to this information to ensure that it could be read and understood by a variety of people from a variety of backgrounds. I developed a research brochure which contained a letter of invitation (appendix 2), an information sheet and an additional sheet which summarised the main points (appendix 3). An additional 'statement of interest sheet' (appendix 4) was also enclosed and participants were required to return this form in the stamped addressed envelope provided, if they wanted to hear more about the research. The information brochure became something that evolved in response to recruitment problems which began to emerge early in the project. These will be discussed later in this chapter. My contact details were also provided in case any of the potential participants wished to contact me. The participants had at least seven days to decide if they wished to participate or not. Davies (2005) suggests that mental health service users can sometimes be unable to provide informed consent because their mental ability may be impaired. It was envisioned from the onset that the potential participants for this research would be well enough to participate because of the fact that they are living in the community, however, through the use of a gatekeeper and inclusion and exclusion criteria, only potential participants who were capable of providing informed consent were approached about the research. Davies (2005) suggests that the potential

participant's community mental health nurse is in the best position to assess the individual's capacity to understand the purpose, benefits and risks of the research. Informed consent was not seen as a static concept; rather it was seen as a dynamic process that was adhered to rigorously. Informed consent was sought at every stage of the data collection process. The voluntary nature of participating in the study was also highlighted on the information sheet and verbally to the potential participants at the beginning of the data collection process. Participants who decided to withdraw from the study were free to do so without any penalty.

Despite the attention given to ensuring that the participants were capable of providing informed consent, it was not something that was problematic in this study. Furthermore there was never a time when I felt that the participants completed the research because of a perceived power imbalance between them and me. It is worth mentioning that potential participants who did not want to participate for whatever reason voiced this opinion articulately and without ambiguity. This is contrary to the generally held belief that vulnerable groups are somehow open to coercion and exploitation. Other strategies that were used to ensure participant comprehension were providing enough time for them to read the information brochure and being available to answer any queries should the arise.

Confidentiality

A guarantee of confidentiality means that researchers will not disclose any information that the participants provide to other parties not involved in the research study (Polit et al., 2001). The very nature of qualitative research prevents researchers from guaranteeing anonymity (Streubert & Carpenter, 2003). Several strategies were adopted to assure that the principle of confidentiality was upheld. A code was assigned to all participants' identities (appendix 1). In the final report participants' names were not used and there is no way of linking individual identities to the data generated from the research. During the research, the CMHNs and other healthcare and allied workers acted as gatekeepers to the research sample. Although these people knew which service users were given information brochures about the research and in some cases were aware of who took part in the research, they had no way of knowing what the potential participants actually said during the interviews. Although this seemed like an

ethical issue, the participants themselves had no problems with this arrangement and were happy to share their experiences with me. I also omitted any names or locations mentioned by the interviewees. When accessing the participants in one location, the management team informed the researcher that I should inform the consultant psychiatrist if any of their particular patients participated in the planned research. This instruction provoked considerable thought and again, reminded me of the need to maintain the participants' independence and their autonomy. This paternalistic view of the participants meant that the locus of the control for them remained with the mental health services negating the philosophy of empowerment underpinning the research study. However, even though the potential participants are living in the community, they still remain under the general care of the consultant psychiatrist and the responsibly for their welfare lies with them. Although they were an additional person in the confidentiality loop, they would know what participants took part but not what was said during the interviews. Consequently it was decided to abide by the decision of the management team to inform the consultant psychiatrist of the participants' decision to be interviewed as part of the research. This information was included on the information sheet for those particular participants and participants who do not wish for their psychiatrist to know about their involvement were excluded from the research (this did not deter anyone from taking part).

Protecting Participants' from Harm

Although participating in research that involves talking about personal experiences may have the ability to be empowering and cathartic (Hutchinson et al., 1994), qualitative research may sometimes contain an inherent potential to be mentally and emotionally distressing for the participants. Protection of the research participants I think was the most important aspect in terms of allowing me to conduct this study, certainly from a research ethics committee perspective. As mentioned earlier, there is a strong belief that people with mental health problems remain vulnerable regardless of their position on the mental health/distress continuum. This was voiced by some of the participants who suggested that there was a sometimes a general negative perception that people with mental health problems are not able to recover from a diagnosis such as schizophrenia. Although I was cognisant of this ethical issue throughout the design of the project, I don't think that I gave it enough consideration in terms of its impact on me as a researcher while conducting the study. In the design of the study, the use of a

gatekeeper and stringent inclusion/exclusion criteria guaranteed that people who may become upset by discussing their experiences were excluded from the research. Secondly, participants were requested to allow me to contact a nominated mental health professional if I felt that the interview process had a detrimental effect on the individual's mental health. A subsequent revision of ethical procedures by the ethics committee insisted that if potential participants did not give me permission to contact the nominated mental health professional then they were to be excluded in this instance. This I believed impacted negatively on the potential participants' autonomy and perpetuated the social stereotype that they were dependent and unable to recover. Fortunately, this issue did not arise during the research process. Potential participants were also advised not to participate in the research if they felt that it may have a detrimental effect on their mental state or if they thought it may cause them unnecessary upset or distress. This information was explicit in the participant information sheet and was also be reiterated verbally at the beginning of the interview.

Although one of the participants became upset and started crying during the interview, this was managed by stopping the interview and providing some time for the individual in question to further talk about her feelings. The interview was only continued after the participant and I were satisfied that continuing the interview would not cause any further emotional distress. At the end of the interview some time was allowed in order for the individual to firstly ask me any questions and secondly to ensure that the individual would not be preoccupied with the content of the interview on their departure. Generally, participants were happy to share their experiences with me and there were no negative consequences. Sometimes I worried unnecessarily about the participants although I had no real reason for doing so. This happened especially if the individual had a history of suicide attempts or self harm. I sometimes overanalysed my interactions with the participants' during the interview and conducted an internal dialogue about how I had upset them and the verbal and non verbal cues that demonstrated this. To reassure myself that the participant was alright, I phoned them on their mobile phone (if they had one) to make sure that they were alright. This only happened twice.

Moyle (2002) found the interviews she completed left her feeling psychologically drained and having an experienced research mentor or supervisor assisted her in

managing the difficult emotions that often arose. Most of my anxiety emerged from recruiting and accessing the research participants and when conducting the interviews revolved around reassuring myself that the participants' were OK following interview as described above. Mostly I found the interviews a very interesting experience even though I was on a steep learning curve. I enjoyed meeting the participants' and listening to their stories although sometimes they were very sad. I don't think I had ever given a lot of time or thought to the importance of communicating with the people who use the services even though I used to do it on a daily basis. It reminded me of how easy it is to become complacent and how important it is to listen to people and to listen to their experiences. It made this whole notion of 'recovery' and 'service user involvement' meaningful to me. It changed the way I thought about the people who use the services and this is reflected now not only in this study but also in my teaching. Even though I completed three years psychiatric nurse training, a number of years clinical practice in a range of settings and a plethora of post registration education, it is this experience that has had the most impact on me in terms of reflecting on and altering my attitude towards the people I have directly or indirectly cared for practically all my adult life. I am not saying that I had a negative attitude towards people who use the mental health services, However, I did unconsciously harbour some of the preconceived ideas that were of concern to the participants in this study.

Once interviews were recorded and a transcript made, the Ethics Committee insisted that the transcript should be returned to the individual if they wished to view it. This information was recorded in the information brochure as well as being reiterated verbally at the beginning of each interview. A high number of individuals requested that I return the transcript to them when it was ready. Although, I had not thought this would be a problem, I was anxious that maybe on seeing their conversation in black and white, that the participants may become upset even though they were not upset initially. It was difficult for me to hand deliver the transcript and even when I did, I could not expect the participant to sit there and read it (the transcripts were at least 20 pages of text) while I waited. This process did cause me some anxiety as I did not want to create a situation that created disharmony with the underlying ethical principles of the research. Although I was probably overreacting, and participant upset was a relatively rare occurrence, I did worry about it. I was tempted to 'play down' this aspect to the ethical guidance

although I never did. Everyone who requested the transcript received the transcript back although the speed of the reply was based on the speed of the transcription company. The transcripts were transcribed by a transcription company used by the School of Nursing and Midwifery and are very familiar with dealing and managing data of a sensitive nature.

Summary and Conclusion of Chapter Five

This chapter described in detail how I put classic grounded theory methodology into practice. The generation of a grounded theory using qualitative data required me to embark on a steep learning curve that impacted on every aspect of the research study. Furthermore it necessitated a cognitive shift which challenged the way that I traditionally completed research in the past. The culmination of these processes was the emergence of a grounded theory that articulates the participants' responses to their main concern when they were discharged from hospital. This process used by the participants is called *'Managing Preconceived Expectations'* and is described in detail over the next three chapters.

CHAPTER SIX: MANAGING PRECONCEIVED EXPECTATIONS

Introduction

The purpose of this introductory section is to briefly outline the structure of this and the next two chapters which present the emergent theory in detail. This theory entitled *'Managing Preconceived Expectations'* describes how the participants in this study responded to the negative assumptions that other individuals had about them following their discharge from a psychiatric hospital. The theory comprises seven categories, most of which contain a number of related subcategories and properties. The categories, sub categories and their properties describe different ways that the participants managed their concerns around the negative assumptions that other people have about them as individuals with a mental health problem. This chapter also presents the first three categories – *'Absorbing Preconceived Expectations'*, *'Acquiring Preconceived Expectations'* and *'Validating Preconceived Expectations'*.

For ease of navigation, the chapter will begin with an overview of the *'Managing Preconceived Expectations'* theory. In addition it will describe the theory as a basic social process. The remainder of this chapter and the following chapters (chapters 7 and 8) will describe the categories associated with the *'Managing Preconceived Expectations'* process. The categories presented here are supported with quotations from the interview transcripts. Information that might expose the participants' identities has been removed. The interview number represents the code that was assigned to the participant. An overview of the categories, sub-categories and their properties is contained in appendix six.

Managing Preconceived Expectations: The Participants' Main Concern and the Core Category

This theory *'Managing Preconceived Expectations'* is what Glaser and Strauss (1967) and Glaser (1978) describe as a Basic Social Process (BSP). This means that the participants begin and end at different points, although not all participants completed the entire process. As mentioned, this theory contains seven categories:

1. *'Absorbing Preconceived Expectations'*,
2. *'Acquiring Preconceived Expectations'*,
3. *'Validating Preconceived Expectations,*.
4. *'Maintaining Preconceived Expectations'*,
5. *'Avoiding Preconceived Expectations'*,

6. *'Reassessing Preconceived Expectations'*,
7. *'Defying Preconceived Expectations'*.

A diagrammatic view of the categories and their relationship to each other is presented in figure 6.1.

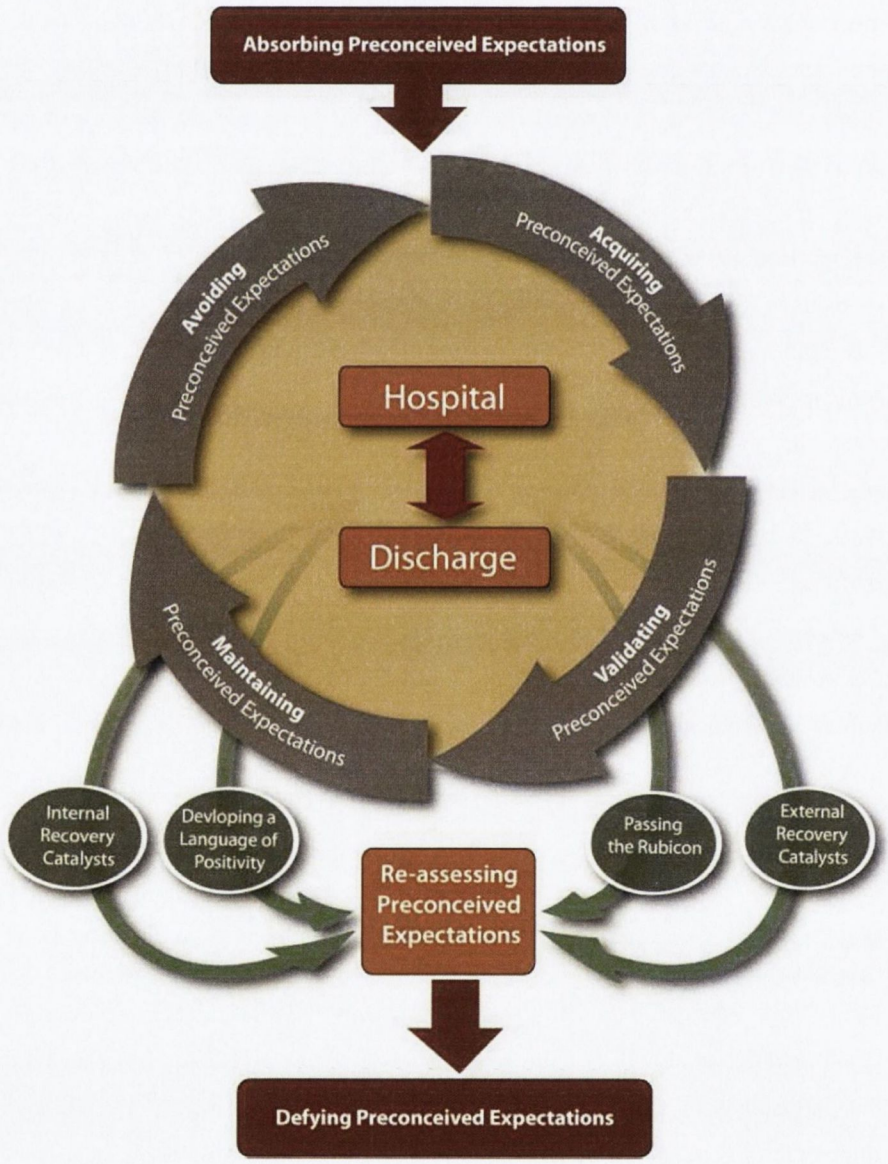


Figure 6.1: Managing Preconceived Expectations

The participants in this study were aware that mental distress and psychiatric hospitalisation were associated with a number of negative assumptions. They were aware that people who use the psychiatric services are labelled and that this label

carries many negative expectations about the nature of the individual and the nature of mental distress. The participants' experience of the mental health services and being labelled 'mentally ill' became for them and others, a master status which impacted negatively on all aspects of their lives. This theory therefore is about how the participants' in this study managed their own, as well as their social audiences', preconceived expectations about them once they came into contact with the mental health services. The theory is complex and multidimensional and emerged in response to a multitude of perceived and real experiences that impacted on the individuals' perception of themselves.

The core category '*Managing Preconceived Expectations*' is the name that I have given to the process that explains the participants' responses to their perceived and actual 'devalued' status following discharge from hospital. Glaser (1978) suggests that the generation of a grounded theory emerges around a core category. This core category describes most of the variation in the pattern of behaviour under scrutiny. Without this core category, Glaser (1978:93) argues that any attempt to develop a grounded theory will 'drift in relevancy and workability'. '*Managing Preconceived Expectations*' was chosen as a core category because it emerged as central, it reoccurred frequently and it related easily and meaningfully with the other categories identified. It was also perceived by me, to have strong explanatory power and grab, variables which Glaser (1978) suggests are important to the generation of grounded theory. In the analytic procedures used throughout this study, many other categories were chosen and rejected as core categories. Each of the related sub categories spent some time as core categories but were rejected after time because of their lack of explanatory power although they remained central to the process that explained the participants behaviours. For example, one of the concepts '*Defying Preconceived Expectations*' was originally thought to be core. However after much consideration, it was felt to lack explanatory power in accounting for most of the variation in the data, relating mainly to one of the processes rather than all of them. For that reason it lost its status as core and eventually was relegated to one of the other sub-categories, although it remained important.

'*Managing Preconceived Expectations*' meets the criteria set by Glaser (1978) of a basic social process in that it contains two or more emergent stages, was something that occurred over time and the stages could be broken into

distinguishable units with their own individual and unique concepts and properties. The stages, I believe are in part latent in that they are not readily perceived by the participants and have been defined by me for ease of description. Other conceptual codes contained in the process are as Glaser (1978) calls in vivo and are clearly perceived and described by the research participants. The process of *'Managing Preconceived Expectations'* as described here and in the following chapters has a beginning and an end, however as mentioned only some of the participants move through the entire process. In this sense the *'Managing Preconceived Expectation'* describes the participant's trajectory along a particular continuum.

The participants do not appear to move back and forward within this process unlike other process theories where the fluidity of movement back and forth between stages is emphasised (for example Kubler-Ross's (1969) Stages of Grief Theory). The process described here has three stages and each of the categories listed earlier are associated with a particular stage. The issue of time and the temporal nature of the process of *'Managing Preconceived Expectations'* was individual and not related to a set time frame. Glaser (1978) suggests that the movement from one stage to the next is contingent on events that occur at a particular time and refers to these as 'critical junctures'. There are a number of critical junctures in the *'Managing Preconceived Expectations'* process. The participants' admission to hospital and their subsequent discharge is the first critical juncture and moves the participants' from stage 1 to stage 2. The movement from stage 2 to stage 3 is contingent on the participants making an irrevocable decision to view their life and experiences in a more positive way, which I have called *'Passing the Rubicon'*. Furthermore the move from stage 2 to stage 3 is also heavily influenced by the use of *'recovery catalysts'* as well as the participants *'developing a language of positivity'*. These critical junctures will be discussed in greater detail in line with their relevance to a particular category.

Absorbing Preconceived Expectations

'Absorbing Preconceived Expectations' (figure 6.2 highlighted in red), the first category in this grounded theory, describes the participants' views and perceptions of the nature of mental distress prior to their admission to hospital. The word 'absorb' is used here to reflect how these perceptions were taken in and memorised unconsciously from various sources such as the media and through normal daily discourses. These unconscious memories were then activated or

switched on once the participants came into contact with the mental health services. Many of the participants suggested that they had little knowledge or previous contact with mental distress or the mental health services. Therefore, it was likely that these perceptions emerged from the participants' contact with their social world as they were growing up.

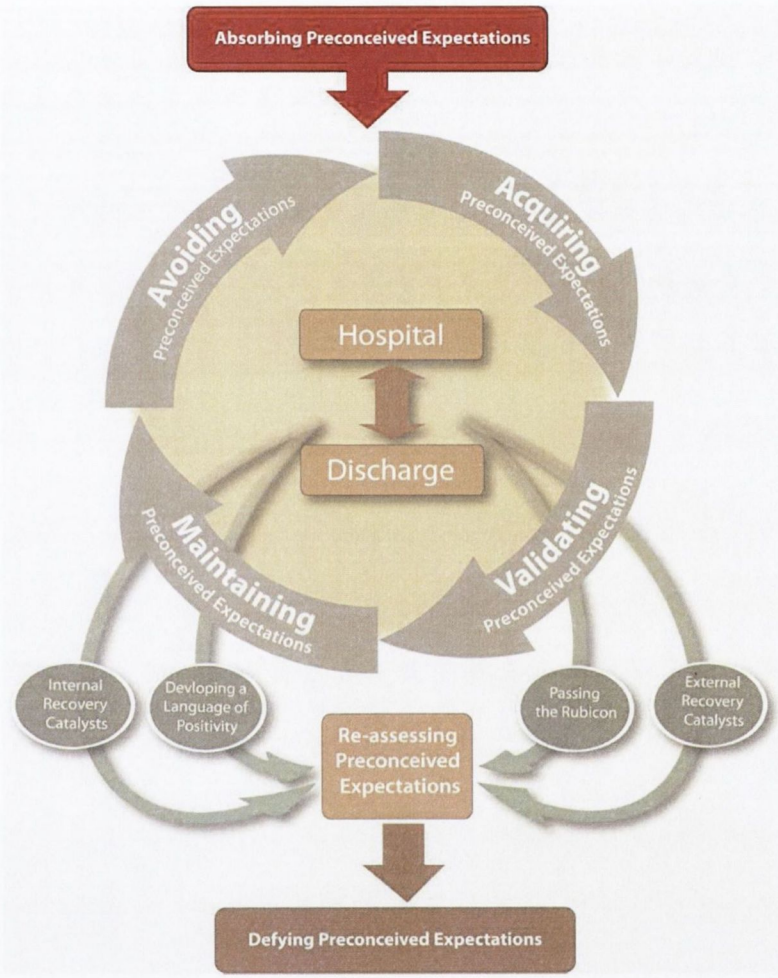


Figure 6.2: Absorbing Preconceived Expectations

Prior to their contact with the mental health services the participants' perceived mental distress in three ways (figure 6.3): something that was poorly understood; something to be feared, and something to be ashamed of.

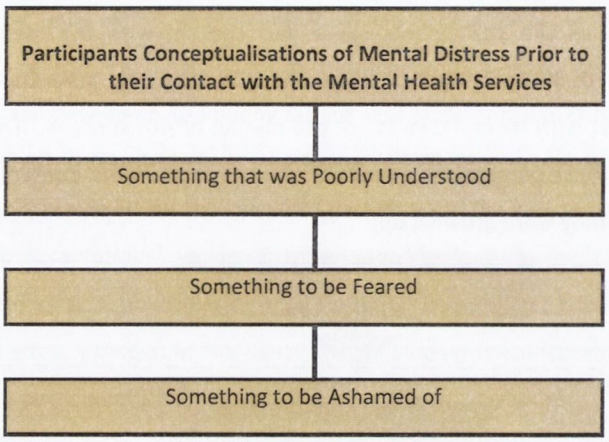


Figure 6.3: Overview of Participants conceptualisations of mental distress

1. Mental Distress: Something that was Poorly Understood

The participants in this study had little or no contact with the mental health services or with the people who use them prior to their admission to hospital. Consequently, for some of the participants mental distress and 'mental illness' were concepts that were totally unfamiliar to them. Their knowledge of mental health and mental distress was vague and mainly gleaned from media sources such as television:

> 'Never heard of a psychiatric hospital in my life. Never heard of a psychiatric doctor. Psychiatrists was something I seen on the telly. Never had any information of any of this at all' (Female, Interview 30).
>
> 'Yeah before I got sick I had no understanding at all' (Male, Interview 16).

The participant below suggests that not only had she never heard of 'mental illness', she didn't realise that there were different types of mental health problems:

> 'I didn't really know what it was. Never, never heard of it. Well I didn't even know that there was illnesses in categories if you know what I mean. Illness and that was it. And I suppose I was happy to think that way' (Female, Interview 24).

This lack of knowledge about mental health and mental distress also suggested a lack of open constructive and positive discussion about mental distress.

2. Mental Hospitals and People with Mental Health Distress: Something to be Feared

Mental hospitals and by association the people who experienced mental health problems were perceived as something to be feared. This fear stemmed from the participants lack of knowledge and understanding of the nature of mental distress and mental health care. Furthermore the media's interpretation of psychiatric hospitals as places of custody which housed violent and unpredictable people fuelled their fears. Although this is understandable given the poor images of psychiatric hospitals generally, there was no evidence to suggest that the participants based their fears on actual events within their own lives, but on myths, local folklore, and media images. This local folklore was intertwined with everyday conversation as people were growing up and attending school:

> 'now [names hospital], when you're in school, like in primary school and community school, the whole thing if a kid was slagging you he'd say ah yeah, go back to [names hospital], or your Ma's in [names hospital], your Ma's a [names hospital] case, because the old [names hospital] was where everyone went' (Male, Interview 16).

Hospitals were perceived in a somewhat mysterious way. Depending on where the person grew up, the name of the local psychiatric hospital was often attached to significant negative images associated with having a mental health problem. One participant described growing up in the vicinity of an urban psychiatric hospital and being afraid to go into the hospital grounds to retrieve her ball in case 'they' kept her in there and would not release her. Some hospitals appeared to be more stigmatised than others. One hospital's reputation was considered notorious despite the fact that the participants had little or no experience of what occurred within the confines of the buildings, even though, it was suggested, that people were well treated there:

> 'I think the biggest fear I ever had when I got sick first was being sent to [names hospital]. I'd an awful fear of that place and I didn't even know it but seemingly it was the whole front outside, it wasn't inside, it was the whole front outside, people were petrified but a lot of people I know got good treatment in there' (Male, Interview 5).

Psychiatric hospitals were perceived as being *'full of loopies and headers'* (Female, interview 23). This perception fuelled beliefs that people with mental health problems were dangerous, unpredictable, irresponsible and in some cases lacking an awareness of the impact of their actions:

> 'Yeah, that would have been a big slagging for someone growing up was go off to [names psychiatric hospital] as in you're mad if someone

> said that stigmatised kind of labelled persons. And that bothered, that kind of made me shy away from telling people and wanted to interact and bumping into people and stuff like that' (Male, Interview 15).
>
> 'If you were going into [names hospital] you'd be going in for a bit of treatment or maybe a lot of treatment. That would mean psychiatric treatment; it's a psychiatric hospital only' (Female, Interview 24).

Furthermore, the use of words like *'hospital'* and *'treatment'* suggested that the participants had aligned mental distress with a medical discourse prior to their contact with the mental health services.

3. Mental Distress: Something to be Ashamed of

The participants' perception of mental distress as something to be ashamed of was not evident until they spoke about their own personal experiences, in particular their admission to hospital. When the participants came into contact with the mental health services they articulated their experiences in a highly negative way where they had let themselves and their families down. The use of the words *'let people down'* in the interviews suggested that participants viewed mental distress as something people had some control over, and consequently if they experienced mental health problems they were in some way to blame. The following two excerpts highlight the use of the word 'let' and emphasise the blame that the individuals place on themselves as well as the perceived 'voluntary' nature of having a mental health problem and their subsequent hospitalisation:

> 'Because I let myself go, I let myself down, but you know, I kind of realize it now when you're ill it does happen, unfortunately, and you shouldn't be made feel guilty' (Male, Interview 3).
>
> 'Just behaviour problems, you know I let myself go after I, after I was dismissed out of my job in X, you know I just, just lost the, took my eye off the ball as regards reality' (Male, Interview 22).

Summary of Absorbing Preconceived Expectations

Prior to the participant's admission to hospital, they had a perception of mental distress as something that was poorly understood, something that was feared and something that they would be ashamed of. To a lesser extent the participants' related mental distress with physical illness through their use of a medical discourse. In the absence of firsthand knowledge about mental distress or direct

contact with people with mental health problems, it was likely that the participants' gained this knowledge from the media, or through the discourses they heard about mental distress as they were growing up. The participants' ability to conceptualise mental distress despite the lack of empirical knowledge supports the standpoint that beliefs, about mental distress were unconsciously memorised as they were growing up. These beliefs were then reactivated once the participants came into contact with the mental health services (Turner, 1982).

Acquiring Preconceived Expectations

'Acquiring Preconceived Expectation' is the second category in this theory and it describes how the participant's acquired new and additional negative beliefs about mental distress when they were admitted to hospital. It also describes how these beliefs were validated through their experiences when they were discharged home. In addition, an overview of the participant's experiences in hospital is provided. This category is divided into four sub-categories: *'Being admitted to hospital: The Psychiatric Hospital as a Place of Security and Safety'*, *'Mental Distress: Indoctrination into the Medical Model'*, *'Receiving a diagnosis: An absence of hope for the future'* and *'Mental Distress: Something to Remain Undisclosed'*. *'Acquiring Preconceived Expectations'* relationship with the other categories is shown in figure 6.4.

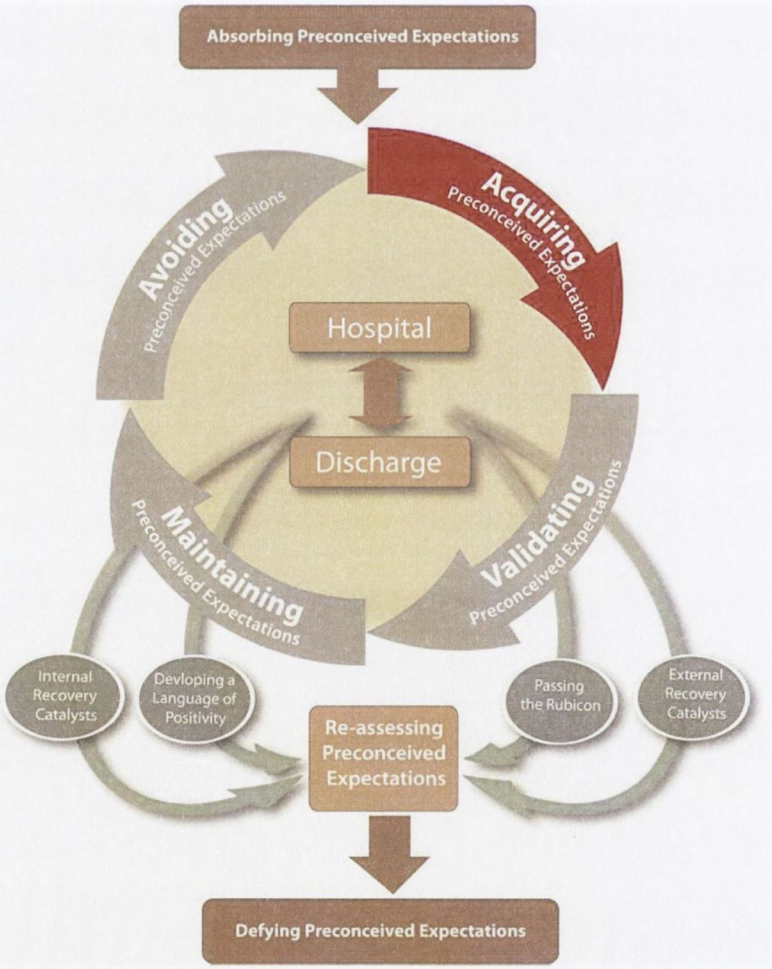


Figure 6.4: Acquiring Preconceived Expectations

1. Being admitted to hospital: The Psychiatric Hospital as a Place of Security and Safety.

This sub - category describes the participants' initial experiences when they were first admitted to hospital. When they were admitted to hospital, they acquired a range of additional perceptions of mental distress. These perceptions built on the conceptualisations that they already had and produced a more concrete mental representation of the stereotypes that were applied to them.

The participants' were petrified about going into hospital, for the first time, as many did not know what to expect. This fear stemmed from their uncertainty about what would happen to them while in hospital. Many of the participants did not believe that they needed to be hospitalised. This was possibly related to their conceptualisation of what it was like to have a "mental illness" conflicting with how they were thinking and feeling. Many of the participants had preconceived ideas about the nature of psychiatric hospitals which influenced their reaction to the suggestion that they should go into hospital for treatment:

> 'Yeah, it was the male ward at the time. And I didn't know what I was coming into. Petrified would be the word' (Male, Interview 5).
>
> 'I didn't want to go in there, I was afraid to go in there. Because I never had any experience of a mental hospital. And I just didn't know what was ahead of me' (Female, Interview 24).
>
> 'It was kind of scary because like I knew like that it was like a mental hospital that I was in like and I had kind of preconceptions about like what, you know other people might be, you know ah this one is mad or you know, kind of like I had kind of had a stigma about it. I suppose the first time that I got unwell it was kind of scary because I didn't really know what kind of to expect I suppose' (Male, Interview 20).
>
> 'Well it's like the standard reaction when people are in hospital the first time, "I don't belong here, what am I doing here, why are you keeping me here' (Male, Interview 11).

Although most of the participants went into hospital voluntarily, their admission was always precipitated by either a doctor or a family member suggesting that hospitalisation was necessary, as they often appeared unable to recognise this necessity themselves. There was a sense, from the participants, that if they did not comply and enter hospital voluntarily they would be admitted involuntarily. Signing themselves in voluntarily appeared to help the participants to retain their autonomy and suggested to themselves that they remained in control of their fate. However this autonomy was a façade as there appeared to be little choice for some when it came to being admitted. There was also a sense that when the participants

signed themselves into hospital they felt that they were not that 'bad a case' – a kind of well 'at least I wasn't signed in', a rationalisation that they weren't that bad after all. This is highlighted in the following quotation:

> 'And anyway he called [the general practitioner] me and he said you know [name] will you go into hospital for a little bit of treatment and I said I'm not mad, you know. And he said, oh gosh its nothing to do with being mad, you know, its to do with just a little bit of treatment. So I wasn't having it anyway. And then my family came up from [names location] that's where I come from originally and between the doctor and my family and they all trying to tell me what to do I gave in, in the end. So nobody had to sign me in. I actually went of my own accord but I didn't want to' (Female, Interview 24).

Despite an initial reluctance to go into hospital, most of the participants welcomed the security and safety that their admission to hospital gave them. The security and safety that the hospital provided was interpreted as protection from the stresses and strains of the world outside the hospital:

> 'I didn't mind, I have to say what you call it right, I did like it, I felt safe and I knew that I couldn't take a drink' (Female, Interview 1).

> 'No, no, and when they locked the doors I really thought they were keeping people out, it didn't occur to me that they were keeping me in at all' (Female, Interview 30).

However from the moment of arrival on the ward the role of staff as guardians or custodians of the participants was evident. The participants spoke about having their day clothes removed and having to wear their pyjamas (sometimes referred to bed rest). This not only reinforced the medical model of distress as illness and the belief that they were sick, but also subtly reinforced the belief that they were somehow unpredictable and might leave the hospital without permission. This occurred despite the fact that most of the participants were voluntary patients. Furthermore, the removal of sharp objects and items like belts and shoelaces reinforced the idea that people with mental health problems are something to be feared, in this case it was a fear that they might harm themselves. The participants generally accepted these procedures once they were admitted, possibly because they did not know what to expect and accepted this as the way things were done:

> 'When you first come in you weren't allowed out because they remove all your clothes so you just have to walk around the ward and I'd have to say you're like a zombie going around because you can't break away from the hospital to go in the

> outside world and take the first air outside. That was horrible, that was horrible, but they had to do for a reason, you know it, you know' (Female, Interview 6).

The sense of security that the participants experienced was intensified by the routine nature of hospital life with it various rules and regulations that dictated what they could and could not do, from the time they got up until they went to bed. In addition, long periods of time spent either asleep or watching television augmented this feeling of security.

The perception of people with mental health problems as unpredictable and requiring constant supervision was further perpetuated by other practices that occurred in hospital such as having to get permission to leave the ward or to enter the kitchen to make tea. Furthermore being supervised (mostly from a distance) during self care activities live shaving or having a shower further reinforced the idea that they were unpredictable or required constant supervision. There were also instances which created the belief that people with mental health problems no longer had control of their lives. A rather extreme example of the control exercised by one member of staff is presented in the following quotation:

> 'I wrote a letter to the consultant, the doctor in [names hospital] at the time and I asked him, actually I said I wanted to sign myself out and go home and I wanted to go out and find work. Obviously I wouldn't have been able for work of any kind but anyway at the time. And I remember I gave it to a nurse and she made me rip it up. No harm for her to give it to the doctor and just for the doctor to say look you know you're not going to be ready for that for a while you know' (Female, Interview 26).

For most of the participants, their admission to hospital was seen as a turning point in the management of their mental health problems which had often been ongoing for a number of months or even years prior to the admission. Their hopes for a resolution to their problems were put in the hands of the mental health professionals that they encountered. The paternalism of the staff was also evident in the interactions between the staff and the participants. This is evident in the following quotation:

> 'and the nurse called in the next morning with the consultant, lovely person, super she was and she had a good registrar and she said if you do what I tell you you'll be fine' (Male, Interview 5).

As the time in hospital progressed the participants became socialised into the ways of the hospital environment and the routine. Some of the participants found the security of hospital helpful. Ironically this security created an apprehension about being discharged, even though they desired to go home. Although some of the participants found the restricted environment disconcerting, they still perceived that they needed to be in hospital and that part of hospitalisation entailed observation. The routine nature of hospital life is described by one participant in the first quotation below. The second quotation demonstrates his belief in the need to be observed during his hospitalisation:

> 'Yeah, you get up in the morning at around half-eight and your breakfast is at nine and then from, after nine o'clock then if you want to go to Mass, Mass is at ten. You have a tea break then, there's tea at half-ten and then the lunch is at half-twelve and then from one o'clock to five o'clock it was boring, boring, boring because all you're doing was sleep, sleep and more sleep, so much so you weren't able to sleep then at night' (Female, Interview 6).

> 'I mean I was fed in the morning, noon and night, at least someone was keeping an eye on me, that [being observed] gave me that was one of the reasons, one of the reasons I went into hospital' (Male, Interview 3).

Some of the participants spoke about getting used to hospital in a negative way as in becoming dependent on the hospital. There was also a suggestion by some that being in a psychiatric hospital was not a normal part of ones reality and that the desire should always be to remain out of hospital:

> 'you can just get used to it, you know. That's time when you pull out, when you pull out then, you go like, you know, when you're getting dependent on it too much, that's when I leave in any way because I can feel it then, you know get too used to it, yeah. I don't know, I don't know, you probably be dependent on it too much, you know. Life is not to live in hospital, life is to live in reality, you know' (Male, Interview 4).

> 'I was going home and after the first instance she [his consultant psychiatrist] said she'd let me out for a half day on the Sunday afternoon and I could come back, and I got to the gate down there at twelve o'clock and I wanted to turn around and come back, and it dawned on me then, that it had to be something to do with the safe environment and the thing I realized at the time that when you come in here they take your life in their hands and they do everything'(Male, Interview 7).

Even though the concept of institutionalisation in relation to psychiatric hospitals is considered by some to be a thing of the past, the participants' in this study spoke about the ease at which one can become institutionalised. Although institutionalisation has a number of interrelated features (Goffman, 1961), the participants mainly considered institutionalisation to be a form of dependency on the hospital coupled with a fear of returning to the community rather than as the result of an oppressive regime where dependency and subservience are encouraged:

> 'See a thing I learned in the early years it's very easy to become institutionalised' (Male, Interview 7)

Subsequent admissions were easier to tolerate as the participants knew what to expect and previous admissions had dispelled some of their fears associated with psychiatric hospitals. Even though the security of the hospital was sometimes associated with passivity and powerlessness, this was not the way it was interpreted by the participants. Arguably the participants' social construction of mental distress perpetuated the ease at which they accepted and socialised to the hospital environment. However, hospitalisation was not perceived by all in a negative fashion. Similar to a general hospital, the participants believed that the role of the psychiatric hospital to look after them, which further aligned mental health problems with physical illness:

> 'Yeah I was delighted to go back because sometimes, you get used to being looked after, yeah and I knew the what do you call it, I wasn't strange going in this time, I knew the nurses' (Female, Interview 1).

For some of the participants repeated admissions increased their dependency on the hospital. The prospect of long term care was easier than living independently had it been given to them as an option. However, this viewpoint altered over time:

> 'It would bother me now if I had to go back into hospital and that's what I'm aiming for at all times, to stay out of hospital. That's my aim. That would be my goal yeah, yeah. Even though at one stage in [names hospital] I was nearly getting acclimatised to it, I was. I was going to say, I had a widow's pension at the time I was going to say to them look here you can have my widow's pension I'd like to stay here for the rest of my life. You see because no responsibilities, no bills, no this, your food given to you. At the beginning you hate it, but then as time goes on it gets very comfortable. But they [the staff] weren't

having that anyway so they left me home' (Female, Interview 24).

Some of the participants resisted this socialisation and did not want to be in hospital at all. This resistance stemmed from the stigma attached to psychiatric hospitals coupled with a lack of acceptance or understanding about the necessity to be admitted to hospital. Some of the participants interpreted the hospital solely as a place of custody and the staff as custodians:

> 'But there was a resistance in me to deal with mental health professionals, and they didn't give me much information about themselves as to what they were trying to do. I didn't know who they were, or what sort of a body they were, or how they were there to help me? All I saw them as, were security guards of some degree' (Male, Interview 18).

Others did not wish to be associated with the hospital or the other people on the ward, as it represented a negative point in their lives:

> 'I hated the regime that they imposed on me, and I hated the patients that I had to deal with, because they were, some of them could be very broken down individuals, they could be very intrusive, and it was a very negative environment. Because I hated being a psychiatric patient, and I'd lost pretty much everything that I had. And I suppose most of all, I despised myself for having come so low, having had quite a good background, and having had good opportunities, and suddenly having nothing' (Male, Interview 11).

2. Mental Distress: Indoctrination into the Medical Model

This sub-category describes how the participants' contact with the mental health services fully exposed them to the medical and illness interpretation of mental distress. Their understanding of mental distress as a biochemical disorder and to a lesser extent a genetic disorder was first acquired when they went into hospital. Throughout the participants description of their experiences they used a medical and an illness discourse. They used the word 'illness' and occasionally 'disease' to frame their experiences as well as talking about 'symptoms' and diagnostic labels. Furthermore they talked about themselves as 'patients' and made references to before and after they got sick to explain events in their lives. In some instances the participants likened their mental distress to a physical event or illness such as having a broken arm or diabetes, albeit one that is not visible or discussed in the same way. The participants interwove their illness and genetic discourse of mental

distress with a lay discourse and talked about having 'a nervous breakdown' or being 'mad'. This lay discourse, conflicted with how they were feeling at the time of their admission. This meant that they did not think that their experiences corresponded with the images they had of those people who are generally admitted to hospital. Initially the participants struggled for a greater understanding of what was happening to them and to make sense of their experiences.

Their experiences were generally explained to them by medical staff using a biochemical explanation which rooted the cause of their distresses in deficient or malfunctioning neurotransmitters. Although the participants did not fully understand these explanations they were reassured as it appeared to deflect some of the blame that they felt for having the distress. This association of mental distress with physical illness also assisted the participants to explain their distress to other people if the need arose. Furthermore, it meant that other people who believed that the participants had control over their distress could be challenged with the biomedical hypothesis. In the first quotation below, the participant recognised that she had perhaps put her family through a lot, however, her family were unwilling to accept that what had occurred stemmed from a disease process and not from purposeful intent. In the second quotation below, this notion of blame is further exemplified where the participant classified his own distress (non-controllable) and that of his brothers (induced):

> 'Oh it can be hurtful and then you say to yourself well what I put them through you know, but still at the end of the day, it was a sickness, but they didn't understand you know' (Female, Interview 1).

> 'And I should point out his problems are alcohol and drug induced, and not natural schizophrenia' (Male, Interview 11).

The participants searched for an explanation for their admission to hospital and the feelings that they were experiencing. For most of the participants, receiving a diagnosis was very important possibly because it further aligned their experience with a medical discourse. Even though the participants received a diagnosis, many continued to use a lay language to describe their experiences, suggesting that their admission to hospital was precipitated by a nervous breakdown:

> 'I had, I don't really know how to describe it, a complete breakdown. But it was leading for years in my life, even up, it wasn't out of the blue' (Female, Interview 30).

Many of the participants had to wait for several months before they received a diagnosis and this was a source of stress for them. Over the course of their hospitalisation, the participants often received several diagnoses which appeared to conflict with each other. Furthermore, the diagnosis often did not adequately explain the participants' experiences. For some, they felt that they were diagnosed incorrectly initially. However, this may have been because they were drinking heavily prior to being admitted to hospital which led to a diagnosis of alcohol dependency syndrome. Regardless of the actual diagnosis, receiving a diagnosis was of central importance to the participants:

> 'I have a diagnosis, the diagnosis that the doctors gave me, well it's a bit confusing, one doctor kind of mentioned unipolar mood disorder, and then other doctors then, then other doctors started treating me for paranoid schizophrenia. And I'm still having queries about them two diagnoses, you know' (Male, Interview 18).

In one of the interviews a participant stated that when he went into hospital, after waiting a while for a diagnosis he was diagnosed as having 'psychotic depression' which he accepted although he did not understand what it meant. Later he concluded through his own personal research that 'psychotic depression' and 'schizophrenia' were in fact the same thing. He felt that the diagnosis of schizophrenia suited him better and explained his symptoms more accurately. However, he still does not fully understand what exactly schizophrenia means:

> 'Well I was told I had psychotic depression. And it wasn't until after a couple of years that it was actually explained to me that psychotic depression is the same as schizophrenia so that was, that wasn't explained to me, the whole lot you know, because when I went into hospital or got out of hospital I thought I was just in there for depression, you know' (Male, Interview 22).

In another interview a participant described receiving a diagnosis of depression even though the signs and symptoms he describes were incongruent with clinical depression. Although it was difficult to know if this was his own personal diagnosis or something that was given by the medical staff. Regardless, this diagnosis was certainly better than what the participant described as a 'more severe' diagnosis and was perceived to be rather straightforward, uncomplicated and acceptable. For some of the participants, despite acknowledging a lack of understanding about

mental distress, once hospitalised, they became more aware of different 'illnesses' and diagnostic categories, for example schizophrenia, depression and manic depression. Although these labels appeared to be poorly understood and in some cases misunderstood, the participants were able to rank them in a perceived order of severity. For example, depression was perceived as less severe than schizophrenia.

The participants' desire for information about their mental health problem was often met with reluctance from staff to share information about their diagnosis or the feelings they were experiencing. Although they were given a diagnosis, it was often left to themselves to figure out what the diagnosis meant and its implications for their future. For some this presented a conundrum as they were dealing with difficult emotions and experiences that they had not experienced in the past:

> 'No-one just sat down and told me the ins and outs and told me this, nobody told me about the symptoms. I just thought to meself like the symptoms I'm having must be giving me the diagnosis of schizophrenia so I was able to make allowances for that, but I was never actually sat down and told the ins and outs of it and how to deal with it and how to cope with it, I was just given the diagnosis and that was that' (Male, Interview 16).

More importantly, there was also a feeling of isolation and confusion with their diagnosis. Furthermore, the participants lacked information about the treatment for these 'conditions' which generally involved taking some form of medication:

> 'Not a thing, nobody told me nothing, they mentioned them and they handed me pills, they didn't tell me how it should be treated or books I could read or information about it. You are given nothing, you are given no control, I would love, I would love to have control in my, my welfare and making myself better but you feel like you are given pills and then the pills are changed but you are not told. You are never told side effects. You are never told what happens if you suddenly stop taking them, which I found out. You are not told how people, you are not told about the illness at all. Like if you had cancer you'd have cancer support groups and you could go to them, people know about stuff but 'mental illness' you are made feel like, you are not in charge, you are too loo-la to take on board any proper information and that's not true because you have moments in your life when you are with it. Especially when you are getting better' (Female, Interview 30).

Many of the participants, although they could not remember receiving information about their diagnosis, apart from the diagnosis itself, suggested that the information may have been given but they may have been distracted at the time. There was also confusion about who the most appropriate person to give this information was and what this information should entail:

> 'Well you see I was still quite distracted over [names husband] dying, so I suppose I was thinking so much about him that I didn't really think about the other, you know. It didn't really register to be quite honest with you' (Female, Interview 24).

There was a sense that healthcare staff were reluctant to divulge this information in case it had some detrimental effects on the participants. This lack of information made it difficult for some of the participants' to come to terms with their distress:

> 'And I was told that I had a psychosis and I asked him [the psychologist] what was a psychosis? And he said he was afraid and he said he couldn't tell me that. And I asked him why only a psychiatrist discusses that. You know so. It was hard to accept something that I didn't understand' (Male, Interview 17).

If information was given about the particular 'illness' it tended to be around the causation of the 'illness' which was explained using the biochemical hypothesis. This was explained in an overtly simplistic way and was generally unquestioned by the participants. This hypothesis allowed the participants to make a theoretical link between what was causing their distress and the medications they were prescribed. Telling the participants that their distress was caused by a chemical imbalance and suggesting that psychopharmacology would rectify this imbalance was overly simplistic and further aligned mental health problems with an illness paradigm and physical disorders. This is highlighted in the following quotations where the participant explains the causation of her distress as explained to her by her general practitioner:

> 'I am, I'm on injection, it wasn't through hospital, it was my GP, my mother brought me to her doctor who is [names doctor] and he sent away tests on my blood and on my brain scan and found that I was missing serotonin which gives you your get up and go, because I was very withdrawn still after hospital. She [the doctor] found I was withdrawn and didn't have an appetite for life. An injection of [names depot injection] which my family noticed a remarkable difference and improvement in me on that injection' (Female, Interview 25).

Despite these explanations about the causation of mental distress, some of the participants did not fully accept or understand these accounts or they were unable to make sense of them:

> 'you know what I mean, if someone new said to me will you sit down and explain to me what happened to you I can tell them the basics but I can't tell them what happened to me head. And a thing I can never understand is that even though the way they operate it at the minute why I could have never had an MRI or a scan on it, especially when the highs are full block' (Male, Interview 5).

For some of the participants there was a tension between a genetic model and a biochemical, model although the outcome was irrelevant and the treatments were the same:

> 'Well they say it's a chemical imbalance in the brain like and then they say is it genetic and all that and is it in the genes and stuff like that, but I was the first person in my family, me Mam's, me Dad's, cousins, aunties, uncles, brothers, sisters, that had schizophrenia but since then actually in the last month me brother has been brought into an acute hospital....I think you have it or not, it's just like cancer, you're either gonna have it or you're not gonna have it. I don't know if it's hereditary or genetic or anything like that but I think it's just there and just it's a matter of time before it's triggered because it's just a gene in your body' (Male, Interview 16).

In addition, to the limited information given about the causation of mental distress, the participants experienced limited information about aspects of their care and treatment. For example, one participant was sent for a brain scan at a local hospital but didn't understand the reason she was going or the outcome of the brain scan:

> I don't know, they just sent me for a head scan when I got sick, I don't know, but I think it came back okay but I don't know, you know. I don't understand that part of it, you know. I don't know whether back then they understood much about mental illness, I don't know (Female, Interview 8)

In another incident a participant returned from leave to find that she had been moved from the acute ward to the 'non acute' ward (described here as 'downstairs'), which caused a setback in her mental state due to the presumption made by staff that she was well enough to make the transition. It also caused an overwhelming sense of anger stemming from the lack of consultation which suggested that if she had been informed about the decision and provided with a rationale, then this upset could have been avoided:

> 'Oh that was horrible, that was horrible, absolutely horrible. It was a nightmare more than anything else. I just had ructions because I was so angry in myself because I hadn't been told about it, they just put you down without saying a word. If you're there that's fine but when you're away for a weekend and you come back on that week, that Sunday night, and you go upstairs because you know that's where you were on the Friday and then all of a sudden you're told, sorry but you've been put down' (Female, Interview 6).

The participants' admission to hospital and subsequent indoctrination into the medical model meant that they were often assigned a passive role in the health professional and service user relationship. This was enacted through the participants' assignment to the sick role and the elevation of the health professional to expert. Furthermore, the lack of information provided to the participants about their mental health problems and their treatment regimes created a perception that the participants' opinions and concerns were not valued. This was also evident in the lack of consultation between health professionals and service users in key decisions that impacted on the participants' life. In addition, the lack of information did little to further the participants' knowledge of mental health and mental distress. Admission to hospital also meant that physical forms of treatment such as psychopharmacology were highlighted as the dominant and in some cases the only treatment or management regime, again positioning the person in a passive role in their own recovery.

3. Receiving a diagnosis: An absence of hope for the future

Current mental health policy in Ireland, most notably the strategic plan for the mental health services, dictates that all services should be based on a Recovery Model (DoH&C, 2006; Mental Health Commission, 2008). Recovery is underpinned by the concepts of hope, optimism and a emphasis on strengths and opportunities rather than illness and symptoms (Mental Health Commission, 2008). The participants in this study recounted receiving their diagnosis in a manner that was described by one participant as 'getting a life sentence'. Although the participants often suggested that they anxiously anticipated a diagnosis, they were unprepared for the manner in which it was imparted and the subsequent impact of this diagnosis on their life:

> 'I was just given the diagnosis, I was told like you have schizophrenia, you'll have it for the rest of your life and you'll be on medication for the rest of your life. As I was saying it was a bit like a life sentence at the time. It was just a bit like a life

> sentence because I wasn't just told this is an illness that you can cope and get over and make a full recovery. I was told that you'll have it for the rest of your life and the symptoms that I was having at the time I was thinking God I don't want to have these for the rest of me life and it was just like, it was just a scary thought that I'd have to deal with this illness but as the time went on like I learned to make that road to recovery but at the time like it was just a very hard thing to hear' (Male, Interview 16).

The manner that the participants were informed of their diagnosis communicated to them that they were no longer capable, that their contribution to society and the expectations that society placed on them were now curtailed because they had a mental health problem. This is exemplified in the following quotation where the participant was advised by the medical staff during his first admission to avoid returning to university and to make a life that he could:

> 'So yeah people, yeah people, I found and I said to the doctor, and his opinion, he said I couldn't go back to university. So I said well what about if I travel to another country. He didn't recommend that. He recommended that I stay in Dublin and make a life that I could. So that was very hard and he recommended that I don't go to [names University] because it would bring back all the negative emotions and it would be a very difficult experience. And that I should leave it really and put it in the past. That was very hard' (Male, Interview 17).

This advice appeared to be a general instruction rather than advice that was given based on a participants' individual need. This is demonstrated in the following quotation where it was recommended that the same participant pursue part time employment, as his chosen career was deemed as too stressful. Interestingly this was the only strategy provided for the participant to manage stress, further highlighting the perceived enduring nature of mental health problems and the absence of hope:

> 'But they did feel even though I was there 2 ½ years and I got my exams and the qualifications, they did say it to me [not to return to work]. And I had at times to see a psychologist there and they felt that to work in that area, would be too stressful for me. They recommended part time work only' (Male, Interview 17).

4. Mental Distress: Something to Remain Undisclosed

This sub category describes how health care professionals and later other people such as the participants' family and friends advised and warned the participants not to tell other people about their time in hospital, their diagnosis or their

experiences. Because individuals were advised not to tell anyone about their experience, it reinforced the idea that disclosure was wrong. Furthermore it sent a strong suggestion that the participants had something to hide, and that their experience of distress should remain silent and unspoken and something to be ashamed of. Thus, it was evident that healthcare professionals were aware of the subsequent stigma that occurred when people were diagnosed and subsequently hospitalised:

> 'So I remember asking my doctor just before that, like what do I say if it comes up if I am on medication or have a mental illness or whatever. He said to me I am not saying you should lie, but not that you should lie but maybe not disclose. So when he asked me medically [the interviewer during an interview] I said that I had a back injury playing rugby, and stuff and eventually he said, ok you are grand. So I didn't really lie I just. And I know there is no way I would have got the job if he had known' (Male, Interview 17).

Summary of Acquiring Preconceived Expectations

The category *'Acquiring Preconceived Expectations'* describes how the participants acquired a number of additional negative beliefs about the nature of mental distress when the participants were admitted to hospital. These were acquired primarily through their contact with the mental health professionals that they encountered during their admission to hospital. Firstly they acquired the belief that they needed to be looked after as well as the belief that mental distress was an 'illness' caused by faulty neurotransmitters. These encounters fostered the belief that mental distress was a life long, recurrent illness where the prospect of recovery was slim. Furthermore, the mental health professionals that they encountered while in hospital, discouraged the participants' from openly discussing their mental health problems when they were discharged from hospital.

Validating Preconceived Expectations

The third category in this theory is *'Validating Preconceived Expectations'* and presents an overview of the participants experiences when they were discharged from hospital. In addition it describes how the participants' encounters with other members of their social audience validated the beliefs that they had absorbed and acquired. *'Validating Preconceived Expectations'* and its relationship to the other categories is presented in figure 6.5.

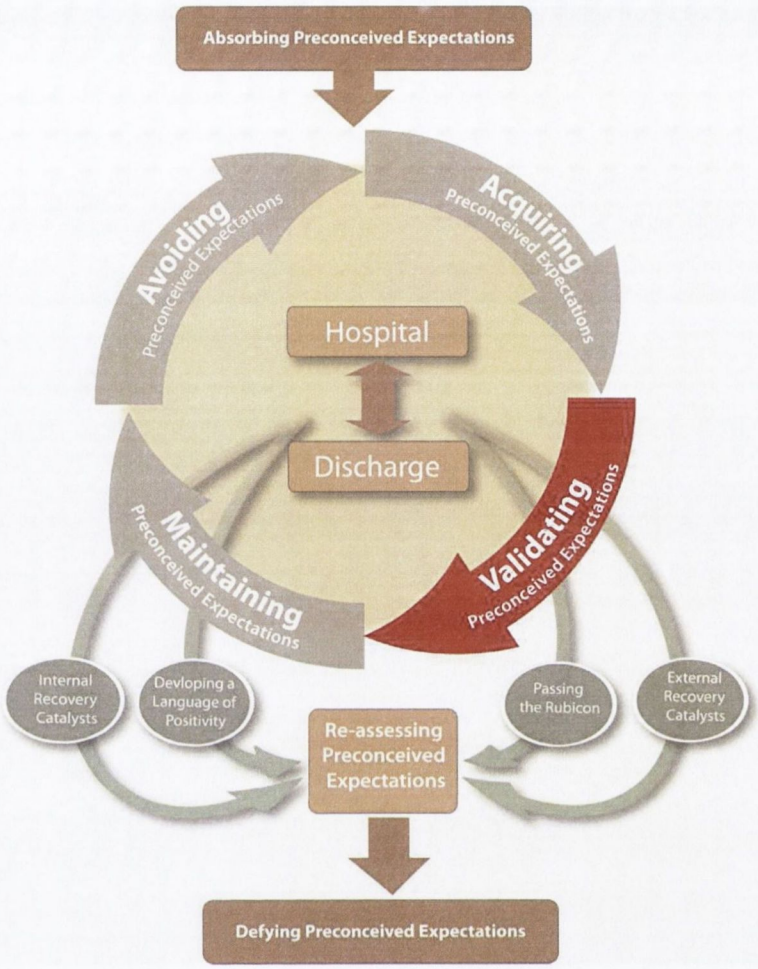


Figure 6.5: Validating Preconceived Expectations

The participants used a custodial language to describe their discharge from hospital and they talked about 'being released' rather than being discharged. This language reflects the restricted control that the individuals had not only of their movements when hospitalised but also the more subtle controls that were placed on their autonomy. It also reflected their attitudes and perceptions of psychiatric care as something that was forced upon them or something that happened against their will. In hospital there appeared to be a sense of unreality and being released was associated with a return to reality. Being released was not easy, it was described as scary and to a certain extent there was a fear of the unknown. For some there was a misunderstanding as to the role of hospitalisation and of the medical and nursing staff. This confusion was associated with a lack of knowledge of mental health and mental distress:

> 'I had no insight into mental health, I thought the system was dragging me in, but I couldn't understand why? What did I feel in hospital? I felt, I didn't know how to communicate any of my issues or problems, or begin to even understand, I had no insight and I didn't know how to communicate with nursing staff in any purposeful manner, maybe just to say "hello" and to be friendly, but that was the size of it really. I didn't know what their job was, I couldn't see it. I couldn't see that they were trying to provide a safe environment, and trying to be helpful to their patients. So, that was about it I suppose' (Male, Interview 18).

Being released was of paramount importance to the participants and successful outcomes of treatment were measured in terms of discharge from hospital. Furthermore, staying out of hospital was often a benchmark to how well the participant perceived they were doing once discharged. The decision that participants were ready to go home from hospital was often taken by the medical staff and participants were informed of their readiness to be discharged rather that it being a mutual agreement. This further reinforced the participants' perception of their inability to make decisions that impacted on their lives:

> 'Well they [the doctors and nurses] tell you when you're ready to go home, you know like if you wanted to discharge yourself, anytime you can do it, but I used to just wait, they'd tell you when you're ready' (Female, Interview 1).

> 'I think it was two days before I left, they said you know you're fine to go home on Wednesday or whatever and I said that's grand' (Female, Interview 26).

For most of the participants there was little preparation for discharge apart from weekend or day leave (day-release). Being released from hospital was evidence that they were no longer 'acutely mentally ill' although in reality most of the participants were not being discharged, rather they were transitioning from inpatient to community care. Some of the participants felt that they were not ready to go home when they were discharged; the example cited here suggests that bed shortages in the hospital may have contributed to his early discharge:

> 'I went home for a couple of hours, came home and then two days later I was going home for good so I wasn't really eased back in properly. I think, as I was saying, like it could have been due to bed shortages back then, there was a high waiting list for beds and stuff like that and I was just closest to the door and the fact that they knew I had family support, like they knew they could send me home to me family' (Male, interview 16).

Although being discharged was the ultimate goal for most of the participants, it emerged early in the interviewing process that there was a realisation that they themselves would be viewed through a different lens once they were discharged. This was articulated as *'feeling different'*. For the participants leaving the hospital following even a short period was a daunting experience as they felt that they were different because of this experience. For them, everything was strange after the security that the hospital offered. In one of the interviews, one of the participants likened the loss of hospital security to having a rug pulled from beneath her. The following quotations describe the participants' feelings when they were discharged from hospital and how they felt different:

> 'No, no, it is very hard when you come home to get used to your house life again' (Female, Interview 1).

> 'I felt really, really different when I went back, do you know like, a weird feeling like being back at home again and not in the hospital. Because you get so, you get used to the hospital like, you know' (Female, Interview 6).

> 'I felt really, really different when I went back, do you know like, a weird feeling like being back at home again and not in the hospital' (Male, Interview 4)

> 'When I come out of hospital, it is a different environment sure, institutionalised maybe, only for three weeks, but if you get on a bus full of bustling people, and you're coming out from say a psychiatric clinic, and you're making your way home on the bus, it does feel different, you feel you're back in a different world. If you leave a psychiatric clinic, its insulated, you're dealing with a certain type of person, either doctor or patient, and when you come out and you see ordinary people living their lives, and they don't relate to any of it, you do feel different' (Male, Interview 11).

> 'I found everything very loud at first, you know a bit overwhelming, I remember it must have been a couple of weeks after I'd come out and me and my mam went up to X shopping centre, everything just seemed so loud and I was totally freaked out by it, just you know. I think it was just things being quiet in the hospital and you know, I don't know, it was like I kind of got used to it, I don't know, that kind of quiet atmosphere, I don't know but everything was really overwhelming and going out was really difficult when I got out, do you know' (Female, Interview 26).

The representations of mental distress that the participants had absorbed or acquired (such as mental distress as something that was poorly understood, something to be ashamed of, and something that they could not recover from)

were validated and reinforced when they were discharged. When the participants were living at home it was their family and friends and to a lesser extent mental health professionals that validated the perceptions of mental distress that they had acquired. As mentioned, the participants felt different when they came home from hospital. In a sense the participants were different in that they felt differently about themselves and were treated differently by their social audience.

When the participants' were discharged from hospital the sense of shame that they felt was validated and reinforced by their social audience causing an amplification of shame. The participants described incidents of verbal and non-verbal actions which impacted on their already fragile sense of self and reinforced the idea that by being admitted to hospital they had let both themselves and other people down. In the following quotation, the participant describes her family's reaction to her when she was discharged from hospital following an admission precipitated by alcohol dependence:

> 'Very bad, none of them were talking to me or anything like that, I didn't exist, when I was in the house They wouldn't even sit in the same room as me, Ah that was going on for a long time yeah' (Female, Interview 1)

If the admission or diagnosis was precipitated by the use of alcohol or illicit drugs as in the example above, there was a heightened sense of self blame which further perpetuated existing feelings of shame. This feeling of shame not only came from the fact that they were admitted because of an addiction or from drug abuse, but from the fact that they could not control their behaviour without getting help. This added to their understanding of mental distress as a 'voluntary' event that could have been prevented. For these participants the sense of blame that they felt was actual and not perceptual in that they were in some cases actively held responsible for what happened to them. This is highlighted in the following quotation:

> 'Yeah, yeah I did, part of me has to realise that I smoked a lot of hash, between the age of 19 and 21 I smoked an awful lot and like it did me no favours, it brought on the psychosis you know, like I mean in my teenage years I was always, you know susceptible, I was hyper sensitive person anyway but with the hash and everything it turned into paranoia like, I just got real paranoid and I don't think that helped. So I would have felt guilty about kind of taking that, you know, you know nearly making myself sick like you know. Yeah I did definitely, things were said at home, you know you've ruined your life, you've

> destroyed your own life and things like that so' (Female, Interview 26).

Some of the participants reported that they did not receive any emotional support from their family and friends either when they were in hospital or when they were discharged. Although some resisted visitors, others were not visited by family members or friends. There was a perception that they were not visited in hospital because their family and friends were ashamed of them. They found the lack of visitors hurtful and this heightened the feelings of shame that they had about their distress. In another incident the participant's admission to hospital received a reaction which amplified the shame that already existed. Being admonished and lectured further reinforced the perception of mental distress as shameful. In addition some of the participants reported feelings of guilt further perpetuating the belief that they had done something wrong:

> 'The amount of time that I was told by my step-mum, because my mother died and my mother was not alive and my step-mum came over and she said your father would be ashamed of you, so that was kind of drummed into me. Because I let myself go, I let myself down, but you know, I kind of realize it now when you're ill it does happen, unfortunately, and you shouldn't be made feel guilty. But then it was like, it was just drummed into me, like my sister came over from the States and she kind of lectured me about this, that and the other and I was really feeling, I felt really, really, really low and it actually made me feel more low than anything else' (Male, Interview 3)

> 'I think it was, I don't know, I don't know, it was like being really ashamed of being mentally ill because and guilty for putting my family through, you know through a tough time you know' (Female, Interview 27).

The lack of hope about the future for people with mental health problems was not restricted to messages from health professionals. Sometimes, when the participants returned home, their family also reinforced this concept and perpetuated the belief that the participant would not recover. In the example below, the participant's family treated the participant as though her past experiences impacted constantly on her present circumstances even though she felt that she had recovered substantially:

> 'Like my aunty like or my ma, how are you feeling today, are you feeling, which way are you feeling, like you know, they say, you know they wouldn't treat me as a person, a whole person you know, they'd treat me like ah she's, this is the one that has all the problems and you know how is she feeling today, my da says

> its like walking on egg shells around you he says like you know. That upsets me like you know because I'm not that kind of person that I was years ago, you know' (Female, Interview 23).

In another example the participant suggested that people generally do not believe in recovery and think that people who have been in hospital are never that far away from having another 'nervous breakdown':

> 'And then going back to the education thing like a lot of people don't know the ins and outs of illnesses and what they are and how to deal with them and they actually, I think the big thing is people don't actually thing there is such a thing as recovery, full recovery. People just think ah they're only day away from cracking up again kind of thing, many people might have that point of view. They don't realize that someone can actually make a full recovery, maintain it and be well, as they say, you know' (Male, Interview 16).

The participants family also strengthened the idea that mental distress was a lifelong phenomenon where there was little hope of recovery and where relapse was almost inevitable. When the participants were discharged home members of their family appeared to create a tension where either the participant felt that they are being watched or where the participant felt that there was a lack of openness or discussion about the participants' experiences. In the following quotation the participant describes how the impact of feeling that she was under surveillance:

> 'Well when you have a mental condition, what do you call it, sometimes if your kids and your husband don't understand. You know it makes you feel what do you call it right, I know I was drinking, I gave them a hard time, they're probably what do you call it right, but it makes you feel, I don't know what you call it, really uneasy in yourself. That when you come home you're being watched' (Female, Interview 1).

In addition the participants felt that their family members were careful about what they said when they were around them. This was associated with the perceived unpredictability of mental distress and linked to the assumption that people with mental health problems never really recover and were always close to having another 'breakdown':

> 'they'll tell me [his daughters]you're not great today, no, and they'll leave it at that, they don't force the issue with me at all, you know. There's days I'd love to sit and have a chat with them' (Male, Interview 7).

The participants' instructions to keep their mental health problems and their experiences in hospital a secret did not just come from mental health professionals. Individuals also became silent about their mental distress and their time in hospital in response to friends and family telling them not to disclose or to be careful about whom they told their experiences to. One participant described being warned not to tell other people about his mental distress (in this quotation he referred to his experience as *'it'* further highlighting how unmentionable mental distress was). He described being accused of wearing his experience *'as a badge'* and subsequently was advised not to tell everyone about being diagnosed with schizophrenia:

> 'I've been warned not to be too open about it. Just my family and close friends have, they sometimes say I wear it like a badge of honour, you know so. The way I talk about it, you know so I've been warned to be more discrete about it. It's been grand, you know but like I've been told that it's not acceptable to speak about it you know' (Male, Interview 22).

Another participant described being advised by her friend not to tell people where she worked (she worked for a mental health voluntary organisation) as she did not want to be associated with someone who had a mental health problem, in case other people would find out that she had a mental health problem as well:

> 'And my friend, my good friend she used to tell me don't tell anybody that you work in [names organisation]. ....she had Schizophrenia as well and she didn't want her friends to know she had it, so if I told them I worked in [names organisation], she was afraid they'd think she had it, you know' (Female, Interview 15).

In the following incident the participant described returning to college after his first period of psychiatric hospitalisation and the advice of his friends not to mention his experiences:

> 'And then one or two friends from college told me listen that is going to go around and all. And you shouldn't tell people about that and it will go around' (Male, Interview 17).

Being advised not to disclose their distress or experiences to other people also heightened the feelings of shame that the participants felt. This is highlighted in the following quotation:

> 'Yes, I wanted my own friends to know but they said look I tried to tell one girl and she said look [name] don't tell anyone, keep it quiet, don't tell anyone. So I felt ashamed, very ashamed' (Female, Interview 30).

The lack of open dialogue about mental distress generally may go some way in explaining why participants did not want to talk about their experiences. However, being told not to disclose by healthcare professionals and other important members of the participants' social network confirmed their conceptualisation that mental distress should not be discussed, further reinforcing their devalued status in society.

For many of the participants, discharge from hospital meant that they had to conform or comply with the medical discourse and the practices associated with the biological interpretation of mental distress. This furthered the perception of mental distress as lifelong where the possibility of recovery was limited. In addition it perpetuated the reliance on traditional forms of treatments and the belief that there were limited treatment choices. An example of this occurred when a participant had problems taking his medications orally following his discharge from hospital. He was reluctant to take an injection instead of the oral medications. Consequently he was threatened by the community staff with re-hospitalisation if he did not comply. This meant that he did not really have a choice as he had to take the medication one way or the other. This happened again later when he did not want to take a prescribed antipsychotic medication because he did not like the blood tests that had to be taken while on the treatment. He felt that his autonomy was compromised and that he was given little choice in this treatment plan. Ultimately the participant and his mental health care team reached a compromise and the participant ended up taking an injection as well as the oral medication. This process of forced compliance further introduced a negative image of mental distress where non conformance with treatment regimes resulted in a threat of punishment i.e. re-hospitalisation. Furthermore it sent a clear message of the control that staff in the community had when the participants were discharged. It also augmented the conceptualisation of the role of psychiatric nurses and other staff working in the community as custodians and that their role primarily centred on ensuring treatment compliance. This is highlighted in the following quotation (note the use of the language 'If I act up' further emphasising the perceived voluntary nature of the experience):

> 'Well like if, well I haven't been in contact with the nurses in a long time but I know they're there if I act up. If I act up, like if I start to reject medication again I know that there'll be, there'll

be trouble ahead you know with the nurses. They might put me back into hospital' (Male, Interview 22).

Summary of Validating Preconceived Expectations

'Validating Preconceived Expectations' is the third category in this theory and describes how the conceptualisations that the participants had absorbed and acquired about mental distress were further validated when they were discharged from hospital. Although the participants anxiously sought their discharge from hospital, they were fearful about going home. This was articulated as feeling different. Once they were discharged from hospital, the encounters the participants had with their social audience validated and reinforced their perceptions of mental distress as life long and life limiting. Furthermore their encounters with mental health professionals in the community furthered their conception of mental distress as illness while also reinforcing their lack of involvement and choice in treatment regimes. Encounters with their family and friends also augmented the belief that mental distress should not be openly discussed and that it was something to be ashamed of.

Conclusion and Summary of Chapter Six

This chapter presented the first three categories of the 'Managing Preconceived Expectations' theory, namely *'Absorbing Preconceived Expectations'*, *'Acquiring Preconceived Expectations'* and *'Validating Preconceived Expectations'*. Prior to the participants contact with the mental health services they had a number of negative preconceived ideas about the nature of mental distress. They conceptualised mental distress as something that was poorly understood, something to be feared and something to be ashamed of. Their subsequent admission to hospital not only reinforced these preconceptions but introduced them to additional beliefs that often highlighted negative assumptions about mental distress. For example, the belief that mental distress was a lifelong and unremitting event was introduced while they were in hospital. In addition they were also indoctrinated in the biomedical conceptualisation of mental distress as well as discovering that is was something that should not be disclosed or talked about. Finally when they were discharged these perceptions were validated and reinforced by the mental health professionals involved in their care and by their family and friends. These absorbing, acquiring and validating processes ensured that the participants were labelled as deviant by their social audience and by themselves. The participants

underwent a process of depersonalisation where they defined themselves in terms of the shared attributes and characteristics of the stigmatised group and not as individuals with a unique identity (Brown & Turner, 1981). They now categorised themselves as part of that particular social group who had a spoiled identity because of their mental health problem. This resulted in self stigma where they perceived themselves as exemplars of the stereotypical assumptions about people with mental health problems. These assumptions as well as their encounters with their social audience influenced their resultant responses which will be described over the next two chapters.

CHAPTER SEVEN: MAINTAINING AND AVOIDING PRECONCEIVED EXPECTATIONS

Introduction

This chapter describes the next two categories in the '*Managing Preconceived Expectations*' theory: '*Maintaining Preconceived Expectations*' and '*Avoiding Preconceived Expectations*'. '*Maintaining Preconceived Expectations*' demonstrates how a number of experiences associated with the participants discharge from hospital maintained their beliefs and conceptions about mental distress. Whereas '*Avoiding Preconceived Expectations*' describes how the participants utilised avoidance strategies to manage their social audiences' perceptions of them and to avoid stigmatising experiences once they had been discharged from hospital.

Maintaining Preconceived Expectations

When the participants were discharged from hospital, a number of additional experiences maintained the negative assumption that the participants had developed about themselves as people who had a mental health problem and who required admission to a mental health services. '*Maintaining Preconceived Expectations*' relationship with the other categories is shown in diagram 7.1. The processes described mainly deal with the broad experience of mental distress based stigma which continually reinforced the participants' beliefs about the nature of their experience and about themselves as discredited individuals. The stigma experiences were based on preconceived assumptions about metal distress and people who use the mental health services. This category also demonstrates how the participants internalised the negative assumptions associated with mental distress and how these impacted on their self esteem and their perceptions of themselves. '*Maintaining Preconceived Expectations*' is divided into four sub categories: '*Being given a wide berth*', '*Not being understood*', '*Internalising negative assumptions*' and '*Encounters with stigma*'.

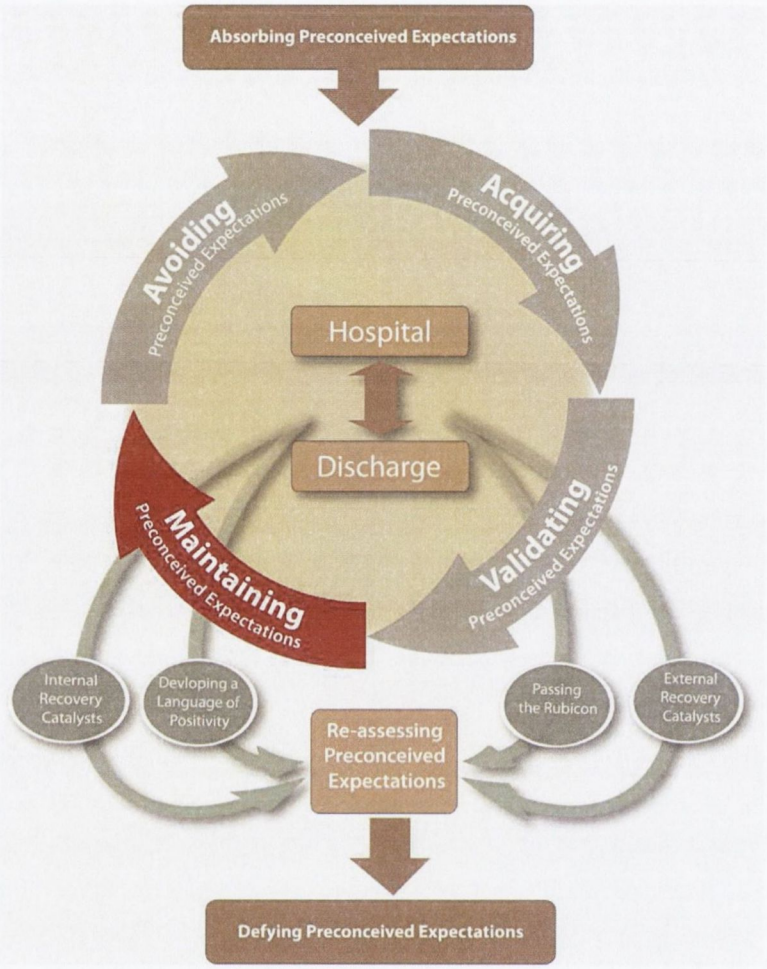


Figure 7.1: Maintaining Preconceived Expectations

1. Being given a wide berth

'*Being given a wide berth*' describes the participants' experiences of being avoided or being shunned by people because of their mental health problem following their discharge from hospital. It also refers to the participants' experiences of loosing established relationships once they were admitted to hospital and subsequently discharged. In established relationships the participants experienced being avoided where they seen less and less of people that they regarded as friends. This avoidance was something that was described as a '*nudging out*' of social relationships in response to judgements about the participants psychiatric experiences:

> 'Everything changed after I got sick really, I lost a lot of friends, like I did.....we all hung out together and I was kind of like nudged out of the group, you know and like they'd be going out

> and I was kind of like nudged out of the group, you know and like they'd be going out like and I wasn't invited and you know they were a bit nasty now and I was bullied by them' (Female, interview 26).

Being avoided and being 'nudged out' of already established social groups was experienced as hurtful and impacted negatively on the participants' sense of self and their sense of identity. For most it exacerbated their already fragile self esteem or reinforced some of the negative feelings that the participants were experiencing about themselves. This is highlighted in the following quotations:

> 'I think they kind of shied away when they heard about the mental illness and stuff like that, they didn't know much about it and I didn't know much about it. But it was a bit hurtful as well because some of them I was good friends with, just to think that they were kind of ditching me because I got this mental illness and this stigmatising and stereotyping'(Male, interview 16).

2. Not being understood

'Not being understood' describes how the participants felt that that their social audience did not understand them or their experiences once they were discharged from hospital. There was a strong sense throughout the data that participants who used the mental health services felt that other people did not understand them or understand how they were feeling. This reinforced and maintained the participants' conception of mental distress as something that was not only poorly understood by those who experienced it but was poorly understood by the general population:

> 'My family are sort of like, they don't understand my, what's going on with me you know and they're not really very supportive people' (Female, Interview 23).

The participants suggested that the invisibility of mental health problems made it difficult for other people to understand or empathise with what they were experiencing. Although spoken of as akin to a physical illness by practitioners, this analogy did not hold true for the participants once they were discharged. Having a mental health problem or what participants described as a 'mental illness' was not like having a broken leg or having the flu, as it was much more difficult to explain the experience. Furthermore, other people could not identify with their experiences as easily as they could with a physical illness. Meeting people who didn't understand the nature of mental distress or 'illness' was consequently described as a *'nightmare'*:

> 'Meeting people, it was a nightmare, you know, I mean you'll have a bad day and someone would say Jaysus you're looking grand [name], you know, and I would say you wanna see it from this side and that was always and it still is my answer, you know. They say you look great but the inside is terrible (Make, Interview 5)'.

Not being taken seriously was another aspect of '*not being understood*' where the individuals felt that their social network did not see them as credible individuals. This stemmed from the belief that the participants problems, distress or 'symptoms' were 'put on' or the participants were opting out of life's responsibilities. In some cases families gave out to the participants, accusing them of copping out:

> 'Well they should have realised what do you call it right, that they're not kids now, I mean they're adults to me, that I was sick: Like you don't go into a hospital for nothing. They should have been a bit more understanding' (Female, Interview 1).

> 'Well at the start I'd a lot of visitors, the family and that would have come in [to hospital], but down through the years they don't kind of accept mental illness and they think it's just like, you know, ah it's just in their head and they just love them institutions and they love the hospitals but it's not really like that, you know, but they do. And I know like myself, I mean I have another friend that would have been admitted to psychiatric hospitals and she'd say the exact same thing, you know, she'd go into hospital and she wouldn't want her family to know because her family would actually give out to her, you know, so I've kind of gone a bit like that really as well, you know' (Female, Interview 8).

The time that the participants spent in hospital and their subsequent diagnosis also perpetuated the belief that they lacked credibility and they believed that this influenced the reactions of significant others towards them. There was an assumption that because the participants had been hospitalised that they were 'mad' and this meant that they were incapable of taking responsibility or being autonomous:

> 'Your kids really think that you're mad. That you're after being in a nut house, Well when you have a mental condition' (Female, Interview 1).

> 'Yeah, I remember going home and things weren't good with my mother, she just thought you know, just snap out of it, she just kind of screaming at me in the car on the journey, did you hear, I was speaking to you and a bit like a half [wit] or somebody in their own world' (Female, interview 25).

'Not being understood' also referred to elements where people misinterpreted what it meant to have a mental health problem or what the participants capabilities were now that they had been discharged. For example, one of the participants was prevented from continuing with her nurse training because she was told by the matron that people with mental health problems were not allowed to look after physically ill people. Her family's reaction to her mental health problem was also one of uncertainty and misunderstanding although they have now proved to be the most supportive people in her life. When no one understood, the participants felt like outsiders as if they were skirting around the peripheries of what they considered as 'normality'. The participants perceived that when people talked to them, they communicated as if they were a list of signs and symptoms and not as a person. This may be because they were unable to understand the person behind the mental distress and that the sterile signs and symptoms were easier to relate to.

3. Internalising negative assumptions

'Internalising negative assumptions' describes how the participant's internalised the negative stereotypes and assumptions that are associated with people with mental health problems. This belief was typified by feelings of inadequacy, feelings of hopelessness, a lack of belief in themselves and a focus on past events. In some cases exacerbation of their distress occurred because of this negative self belief. The following quotation provides an example of the participants' internalisation of negative self belief:

> 'Like I'd get spots when I'd be reading the jobs pages, and I'd look for the lowest level job possible, thinking that it was all I was able to do, and that went on for maybe, for that seven or eight years. Like I got a job as a pot washer in a restaurant, stuff like that' (Male, Interview 11).

For other participants internalising negative assumptions was so strong that they believed that they no longer had any rights. They believed that they were undeserving of the life that they had prior to being a 'patient' in a psychiatric hospital:

> 'but I said to meself the first time I went out of here I said I have no rights now, you know what I mean, I can't go home and demand this, that and the other, which I never did in any way. It's just the feeling that when you get say admitted to a

> psychiatric unit your rights go out the window. I just feel it in meself' (Male, Interview 7).

'Internalising negative assumptions' also impacted generally on the participants overall sense of who they were and their well being:

> 'Now I suffered hugely from depression, was the reason for so many admissions, those first eight years, because I hated being a psychiatric patient, and I'd lost pretty much everything that I had' (Male, Interview 11).

Furthermore, the mental health problem had a detrimental effect on the participants' sense of security and aspirations for the future. Events that were realistic for most people became unrealistic for people who used the mental health services (for example buying a house):

> 'But that is my take on, certainly on reactive depression, and it's the case with me, there are many things like owning my own property, not ever being able to do that, or at least feeling like that, leaves me dreadfully insecure, and it could make me try to commit suicide, rather than face up to the reality' (Male, Interview 11).

The extent of the internalisation of negative assumptions was demonstrated by the participant's beliefs about fulfilling social roles such as employment. As demonstrated in the following quotation, the participant believed once she had given up work because of her mental health problem that she would never work again:

> 'And then I got the CE [Community Employment Scheme], the voluntary work out of that and I didn't think I was ever going to work again, I just took it for granted that I wasn't going to work again and then I got that' (Female, Interview 16).

4. Encountering misconceptions

'Encountering misconceptions' describes the participants' persistent encounters with misconceptions about the nature of mental distress. The first example of these misconceptions is the disparaging language that people use to describe individuals that use the mental health services. This language was not restricted to what other people said, but was also evident through the interpretation of mental health service users in the media. The language was confusing for the participants and misrepresented them as individuals, which is evident in the following quotation:

> '...I didn't know what a psychosis was. ...I sometimes thought it was like from Hollywood or something, like the film pyscho and I didn't understand what the term was. And I had been in science and in my 4th year ....and I just didn't know what it was. ...It was hard to accept something that I didn't understand' (Male, Interview 17).

Furthermore the language that people used to describe those who use the mental health services often created a tension for participants as they were associated with these disparaging comments. These comments that described mental health service users as 'loonies' 'nutters' or 'psychos' and the acceptance of these terms generally perpetuated the belief that people who experiences mental health problems were irresponsible or incapable. This is highlighted in the following quotation:

> 'I had a fella I went to school with on the bus one morning, when I was back in work a couple of years later, and he was just talking to me, and I got on great with him in school and out of nowhere he just came out with a comment, he says you're the schizo of your road, aren't you?' (Male, Interview 15).

Another misconception was the belief that people with mental health problems were dangerous and that they were to be feared. For some participants the realisation that there was an element of fear associated with their distress emerged slowly. Although this initially occurred during hospitalisation or was associated with involuntary admission to hospital, it also occurred when they disclosed their experience to others following their discharge. These incidents are demonstrated in the following quotations respectively:

> 'So I realised he [the doctor] had left, and I left the ward, and I saw him up the corridor, and I ran up the corridor behind him, to engage with him, and by the time I got to him, he was down on one knee nearly, and he had his arm up like this, and he was in the defensive position, and it was the first time I realised that he was in fear of me, there was something to be afraid of there' (Male, Interview 18).

> 'I said [to a girl at work] that I had schizophrenia, she turned around and she looked horrified. 'you wouldn't hurt me would you'? At the time I just laughed' (Female, Interview 26).

Summary of Maintaining Preconceived Expectations

'*Maintaining Preconceived Expectations*' is the fourth category in this theory and describes how the participants' encounters with a range of stigmatising behaviours from other people reinforced the sense of otherness that they felt following their

discharge from hospital. These reinforcements sealed the participants' beliefs about the nature of mental distress and the negative beliefs and attitudes that their social audience held about people with mental health problems. The cumulative experiences of *'Absorbing'*, *'Acquiring'*, *'Validating'* and *'Maintaining'* Preconceived Expectations galvanised the participants initial responses through the processes associated with *'Avoiding Preconceived Expectations'*. These will be described in detail in the next section.

Avoiding Preconceived Expectations

'Avoiding Preconceived Expectations' the fifth category in this theory describes the many processes that the participants in this study used to avoid or minimise the stereotypes associated with being a psychiatric patient. *'Avoiding Preconceived Expectations'* is divided into three sub-categories: *'Avoiding Social Exposure'*, *'Cautious Disclosure'* and *'Justifying Otherness'*. *'Avoiding Social Exposure'* describes how the participants avoided social encounters, and how they tried to resist being labelled as a 'psychiatric patient'. The second sub-category *'Cautious Disclosure'* describes how the participants managed disclosure about their mental health problems. *'Justifying Otherness'*, the final sub-category describes how the participants made allowances for their exclusion. A diagrammatic representation of *'Avoiding Preconceived Expectations'* is presented in figure 7.2.

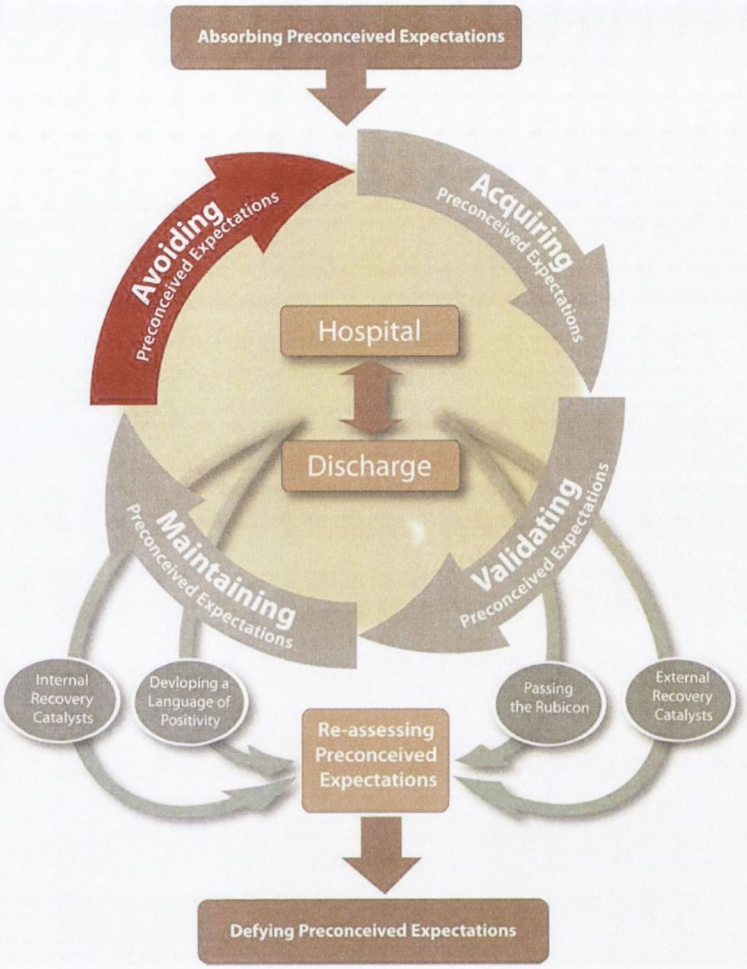


Figure 7.2: Avoiding Preconceived Expectations

Avoiding Social Exposure

'*Avoiding Social Exposure*' is the first strategy that the participants used to avoid preconceived expectations. It describes the participants' reluctance to engage with their peers and their extended social network for fear that they might be exposed as having a 'mental illness' and subsequently stigmatised. This sub-category contains three properties: '*denying discredited status to self*', '*revisiting pre-hospital life*' and '*socially disengaging*'.

1. Denying discredited status to self

'*Denying discredited status to self*' occurred in response to the awareness that the participants belonged to a group with a stigmatised identity. The participants attempted to deny to themselves that they had a mental health problem or that they required treatment. For some, this began when they first went into hospital and they actively sought to be discharged because they believed that they should

not have been hospitalised. Furthermore they hated their psychiatric experience because for many it represented a negative turning point in their lives. In addition, the stereotypes, such as the ones outlined earlier, associated with their psychiatric label were difficult to deal with on an emotional level and it was easier to reject them rather than manage them more effectively. The perception of having a 'mental illness' for the participants was one of failure and despondence. This is highlighted in the following quotation:

> 'I didn't like it, I didn't want to have it [bi polar affective disorder]. I couldn't figure out why I had it. It was hard to accept, now I probably would have denied it to myself as well' (Female, Interview 24).

2. Revisiting pre hospital life

'*Revisiting pre-hospital life*' describes how the participants attempted to go back and do the things that they did prior to being hospitalised and is directly related to the previous concept '*denying discredited status to self*'. This was an attempt to recapture the lost sense of normality that existed prior to hospitalisation. This 'normality' had disappeared since their discharge from hospital:

> 'It was a confusing time because I thought that I could do the things that I could before I went into hospital again, I went out drinking and stuff like that. That kind of rocked the boat a bit again' (Male, Interview 22).

Another example of this occurred when some of the participants stopped taking their medication. The reason they did this was because they believed that they were 'not ill' or they did not have to take medication in order to stay well. For the participants in this study, taking medication reinforced the idea that they were 'ill' and that their 'illness' was lifelong and unremitting. Stopping medication was an attempt to return to their pre diagnosis life – a life where they didn't have to take medication or where they did not have a stigmatising label. Furthermore there was, for some, a perceived belief that the episode that occurred which ended in hospitalisation was a once off event and that it was now in the past. There was also a reluctance to accept that they may now need to manage and pay closer attention to their mental health needs:

> 'We'd be going on a good few months from this now, and I would have got myself back to work, right, and I would have been ok and that and then I said to myself 'sure I'm fine now I don't need these oul tablets' – back to square one again, back in' (Female, Interview 24).

In some cases the participants were on medication and couldn't do the things that they used to do in the past. For example one of the participants suggested that he could no longer drink alcohol because of the medication. Although the participants no longer denied the presence of their mental health problem to themselves, there was a continual reluctance to avoid stigmatisation through processes that centred on avoiding disclosure to other people that they had a mental health problem.

3. Socially Disengaging

'Socially disengaging' refers to the participants' disengagement and withdrawal from their social life and social networks. The participants socially disengaged from previously held social relationships in response to three main issues:

- In response to the way that they were treated by others when they were discharged from hospital.
- In response to how the participants felt about themselves. After the participants were discharged from hospital, they experienced a feeling of shame and despondency where they perceived that they did not deserve or warrant social interaction.
- In response to the anxiety where they worried that they might be confronted with having to explain their absences or what they were doing now when they met people they knew.

To avoid these uncomfortable feelings participants' used *'social disengagement'* to avoid having to discuss their present circumstances. *'Social disengagement'* was sometimes self-imposed and emerged from an actual or perceived feeling of not being accepted or of not being understood. For example, one participant makes it quite clear that she could not handle the atmosphere when she was with her family. To avoid this she socially disengaged and went to her room:

> 'Like I couldn't sit in the same room as them, I had to go up to the bedroom to look at me television, because I used to feel what do you call it right, sitting in the room with them, I used to feel that there would be a cloud all over me' (Female, interview 1).

Another participant followed the same pattern but in this incident it was because he believed that since he had a mental health problem, he did not deserve to occupy the same space as the rest of his family as he had let them down. He described this as a self imposed isolation because of a belief that he no longer had any rights because of his psychiatric experience:

> 'I go home and I'll sit at home and I have the couch in the corner of the room, I've a telly, I've the two computers, I've a video, stereo, anything I want is in that one room and I don't even go to bed. The only way I can describe it's like a self-imposed isolation' (Male, interview 7).

'*Socially disengaging*' also occurred in response to a fear of communicating with their social network. This fear of communication was sometimes linked to a fear of meeting people and having to explain what they were currently doing. Furthermore, the participants often compared themselves to other people and believed that they should not lie about their experiences, if they were asked about their absence from society:

> 'Just fear of going out, just very unwell, fear of communicating and just didn't want to interact with anybody, just kind of still very withdrawn and just going from the couch to the TV to the dinner table and back to bed at night time, that routine going on for six months, I wouldn't go outside the house and then I just had to start going to a day hospital' (Male, Interview 15).

> 'It was because I didn't want to meet people, you know didn't want, and I think what I did do when I came out of hospital as well, like I felt I had to explain everything you know – where were you for the last few weeks, what were you doing, felt like I had to say oh I was in [names hospital] you know' (Female, Interview 26).

Socially disengaging also meant that friends and other social contacts drifted away and lost contact with the participants:

> 'I think we just kind of lost contact and it was due to my stay in hospital was why we lost contact because they knew I wasn't interacting and wasn't coming out like' (Male, Interview 16).

Cautious Disclosure

The second sub-category associated with '*Avoiding Preconceived Expectations*' is '*Cautious Disclosure*'. This sub-category describes another of the processes that the participants used to avoid being negatively stereotyped and negatively judged. '*Cautious Disclosure*' occurred when the participants felt they were not being taken seriously or when they feared that they would be treated differently by others. '*Cautious disclosure*' had the potential to reduce anxiety within social interactions by minimising the tensions associated with telling other people about their mental health problem or hospitalisation. However, cautious disclosure was sometimes counterproductive as it increased anxiety associated with concealment of truths or making false statements about aspects of their lives. The stigma attached to mental

distress meant that negative judgements were often made by the participants' social audience when disclosure occurred. Avoiding these negative judgements and avoiding the preconceived expectations that accompanied them was seen as a necessary reaction and fuelled *'Cautious disclosure'*. Although the processes are presented here in isolation, in reality they do not stand alone and are dynamic where the participants reacted depending on their social audience. *'Cautious Disclosure'* contains five properties *'gauging reactions'*, *'reactive concealment'*, *'perceived reaction concealment'*, *'selective disclosure'* and *'creating an alternative biography'*.

1. Gauging Reactions

Before telling anyone about their illness there was a process that occurred which suggested that the participants attempted to gauge the potential reactions of the person they were conversing with. The participants needed to make a judgment about how they thought the person would react before they mentioned their experience of mental distress. This is exemplified in the following quotations:

> 'I would try maybe, and I wouldn't say it directly what happened to me, but, say for example if you were talking about East Enders or Fair City and there was something that happened where someone is mentally ill. Just to gauge their reaction like that might be' (Male Interview 17).

> 'You have to be very wary of who you tell, you know that's what I'd say, I wouldn't say I don't like to tell or I do like to tell, I think that when you're sick you sometimes, you do tell you know and you're actually suffering from it, although at times you don't believe you're suffering from anything' (Male, Interview 19)

'Gauging reactions' was sometimes about gauging the type of person that the participants were disclosing to. For example, there was an awareness that different people reacted in different ways and it was necessary to judge these different people and work out what reactions might occur. The participants would only tell people that they felt comfortable with telling, and this might occur only after a period of time had elapsed. However, it was not about trust, as sometimes even people they trusted reacted in an unexpected way. In addition, it was important that the participants made sure that they had a chance to get to know the individual before they disclosed their experiences. If this disclosure happened, sometimes it happened slowly and with great caution:

> 'Yeah, well then another girl that I met since that like, this was before Christmas, I told her after about a month and she was

> grand with it, no bother to her, so it just depends on the kind of the person' (Male, Interview 16).
>
> 'But then again meeting new people, like for instance meeting new girls or meeting new friends and stuff like that that I wouldn't have known before, I think it's, I'd like to explain to them meself the ins and outs of what I went through at some stage, like slowly explain to them but I wouldn't be able to jump into it and tell them straightaway kind of thing' (Male, Interview 16).

2. Reactive Concealment

'*Reactive concealment*' describes how the participants learned to conceal their experiences of mental distress following the negative reactions of others when they disclosed their experiences. Typically the participants reported telling acquaintances about their experiences of mental distress, either that they had been diagnosed with a mental health problem or that they had been in a psychiatric hospital. Once they did, a number of negative reactions occurred and these reactions reinforced '*reactive concealment*'. Sometimes the reaction to the disclosure by the person was silence and a gradual '*pulling away*'. Consequently over a period of time the participant saw less and less of this person. This experience reinforced the resultant process of reactive concealment and indeed social disengagement. To put this concept into the words of one of the participants, reactive concealment occurred when she 'learned to keep my mouth shut' (Female, Interview 27). This is exemplified in the following quotations:

> 'And then I had another incident as well, like another person I went to school with, and he is a doctor. He is a consultant now. And he I met him and some other people, at a social. And I saw other people referring to me like that he was [twirling his finger at his temples] they didn't know that I was looking and that really hurt me. Because he was and I was meeting up with him again and it was great to be back in school, and what ever and just to see that was just really like, it just I felt terrible you know' (Male, Interview 16).
>
> 'I have met a couple fellas that I've told that I work in [names mental health voluntary organisation] and they have dropped me like a hot coal' (Female, Interview 15).

When the participants did disclose their experiences they were often rejected. This is highlighted in the following quotations:

> 'I went out with a girl like for three months about a year or two ago and the whole time, not that I was ashamed of it, the last three or four years I've been so confident and I talk about it in public and everything, but at the same time this girl, like I didn't want to tell her straightaway kind off, scare her off, but when I told her after three months she just gone, she just up and left and she says I can't accept this, her best friend's brother had schizophrenia and her best friend's mother had bipolar, which are two of the illnesses I have, so she gets to see the bad side of them so she just straightaway associated me with that and she didn't want to know and she just up and left straightaway' (Male, Interview 16).

> 'A friend of mine, I met this girl in a social club and she invited me back to her apartment and we went out a couple of times and then somebody I think told her that I had a mental illness and she just dropped me like that. I meet her in the street now and she just looks through me you know' (Female, Interview 15).

3. Perceived Reaction Concealment

'*Perceived reaction concealment*' describes how the participants sometimes did not disclose their experiences because of an anticipated negative reaction. '*Perceived reactive concealment*' occurred in response to a perceived lack of understanding by others. Sometimes participants did not tell their family about their hospitalisation, because they perceived that their family did not understand the nature of their mental distress or did not take their hospitalisation seriously. In some cases, the family may have believed that the individual had more control over their 'symptoms' than they actually had.

Another reason for perceived reaction concealment was because participants' lacked the vocabulary to describe the experience. In addition it occurred because of a belief that others would see them in a negative light. It also occurred because the participants were embarrassed about their experiences and did not feel comfortable talking about them:

> 'But I couldn't tell anybody how I was feeling for some reason, because I seemed all right on the outside' (Male, Interview 2).

> 'I couldn't tell me family, I couldn't tell me friends, I couldn't talk to me friends about it as they'd see me as being mad, you know, and kind of they wouldn't understand kind of thing. I thought that yeah, that people wouldn't understand so I just didn't want to talk about it, I didn't feel comfortable talking about me illness and talking about me symptoms and stuff like that because I thought, almost like thinking you're the only one that has them

> and just thinking people think your crazy if you talk about what thoughts you had in your head' (Male, Interview 16).

Furthermore participants used perceived reaction concealment because they feared that they would be laughed at or that their symptoms or experience would not be taken seriously by their social audience including mental health professionals. The quotation below is in response to the question of why the participant did not engage with the mental health services:

> 'Because I thought they'd laugh at me' (Male, Interview 11).

4. Selective Disclosure

'*Selective disclosure*' refers to when the participants only disclosed part of their story or history in an attempt to avoid prejudice and discrimination. '*Selective disclosure*' was about leaving gaps in the participants story or only telling other people what they thought they should know. Selective disclosure began in hospital where the participants described not wanting any visitors apart from their family while they were in hospital. They described not wanting other people to see them in a psychiatric facility, or to see them while they are 'ill'. This process was one of the first steps in limiting the amount of people who know about their experiences:

> 'I had very little visitors whilst I was in hospital, actually I had none as per my own choice, I didn't want anyone to see me in hospital' (Male, Interview 3).

> 'I didn't want people really coming up seeing me that knew me; I didn't want them to know. Yeah that I was in a psychiatric unit like' (Male, Interview 20).

Once the individual was discharged from hospital a continual process of selective disclosure occurred and the participants quickly learned who they could talk about their experiences to and who and where they had to withhold information. For example, the participants engaged in '*Selective disclosure*' about their diagnosis saying that they had 'bi polar disorder' or 'depression' instead of disclosing that they had been diagnosed with schizophrenia. This was due to the participants' belief that the other two disorders 'sounded' better than schizophrenia. In addition there was a perception that one diagnosis was not as bad or severe as the other. The negative perceptions and misunderstandings associated with schizophrenia made the individual believe that other illnesses would not be as stigmatised or they would not provoke the preconceived expectations associated with it. In addition, if the participants were explaining to someone that they had a mental health

problem, their experience, diagnosis or hospitalisation were not explained as thoroughly or as carefully. This is highlighted in the following quotations:

> 'Yeah, ah definitely, yeah, I'd pick and choose what I'd say to people sometimes and certain people like. Certain people you know you'd be able to open up and you'd be able to tell them everything and other people you're just thinking I'll just pick a few things out to tell them. Not that I'd leave gaps, I just wouldn't explain it as thoroughly, you know' (Male, Interview 17).

Most of the participants in this study were unemployed and found that their mental health problem was a major barrier to securing employment. All of the participants' believed that if they disclosed that they had a mental health problem or a history of psychiatric hospitalisation that they would be passed over for any position they applied for. Consequently there was a consistent reluctance to disclose to potential employers that they had a mental health problem. This caused anxiety as the participants did not want to lie as they feared that they would be found out. The few participants, in this study, who were employed, were mostly employed by organisations that were sensitive to the needs of people with mental health problems and actively recruited them.

'Selective disclosure' also refers to limiting or altering the amount of information about their experiences that the participants told to certain groups of individuals. For example, one of the participants said that they would tell their family and friends about their experience, but they would keep it a secret from people at work. The reason that they did this was because they did not want other people to look at them in a different light. This stemmed from their main concern which suggested that once people knew that they had a mental health problem, there are a certain amount of preconceived assumptions made about the individuals' character. Furthermore, these negative assumptions inferred an inability to perform in a number of social and occupational situations. It was recognised that other peoples overall impression of an individual with a mental health problem was tainted which impacted widely on their ability to integrate socially and left them open to discrimination and prejudice. The overall function of selective disclosure as a concept was to avoid this discrimination and prejudice:

> 'Not normally, neighbours and that of my mother, if they don't know, I don't enlighten them' (Male, Interview 11).

> 'Well I'm in two walking groups now and I wouldn't say it to them' (Female, Interview 15).

Another example of selective disclosure occurred where one of the participants described a taxi driver inquiring about his place of work, which was a training centre for people with mental health problems. Instead of disclosing the nature of the centre, it was described as a centre for people with disabilities. It appeared that the word disability was more acceptable as it possibly related more to physical disability rather than mental disability:

> 'So it is very awkward sometimes when you don't want to tell them because if they start to pry into it, you almost have to tell them sometimes or water it down like say its, like I said it's a place for people with disabilities who want to get back to work you know, which in a way it is slightly, its not totally like that obviously' (Male, Interview 19)

5. Creating an alternative biography

'*Creating an alternative biography*' describes the process of concealment through the fabrication of a new history. '*Creating an alternative biography*' was an attempt to conceal the participants' admissions to hospital or their experiences of mental distress. This alternative biography consisted of fabricating a career which served to fill the missing gaps that may have been present if the person had several admissions to hospital. Although similar to the concept of selective disclosure, creating an alternative biography contains elements where the individual made conscious decisions to tell people something that could be true, but was not the truth – although it was not about lying. It was about protecting themselves from the negative effects of telling the truth. There was a sense that the participants' felt that they had to do this, they had no option but to make up a past history. Creating an alternative biography was used mostly when the participants' met people for the first time or when the participants were looking for a job. This is highlighted in the following quotation:

> 'If I think that I am not going to see that person again I sometimes make up a story to hide the fact that I've been in hospital so many times. I might tell them that I worked in a factory or in a shop...it depends. I have told people straight off before and it makes us both feel very uncomfortable' (Female, Interview 13).

Justifying Otherness

The third sub-category associated with '*Avoiding Preconceived Expectations*' is '*Justifying otherness*'. 'Justifying otherness' describes how the participants made

allowances or justified some of their social exclusion by others. In particular, allowances were made when the participants felt that significant people in their lives had pulled away once they were diagnosed with a mental health problem. Participants rationalised that they were socially excluded because other people were not able to comprehend the nature of their experiences because of ignorance. *'Justifying otherness'* contains two properties: *'having a life of their own'* and *'facing ignorance: not knowing any better'*.

1. Having a life of their own

'Having a live of their own' describes a belief system that the participants' developed in response to their social exclusion following their discharge from hospital. Participants' accepted that people who were close to them had changed and moved on with their lives. In contrast their lives had in a way stood still and they were not able to progress in the same way as other people. There was a sense that this was due to a natural progression that the participants could not achieve because they had a mental health problem. Coupled with this was the belief that other people's lives were better because they did not have a mental health problem. This is demonstrated in the following quotation where one of the participants describes his present relationship with his friends:

> 'They're working in banks and they're accountants now and some of them have kids you know so life has changed for them but for the better. I don't see them anymore. Because they're too busy in work and stuff like that and they go out for a few drinks and I can't come with them because. I know that they have lives to live, you know' (Male, Interview 22).

Further rationalisation occurred later in the same interview when the participant suggested that one of the reasons that he cannot go out with his friends anymore is because he was unable to go out and drink alcohol because he was on medication. Another example of this also occurred when one of the participants talked about his friends only visit to the hospital. When they didn't visit again the participant suggested that the reason for this was because people *'wouldn't be able'* to visit a psychiatric hospital (the suggestion here is that visiting a psychiatric hospital would be too upsetting for some people). Furthermore, there was a belief that family and friends should not be concerned with the participants' problems and that the participants should just get on with things rather than bother other people who had their own problems and issues to contend with. This was perceived as a major

difficulty for the participants as many of them relied solely on their family for emotional support.

2. Facing Ignorance: Not Knowing any Better

'*Facing ignorance*' describes the participants' further rationalisation of their social exclusion through their perceived belief that the reactions of others to their mental health problems happened because of '*ignorance*'. By ignorance, the participants meant a lack of understanding and information about the nature of mental distress and its impact on people. They also use the term 'ignorance' in a more colloquial manner to mean 'rude' 'discourteous' or 'impolite'. When the participants were confronted with a negative reaction from individuals, they told themselves that the person has reacted in such a way because of ignorance. Furthermore they suggested that the negative reaction or the verbal or non verbal insult was a result of the person not knowing any better. This rationalisation was tinged with a hint of sadness and despondency that the participants had to continually face this particular problem. In addition, there was a feeling that this lack of understanding was hurtful and stressful, even though there was recognition that what they were experiencing was difficult to understand at times. However, there was a belief that a greater effort should have been made to understand and to recognise what they were experiencing was out of their control:

> 'What do you call it, sometimes if your kids and your husband don't understand? Like when they look at their mum drunk, they don't want to know, mum is just a drunkard. Oh it can be hurtful and then you say to yourself well what I put them through you know, but still at the end of the day, it was a sickness, but they didn't understand you know' (Female, Interview 1).

As mentioned previously, the perceived invisibility of mental health problems made it difficult for other people to understand mental distress and this invisibility provided a basis for other people not to understand. However ignorance was only really applied to strangers rather than people who knew the participant well. Negative reactions from people that the participants consider friends were perceived as extremely hurtful and exacerbated existing feelings of difference:

> 'I felt really offended, I really did and I think, I mean with the girl who said about the schizophrenia, would I hurt her, like I just couldn't, that's just pure ignorance but with my friend saying like ah she's mad, like that really hurt and it really put me, you

know it really did, you know because you feel different, you feel like a freak you know' (Female, Interview 26).

Summary of *'Avoiding Preconceived Expectations'*

'Avoiding Preconceived Expectations' is the fifth category in this theory and contains three sub-categories namely *'Avoiding Social Exposure'*, *'Cautious Disclosure'* and *'Justifying Otherness'*. These categories describe processes that the participants used to avoid being prejudged because of their experiences of mental distress. These processes involved a combination of avoiding social contacts, avoiding disclosing to others about their experiences or curtailing the amount of information that they provided about their experiences. Furthermore a set of rationalising processes entitled *'having a life of their own'* and *'facing ignorance'* helped the participants to justify other people's attitudes and perceptions of them.

Conclusion and Summary of Chapter Seven

This chapter presented two further categories in the *'Managing Preconceived Expectations'* theory. *'Maintaining Preconceived Expectations'* described how the participants' conceptualisations and beliefs about mental distress were maintained through their experiences with their social audience following their discharge from hospital. The participants' experience of stigmatising attitudes and behaviours augmented the beliefs they had absorbed and acquired through socialisation and through their interactions with the mental health services. *'Avoiding Preconceived Expectations'* describes the resultant behaviours prompted by the participants' perceptions of mental distress. These served to avoid activating negative responses to their experiences through avoidance of disclosure. When disclosure occurred, the participants' optimised the chances of a positive response by either altering the content of the disclosure as in *'selective disclosure'* or by making a judgment on how their social audience might react prior to disclosure. For many of the participants in this study, *'Avoiding Preconceived Expectations'* was the final point in their management of preconceived expectations. Although many of these participants did experience a more positive outlook on their experiences they did not use the full range of processes associated with this theory. Many of the

participants sole management of preconceived expectations was through avoidance. This was continually reinforced through their repeated contacts with their social audience. The next chapter describes how the participants move along a more positive trajectory within the *'Managing Preconceived Expectations'* process. This ultimately led to a re-conceptualisation of their position as a 'psychiatric patient'.

CHAPTER EIGHT: REASSESSING AND DEFYING PRECONCEIVED EXPECTATIONS

Introduction

This chapter presents the final two categories of the '*Managing Preconceived Expectations*' theory, namely '*Reassessing Preconceived Expectations*' and '*Defying Preconceived Expectations*'. '*Reassessing Preconceived Expectations*' describes the participants' re-conceptualisation of their experiences and their movement to a more positive relationship with their mental health and their experience of mental distress. '*Defying Preconceived Expectations*', the final category describes how participants actively defy the preconceived expectations that their social audience has about their abilities.

Reassessing Preconceived Expectations

'*Reassessing Preconceived Expectations*' is the sixth category in this grounded theory. It illuminates the range of psychological and social occurrences which assisted the participants to re-assess their experiences and to re-frame them in the light of a greater understanding of mental health and recovery. The participants' mental health problems and their experiences which had become a 'master status' was challenged by some participants through self reappraisal and through personal development. '*Reassessing Preconceived Expectations*' is divided into three sub-categories: '*Passing the Rubicon*', '*Developing a language of positivity*' and '*Using internal and external recovery catalysts*'. Although these processes did not occur in a linear way, for ease of explanation they will be presented here as separate entities. '*Reassessing Preconceived Expectations*' relationship to the other categories in this theory is demonstrated in figure 8.1.

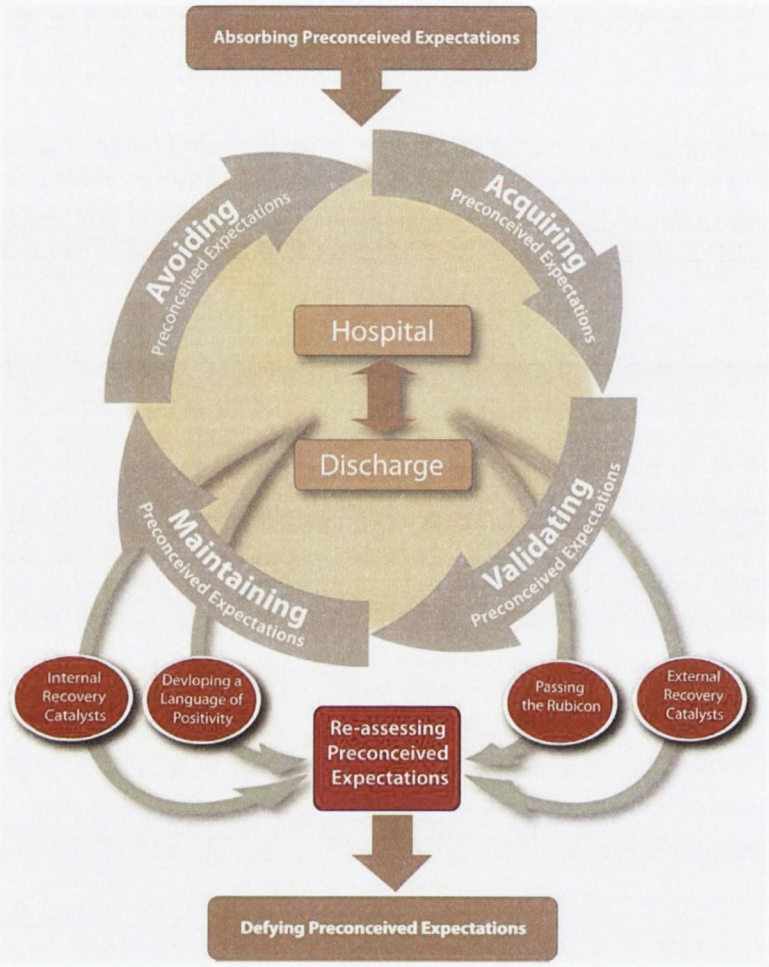


Figure 8.1: Reassessing Preconceived Expectations

1. Passing the Rubicon

'Passing the Rubicon' refers to passing a point of no return and in this context refers to the participants making a decisive, irrevocable decision to move forward with their lives. *'Passing the Rubicon'* describes how the participants' made a firm decision not to continue on their current trajectory of multiple readmissions to hospital interspaced with what they perceived as short relatively unproductive and unsatisfactory spells of living in the community. In addition, the avoidance behaviours, discussed in the earlier chapters were replaced with the participants desire to be more open about their mental distress. *'Passing the Rubicon'* also describes the participants' life affirming decision to no longer allow their mental health problems to dictate their existence or to have a negative impact on their lives. Ultimately, it describes how they made a decision to react in more positive way about their position in life and to alter their attitude about recovery.

Furthermore, it describes how the participants' proclaimed that their lives were going to be better and different and by making this proclamation they reaffirmed and reconstituted their identity, as a worthwhile person. *'Passing the Rubicon'* involved the participants redefining mental health and mental distress and the nature of people with mental health problems. This re-conceptualisation caused the participants to perceive themselves in a different way and to look at their lives through a different lens. It also allowed the participants' to view their experience through a more positive lens and by doing so they re-sized the impact of their experience and the nature of their problems on their lives. Even though the participants' mental health problems were not eradicated and problems with stigma and social exclusion persisted, they were better able to manage these problems and to minimise their impact. *'Passing the Rubicon'* required a determination that acted as a buffer to the environmental and societal stresses, such as stigma, that often remained. This determination provided the participants with a tenacity to succeed often in the face of adversity. This is apparent in the following quotation:

> 'Even though I'm not laden with a career, I don't have family, I don't have children, I live at home with my mother. But I'm determined I won't go back into a group home I'll fight for something better than that for myself, there will be a legacy from my mother's estate, and hopefully I'll have enough to buy something for myself, an apartment' (Male, Interview 11).

'Passing the Rubicon' did not occur immediately or in a defined moment. For most of the participants it was a gradual process that occurred over time and required an environment that could foster self belief and determination. For some it was about the recognition that things had changed, and that in order to reconvene a sense of order, they needed to foster these changes to stimulate personal development. This is illustrated in the following quotation:

> 'I thought ah sure I'm fine now, like we'd be going on a good few months from this now say. And I would have got myself back to work right and I would have been okay and that. And then I said to myself sure I'm fine now, I don't need these ol' tablets. Back to square one again, back in [hospital]. I kept doing it, until one day I woke up and said these tablets must be important to me because why do I keep going back into hospital. Changed the way I thought but it took a long, long time' (Female, Interview 24).

For other participants there was not any single event that acted as a turning point, it was more of a gradual realisation that they were not the only ones who had mental health problems:

> 'Well I couldn't answer that [what made him think about his mental distress differently] really because I just sort of said one day there's thousands like me, you know what I mean. There's thousands out there that have schizophrenia, you know and I said I'm not the only one you know' (Male, Interview 21).

The same participant when asked what helped him to stay out of hospital, provided this rather philosophical statement:

> 'It's knowing that your life has to go on' (Male, Interview 21).

And this notion

> 'just clicked' (Male, Interview 21).

Other participants found it difficult to articulate what occurred in their lives to make them decide that they were no longer willing to continue on this particular path. One of the participants' talked about an internal force that prompted her to realise that she did not want to continue her life as it was at that time:

> 'It wasn't that I got tired of it, it was more that I, something happened inside me that just made me realise that like you know I don't want to end, like anything that the doctor does I question him about like and I say will this like get, like me end up getting like, you know paranoid or you know' (Female, Interview 23).

Furthermore, when the participants pass the Rubicon there was a realisation that maintaining mental health was not going to happen on its own, and although other individuals may be able to help them, the participants had to take responsibility for their own mental health. This approach challenged earlier conceptions that biomedical interventions were the only interventions. In addition, it challenged the expectation that recovery from mental distress was impossible and unrealistic:

> 'Yeah, I think you come to a stage where you kind of go right I've to be responsible for making a life for myself and sometimes you get all choked up with things and you know you kind of feel oh my life isn't going well but you have to make it for yourself.....and I just kind of said to myself well you have to cop on, just for your family as well like, you know for myself as well and for my family' (Female, Interview 26)

2. Developing a language of positivity

'*Developing a language of positivity*' describes how the participants started to reframe their experiences by developing an understanding of mental distress and mental health. References were often made to the lack of explanations that occurred about the participants' mental health problem while they were in hospital. Their problems were discussed using a biomedical discourse that participants didn't fully understand. They longed for someone to come and offer an explanation of what was wrong, with simplicity. Each time they went into hospital they were left feeling confused about the nature of their problems. This confusion was sometimes exacerbated by their medical diagnosis which often conflicted with how they were feeling. On many occasions, the participants' had more than one diagnosis that sometimes appeared to conflict with each other and further heightened their confusion. In response to this the participants began to develop an understanding of the issues that negatively impacted on them, and this began by developing a language which aided their conceptual understanding of mental distress and mental health. The concepts of 'mental illness' and 'mental health' appeared to be used interchangeably to describe 'mental illness' or symptoms of mental ill health. One of the participants suggested that his recovery started when he began to develop a language of mental health and this helped dispel some of the myths associated with having a mental health problem, thereby, challenging his discredited status. For example, he would never have talked about 'mental health' as a concept; it would always have been about 'mental illness' and mental ill health. It would always have been about signs and symptoms and not about recovery:

> 'I didn't recognise that then, I didn't recognise that, and there was lots of conflict between herself [his mother] and me self over my lifestyle, but mental health wouldn't have been terminologies that they would have ever used, and I wouldn't have had the insight to bring the topic up neither, it wasn't until later years that I began to. Then I began to do it professionally, with the friends I made in the community, when I was in [names community organisation] where I began to relate to mental health, I didn't have the language to relate to mental health in my home life, and I'm only developing that now' (Male, Interview 18).

This lack or deficiency in a language around mental health problems came partly from not been given that positive discourse when in hospital or from the lack of discourse around mental health they were growing up. The only language that was

familiar was the stereotypical offensive language that was used in informal daily discourse such as 'nutter' or 'loony'. *'Developing a language of positivity'* happened in response to a real need for an in-depth understanding of mental health and emerged from the stereotypical assumptions associated with 'mental illness'. The participants were told that they had a life altering illness by healthcare professionals and that they were likely to require treatment, in the form of medication, for a long time. For most, this was all the information that was given. When this information was divulged during hospitalisation the participants were not able to absorb this information due to the overwhelming nature of their circumstances. Other factors such as the denial of discredited status discussed earlier may also have prevented or negatively impacted on hearing information about their mental health problem. In addition, explanations that were given during the participants' hospitalisation were steeped in biomedical rhetoric which was not given in a language of hope, optimism or recovery. Perceived power imbalances between participants and professional also prevented information being absorbed and reduced their ability to ask questions or clarify the information provided. A perceived lack of knowledge about mental health and mental distress was also a barrier to developing a language. This is best exemplified in the following quotation:

> 'No, I wouldn't have the confidence at the time [to ask questions], now I would like but at the time I wouldn't have the confidence, I was young as well like, you know, I would be intimidated by the doctor, me Mam wouldn't have been intimidated but she wouldn't have the skills, the kind of skills that me sister would have, me sister is very well educated and she just didn't like what was going on with the high medication' (Male, Interview 16).

There was no talk or discussion by mental health professionals about recovery, there was no talk of getting back to 'normal'. The emphasis was on difference and not normalisation. This lack of information and the absence of a language to articulate experiences forced participants to explore an understanding for themselves. Sometimes the participants' understanding of mental distress was erroneous and led to a process of self stigmatisation which perpetuated negative assumptions. Developing a language which explained mental distress helped the participants to not only understand their experiences but also to give a structure and meaning to their own unique experience:

> 'But I was never actually sat down and told this is schizophrenia, this is what it's about, this is the symptoms, this is how to deal with the symptoms, this is how you can get better and nothing like that like, it was all just, just like you're given the medication, you're sent off home and left there on your own like and so two years later I decided to look it up on the internet and got the ins and outs of the symptoms. That was actually a great help to me, maybe at some stage, the earlier stages, it might have scared me but when I was well enough to actually look them up it gave me great ability to think, like even for example when I was a bit paranoid at the time it was when I was at home thinking that cameras were watching me and stuff like that, when I read about other people's experiences having the same thing I was actually able to say well Jesus it's not just me, I'm not mad, there's actually other people have them experiences so it's not just on me own, you know' (Male, Interview 16).

Developing a language helped the participants to demystify their experience. Furthermore, it helped them to further contextualise their experience and helped them to equate the experience to something else, to some other illness for example, – to say to ones self that you can recover:

> 'Yeah I think that's it and a big thing is down to the lack of education, sometimes ignorance but sometimes mainly lack of education, which I'm a big believer in educating people around mental illness and normalizing it because to me like it's not different to arthritis or diabetes or something like that, it's just an illness that can be managed but because there's such a bad stereotype out there about mental illness people being mad and just the media portraying it and stuff like that, because of all them things people just look down on it kind of rather than just educating themselves and realizing it's just another part of life' (Male, Interview 18).

Coming to realise that 'you can recover' or 'learn to manage' and that it can be controlled was helpful for the participants. In addition, knowing that mental distress was a temporary phenomenon and that one could recover helped the participants to manage their experiences. Furthermore, conceptualising these experiences within a positive framework of planned action rather than reacting in a negative way which may have lead to readmission to hospital, was central to '*Developing a language of positivity*':

> 'Well you know you either go back to the drawing board with the [names drug] and maybe take an extra little bit at night if its really bad and usually that will settle it you know but like I mean just you know being able to realise and say ok this is an illness, its flaring up and you know I might need a bit more now or you know for a couple of nights and more or less it will sort things

> out, I kind of do have to make myself realise that those voices aren't real' (Female, Interview 26).

Developing a language occurred through reading about their experiences as well as talking to and listening to other people discuss their experiences. The participants used mostly information leaflets and internet sites as the primary source of information. This was sometimes referred to by participants as gaining an insight, not just into what had happened to them, but an insight into the person's sense of who they were:

> 'I gained that insight myself from reading up on it, and from listening to other people who had insight about it, mainly service users' (Male, Interview 18).

Another example of *'developing a language of positivity'* occurred where the participant talked about having two diagnosis' – one for 'schizophrenia' and one for 'schizoid tendencies'. He felt that both of these terms did not adequately explain the way he felt or the things he was experiencing. He doesn't remember where he first heard the term psychosis but he learned about it and thought that it better described what he was experiencing:

> 'Well my doctor diagnosed me with schizophrenia, also schizoid tendencies, where I heard the word psychosis first I don't know but it seems to suit as well what I have, or had. In my case yeah, for some other people schizophrenia would be right down the line you know' (Male, Interview 19).

One participant talked about just making sense of her experience in a relatively ad hoc way. While working on a helpline for a particular charity, she developed an understanding about her experiences through talking to people on the helpline and through reading the literature that was there in the organisation. Before that, the individual in question had no idea or understanding about what was 'wrong' or what was going on in her life:

> 'Well when I was in [names voluntary organisation], I kind of like, I used to come across it in, like I was on the helpline line and you know the literature in [names voluntary organisation] I would read that and just listening to people talking' (Female, Interview 15).

3. Using internal and external Recovery Catalysts

'Recovery catalysts' in this context are strategies that the participants used to help themselves to further their personal development and to remain well. This section presents the range of recovery catalysts used by the participants. Although the two

previous sub-categories are important, *'Passing the Rubicon'* and *'Developing a language of positivity'* do not occur without the influence of the various recovery catalysts that the participants used to propel them along a unique and individual recovery trajectory. To make the recovery catalysts easier to explain they are discussed here as separate entities under the heading 'internal' and 'external' catalysts. A concept that acts as an underpinning philosophy, particularly to the internal recovery catalysts is the participants desire to know themselves and to know what helps and what doesn't help.

a) Internal Recovery Catalysts

Internal catalysts refer to the range of catalysts that motivated and sustained a desire to maintain and develop positive self belief that the participant mainly did for themselves. Possibly the earliest recovery catalyst that occurred was the act of building a supportive network of people who had similar experiences to the participants. For most of the participants this began in hospital where there was recognition of the supportive power that other people with mental health problems had. The participants also appeared to draw strength from the mutual acceptance that is demonstrated between service users. They also felt a sense of acceptance and openness between each other because of their shared and common experience. This is demonstrated in an ability to talk to other people and to be candid about their experiences:

> 'Yeah, yeah, like I could, you can talk to anyone up there, do you know like sometimes you can't talk to your family, like when they look at their mum drunk, they don't want to know, mum is just a drunkard' (Female, Interview 1).

Participants talked about being able to freely discuss their experiences with other people who had similar experiences. This also occurred in hospital and the participants described getting on well and relating well to other people in hospital. For the participants' this sense of solidarity while in hospital was something that they valued and appreciated and assisted the participants in socialising to hospital. This sense of being open, honest and the sense of being free to discuss issues and problems continued to exist on discharge. Ultimately, other people who used the mental health service became the participants' major source of both emotional and social support. Furthermore there was also a sense that once people were forced into a marginalised group they were also forced to look to the other members of this group for emotional and social support:

> 'I mean you kind of, what you kind of do is you kind of stick to kind of like your own, it's terrible to say, like you know, people that have mental illness because you feel that they'll understand you better and stuff like that. I suppose it's like drug addicts, I mean they stick with people, alcoholics – they stick with alcoholics, gay people stick with gay people, so I don't know. It's like a little communities, you know.....Because they feel comfortable within them groups, they feel they can talk within them groups, you know, so that's just, you know. Now saying that as well I mean theirs is an awful lot of good people out there and they're very understanding towards mental health or whatever issue it may be, you know, but there is an awful lot of ignorance out there as well' (Female, Interview 8).

> 'The other patients, I think that helped me to come around as well because you know there were other people there sick as well as myself, you know so it brought me around a bit'(Female, Interview 26).

Later, this sense of acceptance became of paramount importance for this individual in question where she found that she created a new social circle consisting solely of her family and other service users. This occurred in response to the stigma and lack of acceptance she experienced from the friends she had prior to her experience with the mental health services:

> 'The friends I made in school, I stopped seeing them about 3 or 4 years ago, just because I just didn't feel they, I felt they didn't understand and I just kind of said right its just time to let those go, you know, those friendships go because you know our lives just went in different ways I suppose. I've made new friends since and probably better friends than I, you know and people that I can talk to about stuff, that I wouldn't have been able to talk to with my old friends like' (Female, Interview 26).

Meeting and developing relationships with people who had a shared experience minimised the sense of isolation that the participants experienced on discharge from hospital and fostered not only a sense of belonging but also promoted feelings of normalcy:

> 'And just listening to other people that had similar things and I felt like I was the big N word, normal, you know. Yeah, that's it, yeah, and just feeling like I wasn't the only one, I was breaking away from the isolation' (Male, Interview 16).

Furthermore, meeting other people with similar experiences allowed the participants to discuss their experiences in an open and reciprocal forum where there was an equal distribution of power. This reciprocal forum allowed for a sharing of ideas about the nature of mental health and mental distress that was

safe and non-threatening. It also allowed for what was described by one participant as a 'thrashing out' of ideas. This meant that the issues of interest and concern could be pulled apart using a language that was comprehensible to both parties, something that did not always happen when there were conversations with mental health professionals:

> 'And when I went there [names voluntary organisation], and I met some people then that I became, I met one particular chap that I became, that I'm still friends with today, and close friends we are, and that relationship was very supportive in he had a diagnosis of paranoid schizophrenia, and I had a diagnosis of paranoid schizophrenia, and we would, we would thrash out what that meant' (Male, Interview 18).

The purpose and advantages of this *'thrashing out'* strategy was clear. Trashing things out was the first key step in helping the participants to come to terms with having to manage their distress. It also assisted them to begin to review their perception of themselves and move beyond the label of 'psychiatric patient':

> 'We would thrash it out, we would work out where, how we could kind of alleviate ourselves of being, like low self esteem, and isolation, and even recognising paranoia, or considering paranoia within the communication, and all that sort of thing. So recognising even symptoms, or recognising, so that was the first time...'(Male, Interview 18).

It was more than just having somebody to talk too. It was about being an equal partner in the conversation – it was about being able to talk and be talked to at an equal level:

> 'I still have one good friend that I met in hospital that I meet regularly, and that is very lifting, to have somebody you can relate to and talk to' (Male, Interview 11).

Having someone to talk in this way counteracted the silence and lack of openness that occurred when the participants were talking to people who did not use the mental health services. Furthermore, it introduced the participants to a forum where discussion and learning could occur, consequently influencing the reassessment and reappraisal process.

Relationships with other people were also important in fostering a sense of recovery and optimism. For example, relationships formed with mental health professionals such as doctors and nurses which promoted an open dialogue about

participants' experiences and the impact on their lives were valued and desired. When this occurred, the dialogue was different to what happened previously. Participants also felt that they were listened to and that their specific needs were being met. This relationship with mental health professionals further encouraged honesty and truth telling within that relationship. These relationships fostered a sense of worth for the participants as well as encouraging the participant to reflect differently on their experiences:

> 'So it wasn't until I got much more friendly with the doctors and with the nurses and things, that I started to open up, and then the meds were improving as well. I could have a much more comfortable relationship with my doctors.... truth telling, and the doctor listening to you, is just as important' (Male, Interview 11).

Another internal recovery catalyst that many of the participants used was having a routine:

> 'I think the routine I have now, like coming here [community day centre] three days a week and I go to another place in the [names community centre], I go there two days a week' (Male, Interview 2).

Having a routine did not necessarily have to be about paid employment, although this was very important. It was mostly about keeping physically and mentally active, and achieving a sense of utility and purpose which was sometimes lacking because of difficulties getting a job or maintaining employment:

> 'I came home that Saturday and I felt more relaxed this time and I came home that Saturday I just started ironing and doing things and the house what hadn't been done. You know like trying to occupy my mind' (Female, Interview 1).

One of the positive by products of having a routine was being able to meet people and to have contact with people on a daily or weekly basis. This encouraged and fostered the formation of social and occupational relationships. As described in the following quotation, having a daily routine and staying occupied kept the participant in touch with other people and removed or minimised the social isolation that they felt:

> 'Yeah, I'm sort of more in touch with the people, I'd no real contact with anybody before and I find things working out for me much better' (Male, Interview 2).

It is important to note here that maintaining a routine and keeping occupied was not a solitary activity. It was mostly done in the company of other people. Many of the participants talked about the diversity of activities that they were involved in and how this involvement assisted in reassessing their preconceived expectations. For example these activities provided a structure for the participants, as well as environment for growth and personal development. Furthermore they described how the lack of routine and organisation following discharge arrested or slowed their assimilation to the sense of normalcy that they had prior to hospitalisation. For some the prescribed medication temporarily prevented them from pursuing previous activities or occupations:

> 'Well the medication at the start zonked me out but I suppose it was getting rid of the symptoms so it was doing its job and it had some side effects but then when that got into me system and I was able to manage it and the dosage went down and I was able to get me energy back I start doing me hobbies, getting back into me hobbies, sports, activities, all them kind of things and they're a big step, and then back with friends and a big social network of friends. And that was kind of my alternative therapy was sports and activities and stuff like that' (Male, Interview 16).

Entering hospital represented a loss of their familiar routine. When the participants were discharged from hospital there was an active desire to rebuild the routines that were familiar. This represented a return to independence as described in the next quotation:

> 'Well before I went into hospital, I would have been stopped in my tracks from what I was doing, so I would have came out of hospital, I would have had no routine, including sleep, well a sleeping habit maybe, and maybe I had a sleeping routine, maybe about the only thing I had, and eating routine, that would have fallen away to the wayside, but I had to build up once again all my activities, all the little nuances, or little activities that I had, whether they be good routines or bad routines, I still had to build up my own routines once again, and I found that journey, I was doing on my own' (Male, Interview 18).

The development of a routine also extended to self care activities such as getting up in the morning or taking ones tablets at the same time every day. Participants' described a routine that was permeated with periods of rest and relaxation which provided a balance necessary for mental health. Furthermore having routine involved being able to pursue the things that the participants wanted to do.

Sometimes it was an acknowledgement that there was more to recovery than just taking medication. This is exemplified in the following quotation:

> 'Well I like going for long walks, might walk down to [names location] or even sitting having a coffee with your friend in the morning times, talking about things, you know it helps. Like medication and all sometimes that doesn't help, that makes you worse I think' (Female, Interview 1).

The importance of keeping occupied was described by the following participant:

> 'Because if I'm not doing anything then my head starts racing and I just, you know, I think it's very important that I'm doing something during the day you know' (Female, Interview 23).

Another internal recovery catalyst was regaining control over life and having a sense of being in control. For example, one of the participants suggested that when he went into hospital he felt that he gave up his control. One of the ways that this manifested itself was through loss of voice or doing things that one didn't really want to do. This particular participant had electroconvulsive therapy which, he didn't want. He thinks now that given the same scenario he would not have treatments he didn't want again. The participants did not lose control in an actual sense; they had a perceived inability to control their lives which was perpetuated by a system that often tried to paternalistically protect people with mental health problems. Part of regaining control occurred once the participants regained their voices and began to ask questions and to seek out answers. This activity challenged their own and other peoples' perceptions of them as passive bystanders who passively accepted what had occurred rather than challenging it.

There was a recurring theme in some of the later interviews where the participants talked about self esteem and the negative impact that having a mental health problem had on that self esteem. The self stigmatisation that occurred when they had a mental health problem impacted on the participants' sense of worth and sense of self. Reclaiming sense of worth was difficult and one of the ways this occurred was through having friendships. Another way was through employment, which was not necessarily paid employment. Participants exclusively referred to their self esteem and to the impact that having a mental health problem had on it. This is exemplified in the following quotation:

> 'I met a girl in the day hospital that had a good influence on my life, she gave me a lot of confidence and helped to build up my self esteem' (Female, Interview 15).

When asked how this particular individual helped her to build her confidence and esteem the reply was very simple:

> 'Just being a friend' (Female, Interview 15).

Other recovery catalysts tended to be different strategies that the individuals used to affirm their worth. For example one of the participants talked about 'Angel cards'. These were cards that that had a life affirming statement written on each one. Another participant talked about reading books and listening to audio tapes which encouraged positive thinking. The participants believed these strategies, encouraged hope and a belief in a more hopeful future. Another participant used a self help text and praying to help her to stay well and remain positive and focused:

> 'It's just mostly like I have a book at home that I read, what is it – 'The Language of Letting Go'. And I find that very helpful and I got a book of prayers as well and I say my prayers like and that sort of like helps me as well you know. Different things yeah' (Female, Interview 23).

Another participant described a process where he was able to debunk and challenge what he described as 'unreal thoughts'. This participant who had spent long periods in hospital since he was a teenager was consistently troubled with intrusive thoughts of a religious nature. Part of his recovery required him to think critically about the distressing thoughts he was experiencing and to differentiate between thoughts that were 'real' or 'unreal'. He described these thoughts as 'schizophrenic thoughts' and he explained that they were thoughts that were retained even when he felt well. Debunking these thoughts allowed him maintain a wellness even though the 'schizophrenic thoughts' persisted:

> 'As time went on I had to debunk a lot of thoughts, I still have to debunk thoughts, you know get rid of them and say that's not true, that's only schizophrenic thought, you'd know when you have a schizophrenic thought in your mind and you can say well you shouldn't be thinking that' (Male, Interview 19).

The strategies that the participants used to reassess their preconceived expectations stem mostly from a desire to return to normalcy following their discharge and subsequent labelling as a 'psychiatric patient'. In addition the participants ability to reassess and re-contextualise their psychiatric experience

was heavily influenced by their hopeful optimism, or in the words of one of the participants:

> 'I don't know, I mean obviously to be able to look to the future with the possibility of good things in it, you know, yeah' (Female, Interview 26).

b) External Recovery Catalysts

External recovery catalysts describe the range of catalysts that occurred to assist the participant in the recovery process. As with the previous property (internal recovery catalysts) these interventions occurred in tandem with *'passing the Rubicon'* and *'developing a language of positivity'*. For the most part these interventions are not health care professional related but come from family and friends. They demonstrated how other people assisted the participants make a recovery or to rethink their perception of themselves and their circumstances. Furthermore they are directly related to the attitudes of other individuals rather than explicit helping actions. Arguably the most important attitude demonstrated was a belief in the participant's ability to succeed and to recover. Being believed in instilled a sense of confidence in the participants which reinforced and augmented their desire to move along their unique and individual recovery trajectory. This is highlighted in the following quotation where the participant talked about his parents:

> 'yeah, they [my parents] always gave me confidence, they kept saying to me you will get better, just keep going, you will get there, just to hear that, gave me a bit of confidence' (Male, Interview 16).

Hearing positive statements about recovery like this and being encouraged to believe in themselves helped to dispel the persistent beliefs that their mental health problems were lifelong. This negative self belief often became a self fulfilling prophecy. It helped to alter the way that they perceived themselves thus altering their perceptions of their future as a person living with mental health problems. Another example occurred where the participant talked about having a negative outlook on life; he described his outlook as 'bad'. However there was something that altered this perception - something that made him change his viewpoint and helped to turn it around. This was the support and encouragement he received from his family, and their belief in his ability to succeed. In the quotation below, the participant praises her mother and her family for the support and encouragement she received from them:

> 'I'm lucky because I get great support at home and from my family so I'm very lucky but like you know mam would say to me you're well able, but then say if I wasn't handling it ok she'd be the first to say [name] you know maybe you should think about taking a step back or you know, but like yeah' (Female, Interview 26).

Summary of *'Reassessing Preconceived Expectations'*

'Reassessing Preconceived Expectations' is the sixth category in this theory. *'Passing the Rubicon'* the first sub-category, describes a major turning point in the participants' lives. Although this was a major turning point, it did not necessarily mean that it was precipitated by a major event. For the participants who reached this point, it was generally a gradual dawning or realisation that they could no longer continue to live their lives worried about what other people thought of them. In addition *'Reassessing Preconceived Expectations'* described a range of internal and external catalysts that assisted the participants to re-conceptualise and re-contextualise their experiences with mental distress and the mental health services. This allowed the participants to view themselves and their experiences in a more positive light. In tangent with these processes the participants' began to develop a language of positivity which provided them with a greater comprehension of their experiences. The range of internal and external recovery catalysts described in this section provided the participants with motivation, hope and a desire to remain on a positive recovery trajectory.

Defying Preconceived Expectations

The final category associated with this grounded theory is *'Defying Preconceived Expectations'*. This category describes how some of the participants moved along a recovery trajectory to this final point in managing their concerns about other peoples' preconceived expectations about them following their discharge from hospital. The two sub-categories associated with *'Defying Preconceived Expectations'* namely *'Becoming a success'* and *'Maintaining mental health'* assist the participants to defy the prejudgements and assumptions that they were exposed to. Not all of the participants in this study managed to reach this particular stage in the process; however, many did speak of the recovery catalysts described in the previous section. For some the recovery catalysts provoked a re-evaluation of their position as a 'psychiatric patient' and challenged the persisting and pervasive view that people with mental health problems are no longer active or contributing members of society. In addition they challenged the notion that mental health problems are chronic and debilitating illnesses or disorders. This

category emerged in direct response to a desire to defy these negative assumptions. For the participants' in this study casting off the preconceived shackles of what it meant to have a mental health problem was important to their self development as an individual and for some it replaced their earlier avoidance or denial of their mental health status. Defying preconceived expectations was difficult but important – it was about not wanting to be a 'statistic', not wanting to be seen as one of 'them' or as a 'psychiatric patient'and not wanting to be pre-judged. This is exemplified in the following quotation which occurred early in the data collection process:

> 'I have to go through [names street] Street to get the bus to where I live, at the moment I live in [names area], and the times I see people there with cans in their hands and drinking and whatever and I'm just determined not to be one of that, well to be one of the statistics because I think I'm an individual, I don't see myself as a statistic or statistics. So I think that helps me' (Male, Interview 3).

As mentioned, *'Defying Preconceived Expectations'* is further divided into two sub-categories *'Becoming a success'* and *'Maintaining mental health'*. Its place in relation to the rest of the theory is demonstrated in figure 8.2.

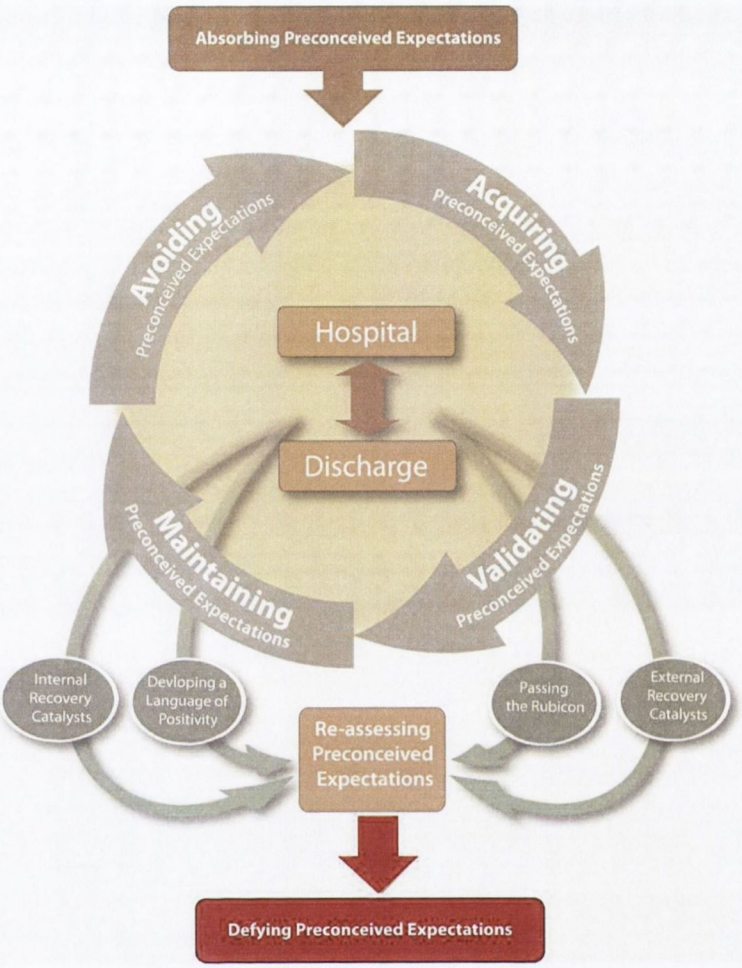


Figure 8.2: Defying Preconceived Expectations

1. Becoming a Success

As mentioned earlier, many of the participants gauged their success or indeed their mental health status by the length of time that they managed to stay out of hospital. Staying out of hospital was one indicator of success. For example, the participants perceived themselves as a success if they only have one admission to hospital or if there was a long gap between admissions. This aspect of becoming a success helped to challenge their own and other peoples' assumptions that if having a mental health problem meant having an unremitting and chronic illness. It also challenged the belief that periods of hospitalisation were not just necessary but to be expected. Becoming a success was also about the participants' being able to review their achievements and tell themselves that they had done something worthwhile with their lives. This happened despite an awareness that some people believed that they were unable to make anything of their lives because they had a

mental health problem. It was about articulating to themselves and to others - look, I have done something despite the limitations that society has placed on me:

> 'It partly did because after, a year, you know both in and out of the hospital at [names hospital] and [names hospital] hospital I have managed to stay out for 3 to 4 years. And I have managed in that time to do nearly 3 years of training, studying internet programming. I have done a course' (Male, Interview 17).

Becoming a success appeared to be about the participants being able to turn their lives around and being able to stifle or redress the negative perceptions that other people had of them. One of the participants described an aspect of this as being able to 'carry their illness well'. By this the participant meant that they didn't look or behave like someone who had a mental health problem. They did not act or behave like other people thought individuals with mental health problems acted or behaved. Part of this was a conscious decision to alter they way that other people perceived them through the way they acted or spoke, this allowed preconceived judgements to be avoided by attempts to 'pass' as 'normal':

> 'So I carried my mental illness very, very well. Like I don't go around beating my chest about it, and say to everybody I meet "I'm mentally ill" I don't. But if I'm in a situation where somebody needs to talk about it or that, I can do. And I get on fine with it' (Male, Interview 11).

Another participant suggested directly that he was a success story:

> 'But I see myself as, as an element of having a success story, you know' (Male, interview 18).

In the above quote, the suggestion here is that other people with 'mental illness' do not make a recovery or they do not become 'success stories'. To be a success, to make something of their lives was to be an exception to the rule. This occurred because other people made the assumption that the participants were relegated to a certain career of 'mental illness' as described by Scheff (1999). These assumptions were difficult to shift or to change and remained with other people despite the participants' attempts to improve and turn around their lives. The participants often had to inform other people that they were not the same person they were in the past and that they deserved to be treated in a different way because they have now managed to make a success of their lives:

> 'I got an opportunity to explain to him [old acquaintance] that I was working in mental health, and I had a job, and things were

> going well, and I've a partner, and I'm living up in [names location], and all that sort of thing, I got all that out to him, and he began to relate to me' (Male, Interview 18).

Becoming a success and defying the preconceived expectations was best summed up in the words of one of the participants based on his turbulent experiences with the mental health services:

> 'Like I've gone from the stage of trying to commit suicide because I was a psychiatric patient, to going on national radio talking about it' (Interview 11).

2. Maintaining mental health

As the participants utilised the internal and external recovery catalysts and as they progressed along a positive recovery trajectory they began to re-contextualise their experiences and the way they thought about their mental health. They began to think about their mental health in a less abstract way and seen it as a tangible construct that could be maintained and nurtured. This encouraged a move away from their traditional perceptions of mental health as purely an 'illness'. This was important as it helped the participants to differentiate between mental health and 'mental illness' and acknowledge that although the two concepts can be separated, there was a relationship between them and knowledge about this relationship was imperative to a successful outcome. The first step in *'maintaining mental health'* following this revelation was learning about their individual mental health. This required a certain amount of self analysis and a level of personal insight which challenged existent beliefs about the nature of people with mental health problems. *'Maintaining mental health'* required the participants to examine their experience in light of their beliefs about 'mental illness' and mental health. In practical terms this necessitated the participants familiarising themselves with both their 'illness symptoms' or their individual reactions to mental distress, as well as their mental health. In addition the participants developed knowledge of the triggers to their mental distress /relapse and learned how to avoid or cope with these more effectively. This development of a personalised knowledge was effectively a rethink of earlier strategies which concentrated on biomedical strategies although it does not ignore or deny their value. It also recognised the importance of stress as a variable that impacted on mental health and equally the importance of reducing stress and its negative consequences. This is demonstrated in the following quotation:

> 'It's hard to tell, like I don't know if it's because they can't get a medication that can suit or is it that their own personal things that they're doing in life is not working well. Like I know like the two big triggers of mental illness for me that I know of is stress and illicit drugs. So meself like it's always been stress that trigger my two episodes so I just have a belief if people keep stress free and drug free and stuff like that they can have a better chance and then just doing things that, getting routine into their day and doing things they enjoy doing and doing things that make them happy and keep away from things that stress them out and just routine. They're tips to getting well but like I know there is people that don't make a full recovery and just have the life long symptoms. But even like I know people that work with me and even people in a high position in (names University) who actually still hear voices and they learn to cope with them things and they learn to deal with them and to maintain them and live every day and still go about their every day with the symptoms of mental illness so it's a matter of just coping and getting on with things and getting into a routine, getting into the kind of things that keep you going' (Male, Interview 17).

Part of this re-contextualisation was also about altering the outlook that the participants had on their lives and redressing the imbalance between positive and negative thinking. This assisted the participants in learning to have a greater involvement in their own life and the things that they do to stay well:

> 'I was very negative years ago and now I feel more positive about myself and I try and get involved with things you know now than I did years ago. Back then I wouldn't have done what I do now you know. Stayed in my house and that was it like and not did anything like for myself like' (Female, Interview 23).

Maintaining mental health was about realising or coming to terms with the notion that they had mental health and not just mental distress. There was a realisation that mental health is ever present whereas mental distress appeared to come and go on a continuum which was influenced by other factors such as stress. When mental distress occurred, it took some time for the participant to realise that it was a temporary anomaly on a mental health trajectory and that the participants are more vulnerable to poor mental health. Therefore they needed to have a heightened awareness of their mental health. The focus of the mental health services therefore, according to one of the participants, was support for his mental health, rather than treatment for his mental illness:

> 'But understand them, I can, I feel that, now I feel that I need to take care of my mental health, and that I'm in a risk group, and that I need support for my mental health' (Male, Interview 18).

Initially, for the participants', having a mental health problem and being diagnosed with a 'mental illness' was all about getting out of hospital and attempting to deny to themselves and others the presence of mental distress. Rather than encouragement to accept their vulnerability to distress there was a desire by both mental health professionals and the participants' to categorise the illness into symptoms and to abolish or minimise these symptoms with medications. This meant that the focus was on pathology which impacted negatively on the persons sense of self, reinforcing the perceived abnormality of their situation. The participants exposure to recovery catalysts coupled with a sense of determination to alter their recovery trajectory assisted them in reclaiming their identities as not just individuals with a 'mental illness' but individuals who for whatever reason have sensitivity to environmental, psychological, or biochemical stressors which they needed to be aware of. This discovery of self promoted self understanding and gave the participants a direction in terms of how they wanted to lead and live their respective lives. Re-conceptualising 'mental illness' in this way assisted the participants to reclaim their identity. By doing this they were able to minimise the impact that being diagnosed had on their lives by re-sizing it so it becomes a facet of their identity rather than dictating and influencing their entire identity:

> 'But I know the effects to my mental health. So it has made a, it has changed my life I'd say, or given me a sense of direction maybe. And its more a journey, there was no one time, I mean coming out of hospital, when I was in hospital, I just worked towards getting out of hospital, that was my focus, just to try and get out of hospital. But I think my self image improved. I have become more understanding of myself, whereas up until I was first hospitalised, it was all about having the craic, and now I seem to have the craic and yet I'm taking care of myself, you know' (Male, Interview 18).

Speaking to others and listening to other peoples experiences was seen as important. These communication strategies helped the participants to learn valuable insights about themselves and mental health. This was an ongoing journey of self discovery:

> 'And then my brothers are alive, and I'm in communication with them, and that would be part of the communication kind of developing insight with them about mental health in general, and we utilise my experience as the catalyst for how to relate to mental health. We're still in the infancy about that now, we're still, I suppose we're talking a lot more now since my mother passed on, but I know in developing that with my older brother, definitely, and my younger brother, who lives here, he's very

> supportive and has a big listening ear, and would give me his angle on things' (Male, Interview 18).

Another aspect of '*maintaining mental health*' was learning to assimilate the experience of 'mental illness' and hospitalisation into ones life. This was about putting the experience in context, minimising the experience and putting it firmly into the past as a reference point for learning and development:

> 'I would see meself as having had schizophrenia, not having it, I think that's the way, and people are like, like you know, it's probably similar to an alcoholic, a person that has alcohol problems. They might be twenty years off the drink but they still call themselves an alcoholic. I think do I still have to call meself a schizophrenic for the rest of me life because I'm not a schizophrenic, I'm someone that had experience with schizophrenia, so that's one way of looking at it but as I say the stigma and discrimination is huge in society today' (Male, Interview 16).

'*Maintaining mental health*' was about going about things as normally as possible. It was an attempt not to focus on or be over concerned about the mental distress all the time. In order to move on the participants needed to move away from the concept of 'mental illness' which was a negative phenomenon which attracted negative images and negative stereotypical assumptions – to mental health which was much more positive and inclusive. 'Mental illness' was a concept that was exclusive and isolating, mental health on the other hand was open to all. Recognising this gave the participants permission to make mistakes and to have setbacks and to recognise that these were a normal part of life and not only for those with a diagnosis of 'mental illness'. This challenged the way that they saw themselves and required a modification of self perception that no longer defined the participants in terms of just their experiences with 'mental illness':

> 'and I don't really consider myself mentally ill. Its like a friend of mine said years ago, he said "I had a break through, not a break down" (Male, Interview 11).

'*Maintaining mental health*' put a different perspective on the participants' notion of disclosing their experiences to other people. Discovering a voice and being able to talk about their experiences in a safe, non judgemental and equalitarian environment was perceived as extremely helpful. Being able to be open about their experiences was cathartic because it released them from the confines of silence which was what they were previously used to and in some cases actively encouraged to do. This is highlighted in the following quotation:

> 'It was great to get it off my chest to all the, because what I did was, I went up to the clinic and I asked could I see a doctor, in [names location], and there's a girl there, she's still there today, and she's from [names location]....and I knew her and liked her, and I asked could I speak to her, I wanted to tell her my story. So that was the first time, it was about the time that I was starting [names antipsychotic drug] so it was kind of a watershed for me' (Male, Interview 18).

Being able to talk about their experiences assisted the participants in the building of esteem and confidence which fostered a sense of control on their lives. This promoted their ability and confidence about having a say in what went on in their lives and the treatment that they received. It removed the sense of role passivity that they were expected to fulfil when they were discharged from hospital and the perception that they should remain invisible like their distress. Being more open about their distress and disclosing in this way also challenged the way other people perceived those with mental health problems. An example of this is contained in the following quotation:

> 'I remember just confiding in one woman after about six months and she said oh my God, you would never have known, and she was great about it, like you know' (Male, Interview 16).

The point raised in the above quotation was that she 'never would have known' – its interesting because the participant had defied typical expectations of what it was like to have a mental health problem or what you look or act like when you have a mental health problem. One doesn't look like someone who had a 'mental illness' one looked like a 'normal' person, people were not able to pick them out of the crowd and they were able to blend in. Furthermore there was a feeling of altruism to some aspects of disclosure where the participant disclosed their experiences in an attempt to help, support or educate another person with similar experiences:

> 'But if I'm in a situation where somebody needs to talk about it or that, I can do' (Male, Interview 11).

Here the participant in question furthered this desire to educate and help other service users and to influence and change the mental health services through his involvement with the service provider to provide more individualised and specialised care:

> 'If that relationship is good it can be very rewarding, so I'm doing things now like the integrated care plan up in (names

> hospital), and that involves sitting down with the team of doctors, nurses, social workers, community nurses, and myself, and we thrash through how they handle the treatment of patients' (Male, Interview 11).

However, stereotypical attitudes and perceptions were persistent and other peoples' perceptions of 'mental illness' as unremitting and lifelong were difficult to shift. In the following quotation the participant describes what he felt occurred after he disclosed his experiences to a potential girlfriend:

> 'But that's once again the same thing, some people just haven't got the tolerance and the patience for them kind of things and she didn't realize that I was well and I was gonna stay well as long as I kept maintaining me mental health but she couldn't just see that side' (Male, Interview 16).

Summary of '*Defying Preconceived Expectations*'

The final sub category in this substantive theory describes how the participants defy the preconceived expectations that they feel are placed upon them because they have a history of mental health problems. They did this using two processes: firstly, by '*becoming a success*' they defied the expectation that they were unable to have successful outcomes following their 'illness' and hospitalisation (e.g. getting a job). Secondly they defied expectations by '*maintaining their mental health*', thus, defying the expectation that their illness was life long and unremitting and that they are always close to 'having a nervous breakdown' or being admitted to hospital again.

Conclusion and Summary of Chapter Eight

This chapter described the final two processes associated with this grounded theory. These processes describe how the participants in this study reassessed their position as 'psychiatric patients' and decided that they did not want to continue letting their experience of mental distress impact negatively on their lives respectively. This decision was preceded by and supported by their use of recovery catalysts and a change in the way they interpreted their experiences. The four processes associated with '*Reassessing Preconceived Expectations*' acted as a segue and prompted the participants to use the strategies associated with '*Defying Preconceived Expectations*'. In the final stages of the entire process the participants actively challenged the misconceptions commonly held about people who experience mental distress through '*becoming a success*' and '*maintaining mental health*'.

Summary of the Research Problem and the 'Managing Preconceived Expectations' Theory

The last three chapters have presented the emerging '*Managing Preconceived Expectations*' theory in some detail. Prior to moving on to the discussion of the findings, this concluding section to this chapter will provide an overview of the research problem, the methodology and the emergent theory. The high number of readmissions to hospital in Ireland and an interest in the concept of relapse prevention prompted the development of this research whose central aim was to explore mental health service users' experiences of going home from hospital. Despite the availability of an extensive literature on relapse prevention and related concepts, there was a lack of information which explored service users' actual experiences of discharge and going home from hospital. Grounded theory as described by Glaser and Strauss (1967) and Glaser (1978) was used as the methodological approach. Classic grounded theory was chosen as I wished to develop a substantive theory which explained the psychological and social processes that occurred when mental health service users went home form hospital.

Data was collected using interviews and participants' were recruited from two mental health services, from vocational training organisation and from a voluntary organisation. Data collection and data analysis occurred simultaneously and thirty five interviews with 31 participants who had all been discharged form hospital were completed. In line with grounded theory methodology, theoretical sampling was used and interviews, although unstructured initially, became more focused as the data collection and data analysis progressed. Data was analysed using the constant comparative method and memos were written which detailed the analytic processes and the emerging theory.

Simply put, grounded theory requires researchers to search the data for the participants' main concern. Once this is articulated, researchers must find the processes that the participants use to continually resolve this main concern. The substantive theory is generally presented using a core category and a number of related sub-categories. The articulation of the main concern and the core category proved to be a complex and difficult task. My analysis of the data culminated in the emergence of a main concern and core category that was conceptually distant from

the reasons that I completed the research in the first place. *'Managing Preconceived Expectations'* was chosen as the main concern as it clearly explained the issues that impacted negatively on the participants when they were discharged from hospital (i.e. the negative assumptions that their social audience had about them once they were discharged from a psychiatric hospital). *'Managing Preconceived Expectations'* was also chosen as the core category as it had the most explanatory power in describing how the participants continually resolved their key concern.

The *'Managing Preconceived Expectations'* process is divided into seven categories: *'Absorbing Preconceived Expectations'*: *'Acquiring Preconceived Expectations'*; *'Validating Preconceived Expectations'; 'Maintaining Preconceived Expectations'*; *'Avoiding Preconceived Expectations'*; *'Reassessing Preconceived Expectations'* and *'Defying Preconceived Expectations'*. *'Absorbing Preconceived Expectations'* describes how prior to the participants contact with the mental health services they had already formed certain conceptualisations of mental distress. They conceptualised mental distress as something that was poorly understood, something to be feared and something to be ashamed of. When the participants were admitted to hospital they developed and learned additional understanding of mental distress through their interaction with the psychiatric services including the other service users and staff. This included an indoctrination into the biomedical interpretation of mental distress and the absence of hope for the future once the participants were diagnosed with a 'mental illness'. Furthermore, once the participants' came into contact with the mental health services they were encouraged not to tell other people about their experiences.

When the participants were discharged from hospital, the conceptualisations they formed prior to their contact with the services and during their admission to hospital were validated. This impacted on the participants interpretation of their experience and they articulated this as 'feeling different' once they went home from hospital. Furthermore, the conceptualisations they had about mental distress and the people who use the mental health services were further reinforced through the processes associated with *'Maintaining Preconceived Expectations'*. The participants' interaction with the mental health services and the reactions of their social audience once they were discharged provoked a number of processes conceptualised as *'Avoiding Preconceived Expectations'*. These were: *'socially*

disengaging' where the participants became socially isolated and *'denying discredited Status to Self'* where the participants denied the presence of a mental health problem and attempted to continue their lives as before. *'Cautious disclosure,'* where the participants either withheld information about their mental distress or altered aspects of their biography to suit the various social audiences they were in contact with also assisted the avoiding processes. Along with these processes was *'Justifying Otherness'* where the participants rationalised their social audiences' reactions to them following their discharge from hospital.

The final two categories *'Reassessing Preconceived Expectations'* and *'Defying Preconceived Expectations'* describe how the participants move along a more positive trajectory and develop a more meaningful and positive relationship with their mental health and their experiences of mental distress. Firstly, the participants' re-examined their experiences and this provided them with a greater understanding of mental health and recovery. This re-examination was influenced by a number of factors which are described here as *'recovery catalysts'*. In addition, the participants also made an irrevocable decision not to allow their mental distress to override the other facets of their identities. The processes described in *'Reassessing Preconceived Expectations'* proved for some of the participants to be a segue to the final process in this grounded theory. In *'Defying Preconceived Expectations'* the participants actively defied the preconceptions that were made about them because they had a mental health problem. They did this in two ways: through *'being a success'* and *'maintaining mental health'*.

The next chapter will discuss the *'Managing Preconceived Expectations'* theory in light of related literature and theory.

CHAPTER NINE: DISCUSSION OF THE FINDINGS

Introduction

The previous chapters examined the emergent *'Managing Preconceived Expectations'* theory; however, this discussion generally occurred in isolation to existing theoretical explanations that might aid understanding of the emerging concepts within the theory. The purpose of this chapter is to discuss the theory in light of other existing empirical literature and theory. It will therefore consider the *'Managing Preconceived Expectations'* theory from a number of different perspectives. Consequently this chapter will examine mental distress as 'other', the existence of mental distress based stigma and how the participants managed this stigma, power in social relationships, and the absence of a recovery orientated services. Finally, this section will discuss how the development of this theory challenged my own personal expectations about the nature of mental distress and the people who use the mental health services.

Managing Preconceived Expectations: Indoctrination into the World of 'Other'

The concept of 'other' describes the perception of people with mental health problems as looking and acting differently from other people (Foster, 2007). In this sense 'other' describes those individuals who are set apart and differentiated from society as they do not conform to conventional social norms. Within this study, the participants' admission to hospital and subsequent discharge immersed them into a world of 'otherness'. This sense of 'otherness' was not only applied by their social audience but by themselves as well. This relegation into the world of 'otherness' occurred through the application and maintenance of the deviant label of 'psychiatric patient' which was applied to the participants when they were admitted to hospital and subsequently discharged.

The sub-category *'Absorbing Preconceived Expectations'* suggests that prior to the participants' admission to hospital they had already been socialised to perceive people who experience mental distress as 'other'. Their subsequent contact with the mental health services and the processes associated with *'Acquiring Preconceived Expectations'* and *'Validating Preconceived Expectations'* firmly indoctrinated and reinforced their perceptions of people who experience mental distress as belonging to the world of 'other'. Foucault (1989) argues that the society we live in has been socialised to perceive 'madness' as 'other'. Early institutional treatment regimes fostered this sense of otherness by concentrating

on segregation and social distance between those who were considered 'normal' and those that were 'mad' (Foucault, 1989). In this study, the participants' sense of otherness was experienced as feeling different following their discharge from hospital. In short, the theory presented here suggests that the formation of negative social stereotypes by the participants about the nature of mental distress was inevitable given the harmful images and discourse that exist everywhere about people with mental health problems.

The participants' self identified lack of knowledge and understanding of mental distress supports the standpoint that negative beliefs, attitudes and stereotypes about mental distress were unconsciously memorised and reactivated (Turner, 1982) once they came in contact with the mental health services. In addition their conceptualisation of mental distress as something to be feared and something to be ashamed of reinforces Stangor and Schaller's (1996) assertion that social stereotypes were formed through collective belief systems and that learning occurred from indirect sources such as the media. Furthermore, it also supports the proposition that society itself stores knowledge about social groups and these are shared through communication and the language we use when we are talking to each other (Stangor & Schaller, 1996). In this sense the participants had been prepared for their graduation into 'otherness' through the socialisation processes that they were exposed to as they were growing up. The '*Managing Preconceived Expectations*' theory therefore supports Scheff's (1999) assumption that conceptions of mental distress are developed in early childhood and are continually reinforced through the mass media and through our daily discourses about the nature of mental distress. Furthermore, it challenges Gove's (1980) hypothesis that labelling and stigma are generally innocuous phenomena that have a negligible impact on users of the mental health services.

A number of participants in this study discussed the role of the media particularly television and film, in shaping their understanding of mental health problems. Thornicroft (2006) argues that because there is little information about mental distress within formal educational strategies most of what people learn comes from the mass media. This is supported by Philo (1996) and Hinshaw (2007) who suggest that education may mitigate some of the negative attitudes that are commonly held about mental distress. However, Hinshaw (2007) advises caution about the nature and scope of educational strategies as it may further perpetuate

extant social stereotypes if it emphasises chronicity and negativity. Furthermore, Wahl (1999) argues that the public's negative perception about people with mental health problems stems from the misinterpretations that are gleaned from the media rather than from direct contact or observation of people with mental health problems. He believes that individuals respond to the stereotypical images displayed through media such as the cinema, who consistently portray people with mental health problems in a negative light. This ultimately leads to stigma, fear of disclosure, guilt and shame (Wahl, 1999). Although there is considerable work describing media representations of mental distress (for example Philo et al. 1982; Signorielli, 1989 and Philo, 1993; 1996), Stout et al. (2004) suggest that this research is 'flawed' and limited in scope. In their view, the majority of this research measures the number and type of depictions without offering an explanation of how these images influence attitudes and behaviour or challenging such imagery (Stout et al., 2004).

Two theories that may explain the effects of media on attitudes and perceptions of people with mental health problems are social learning theory (Bandura, 1977) and cultivation theory (Gerbner & Gross, 1976). Bandura (1977) suggests that psychological functioning and behaviour can be explained through a continuous interaction between personal and environmental determinants. Consequently learning occurs through the observation and replication of individuals' behaviour. With regard to the mass media, writing mostly about cinema and the television, Bandura (1977) suggests that these mediums can become symbolic models. The more that versions of reality are derived from the mass media as a symbolic model, the greater their impact on social learning. The social learning view basically argues that what we see and hear within the mass media will influence our behaviour. The '*Managing Preconceived Expectations*' theory suggests that the participants' understanding or indeed misunderstanding of mental distress prior to the contact with the mental health services had been formed from watching television and from interaction with their social world. '*Absorbing Preconceived Expectations*' in this sense reflects the participants' unconscious learning about mental distress that was perhaps brought to consciousness once they were admitted to hospital and the label of 'mentally ill' applied to them.

Cultivation theory, on the other hand, concentrates on attitudes rather than behaviour and argues that the mass media (mainly television) 'cultivates' extant

attitudes and beliefs thus reinforcing and propagating them. Emanating from the work of Gerbner and Gross (1976) cultivation theory believes that the more individuals are exposed to particular stimuli the more it influences their perception of reality. Through the medium of television, symbolic meanings about phenomena are communicated and it is this symbolic meaning that influences perceptions of the world. For example, images that depict people with mental health problems as violent reinforce the belief that everyone with a mental health problem is violent. In terms of its symbolic effects, the cultivation process therefore leads to a homogenising of opinion where heavy viewers of television will all have similar attitudes and perceptions of the world they live in.

In support of cultivation theory, Diefenbach and West (2007) tested a number of hypotheses around television viewing and attitudes towards people with mental health problems. They concluded that people with mental health problems are disproportionally represented as violent criminals who have an overall negative impact on society in general. These depictions influenced the participants in their study's attitudes towards people within the mental health services. Furthermore, it negatively influenced their beliefs about levels of safety given the community orientation of the psychiatric services. Granello and Pauley (2000) specifically tested individuals' tolerance towards people with mental health problems using a community attitude toward the mentally ill survey. They sampled students (N=183) whose primary source of information about 'mental illness' was television. The results showed that students were more likely to demonstrate authoritative attitudes and less likely to demonstrate benevolence and community care ideology the more television they watched. Augmenting Gerber and Gross's (1976) assertion that heavy users are more likely to be influenced, they maintain that even moderate viewing is linked with intolerance.

McQuaid (2010) suggests that the study of methods of mass communication is underpinned by the assumption that media depictions of mental distress do influence attitudes and behaviours towards people who use the mental health services. However there is stark disagreement to the extent and nature of this effect (McQuaid, 2010). The research to date has mainly concentrated on the prevalence of social stereotypes about mental health service users within the media and the tendency to exaggerate these social stereotypes. Social learning theory and cultivation theory have attempted to explain a causal link between

media representations and the maintenance of social stereotypes although they have been criticised. More recent media representations according to Harper (2008) have become more positive and sympathetic but with this there are new and different challenges. For example, there are many examples of sexist and racist portrayals of characters or representations that perpetuate the social stereotype that there is a thin line between madness and genius (for example the Oscar winning drama 'A Beautiful Mind'). Furthermore, although non fictional accounts of mental distress are now more prevalent, they often perpetuate the biomedical view of mental distress. In addition, media representations often associate violent behaviour with non adherence with medication (Harper, 2008) further perpetuating the biomedical model. In this study, the participants were able to conceptualise 'mental illness' from a number of different viewpoints: something to be feared, something to be ashamed of something that was poorly understood. It is likely that the participants' conceptions of mental distress were already formed prior to their contact with the mental health services. The '*Managing Preconceived Expectations*' theory presented here, supports the hypothesis that media images of mental distress are in some way influential to the '*Absorbing Preconceived Expectations*' process. As suggested here, the media may have reinforced these representations of mental distress through non-fictional (biomedical and disease based conceptions) and fictional (fear and shame based conceptions) depictions of mental distress. In addition, the participants' conceptualisations of mental distress were also reinforced by their experiences in hospital and when they were discharged. In the first instance, their conceptualisation of mental distress as shameful was reinforced and perpetuated by their social audience once they were admitted and subsequently discharged. Furthermore, their encounters with stigmatising attitudes also reinforced the beliefs that they had picked up through their socialisation process.

Managing Preconceived Expectations: Evidence of the persistence of Mental Distress Based Labelling, Stigma and Social Exclusion.

The theory of '*Managing Preconceived Expectations*' provides evidence of the continued existence of mental distress based stigma. All of the participants described instances of stigma and this experience shaped their behaviours following their discharge from hospital. The term stigma according to Goffman (1963) refers to attributes that are extremely discrediting for individuals who possess them. Stigma is defined by Bryne (2000:65) as a:

'Sign of disgrace or discredit that sets a person apart from others'.

Although most work on stigma has emerged in the shadow of Goffman's Work 'Stigma: notes on the management of a spoiled identity' (Goffman, 1963), recent conceptualisations of stigma however place an emphasis on stigma as a process rather that a distinct entity. As a process stigma occurs once a person has been labelled as deviant. This label carries many negative characteristics which are uniformly applied to a social group resulting in status loss, social exclusion and discrimination. Therefore, it is the consequences of stigma rather than the stigma itself that cause problems (Becker, 1963). Central to labelling theory are the existence of negative stereotypes which characterise groups of heterogeneous individuals with negative attributes. In this study a number of attitudes and beliefs about people with mental health problems were universally applied. These attitudes have been described as dimensions of mental distress based stigma and are summarised in the table below.

Dimensions of 'Mental Illness' Based Stigma
Authoritarianism – People with mental health problems are unable to make life decisions and therefore they should be made on their behalf.
Benevolence – People with mental health problems need to be cared for or are unable to care for themselves.
Fear and Exclusion – People with mental health problems are unpredictable and dangerous and should therefore be avoided.
Blame – People with mental health problems are somehow responsible for their 'illness' and therefore do not warrant sympathy.

Table 9.1: Dimensions of Mental Distress Based Stigma (Hayward & Bright, 1997)

It is suggested in this study that the participants had already developed a number of the negative stereotypes about mental distress, as described above, prior to their admission to hospital. While in hospital additional beliefs were acquired and these were subsequently validated and maintained following their discharge from hospital. However it was also the practices that the participants encountered while in hospital that contributed to the self stigma that they experienced. For example, in the process *'Acquiring Preconceived Expectations'* the mental health practitioners that the participants encountered in hospital introduced the notion of mental distress as life long and unremitting. Furthermore, mental health practitioners working in the community sometimes used the threat of rehospitalisation as a means of ensuring compliance with treatment regimes thus reinforcing the notion that hospitalisation was a negative experience. Enacted stigma was generally experienced following their discharge from hospital and

served to augment the sense of otherness that they experienced. For example, the participants were often very reluctant to disclose their experiences of mental distress for fear that they would be ostracised from social groups. Although community care both abroad and in Ireland is considered as a way of redressing social exclusion and segregation, the findings from this study suggest that labelling and mental distress based stigma remains prevalent.

In this study the participants underwent a formal phase of labelling by being admitted to hospital and being diagnosed as 'mentally ill'. This labelling process mirrors the boundary maintaining ceremonies Erikson (1966) described in his book about wayward puritans. He argues that boundary maintaining ceremonies serve to inform those that have been labelled that they have violated the norms and values of a given society. This labelling ceremony is seldom reversible (Erikson, 1966) and in this study the participants were conscious of their 'spoiled identity' (Goffman, 1963) and their new 'psychiatric patient' role. Furthermore, Erikson (1966) maintains that those labelled are confused about their role when the sanctions for breaking social norms have finished (in this case following the participants discharge from hospital). The confusion and uncertainty following their discharge was articulated as a feeling of difference. This feeling of difference impacted on their sense of identity in a way that it influenced their self concept, consequently influencing their behaviour. For example, the participants felt ashamed about their label and did not want to meet people they knew in case they had to disclose their experiences. Furthermore their experience as 'psychiatric patients' became a 'master status' consequently overriding their other identities (Becker, 1963; Erikson, 1966). Equally confused about the participants' role following their discharge from hospital were their social audience and this confusion led to the dimensions of 'mental illness' based stigma being applied by a number of audiences, including the participants' family and friends. This was demonstrated through their avoidance of contact with the participants or through their perpetuation of the social stereotypes that exist about people with mental health problems (for example, their social audience believed that they could not recover because they had a mental health problem).

According to Turner (1982) the participants' tendency to self stereotype may have occurred through a process that he describes as a 'Referent Informational Influence' (RII). Turner (1982) argues that individuals categorise themselves as part

of a distinct social group. Consequently they form or learn the norms of that social group and these norms are based on stereotypes. These stereotypes are either learned through the socialisation process or from their contact with exemplars (the exemplars can also be themselves). They then determine that certain behaviours are characteristic and attributes of that distinct social group and these are applied to themselves as well as other members of that particular group. Consequently their behaviour becomes more conformist or normative with the acceptance of social group membership. The RII as described by Turner may explain why, on discharge, the participants reacted to their contact with the mental health services through the processes associated with '*Avoiding Preconceived Expectations*'.

Goffman (1959) also emphasises the socialisation process that occurs by borrowing one of Merton's concepts 'anticipatory socialisation'. Here it is argued that the adoption of a new position in society (in this case the assumption of the 'psychiatric patient' position) is fraught with difficulty as individuals are often unsure of how to act within this role. However, Goffman (1959) maintains that the process of socialisation ensures 'that he already has in his repertoire a large number of bits and pieces of performances that will be required in the new setting' (p.79). This is possibly best exemplified in the categories '*Avoiding Preconceived Expectations*' in particular '*perceived reaction concealment*' where the participants do not disclose their mental health status for fear of rejection or embarrassment. This decision not to disclose was often based on a perception that they would be stigmatised rather than direct experience.

Evidence of the continued existence of stigma and social exclusion is also revealed in the participants social circumstances. For example, of the 31 participants, only six described themselves as being in fulltime employment. Of those six, half were employed with agencies that were sensitive to employing people who used mental health services. A further five of the participants were at the time of the interviews, completing a community employment scheme. These are schemes dedicated to re-skilling people who are unemployed. The centre where these individuals were based was also biased towards people who used the mental health services. The remaining participants described themselves as either unemployed or in receipt of long term social welfare payments. The absence of meaningful employment for people with mental health problems impacts far beyond financial loss, although this is important. Current mental health policy in Ireland recognises the importance

of employment for people with mental health problems (DoH&C, 2006). However many of the participants were sceptical about their chances of achieving meaningful employment due to their experience of mental distress. The impact of unemployment and social exclusion for people with mental health problems has been described by the National Economic and Social Forum (2007). Furthermore, strategies to manage social exclusion such as unemployment have been detailed (DoH&C, 2006; NESF, 2007), however these strategies have yet to be realised. Given the current economic climate, where unemployment has soared to 13.4% (CSO, 2011), it is likely that strategies for a more inclusive workforce may not be prioritised.

Fundamentally the theory that emerged from the participants' experiences of their discharge from hospital describes their experience of enacted or felt stigma. The persistence of mental distress based stigma and its consequences has been recognised both in Irish mental health policy and published research. Prior to the publication of Vision for Change (DoH&C, 2006), consultations with mental health service users revealed stigma as a basic problem which impacted negatively on their lives (DoH&C, 2004a, 2004b). Consequently, the resultant mental health policy included an entire section devoted to tackling stigma and social exclusion. The strategies to be adopted, advocate for greater contact with those who use the services and those who do not (known as the contact hypothesis), as well as education and actions that challenge stigma. Some of the participants in this study managed stigma through non disclosure and through strategies that defied the predetermined assumptions that people made about them. They did this through the use of recovery catalysts that helped them to re-assess their experiences with the mental health services. For example, the participants' regained a sense of control over their mental health and began to develop strategies to manage their mental distress. The current policy outlined in 'Vision for Change' (DoH&C, 2006) is, in my opinion, limited as it addresses stigma and social exclusion as being solely within the domain of individuals without mental health problems and within the community. It fails to address the issue of self stigma where individuals' perception of themselves is compromised once they come in contact with the mental health services.

The findings of this study reveal that self stigma or felt stigma impacted negatively on the participants once they came into contact with the mental health services.

The cognitive experience of being diagnosed (labelled) and admitted to hospital had a far reaching negative impact which altered the participants sense of self and their perception of themselves as valid individuals. Facilitating participants to develop strategies that prepared them for this experience would have been beneficial. Strategies that might help the participants challenge the negative perceptions of themselves may also have helped the participants to perceive their experiences in a more positive light. Mental health professionals, who were involved in the participants' care while in hospital, were in a prime position to plan and carry out these strategies, but did not. Secondly, although Vision for Change (DoH&C, 2006), advocates for a recovery orientated service, it fails to address the idea that mental health professionals both in hospital and in the community can hold stigmatising attitudes towards people with mental health problems. This is supported by the participants in this study who recounted incidents that confirmed this view, (for example, the belief that mental health problems were life long and unremitting).

As mentioned, the prevalence of mental distress stigma has received renewed attention recently in Ireland. A national attitude study completed on behalf of the Health Service Executive (2007) reported generally positive attitudes towards people with mental distress. For example, 58% believed that anyone could experience a mental health problem and 52% believed that people with mental health problems should have the same rights as everyone else (N=1000). However, when this is juxtaposed with the findings from a study examining public attitudes to disability conducted by the National Disability Authority in the same year (NDA, 2007) a number of irregularities arise. For example, in the NDA study, only seven percent of the respondents felt that employers would be willing to employ a person with mental health problems. Furthermore, only 41% of the respondents in that study agreed that people with mental health problems should have children. Both of these findings reveal that stigmatising attitudes towards people with mental health problems is prevalent even in the face of seemingly tolerant attitudes. More recently, a study commissioned by See Change, (Jupp et al., 2010) the current national anti stigma campaign established in 2009, highlighted the awareness of the need for more accepting attitudes towards people with mental health problems (94% positively responded to the need to have more positive attitudes towards people with mental health problems, n=977). The same percentage also believed that mental health problems should be openly discussed.

However, a study conducted by Amnesty International in conjunction with Dublin City University (Hear My Voice, Amnesty International, 2010) catalogued the experience of stigma for people with mental health problems in Ireland. For example, 64% (n=299) of the respondents reported being treated unfairly by their friends, 61% (n=293) reported being treated unfairly by their family and 58% (n=279) reported being treated unfairly by mental health staff (Amnesty International, 2010). The '*Managing Preconceived Expectation*' theory developed in this study strongly support these findings. All of the participants' experienced mental distress based stigma. In addition it reveals that stigmatising attitudes are embedded and multilayered in society. Furthermore the theory demonstrates the difference between attitudes towards people with mental health problems and behaviours towards them. It may be that people are aware that negative attitudes towards people with disabilities or mental health problems are unacceptable and will respond positively when asked on survey instruments. However these positive attitudes are not reflected in behaviour when individuals encounter people with mental health problems. This is evidenced by the participants experiences when they continually encountered negative attitudes following their discharge from hospital.

Managing Preconceived Expectations: Coping Orientations to Manage Mental Distress Based Stigma

According to Goffman (1963), the management of stigma revolves around the stigmatised person's attempts to manage information about their spoiled identity through a range of strategies:

> 'The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display, to tell or not to tell, to let on or not to let on, to lie or not to lie; and in each case, to whom, when and where' (Goffman, 1963:57).

Strategies of information control are forms of coping and the processes associated with '*Managing Preconceived Expectations*' such as '*Avoiding Preconceived Expectations*' could be likened to the coping orientations described by Lazarus and Folkman (1984). Coping according to Lazarus and Folkman (1984) refers to behavioural and cognitive efforts to deal with demands that are perceived as stressful and beyond the resources of the individual. Two types of coping are listed: emotional focused and problem focused. Emotional focused coping attempts to lessen stress through either minimising the impact of the stressor or through

avoidance. On the other hand, problem focused coping attempts to manage stress through effective problem solving such as defining the problem and generating a range of possible solutions. Central to these coping strategies is the individuals' appraisal of the situation or event as stressful. During the *'Managing Preconceived Expectations'* theory, there was an interplay between emotion focused and problem focused coping strategies for the participants in this study. The participants' reaction to their discredited status provides evidence that they were worried about what other people might think of them following their discharge from hospital. Consequently emotional focused coping strategies were used by the participants in the sub category *'Avoiding Preconceived Expectations'*. Here processes like *'denying discredited status to self'*, *'revisiting pre-hospital life'*, *'socially disengaging'* and the multiple processes associated with *'cautious disclosure'* served to reduce or minimise the stress caused by the participants altered social status following their discharge. In addition *'justifying otherness'* could be interpreted as the participants' attempts to gain some positive value from a negative event by removing the locus of blame for stigmatising attitudes and behaviours away from perpetrators such as their family and friends .

In the sub-category *'Passing the Rubicon'* and *'Reassessing Preconceived Expectations'* a number of problem focused coping strategies allowed or influenced the participants ability or desire to reappraise their respective situations. This ultimately altered the meaning of their experiences for the participants and down sized its negative impact. In this instance the meaning of the stressful situation (other peoples' preconceived expectations) was reinterpreted; consequently, lowering the level of threat experienced without altering the situation. In this study these emotion and problem orientated coping orientations were labelled as recovery catalysts. The sub category *'Defying Preconceived Expectations'* may also be interpreted as an emotional and problem focused coping strategy. During this process the participants were again able to reappraise the meaning of the deviant label that was applied to them, consequently, lessening the stress that it caused. Lazarus and Folkman (1984) suggest that emotion focused coping strategies are most often used when there is a perception that nothing can be done about the perceived stressor. In this case, it could be argued that the participants felt that there was little they could do to tackle or rectify the preconceived expectations their social audience had about them. Consequently their ability to defy it, despite its continued existence, was stress relieving for the participants. On the other hand

the processes of '*becoming a success*' and '*maintaining mental health*' could be interpreted as problem focused coping strategies where the participants consciously reappraised their situation and used objective analytic processes to 'defy' the preconceived expectations that their social audience held about them.

Link and his colleagues have published considerable work on stigma most notably Link and Phelan's (2001) conceptualisation of stigma. In 2002 they built on this work through the development of what they describe as approaches to coping with stigma (Link et al., 2002). They designed a number of self rating scales and administered them to mental health service users (n=88). The coping orientations described are secrecy, withdrawal, educating, challenging and distancing. The findings from Link et al.'s (2002) study suggest that coping orientations such as withdrawal may have a negative impact on people's life chances. Despite this, secrecy and withdrawal were seen as necessary coping reactions for a large number of the respondents. Similar avoiding behaviours were demonstrated by the participants in the '*Managing Preconceived Expectations*' process, such as in '*Cautious disclosure*'. In Link et al.'s (2002) study the respondents also endorsed the educating and challenging coping orientations as well as indicating that they found it easier to associate with other mental health service users. The coping orientation of distancing was found to be less likely for the respondents in Link et al.'s (2002) study with only a minority agreeing with the statements suggesting that their problems were very different from other people with mental health problems. Distancing as a coping orientation did not emerge in the findings of this study.

In the '*Managing Preconceived Expectations*' theory, withdrawal and concealment are processes that occur for all participants initially. However for a minority of the participants, challenging occurred in the form of defiance. This challenging was different to what Link and his associates described and were not a pointing out of stigmatising behaviour. For example, one of the items in their study was 'when someone says something that stigmatises people with 'mental illness' you let them know you disagree with them' (Link et al., 2002:230). In this study this was not the case, rather it was about challenging actual perceptions through behaviour and action rather than verbally challenging the stigmatising behaviour displayed. For example, the participants' in this study were more likely to challenge the negative assumptions by getting a job rather than pointing out negative attitudes or behaviour. Link et al.'s (2002) ideas about challenging as well as education were

subsumed into the *'Defying Preconceived Expectations'* processes as additional facets or ways that stereotypical beliefs were 'defied'. Furthermore cognitive beliefs about their experiences were translated into affirming actions: for example, positive thinking and attitudes about their experience were reinforced by positive experiences like maintaining meaningful employment. Although the coping orientation of distancing in the context described by Link et al. (2002) was not articulated in the same way by the participants' in this study, there is perhaps some evidence of its existence. For example, in this study, concealment and withdrawal could be seen as a form of distancing in this context. Furthermore some of the participants who admitted to their experiences sometimes used a language that they believed was less stigmatising (for example saying they had depression rather than schizophrenia). This could be seen as a way of cognitively distancing themselves from other mental health service users. Regardless, it was more likely that the participants in this study demonstrated effective coping through creating alliances with other mental health services users rather than through distancing themselves from them.

Goffman's extensive work on how individuals behave when they are in the company of others could further explain the coping orientations used by the participants in this study. His perception of human interaction emphasises how individuals foster and maintain a specific picture of themselves in front of others (Gouldner, 2000). The strategies he described further elaborate and support the processes that the participants in this study used to manage preconceived expectations by altering their outward social conception. However this outward social conception is fragile and is held together by ritual and tact:

> 'One must look rather to the fact that societies everywhere, if they are to be societies, must mobilise their members as self regulating participants in social encounters. One way of mobilising the individuals for this purpose is through ritual; he is taught to be perceptive, to have feelings attached to self and a self expressed through face, to have pride, honour, and dignity to have considerateness to have tact and a certain amount of poise' (Goffman, 1967:44).

According to Goffman (1967), the concepts of 'Line' and 'Face' are central to how individuals verbally and non verbally express themselves. Line in this context is a pattern of behaviours through which an individual can express their perception of a social encounter (Goffman, 1967). Face, on the other hand, is the positive social

image that an individual has projected within a social encounter. Thus, positive social value is drawn from the 'line' they have taken during a particular social encounter. Individuals strive to have, to be in or to maintain 'face' and this occurs when the individual presents a conception of themselves that is internally consistent (Goffman, 1967). In addition, individuals are also required to maintain others within their social encounters 'face' as well. Goffman (1967) maintains that when social encounters occur, the participants are charged with the responsibility of ensuring an expressive order where everyone is able to maintain their respective faces. The concept of maintaining face goes some way to helping explain why the participants' in this study did not want to meet people they knew or tell others about their experiences when they were discharged from hospital. The participants experiences of others reactions and their subsequent labelling as 'mentally ill' may, in the participants eyes, have contributed to them feeling that they were in 'wrong face' or 'out of face'. Goffman (1967) argues that being in 'wrong face' or 'out of face' promote feelings of shame and inferiority because the image of themselves that they usually present and which they have become emotionally attached to is now under threat. Consequently, the participants engaged in a similar process to what Goffman (1967) calls 'poise'. Poise involves concealment and suppression of issues that might contribute to those involved in the social encounter becoming out of face. In this instance, the participants attempted to save face thorough *'Avoiding social exposure'* where they avoided engagement with their peers. They also attempted to save face by not telling their social audience about their experiences with the mental health services, when they did it was within a *'Cautious disclosure'* context.

In addition, Goffman (1967) maintains that 'face' is a precarious concept as it is on loan from society. Being in face can be easily jeopardised if individuals do not act accordingly, if they become discredited or radically alter the 'line' other social partners are used to. If this occurs, their social partners become confused as they are now unsure the 'line' to play in this social interaction. Consequently defensive and protective actions (those actions that will save his/her face or save the face of others) will be activated in the form of 'poise'. Goffman (1967) suggests that 'face work' are the individuals' attempts to make whatever they are doing compatible with 'face'. 'Poise' and the 'avoidance' processes described by Goffman here are consistent with some of the actions associated with *'Avoiding Preconceived Expectations'*. For example, avoiding contacts or making a gracious withdrawal are

all resonant of the social behaviours the participants in this study engaged in following discharge from hospital. Furthermore, the social behaviours experienced by the participants from others were also similar, for example when others were unsure what 'line' to play participants experienced what they described as *'getting a wide berth'*. In some instances, social encounters were permeated with the 'tactful blindness' (e.g. acting if nothing happened) that is also associated with face work. Goffman (1959) perhaps presents a clearer explanation for why this occurs in an earlier text entitled 'idealisation'. Here it is suggested by Goffman (1959) that every individual's interaction is socialised in a manner that fits with the expectations of their audience. They therefore conceal or downplay the facets of their experience that might jeopardise or upset the social interaction.

In the book 'Presentation of Self in Everyday Life', Goffman, (1959), outlines a dramaturgical theoretical perspective on how individuals consistently try to present themselves in a manner that is congruent with their own interests and image. The work consists of six overarching theoretical frameworks which uses the imagery of the theatre to describe a broad range of behaviour within social relationships. Goffman's (1959) work does not attempt to seek a cause of the social behaviour, but rather emphasises the context and type of behaviour. Two of the broad theoretical concepts are discussed as relevant to the *'Managing Preconceived Expectations'* processes in particular the processes associated with *'Avoiding Preconceived Expectations'*. These are 'Performances', and 'The Art of Impression Management'.

Performance according to Goffman (1959) refers to the social interactive behaviours that individual's exhibit before a group of observers in order to exert some influence on them. Goffman (1959) maintains that social interaction is reliant on a number of key factors such as the audience being performed to and uses theatre metaphors to illuminate their meaning. In this sense Goffman (1959) differentiates between front stage and back stage. In front stage performances the individual presents a version of themselves that is immersed in tact and ritual and is congruent with social convention. In back stage performances, when the individual is away from their audience, a more informal and less ritualised performance occurs. It is only when the individuals are off stage that they are not involved in any performance. Individuals generally keep their front and back stage performances separate through 'audience segregation'. With reference to the

current study, audience segregation occurred most notably in the participants desire to remain off stage. This occurred through the processes associated with *'Avoiding social exposure'* and represents the participants' desire perhaps not to perform or to put on a 'front'. Social interactions with the participant's family members who were aware of their hospital experiences could be described as a back stage performances as the participant's performance was more relaxed than when the person was front stage. The participants' front stage performances were difficult as they felt uncomfortable in the presence of others and they did not like having to maintain a front for fear that they might be found out. When the participants were engaged in a social encounter they were often obliged to present a false front. They did this in order to prevent themselves from becoming discredited. In these situations the basic problem was information control and the participants' desire to prevent damaging information from being leaked to the audience. Consequently this resulted in the incorporation of 'white' lies into the participants front stage performances, such as when they *'created an alternative biography'* by concealing their experience of mental distress through the fabrication of an alternative history. This also happened again when the participants censored the type and breadth of information they revealed about their mental distress as in *'selective disclosure'*. These served to protect the participants from telling out right lies or revealing dark secrets. Other communication approaches such as innuendo, strategic ambiguity and omissions as described by Goffman (1959) correlate with the processes associated with *'Cautious disclosure'*. This suggests that that the maintenance of expressive control is fragile and can be destroyed by even the most minor of social mishaps (Goffman, 1959). People with mental health problems may find that they have to be different things to a number of different people. This effectively managed through role and audience segregation which mirrors the process of *'selective disclosure'* (Goffman, 1959).

Managing Preconceived Expectations: Managing a Spoiled Identity

Goffman's (1963) 'Stigma: Notes on the Management of Spoiled Identity' adds to his work on how people interact socially. The chapter in his book on information management provides fresh insights into some of the processes the participants engaged in during the *'Managing Preconceived Expectations'* process. Goffman (1963) argues that key to controlling information about the stigma is its 'visibility'. According to Goffman (1963) visibility comprises three factors – 'known

aboutness'; 'obtrusiveness' and 'perceived focus' and the theory that emerged from this study supports these concepts.

Known-aboutness and *Obtrusiveness*: These concepts relates to how much people know about the stigma and how much the stigma interferes with social interaction. In this study the participants were aware that they were stigmatised. For some of the participants, their awareness of their stigmatised identity emerged in response to disclosure. Consequently there was a desire by the participants, to restrict the known-aboutness of their experiences through non disclosure. Obtrusiveness refers to how the stigma impacts on social interaction when people know about it. This was apparent when the participants socially disengaged following their discharge from hospital in an attempt to limit the people they interacted with. In addition socially disengaging also meant that the participants did not have to talk about their experiences or explain to others what they were doing now.

Perceived Focus: This relates to the impact of the stigma on what the person can and can't do. Goffman (1963) suggests that within social relationships, conceptions are developed about what the stigma prevents an individual from doing. In this study, the participants experienced preconceptions that were based on the fact that they were labelled as 'mentally ill'. These preconceptions impacted negatively on their perception of themselves and were reinforced through the actions of others and were managed through non disclosure and through *'Defying Preconceived Expectations'*.

Goffman (1963) spends considerable time discussing the concepts of 'passing' and 'covering'. Central to these concepts is the individuals' 'discredited' or 'discreditable' status. For example, individuals who are blind are unable to conceal their stigma. In addition they often possess a number of identifiable stigma symbols such as dark glasses or a guide dog and these will further reveal their 'discredited' status. Goffman (1963) argues that there is a presumption by the individual that the 'known-aboutness' of their stigma is obvious. Even though their status is 'discredited' individuals will still continue to using strategies to 'cover' (e.g. in this example, facing a person when they talk to them). Other individuals are said to be 'discreditable' when their stigma is invisible and not obvious to those they are interacting with. For these individuals, 'passing' and 'covering' is easier and as mentioned is mainly done through information control as in this study. Passing and

covering prevents individuals from moving from discredited to discreditable statuses. However, the participants in this study could be considered to possess a dual status of both discredited and discreditable depending on their social audience. This requires the participants' to switch between their statuses frequently, arguably making their discredited/discreditable status a major feature of their cognitive processes. The participants were also subjected to tacit and explicit forms of stigma ('*Encounters with stigma*') when their discredited status was revealed. For example, people who knew about their hospitalisation experiences avoided them or minimised the impact of mental distress through not taking them seriously. In addition, mental health professionals, family and friends utilised more subtle forms of stigmatising behaviour (e.g. as in '*Receiving a diagnosis: An absence of hope for the future*') which also negatively impacted on the participants and provoked processes such as '*Avoiding Preconceived Expectations*' or '*internalising negative assumptions*'. Furthermore, when the participants were in the 'discreditable' role, they worried that their discredited status might at any time be uncovered. In addition, they were subjected to what Link and Phelan (1999) describe as 'incidental rejections'. These are rejection experiences that occur because people verbalise 'mental illness' based stereotypes while in the presence of someone with a mental health problem. Therefore, hearing a word like 'nutcase' or 'lunatic' might remind a mental health service user that they are part of a stigmatised group and trigger a chain of negative effects which reminds them of their discredited status. It might be assumed that people with mental health problems are better able to 'pass' and 'cover' and therefore do not need to worry unnecessarily about the impact of stigma. However, for the participants' in this study their dual status as discredited and discreditable duplicated the impact of stigma and arguably provoked the processes described.

The processes associated with '*Defying Preconceived Expectations*' could be interpreted in a number of different ways. In line with the work of Allport (1954) '*becoming a success*' and '*maintaining mental health*' could be seen as enhanced striving or symbolic status striving strategies. Enhanced striving according to Allport (1954) involves stigmatised individuals redoubling their efforts in response to obstacles (e.g. working or studying harder to overcome their 'handicap' (Allport, 1954:156). Symbolic status striving on the other hand, are strategies that prejudiced individuals use to elevate their status (Allport, 1954). These according to Allport (1954) are healthy responses to their perceived inferiority. In this study,

symbolic status striving strategies such as getting a job and staying out of hospital may have served to alter the participants' perceived marginalised status. Allport's (1954) use of the concept *symbolic status striving* in his book is tinged with negativity and relates to strategies he believed were used by black communities. In the present study, symbolic status striving strategies can also be interpreted as clear symbols that challenge the perceived expectations that mental distress is not life limiting and people with mental health problems can not make a positive contribution to society. Earlier in this section stigma symbols (Goffman, 1963) were mentioned. Adapting the concept used by Allport (1954) and Goffman (1963) '*being a success*' and '*maintaining mental health*' could be seen here as recovery symbols and not status symbols as Allport (1954) believes. The purpose of these recovery symbols is to defy preconceptions rather than challenge or overcompensate for them. Furthermore, recovery symbols could be interpreted as a way of managing the perceived stereotype threat that exists for people with mental health problems (Blaine, 2008). According to Blaine (2008) stereotype threat is the belief in ones own disability given the prevailing attitudes that exists. Recovery symbols in this sense helped the participants to manage the stereotype threat and disconfirm the negative labels that were applied.

Managing Preconceived Expectations: Resistance to Power in Social Relationships

According to Link and Phelan (2001) the existence of stigma is dependent on social, economic and political power. It is this lack of power that allows not only stigma to exist, but also produces it's by products – prejudice, self stigmatisation, social exclusion and social disadvantage. Power in this sense is perceived as being held by one social group and exercised over another, resulting in concepts such as disempowerment or powerlessness. These have been discussed widely in the literature and it is argued that disempowerment in mental health contexts has produced resistance for example the survivor or service user movement. Jones et al. (1984:224) suggest that individuals who are stigmatised are 'almost by definition low in power' and that this puts them at a disadvantage during social encounters, consequently, creating a power imbalance. This section will explore the traditional view of power in relation to the theory presented in this thesis. Foucault's ideas reject the view that power is held by individuals or groups and suggests that power is dispersed among groups and held by everyone (Rogers & Pilgrim, 2005). However, where there is power, resistance to this power is inevitable, and

according to Foucault, results in the generation of new power in the form of new discourses (Gutting, 2005). The process of *'Defying preconceived expectations'* through *'being a success'* and *'maintaining mental health'* will also be explored using this Foucauldian perspective.

Jones et al. (1984) suggests that people with mental health problems are traditionally viewed as a being without or lacking power. This they believe stems from the belief that people with mental health problems' have low power scripts (Jones et al., 1984). Similar to the dimensions of stigma discussed earlier, low power scripts are schematic beliefs that the general public hold about stigmatised people which subsequently influence their reactions to them within a social dialogue (Jones et al., 1984). Jones et al. (1984) describe three main scripts, these being 'the child among adults', 'illness and disease' and 'the moral deviate' script. In the child among adult script, individuals apply social reactions normally used when interacting with children to the stigmatised individual. These take the form of talking 'over the head' of the individual or failure to take the individuals concerns and requests seriously. Within this study, the child among script occurred in the processes associated with *'not being understood'*. The illness and disease script emphasises sympathy and withdrawal from society for recuperation as well as the belief that limitations on productivity and ability to maintain social roles are greater than they actually are. This occurred when the participants were admitted to hospital and indoctrinated into the medical model. Furthermore, the absence of recovery and the belief that the participants would not recover also supports this script. In the moral deviate script, individuals are stigmatised because of their non conformance with social conventions or the belief that their mental distress has nefarious origins. In this study many of the participants felt ashamed or were made to feel ashamed by family or friends, following their contact with the mental health services.

The participants' reaction to their low power scripts through avoidance and concealment has already been discussed earlier in this chapter. An alternative reaction as described by Jones et al. (1984) is confrontation and breaking through the scripts, which has similarities to the category *'Defying Preconceived Expectations'*. Here it is hypothesised that the individual's strategic goal is to openly acknowledge their experiences in a desire to remove its master status. In addition the individuals experience is re-appraised in a more constructive way. This

is achieved through self presentational strategies that attempt to change the perceiver's view of their distress or to challenge, inform and educate perceivers in an attempt to normalise their experiences. Jones et al. (1984) argue that low power scripts can also be enhanced through what they describe as effective heroic coping. Here the ability to overcome perceived limitations are seen as attractive and redresses some of the power imbalance that occurs through diagnosis or hospitalisation. Furthermore, through education and information, the participants were keen to normalise their experiences and to place them in a different context. This included strategies to challenge other people's views and perceptions of mental distress, in particular their perception of mental distress as perpetually disabling. This was achieved here through *'being a success'* and *'maintaining mental health'*.

Foucault's ideas are less about defining power and subsequently knowledge, but are more about the construction of a concept (power/knowledge) that helps us to understand what underpins and conditions our practices and beliefs (Couzens Hoy, 1986). In 'Discipline and Punish' Foucault (1991) introduced technologies of power and describes a power that has moved away from the traditional view of power as being one dimensional. Foucault sees power as being dispersed among all subjects and not hierarchical as it was previously conceptualised. This power is exercised and not possessed and in this sense exists in a complicated, unending system of 'micro-powers' that impact on every facet of society. Power operates through discipline where discipline in this sense describes a society that is totally controlled through ardent adherence to rules and regulations (Sheridan, 1980).

Foucault (1991) uses the concept of panopticism[1] to describe how individuals become self regulating due to fears that there will be penalties for non conformance and disobedience therefore becoming subjects of control (Roberts, 2005). Furthermore, within this power relation of panopticism, new discourses emerged (such as psychiatry) which worked to reinforce and augment panoptic power (Roberts, 2005). Consequently power and knowledge are inextricably linked and do not operate alone and are described together as 'power/knowledge'. Ultimately, the concept of power/knowledge contributes to self regulation and

[1] Based on a prison design by Jeremy Bentham, the panopticon allows inmates to be observed by a central figure that they cannot see. The unseeing inmate regulates and controls their behaviour convinced that they are subject to observation at any time.

control because we refer to knowledge in order to make sense of the way we are (Danaher et al., 2000).

Drawing on Foucault's work in 'Discipline and Punish' it could be suggested that the participants in this study were subjected to the disciplinary techniques of normative judgements and dividing practices. Foucault (1991) argues that normative judgements are used to monitor individuals according to a stated norm or average whereas dividing practices operate to divide social groups into distinct categories. When the participants were admitted to hospital, normative judgements were made about their actions and behaviours, causing them to be classified in two ways. Firstly they were classified as 'mentally ill' and their admission to hospital constituted a dividing practice (those who are mentally ill and those who are not). Secondly, the participants were classified as 'sick' and therefore in need of treatment. In Foucauldian terms, admission to hospital provides evidence of the subtle interplay between power and knowledge. Medical and nursing staff acted as normative judges assigning the participants to a sick role and reinforcing their inability to maintain social roles. This was achieved through imposing sickness symbols (such as wearing pyjamas and being confined to the ward) and through the careful use of information (using medical jargon, diagnostic labels or limiting the amount of information that was given to the participants). While in hospital the participants were subjected to surveillance techniques through psychiatric assessment and observation. Furthermore their behaviours, thoughts and emotions were classified as 'other' and therefore subjected to treatment in the form of psychotropic medications.

The authoritative, judging clinical gaze and surveillance that the participants were subjected to by their peers and the mental health staff was also directed at themselves by themselves. Consequently they viewed themselves through a lens that constituted themselves as 'other' and into a deviant role. From this power/knowledge discourse emerged an alternative discourse and identity that was new for the participants in this study. This was a 'psychiatric patient' discourse which they articulated through a dialogue of shame. Furthermore, this 'psychiatric patient' identity was enacted through the processes of '*Social Disengagement*' and '*Cautious Disclosure*'. Therefore, through the convergence of a psychiatric and moral discourse the participants in this study re-identified themselves as 'mentally ill' and assumed the roles and practices socially ascribed to them. It would be easy to suggest here that the participants were powerless to confront the apparently

dominant practices of psychiatry. However, in Foucault's world, the participants were not oppressed, rather they resisted this power by consistently attempting to reject the psychiatric discourse when it was applied to them. For example, some of the participants had to be involuntary detained in order to get them into hospital, and once in hospital all the participants constantly sought their discharge regardless of how they felt. In addition they formed allegiances with other mental health service users which served to bolster their ability to resist the power imbalance through the provision of support and affirmation of worth. Furthermore, '*becoming a success*' could also be seen as a resistive strategy.

Building of his theory of Power, Foucault introduced the term 'bio-power' which is described by Danaher et al. (2000) as techniques of regulating, defining and controlling individuals. Perron et al. (2005) argue that bio-power also manages communities and populations and is a subtle and covert form of power. Foucault appears to be suggesting that these forms of power (discipline, mentioned earlier and bio-power) are directed at preparing and developing a population that is both useful and docile (Smart, 1986). The participants desire to reject their deviant status and their use of processes such as '*Avoiding Preconceived Expectations*' could be, in Foucauldian terms, seen as the subtle dynamics of bio-power. Here the desire to fit in and to conform provides evidence of bio-power's strength in projecting perceptions of what is normal and the way that things should be. Furthermore, the interplay between discipline and bio-power could be interpreted as society's way of penalising and punishing individuals who do not conform to normative values and beliefs. In this case the participants' were admitted to hospital and subsequently stigmatised because of their experiences.

The sub – category '*Defying Preconceived Expectations*' describes how the individuals in this study re-contextualised their experiences through a process of re-assessment and through the use of recovery catalysts. For many this process constituted a turning point in their lives. This also marked a turning point in the way they perceived themselves. This meant that the 'master status' of 'psychiatric patient' that the participants had applied to themselves was downsized and became more manageable. The participants' use of recovery catalysts is evidence of the many varied and diverse discourses that impact on their subjectivity and allowed for this transformation. The recovery catalysts stemmed from biomedical, psychological, social and lay discourses and perhaps in this sense could be seen as a

recovery discourse. In Focauldian terms this could be interpreted as an alternative discourse which is resistive to traditional perspectives on mental distress. In addition, the recovery catalysts described could also be seen as technologies of the self which Foucault (1988:18) argues 'permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality.' The processes of '*Defying Preconceived Expectations*' through '*maintaining mental health*' and '*being a success*' provide further evidence of the participants' desire to transform and to serve the society they belong to.

Managing Preconceived Expectations: Antithesis to Recovery Orientated Mental Health Policy and Service Provision.

Recent policy documents produced by the Mental Health Commission (2005) and the Expert Group on Mental Health Policy (2006) argue for the implementation of a Recovery orientated mental health services in Ireland. These documents, produced following consultation with mental health service users advocate for greater collaboration between the mental health services and the individuals who use them. More importantly, the Recovery philosophy/ethos requires that both users and providers of mental health services rethink their beliefs and attitudes about mental distress. In practical terms this means that traditional paternalistic and negative attitudes towards people with mental health problems should be replaced with a belief in the individuals' ability to succeed. In addition, mental health services should be delivered in an environment that fosters and encourages personal development and focuses on strengths rather than limitations. The participants' experiences of the mental health services in this study provide evidence that Recovery as a philosophical concept did not underpin the care that they received either in hospital or when they were discharged. For example, fundamental concepts associated with recovery such as the presence of hope inspiring relationships and collaborative rather than prescriptive care plans were often absent.

Recovery orientated services may suggest to some that there is something to 'recover' from. In this study the participants were firmly instructed to perceive mental distress as an illness and that recovery was from this illness in the shape of remission from symptoms. However the participants' concerns centred on how other people perceived them once they were labelled as 'mentally ill'.

Consequently their recovery involved reconciliation with their discredited self concept rather than their diagnosed illness. However, the impact of being diagnosed as 'mentally ill' and the stigma of being admitted to hospital was not considered by the mental health professionals who were involved in the participants' care. Their reluctance to go into hospital provides some verification that the participants were aware that admission to a psychiatric ward would damage their credibility. At this point however, strategies that could have centred on a dialogue between the participant and the mental health professionals did not occur. Instead the participants self determination and sense of control over their lives, important components of mental heath recovery (Higgins & McBennett, 2007), were compromised. During and after hospitalisation, the participants' indoctrination into the medical and biological perception of mental distress further eroded their self determination and perpetuated the belief that medical interventions were the only valid form of intervention. This negated the idea that personal resourcefulness and self help could be useful adjuncts to traditional forms of treatments (Higgins & McBennett, 2007). The dominance of the faulty brain hypothesis (Sayce, 2000) is advantageous in removing some of the blame that is often associated with having a mental health problem. However, it arguably removes the sense of responsibility or ownership of experience that the individual has of managing their distress due to the over reliance on psychotropic medications. In addition, the participants encountered negative perceptions about their ability to recover and live meaningful lives which fostered a sense of hopelessness about their future. For example, the manner in which they were given their diagnosis often suggested to them that their chances of recovery were slim. The concept of hope is a central theme that runs through the recovery literature and encouraging hope and optimism underpins the recovery movement (Anthony, 1993; Repper & Perkins, 2003; Mental Health Commission. 2005, 2006, 2007). However, its absence here and the lack of hope displayed by mental health professionals and the participants' social network following their discharge influenced the participants' negative self concept.

The Mental Health Commission's Quality Framework for mental health services in Ireland suggests that mental health service users should be active participants in every aspect of their care (Mental Health Commission, 2006). The findings from this study suggest that this was not the case and for many of the participants they were passive bystanders in caring and treatment processes. Furthermore, many of the

participants were not given information that allowed them to make informed judgements on the issues that were of concern to them. For example, many of the participants were told when they were ready to be discharged from hospital rather than being involved in a mutual discussion or decision. In addition some of the participants, once discharged found that they had little choice in terms of the services that they received when they returned to the community. The lack of choice assisted in furthering the prominence of the bio/medical model because alternative modes of intervention such as cognitive behaviour therapy for example, were not available. Furthermore, this lack of choice demonstrated the absence of self determination and personal choice that underpinned interventions by mental health professionals. The findings of the report 'What we heard' (DoH&C, 2004b) found that only 40% of service users (n=100) felt that they had any choice within the current mental health services. Furthermore, the same report states that although 86% of the mental health service users could clearly articulate their needs, they felt that the responses they received from mental health professionals were variable. The responses ranged from feeling like they were being fobbed off to a fear of repercussions if they spoke their mind (DoH&C, 2004a). The participants' in this study also felt that they were not taken seriously or that their concerns lacked credibility.

According to Shephard et al. (2008) and Repper and Perkins (2003) valuing individuals as human beings, understanding and accepting individuals and believing in the individuals abilities are central components of hope inspiring relationships. These were not always present in the relationships that the participants in this study experienced with the health professionals that they encountered or with their social network once they had been discharged. Although the participants did not directly talk about recovery as an attitudinal or philosophical concept, they did mention behaviours and attitudes that assisted them which corresponded with the recovery philosophy of care. Most notably here was the development of supportive relationships with other mental health service users further reinforcing the strength that acceptance and understanding has on recovery and self development. For many of the participants in this study, fostering relationships with other service users was the first step on their journey of recovery. The propensity for the participants in this study to foster allegiances with other mental health services users and to assimilate them into their own personal support network is not a revelation. Allport (1954) describes this as a response to threat,

and threat he believes is a natural human cohesive. In addition Allport (1954) argues that stigmatised individuals often find the fault for this marginalisation lies with the dominant group. For example, in this study, when the participants in this study were stigmatised and treated unfairly, they rationalised their social audiences' behaviour as being faulty. In the process *'Justifying Otherness'* the participants believed that they were treated badly because their social audience knew no better (*'facing ignorance'*) or that they had problems of their own to contend with (*'having a life of their own'*).

Managing Preconceived Expectations: Challenging my Own Personal Preconceived Expectations

Although I had an awareness that the blanket assumptions made about people who use the mental health services existed, I had no idea prior to conducting this research how pervasive and detrimental to health and wellbeing they can be for mental health service users. An example of how I and other academics and health professionals validate preconceived expectations arose prior to collecting the data for this study. When applying for ethical approval, the ethics committees and the mental health services used to access the potential participants all emphasised the 'vulnerable' nature of people with mental health problems. For example, on the ethics form used by this University, researchers are required to tick a box indicating that they are completing research with vulnerable groups. One of these vulnerable groups are people who have used the mental health services regardless of their position on the recovery/distress continuum. Furthermore, having served as a member of an ethics committee for a number of years I too had a heightened awareness of their perceived vulnerability. Consequently in applying for ethical approval myself, I incorporated stringent guidelines for myself to ensure that these 'vulnerable' people's integrity was not compromised. Although I am in agreement that caution should be adopted when conducting research with human subjects, the blanket assumptions that people with mental health problems are consistently vulnerable, perpetuate already ingrained beliefs that they cannot recover. Furthermore, the request from some mental health providers to seek permission from the participants consultant psychiatrists even though the participants' were living in the community, maintained the belief that mental distress is a lifelong enduring problem again perpetuating preconceived expectations. In addition, it reinforced the idea that people with mental health problems are unable to make life decisions for themselves and need to be protected. These ideas directly correlate with the low power scripts described by Jones et al. (1984) earlier in this

chapter. Furthermore it supports the point made that stigma and negative attitudes towards mental health service users is not being just located outside the mental health services but perpetuated by them in the form of benevolence.

I started doing this study officially in April 2006, although, in reality, I had been thinking about it for at least one year prior to this date. This study started life as an exploration of mental health service users' experiences of discharge from the acute mental health services. My interest in the substantive area of discharge from hospital arose from both my experience as a psychiatric nurse and secondly as a teacher of psychiatric nursing. When I was a staff nurse the high number of readmissions to hospital was surprising and was generally put down to non compliance with medication rather than a lack of community supports. Later as part of my teaching the literature on relapse prevention was highly influential in my thinking and much of it spoke about the natural tendency of people with mental health problems towards relapse and chronicity. Even the terms used to describe frequent users of the services such as 'chronic' or 'severe' and 'enduring' are tinged with negatively and perpetuated social stereotypes about individuals' ability to recover from mental health problems although I never considered this at the time. My point is that for a long time my perceptions of why people were continually readmitted to hospital were generally bio-medically based and often placed at least some of the blame with the service users themselves without considering or reflecting on the complexity of the issues concerned. By bio-medically based I mean that relapse and subsequent readmission to hospital was prompted by a resurgence of symptoms, often I believed to be caused by non adherence with instructions from mental health professionals or refusal to take medication.

Completing this research using grounded theory has permitted me to view the participants' experiences while pushing aside my own preconceived expectations on the nature of the participants' main concern. However, this was not easy and my own personal construction of 'mental illness' as a biologically based phenomenon often tried to force its way into the analytic process. In this sense my perceptions of 'mental illness' were etched onto my consciousness through my psychiatric nurse education and training as well as my subsequent working experience. This socialisation process that I experienced throughout my life and career needed to be challenged as the participants voices were in danger of being quietened by my insensitivities to their central concern. I have to admit that this

took a while as I was consistently reluctant to shift my preoccupation away from what were essentially my concerns and not the participants. This major issue was resolved by adhering closely to Glaser's (1978) mantra of sticking close to the data and through repeatedly challenging my preconceptions and being challenged not only by my supervisors but by the data as well.

My immersion into the biological world of psychiatry is typical of the systems that psychiatric nurses and other mental health professionals continually work within. Resistance to this socialisation process is difficult given its continual reinforcement and the sheer dominance of bio-psychiatry in everyday mental health practice. Consequently approaching this piece of research through a biomedical lens was a by-product of my entire socialisation into the world of psychiatry and possibly my socialisation generally. The issue of discharge planning did not really emerge as a prevalent concern for the participants despite all of the participants admitting that they had little or no involvement in the decision to be discharged. Furthermore, apart from weekend or day leave, most had no other preparation for the transition from hospital to home. However as the theory emerged from the data, this lack of involvement in the decision making processes proved to be another example of how mental health service users are relegated to a social group who are perceived as incapable. This perception of mental health service users as incapable or needing to be cared for impacted on the participants in this study more than the reasons that they were admitted to hospital in the first place. This could have easily been missed had other methodologies been used in this study. To summarise, this study began life as a qualitative exploration of mental health service users' experiences of discharge which was firmly positioned within a biomedical paradigm. Using classic grounded theory has allowed the central concern for the participants to 'emerge'. Using other qualitative research approaches may have resulted in a description of the participants experiences possibly laced with my preconceptions. Although difficult, the analytic processes associated with GT have dramatically altered the original focus of this study while remaining true to the substantive area.

Summary and Conclusion of Chapter Nine

The aim of this chapter was to discuss the '*Managing Preconceived Expectations*' theory as it relates to other theoretical explanations of the concepts that emerged from the substantive area. In that sense it sought to view the theory from a

number of differing theoretical perspectives. In terms of completing this study, the discussion was the most challenging chapter as it was, in simple terms, additional data collection (albeit from the literature) which helped to further elaborate the substantive theory presented earlier. This extension of the theoretical sampling process, although anticipated at the beginning of the study, was poorly understood by me. The theory that emerged from the data describes the participants' interactions with the mental health services which were perceived from the outset as a highly negative experience. Following their discharge this negativity was reinforced by their interactions with their social audience. In this chapter, this negative interaction with the mental health services were discussed in relation to the unconscious development of stereotypes and negative attitudes towards people with mental health problems. The resultant stigma and how the participants managed this through avoidance and other processes was discussed in tangent with the work of Erving Goffman, in particular 'Stigma: Notes on the Management of a Spoiled Identity' (1963) and Goffman's concepts relating to information control, passing and covering.

Goffman's extensive work was also used to help elaborate and explain the social processes that occurred when the participants' interacted with their social audience. His writings about the presentation of self (Goffman, 1959), line work and face work (Goffman, 1967) help to illuminate the complexities of the participants interactions with their peers once they were discharged from hospital. The presence of power imbalances between the participants and the mental health services were also discussed. In addition Foucault's notion of power and the participants subsequent resistance to this power was discussed in relation to the concepts associated with discipline and punishment. Ultimately the participants desire to conform to societal rules was interpreted as resistance to the 'psychiatric patient' identity. In addition, their resultant stigmatisation was evidence of the penalties that society place on individuals for non conformance. When the participants were admitted to hospital, the lack of optimism that was encountered by the participants from mental health professionals was discussed as incongruent with the current drive for recovery orientated mental health services.

Finally, this chapter concluded with a discussion about how the development of this substantive theory challenged my own personal interpretation of mental distress and my immersion into the practices associated with the biological

perspective of mental distress. On reflection my psychiatric nursing practice, skills and education were steeped in the biomedical discourse. Completing this study has allowed me to critically reflect on my education and practice which has ultimately reshaped my understanding of my role as a psychiatric /mental health nurse and educator.

CHAPTER TEN: LIMITATIONS, IMPLICATIONS, RECOMMENDATIONS, AND TRUSTWORTHINESS OF THE MANAGING PRECONCEIVED EXPECTATIONS THEORY.

Introduction

This, the final chapter of this thesis, will begin by acknowledging the limitations of this study. In addition this chapter will discuss the implications of the *'Managing Preconceived Expectations'* theory as well as offering recommendations for education, for clinical practice, for policy and for research. Finally, the criteria that are used to judge the trustworthiness of the theory mentioned earlier in chapter four will be elaborated on.

Limitations

Bearing in mind that the focus of this study was not a description of the participants' experiences or to generalise the findings, the *'Managing Preconceived Expectations'* theory must be viewed with the following limitations in mind:

- The participants who reported their experiences relied on memory and therefore may have not have reported their experiences accurately.
- The data were collected by interviews with the participants. Observing the participants may have strengthened the credibility of the findings.
- It could be argued that the service users, who volunteered for interview, put themselves forward because they had a particular agenda that they wanted to be heard.
- Although the sample size was relatively large for a qualitative study, it was heterogeneous in terms of age, gender and service use which could detract from the findings of the study.
- I was relatively inexperienced at the beginning of this study which may have had a detrimental effect on the depth and length of the interviews initially.
- Grounded theory is a complex and challenging methodology and I was on a steep learning curve throughout the entire data collection and analytical procedures.
- The concept of theoretical saturation is both a complex and subjective phenomenon. Consequently other researchers may have reached it earlier or even later in the data collection process.

- The difficulties encountered with access and recruitment during the early parts of the study meant that theoretical sampling was not always as fluid as is required of a grounded theory study.

Implications and Recommendations

The original aim of this study was to develop a conceptual understanding of the psychological and social approaches that occur when mental health service users are discharged from hospital. The substantive theory that emerged from the participants' experiences demonstrates that mental distress based stigma is not only prevalent, but is complex and multi dimensional. In examining the participants' experiences, the negative assumptions that exist about people who use the mental health services were influential prior to their admission to hospital, during their admission and once they were discharged. Central to this experience of stigma was the negative attitudes that were demonstrated by mental health professionals, the participants' families and their friends. Furthermore, the negative attitudes that they were exposed to, fuelled the participants' negative impression of themselves once they came into contact with the mental health services. Although this in itself is not a revelation, the '*Managing Preconceived Expectations*' theory demonstrates that despite the existence of mental distress based stigma, people with mental health problems can manage the negative assumptions that are held about them through avoidance, although this is not ideal. In addition, the theory demonstrates that for some of the participants in this study, they were able to defy these negative assumptions. However, this movement along this recovery trajectory is contingent on a number of inter and intra personal factors that have been described as recovery catalysts.

This theory adds to the extensive literature which examines mental distress based stigma and develops our understanding of a complex and controversial phenomenon. The theory aids our understanding by presenting a conceptual framework of the participants' experience that is based on their qualitative descriptions of the phenomenon. In addition, the context of the study, (i.e. discharge from hospital) supports the argument that psychiatric hospitalisation is stigmatising and that mental health services should be located in the community. Despite the relocation of most acute psychiatric wards to general hospitals, the findings from this study suggest that psychiatric wards still conjure up negative images which influence the attitudes and behaviours of the general public and people who use the mental health services. As it is likely that psychiatric

hospitalisation will remain a prominent feature of the mental health services, this presents as a major challenge to anti stigma campaigners and policy developers alike. Once admitted to hospital, the participants' perception of psychiatric hospitalisation as a negative turning point in their lives was confirmed. Furthermore, the experiences that they had in hospital coupled with their interaction with mental health professionals, reinforced these beliefs and experiences. Once they were discharged their assimilation into a world of otherness was confirmed by the negative interactions they had with their peers. However, with time and with the use of recovery catalysts, these negative reactions fuelled the participants desire to redress the impact of their experiences. Given the breadth of the theory described and in an attempt to keep the recommendations focused, they will presented here under the headings of recommendations for education, research, policy and practice.

Recommendations for Education

- Literature suggests that children are exposed to negative discourses about mental distress from an early age (Wilson et al, 2000). Consequently it is recommended that primary education curriculums develop strategies to introduce the concepts associated with mental health and mental distress to children in a positive and congruent way. This education should be developmental and focus on equipping children with skills to challenge the images and discourses they encounter in an attempt to formulate attitudes and behaviours that are sensitive and positive towards people with mental health problems.
- In second level education, strategies should be adopted to maximise the contact hypothesis of reducing mental distress based stigma. Exposing the students to mental health service users' experiences through the use of video, interaction with service users and open discussion will help promote mental distress as a human experience. According to Sartorius & Schulze (2005) hearing service users' personal experience had a greater positive impact on attitudes than information alone. Furthermore, second level students should be encouraged to participate in voluntary activities as appropriate in non-governmental organisations such as Grow and Shine. This would also help to minimise negative stereotyping through increasing contact between those who use the mental health services and those who do not.

- Building on from first and second level educational strategies, all third level programmes should include a module on mental health and mental distress. Part of this module should be delivered by users of the mental health services as well as including reflective strategies to assist students to critically appraise their attitudes to mental distress and the people who use mental health services.
- It is recommended that undergraduate and post-graduate courses preparing mental health professionals to work with people with mental health problems continually challenge the depictions of mental distress as life long and unremitting. Furthermore, education programmes should be underpinned by the philosophy and practices associated with recovery. In this sense, the nature and impact of stigma on mental health service users should be central to education programmes for mental health professionals. In addition these programmes should be evaluated for their impact.
- In service education programmes developed for staff who do not pursue postgraduate education also need to address negative attitudes towards people with mental health problems.

Recommendations for Research

- A meta-analysis exploring the conceptual understanding of hospitalisation for people with mental health problems, in terms of coping and adjustment, should be undertaken. This will bring together what is known about these concepts and illuminate possible areas that need further investigation.
- Further research is required to explore the concept of *'Re-assessing Preconceived Expectations'* and the strategies that influence service users reaching this stage. In addition, this will assist in further examining the internal and external recovery catalysts that help service users to reach the endpoint of *'Defying Preconceived Expectations'*.
- The *'Managing Preconceived Expectations'* theory suggests that mental health professionals often held negative attitudes towards people with mental health problems. It is recommended that a study be undertaken to examine the attitudes of mental health professionals towards people with mental health problems. Furthermore, a study examining how mental health professionals construct mental distress and the impact of these constructions should be completed.

- A study to explore how people who come into contact with the mental health services construct their identity following hospitalisation should be conducted. Furthermore, a study to explore the impact of mental distress on service users self image should also be conducted.

Recommendations for Policy

- Much of the work of the mental health policy developers in recent years has been to raise awareness about the concept of recovery (Griesbach et al., 2010). Reiterating the point made by the Scottish Recovery Network, mental health policies need to develop longer term, sustainable structures to support recovery practices into the future.
- The Department of Health and Children (2009) argue that health policies that advocate for greater service user involvement in policy development are not always successful in ensuring this happens. The task for policy makers in Ireland is to successfully engage with mental health service users in mental health policy formation and implementation.

Recommendations for Practice

- The impact of mental distress based stigma has continued to be a source of major stress and a major impediment to recovery for mental health service users. It is recommended that the strategies that have been detailed in Vision for Change (2006) and the National Social and Economic Forum (2007) to address stigma and social exclusion are fully implemented and evaluated. Furthermore the work of the national anti-stigma campaign 'See Change' should be extended to target people who use the mental health services as well as the general public. In addition the work of 'See Change' should be evaluated.
- Strategies to challenge negative attitudes about people with mental health problems should be developed for those who work in the mental health services.
- Strategies to assist service users to challenge the negative attitudes they have about themselves following contact with the mental health services need to be developed, implemented and evaluated. Psychiatric nurses are in a key position to design these interventions in conjunction with mental health service users.
- The possible impact of stigma for service users should be openly discussed by mental health professionals in partnership with service users and decisions about disclosure (e.g. in a job interview setting or when meeting

new people) should be explored using problem solving approaches and candid discussion.

- Service users should be prepared for their discharge from hospital. This preparation should be individualised and should focus on the service users psycho-social needs as well as managing their 'symptoms'. Furthermore, service users should be equipped with strategies to manage difficulties that emerge following their discharge from hospital. These should be psycho-social and be underpinned by the concept of self help.

Demonstrating the Trustworthiness of this Study

Chiovitti and Piran (2003) argue that researchers need to be explicit about the ways that they have maintained rigor in their qualitative studies. Furthermore, grounded theory is open to error in the same way as other qualitative methodologies (Elliott & Lazenbatt, 2005). For these reasons it is important to address the area of trustworthiness in this study. Normally, the concepts of credibility, dependability, transferability and confirmability are used to establish the rigor of qualitative research studies (Guba & Lincon, 1994). In classic grounded theory studies, there are a number of different criteria for establishing trustworthiness. These are 'fit', 'workability', 'modifiability' and 'relevance' (Glaser, 1978; 1998). These will be discussed in relation to the '*Managing Preconceived Expectations*' theory in this section.

Fit

Fit in grounded theory parlance refers to the core and related categories ability to explain the patterns and variations in the data (Glaser, 1978). In grounded theory research, there are inbuilt methodological strategies for ensuring fit and researchers are encouraged to adhere to these. Firstly, this study was completed under the supervision of an experienced grounded theorist and decisions about the progression of the theory and the analytical procedures were made following consultation with her. Every effort was made to learn about the methodology and this included attending supervision sessions as mentioned and attending grounded theory seminars which were facilitated by Glaser in London, New York and San Francisco. Furthermore an informal grounded theory support group was established between Dublin City University, University College Dublin and Trinity College which allowed for open and candid discussion of the methodology. The processes associated with grounded theory were also adhered to rigorously. Firstly, every attempt was made to remain open and to allow the theory to emerge from the data. Although a literature review about the substantive area was completed

prior to collecting the data, this had no relationship with the core category once it had emerged. The final theory contained in this thesis is conceptually different from the ideas that I had prior to conducting this study consequently demonstrating analytical openness.

Secondly, the constant comparative analytic process was used throughout the theory development. This ensured that the categories and concepts were rooted in the data and not in my preconceptions. In addition, theoretical sampling was used throughout and this meant that trends in the data were only included if they patterned out in future data collection. Throughout the coding processes, attempts were made to ensure that in-vivo codes were used and only those codes which conceptually described the data were used. These codes were continuously revisited and reviewed throughout the data analysis process and only those that demonstrated the best 'fit' were used. The analytical processes and decisions about the progression of the theory were documented continually in the memoing processes. Large amounts of time were devoted to searching for cognitive and conceptual clarity and this involved constant note taking, diagramming and rewriting of the theory. The final theory contained in this thesis represents a synthesis of the numerous memos that were written throughout this entire process. Although many qualitative writers such as Tobin and Begley (2004) advocate for member checking to confirm the findings from qualitative studies, this is not the case in grounded theory. However, this is not to say that the views of the participants about the emerging theory were not sought. The process of constant comparative analysis and theoretical sampling ensures that the emergent theory and their categories are included in subsequent data collection processes to ensure that they pattern out. Consequently, the participants are asked about the developing theory during the data collection process.

Finally, returning to the concept of openness briefly, attempts were made to ensure that a level of reflexivity was incorporated into the analytical procedures. Although I am sceptical of bracketing and the ability to 'push' my preconceptions from my mind, I have endeavoured to acknowledge their existence throughout the entire study. I also acknowledge that attempts were made to force the data into preconceived hypothesises early in the data collection/analysis stages. However the processes utilised in this study and adhering to the grounded theory methodology have ensured that this did not happen.

Workability

According to Glaser (1978), workability refers to the theory's ability to explain the participants' main concern and the processes they use to continually resolve this concern. Having worked on this study for almost five years it is my sincere belief that the '*Managing Preconceived Expectations*' theory is a 'true' conceptual representation of the participants experiences. In the description of the theory, I have included many direct quotations from the transcripts of the interviews to highlight examples of the concepts. Furthermore, in hindsight, the participants' description of the main concern were articulated very early in the data collection process and I cannot believe that it took me so long to find it. This I believe was the result of my desire to force the data into a preconceived framework. Researchers analysing the same data, although they might use different terminology, would, I believe, describe a similar theory.

Modifiability

According to Lomborg and Kirkevold (2003) modifiability refers to the theory's ability to respond to new and emerging concepts as they becomes available. The theory described here represents a detailed conceptual account of the participants' experiences when they were discharged from hospital. As with any theory, it is subject to modifications and as such is a rendering of their main concerns in the here and now. Consequently changes in practice and even location may provide additional data that develops the '*Managing Preconceived Expectations*' theory and our understanding of the participants experiences further.

Relevance

The final indicator of the theory's rigor or trustworthiness is its relevance and practical utility. Firstly, the theory demonstrates that the participants' concerns following their discharge from hospital were not the 'symptoms' that they were admitted for, but other people's perceptions of them now that they had been labelled as a psychiatric patient. Furthermore it provides evidence of the mental distress based stigma that exists. For these reasons it is relevant on a number of different levels. It helps to further understand how service users manage stigma following discharge as well as illuminating the complexities of the psychiatric experience which transcends the 'symptoms' of illness. This theory has also been presented at national and international conferences and its relevance to clinical practice and to the people that use the mental health services has not been questioned. Furthermore discussions at grounded theory seminars have commented on the theory's usefulness in describing a complex phenomenon.

Once the theory was fully articulated, attempts were made to situate it within the wider literature and extant conceptualisation of how individuals manage mental distress based stigma. This theory is not only supported by the literature but it adds to the literature and has a practical application for mental health practitioners and users of the services.

Summary and Conclusion of Chapter Ten

This aim of this final chapter was to present recommendations based on the emergent theory. Furthermore it described the steps that were taken to maximise the trustworthiness of this theory. In addition a number of limitations of this research were presented. The '*Managing Preconceived Expectations*' theory described in this thesis demonstrates that even though steps have been made to reduce the stigma attached to mental distress, it still remains a prevalent problem. Furthermore the theory demonstrates that self stigma is a major problem for users of the mental health services in Ireland. On a more positive note, the theory also describes how service users can manage stigma and achieve a good quality of life even in the face of adversity. Mental health professionals and service providers can assist service users to manage the seemingly overwhelming experiences of being admitted to a psychiatric hospital or developing a mental health problem.

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APPENDIX ONE – BRIEF OVERVIEW OF PARTICIPANTS

Number	Age	Gender	Occupation	Relationship Status	Children	Experience of Psychiatric Hospitalisation
1.	57	Female	Long term disability.	Married	6	Two previous admissions to hospital, one for six weeks and one for 4 weeks. The last admission was in 2007.
2.	63	Male	Long term disability	Single	None	Last admission in 1983 for 3 months.
3.	47	Male	Unemployed	Single	None	One previous admission to hospital seven years ago for one week.
4.	33	Male	Long term disability	Single	1	Five previous admissions to hospital the last being in December 2007 for one month.
5.	61	Male	Long term disability	Married	4	Sixteen previous admissions the last being in 1999 for 6 months.
6.	45	Female	Unemployed	Single	None	Several previous admission the most recent for three and a half months in 2006
7.	-	-	-	-	-	Repeat interview (original code 5)
8.	28	Female	Long term disability	Single	None	15 previous admissions since the age of 20. Last admission in early 2008
9.	47	Female	Currently in a CE scheme[1]	Single	None	Numerous admissions for varying lengths of time, the last was in 1998 for 6 months
10.	50	Female	Unemployed	Single	None	Several

[1] Community employment scheme designed to help people who have been out of work or are in need of training to return to work. Provides a recognised qualification under the National Framework of qualifications and are administered by FAS.

						admissions to hospital since 1977, the most recent in 2004
11.	44	Male	Long term disability	Single	None	Multiple previous admissions to hospital the last being in 2007 for 3 weeks.
12.	45	Female	Unemployed	Single	1	One previous admission to hospital lasting 6 months.
13.	-	-	-	-	-	Repeat interview – original code 10
14.	47	Female	In full time employment	Single	None	One previous admission to hospital for 3 months in 1989.
15.	56	Female	In part time employment	Single	None	Numerous previous admissions to hospital the first being in 1993. Last admitted in 2005.
16.	27	Male	In full time employment	Single	None	2 previous admissions. One in 1999 for six weeks and another in 2005 for 5 weeks.
17.	41	Male	In full time employment.	Single	None	First admission to hospital in 1990, has been admitted several times since, the last time being in March 2001.
18.	49	Male	In full time employment.	In a relationship	None	Last admission was in 2002 which lasted about three months. Eight admissions in total since he was 25.
19.	51	Male	Currently in CE scheme	Single	None	Five previous admissions to hospital, the longest admission was for nine months. His last admission was

						in 1984.
20.	25	Male	Currently in CE scheme	Single	Male	Four admissions in total, the most recent in 2007 for 4 months.
21.	48	Male	Currently in CE scheme	Single	Male	Six previous admissions to hospital the most recent in 1999. Admissions lasted between four and six months.
22.	25	Male	Currently in CE scheme	Single	None	One previous admission to hospital in 2004 for ten weeks.
23.	30	Female	Currently in CE scheme	In a relationship	None	Numerous previous admissions since 1996 the most recent in 2004. Length of time in hospital varied.
24.	57	Female	Currently in CE scheme	Married	None	A total of eight previous admissions to hospital since 1986 the last one in 2000. Length of stay never more that twelve weeks.
25.	50	Female	Currently in CE scheme	Single	None	One previous admission to hospital (can't remember the date)
26.	35	Female	In full time employment.	Single	None	Two previous admissions one in 1996 and once in 2002. First admission was for one month and the second admission was for less that a week to facilitate a change in medication.
27.	40	Male	Long term disability	Single	None	Initially hospitalised abroad while on

						holiday in 2000, subsequently admitted to hospital here in Ireland on return for two weeks.
28.	-	-	-	-	-	Repeat interview – original code 10
29.	58	Female	Long term disability	Separated	4	Approximately 20 previous admissions the most recent in 2006.
30.	42	Female	Long term disability	Single	Male	Approximately 5 previous admissions, the most recent in 2003.
31.	37	Male	In full time employment	Single	None	Thirty three previous admissions since 1995. Hospital stays ranged from two weeks to two months. His most recent admission was in 2008.
32.	34	Male	Unemployed	Single	None	Last admission in 2006, in hospital on two occasions once for 2 months, once for 2 weeks.
33.	58	Male	Unemployed	Single	None	One previous admission to hospital in 1979.
34.	37	Male	Unemployed	Single	None	Four admissions to hospital most recent in august 1997.
35.	59	Male	Unemployed	Married	2	2 previous admissions to hospital in 2008.

Summary

Male	18
Female	13
Mean age	44.5
Median age	47
Mode age	47
Youngest	25
Eldest	63

APPENDIX TWO – PARTICIPANT INFORMATION SHEET

Title of the Study:

Mental Health Service User's Experiences of Going Home from Hospital

Dear Sir/Madam,

My name is Brian Keogh and I am a psychiatric nurse and a nurse lecturer at Trinity College Dublin. I am currently undertaking a research degree at the School of Nursing and Midwifery, Trinity College. I am very interested in understanding what it was like for you when you were discharged from hospital. In particular, I am interested in finding out what went well for you when you were discharged and also what didn't go so well.

Background:

It is very important that psychiatric nurses get an understanding of what it is like for people when they are discharged from hospital and also to find out what things are helpful and what things are unhelpful for people's recovery. This information will be used to help psychiatric nurses better prepare service users for their discharge so that the likelihood of readmission to hospital is reduced. I would also like other people to learn from your experiences so that they have the opportunity to practice and develop the strategies that you use to stay well.

Procedures:

In order to find out this information, I would like to talk to you about your experience. If you would like me to contact you about this study, you need to read the information sheet attached and return the enclosed form to me in the envelope provided. I will then contact you to see if you are still interested in participating in the research and to answer any questions that you might have. Once this is completed a time for our meeting and discussion, that is convenient for you, will be arranged. The discussion will take place at the Community Mental Day Hospital where you attend. If this is inconvenient for you than I can arrange an alternative venue if you wish. The interview will last about one hour and I will tape record it so I can listen to it after the interview is finished. During this study your name will remain confidential. Your name will not be published and will not be disclosed to anyone. Your participation in the study is voluntary. You may decide that you do not wish to continue talking to me at any time. If you decide to stop talking to me or if you what to leave the interview, you are free to do so. This will not impact in any way on the care you are receiving from the nurses and doctors, as I will not be telling them.

If you do not want to take part in this research for whatever reason, I would appreciate if you could return the enclosed form stating that you do not want to be contacted further about this research. This research has been granted ethical approval from the Faculty of Health Sciences, Trinity College, Dublin.

If you need any further information or if anything in this document is unclear, please contact me at the following number 01 8963109 or at the following email address: bjkeogh@tcd.ie and I will be to happy discuss any of this information with you.

Next steps:

1. Please read the enclosed information sheet.
2. Decide if you wish to take part in this study or not.
3. Complete the pink sheet stating that you want to or do not want me to contact you to talk further about the research. I will not contact you if you have stated that you are not interested in participating.
4. Make sure that you have put your name and a contact details on the pink sheet if you are interested in participating. If you have a preferred time for me to contact you please state that as well.
5. Return the enclosed form (the pink sheet) to me in the envelope provided.
6. I will then contact you to discuss the research further.

Thank you for taking the time to read this information

Yours sincerely

_____

Brian Keogh

Mental Health Service User's Experiences of Going Home from Hospital

My name is Brian Keogh and I am a psychiatric nurse and a nurse lecturer at Trinity College Dublin. I am currently undertaking a research degree at Trinity College and I am very interested in understanding what it is like for people when they are discharged from hospital. In particular, I am interested in finding out what went well for you when you were discharged and also what didn't go so well.

Background:

It is very important that psychiatric nurses get an understanding of what it is like for people when they are discharged from hospital. It is also very important to find out what things are helpful and what things are unhelpful for people's recovery when they are discharged. This information will be used to help psychiatric nurses better prepare service users for their discharge so that the likelihood of readmission to hospital is reduced. I would also like other people to learn from your experiences so that they have the opportunity to practice and develop the strategies that you use to stay well.

Procedures:

In order to find out this information, I would like to talk to you about your experience. This will take place at the Community Day Centre where you attend. If this is not suitable than an alternative venue can be arranged. If you have been discharged from hospital over three months ago I would be very interested to meet you and talk about your experiences. If you are interested in taking part you must read this information. I will then contact you to see if you are still interested in participating in the research and to answer any questions that you might have. Once this is completed, and you still want to talk to me, a time for the interview that is convenient for you will be arranged. The interview will last about one hour and I will record it so I can listen to it after the interview is finished. You can have a copy of the interview if you wish. During the interview I will be asking you about what it was like for you when you were discharged from hospital.

If you think that talking to me about this subject might upset you or cause you any sort of distress then I would prefer that you did not take part in this study, as I do not want to cause any distress that may interfere with your treatment. If you don't feel well enough to talk to me about your experience then I would prefer if you did not participate in this research. Should any unprofessional practice be disclosed during the interview I am obliged to report this to the relevant authorities.

Benefits:

While their may be no benefits to you directly, it is hoped that the knowledge generated from this study will provide an understanding of your experience and will have a direct impact on improving the quality of service for future service users.

Risks:

Should you become distressed or upset when discussing your experiences the interview will be stopped and I will provide some time for you to talk about your feelings. The interview will only be continued if it is not going to cause you any further upset. You may stop the interview at any time. If I feel that the interview has been too upsetting or distressing, I will, with your permission, contact your mental health worker to let them know what has happened. If you do not want me to do this then I would prefer if you did not participate in this instance.

Confidentiality:

Your identity will remain confidential. Your name will not be published and will not be disclosed to anyone.

Voluntary Participation:

You have volunteered to participate in this study. You may withdraw at any time. If you decide not to participate, or if you withdraw from the study, you will not be penalised in any way.

Permission:

This research has been granted ethical approval from the Faculty of Health Sciences, Trinity College, Dublin.

Further information:

If you need any further information or if anything in this document is unclear, please contact me at the following number 01 8963109 or at the following email address: bjkeogh@tcd.ie and I will be happy discuss any of this information with you.

Thank you for taking the time to read this information

Summary

Mental Health Service User's Experiences of Going Home from Hospital

- If you have been discharged from hospital over three months ago you can participate in this research.
- Participation in this research will require you to attend for one interview at the community mental health Centre that you attend (or a place of convenience for you if this is not suitable). This interview will last one hour and will be tape-recorded.
- During the interview I will be asking you questions about what it was like for you when you were discharged from hospital. In particular I will be asking you that went well for you and the things that didn't go so well.
- Participation in this study is voluntary.
- You can also withdraw from the study at any time if you decide to participate.
- Do not take part in this study if you think that it might upset you or cause you any unnecessary distress.
- Do not take part in this study if you are not feeling up to it for what ever reason.
- If you want a copy of the interview, let me know and I will send it to you when it is ready.
- If you are interested in taking part in this research you must send me back the pink sheet (page 6) in the envelope provided as soon as possible
- Make sure that you put your name and your contact details on the pink sheet and I will contact you to talk about the research to see if you are still interested in talking to me.

Please contact me at 01 8963109 or bjkeogh@tcd.ie if you any questions about the information in this document.

APPENDIX THREE – PARTICIPANT CONSENT FORM

PARTICIPANT CONSENT FORM

TITLE OF THE RESEARCH STUDY:
Mental Health Service User's Experiences of Going Home from Hospital
RESEARCHER'S CONTACT DETAILS:
Mr Brian Keogh, Telephone : 01 8963109 E-mail : bjkeogh@tcd.ie
BACKGROUND AND PROCEDURES:
The purpose of this study is to explore the experiences of people as they were discharged from hospital and returned to living in the community. Participation will involve one interview. The interview will last approximately one hour and with your permission will be audio-taped. During the interview you will be asked to provide some general background information. You will then be asked to describe what it was like for you when you were discharged in particular what went well for you and what didn't go so well. After the interview I will listen to the recording and analyse it. The findings of this research will be written up as a report and may be submitted for publication and/or presentation at a conference.

DECLARATION

- I have read the study information sheet and this consent form.
- I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.
- I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential.
- I understand that the interview will be audio taped.
- I understand that if I wish to do so, I may have a copy of the interview.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I have received a copy of this agreement and I understand that the results of this research may be published.
- I understand I may withdraw from the study at any time.

PARTICIPANT'S NAME (Block Capitals):
CONTACT NUMBER:
PARTICIPANT'S SIGNATURE:.....

Date:
Statement of investigators responsibility: I have explained the nature and purpose of this study to the persons named above, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and have fully answered such questions. I believe that the person named above understood my explanation and have freely given informed consent.

Investigators Signature

.....**Date**.....

For Investigator's Use Only

Participant Code:

APPENDIX FOUR - STATEMENT OF INTEREST FORM

Mental Health Service User's Experiences of Going Home from Hospital

Please complete this form and return it in the envelope provided

Name: _____

Please tick one of the following boxes:

I am interested in hearing more about this research ☐

I do not want to be contacted about this research ☐

If you are interested in hearing more about this research please complete the following details:

Address: _____

_____

_____

_____

Phone:_____

Email:_____

Preferred time of contact:_____

APPENDIX FIVE – FORM FOR COLLECTING DISCHARGE INFORMATION

Exploring Mental Health Service Users Experience of Going Home from Hospital: A Grounded Theory Study

Background Information

Participant code:

Participant's Age: _____

Gender: Male ☐ Female ☐

Occupation/Previous

Occupation:_____

Where does the person live?

Urban location ☐ Rural location ☐ Living alone ☐

Not living alone ☐

If not living alone, who is the person living with?

_____

Is the person: Single ☐ Married ☐ Widowed ☐ Widower ☐

Other _____

Children: Yes ☐ No ☐

Discharge Information

APPENDIX SIX – OVERVIEW OF THEORY CATEGORIES AND SUB-CATEGORIES

Core Category: Managing Preconceived Expectations

Number	Category	Subcategory
1.	Absorbing Preconceived Expectations	➢ Mental Distress: Something that was Poorly Understood ➢ Mental Hospitals and People with Mental Health Distress: Something to be Feared ➢ Mental Distress: Something to be Ashamed of
2.	Acquiring Preconceived Expectations	➢ Being admitted to hospital: The Psychiatric Hospital as a Place of Security and Safety. ➢ Mental Distress: Indoctrination into the Medical Model ➢ Receiving a diagnosis: An absence of hope for the future ➢ Mental Distress: Something to Remain Undisclosed
3.	Validating Preconceived Expectations	
4.	Maintaining Preconceived Expectations	➢ Being given a wide berth ➢ Not being understood ➢ Internalising negative assumptions Encounters with stigma
5.	Avoiding Preconceived Expectations	➢ Avoiding Social Exposure ➢ Cautious Disclosure ➢ Justifying Otherness'.
6.	Reassessing Preconceived Expectations	➢ Passing the Rubicon ➢ Developing a language of positivity Using internal and external recovery catalysts
7.	Defying Preconceived Expectations	➢ Becoming a success ➢ Maintaining mental health

APPENDIX SEVEN – ETHICAL APPROVAL TRINITY COLLEGE DUBLIN

THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE

SCHOOL OF MEDICINE
FACULTY OF HEALTH SCIENCES

Trinity College, Dublin 2, Ireland
Tel: +353 1 608 1476
Fax: +353 1 671 3956
email: medicine@tcd.ie

Professor Dermot Kelleher, MD, FRCPI, FRCP, F Med Sci
Head of School of Medicine
Vice Provost for Medical Affairs

Ms Fedelma McNamara
School Administrator
email: fmcnamar@tcd.ie

Mr Brian Keogh
Staff
School of Nursing & Midwifery
24 D'Olier St
Dublin 2

Wednesday, 02 August 2006

Study: An exploration of the strategies used by people who have been discharged from psychiatric hospitals to aid recovery and prevent readmission.

Dear Mr Keogh

Further to a recent meeting of the Faculty of Health Sciences Research Ethics Committee, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely

Professor Chris Bell
Chairperson
Faculty of Health Sciences Ethics Committee

Cc. Ms Agnes Higgins – Nursing & Midwifery

APPENDIX EIGHT – ETHICAL APPROVAL HEALTH SERVICE PROVIDER

THIS NOTEPAPER MUST NOT BE USED FOR PRESCRIPTIONS OR INVOICING PURPOSES

SJH/AMNCH Research Ethics Committee Secretariat
Dan Lynch Ph: 4142860 email: Dan.Lynch@amnch.ie
Ursula Ryan Ph: 4142342 email: Ursula.Ryan@amnch.ie
Secretariat Fax 4142371

THE ADELAIDE & MEATH HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND
TELEPHONE +353 1 4142000

Mr. Brian Keogh
School of Nursing and Midwifery
Trinity College Dublin
24 D'Olier Street
Dublin 2

May 30th 2008

Re: An Exploration of the Strategies Used by People Who Have Been Discharged from Psychiatric Hospitals to Aid Recovery and Prevent Re-admission.

Please quote this reference in any follow up to this letter: 2008/17/14

Dear Brian,

Thank you for your letter dated May 19th 2008 in which you requested approval of some changes to the above referenced study.

The Vice-Chair, on behalf of SJH/AMNCH Research Ethics Committee, has reviewed your request to widen your data collection strategies and to recruit mental health service users from the Mental Health Day Hospital situated at St. James's Hospital and has given his ethical approval

Yours sincerely

Daniel R. Lynch,
Secretary,
SJH/AMNCH Research Ethics Committee

APPENDIX NINE – EXAMPLE OF EARLY THEORECTICAL MEMO

Suspending Control

A common thread that appears to come from the data is this notion of control. Control appears to be something that is temporarily lost prior to hospitalisation and often acts a precursor to hospital admission. Although the participants went into hospital voluntarily, their admission was always precipitated by either a doctor or a family member suggesting that hospitalisation is necessary as they appeared unable to recognise this necessity themselves. Lorencz (1991), in her small study also made reference to the disconnected nature between the autonomy of the individual and the admission to hospital. Once they were admitted to hospital it appeared that they freely allowed the hospital and the hospital staff to take control of them albeit temporarily. It was as if they had enough of autonomy and consciously decided to allow people to control their actions for a while. This was exacerbated by the routine nature of hospital life with it various rules and regulations that dictated what one could and could not do from the time you got up until the time you went to bed. In addition, long periods of time spent either asleep or on medication augmented this feeling of control. It was like the participants had a protective cocoon wrapped around them that protected them form the outside world and made them feel secure. Although being controlled by others is often perceived in a negative fashion, it appears from the data that giving up control was somehow part of the recovery process. When the participants were eventually discharged the locus of control returned and there is a sense that regaining this control was difficult and it took time to get used to being in control again. However, other variables negatively influenced the participants' ability to regain control. These influences could either be internal or external. For example, internal factors stemmed from the individuals perception of mental illness and being in hospital. An example of this is the participant who spoke about 'losing his rights' after he became a 'psychiatric patient' and felt that he could no longer ask his family for anything. An example of an external factor is described in interview 1, where the participants' husband and family were not willing to allow her to have control because of their past experiences and the risk that she might loose the control again. This was demonstrated actively and passively.

APPENDIX TEN – EXAMPLE OF LATER THEORECTICAL MEMO

Cautious Disclosure 3rd November 2008

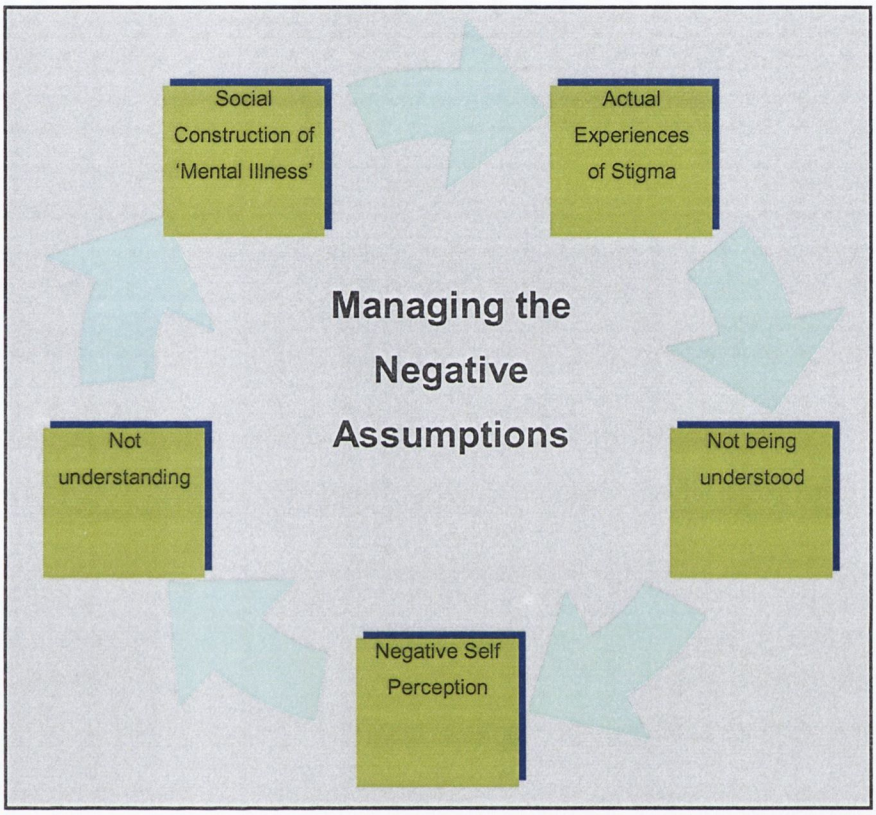
At the grounded theory seminar in New York everybody had great interest in this concept. Barney announced that in my study this was the core category. I am dubious about this as firstly I am not sure about the originality of the concept. Initially I had referred to it as partial disclosure but when I thought about it further I decided that cautious disclosure was more appropriate. People do want to tell people about their mental illness but they don't tell everyone they only tell certain people. It was suggested that partial disclosure might be a property of cautious disclosure. Another property might be tailored or adapted closure and finally undisclosure (is that a word) where the individual conceals everything. Perhaps concealment is a better word. Cautious disclosure occurs in response to people's reaction to having a mental illness or their reaction to being in hospital. It also occurs when they are not being taken seriously. It also occurs when they fear that they will be treated differently by others. Charmaz's (1991) work about chronic illness and time devotes an entire chapter to disclosing illness. In it she refers to avoiding disclosure which is different to concealment of the illness. For people with mental illness concealment may come a little easier as the illness is not visible in terms of something like the physical chronic illnesses that Charmaz talks about. A chronic illness that impacts on ones ability to walk for example is impossible to conceal or to avoid disclosure. For Charmaz avoiding or concealing disclosure appears to have some anxiety reducing properties a bit like the defence mechanism denial. For people with mental illness this is different I think as the stigma attached to mental illness is somewhat more intense than that of physical illness although not all physical illnesses. I do agree with her when she talks about losses and risks associated with disclosure. In my study people do not want to disclose because they fear rejection and this rejection I feel is associated with the misconceptions associated with mental illness. One individual put it really well, when you disclose people start to pull away from you. They don't want to know. There is a reference to cautious disclosure in her work and this relates to one person who became 'very careful' about who she told about her illness. Illness is a private event I think but people would disclose if it were made more acceptable for them to disclose and if people were more understanding. Charmaz's discussion about bodily function and disclosure is interesting. In one of her stories, she mentions that one of the individuals wants to talk about an illness, but as soon as she does she is cut off. The nature of the illness is easier to disclose and in this case where the individual had sporadic diarrhoea, people didn't want to know because of the 'dirty' nature of the illness. For people with mental illness, disclosure is different because not only to people not understand them, generally speaking people fear them and think they are unpredictable. Although some illnesses are probably better understood them others, most people think that talking about a particular individuals mental health will only make it worse. Goffman (1968) talks about the known about-ness of a particular attribute. In this case mental illness is often easier to hide or conceal because of the invisible nature of the symptoms when people are in recovery. Page (1984) suggests that there are two main ways that people attempt to manage their spoilt identities as he refers to it – firstly by passing and secondly by covering. Passing involves the individual attempting to 'pass' as normal. The frequency of this act depends on the type of stigma experienced for example people with physical disabilities may not be able to do this while people with mental illness may find it easier. Passing contains attributes of cautious disclosure as in passing people will restrict who they tell about their stigma. Covering on the other hand involves

attempting to reduce the tension during social interaction by attempting to reduce the unobtrusiveness of their disorder. For example a blind person who covers may act the way it is deemed socially accepted for people who are sighted e.g. looking at the person who is talking etc. Page(1984) finally mentions 2 types of stigmatised people those who reject and those who accept. Those who accept will use the strategies of covering and passing while those who reject will not. I think that people with stigma do cover in that they do their best not to draw any attention to themselves in social situations in that way they will not talk about their illness but they do desperately what to talk about it.

APPENDIX ELEVEN – EARLY LIST OF OPEN CODES

Admission	Hospitalisation	Going Home
Admitting defeat	Taking time.	Having no voice.
Losing control	Passing time.	Not wanting to go back into hospital.
Becoming dependant.	Being accepted.	Begging to stay well.
Being shell shocked.	Feeling secure.	Feeling strange
	Being cocooned.	Nobody understanding.
	Socialising to hospital.	Feeling weak.
	Not making progress.	Being blamed.
	Feeling uncomfortable.	Taking responsibility.
	Accepting fate.	Being judged.
	Being bored.	Getting back on my feet.
	Forced isolation.	Being ready
		Getting back to normal.
		Being treated differently
		Regaining independence
		Earning independence.
		Being depressed.
		Being dependant.
		Being wary of me.
		Reclaiming my role.
		Being independent.
		Regaining control.
		Keeping occupied.
		Feeling self conscious.
		Lacking confidence.
		Making a break.
		Fending for myself.
		Looking ok on the outside.
		Being determined.
		Being an outsider.
		Uncertain about the future.
		Feeling shaky.

APPENDIX TWELVE – EARLY THEORY ELABORATION



APPENDIX THIRTEEN – LATER THEORY ELABORATION

