University of Southampton

What is the lived experience of being discharged from a psychiatric inpatient stay?

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UNIVERSITY OF SOUTHAMPTON

GENERAL ABSTRACT

FACULTY OF SOCIAL AND HUMAN SCIENCES

Psychology

Doctor of Clinical Psychology

WHAT IS THE LIVED EXPERIENCE OF BEING DISCHARGED FROM A PSYCHIATRIC INPATIENT STAY?

By Anna Redding

The first part of this thesis contains a narrative review of the literature relating to how people with mental illness cope with stigma. The majority of the research has focussed on models of stigma, the impact of stigma on individuals and campaigns to combat stigma. There is limited research exploring how people cope with stigma and the effectiveness of these strategies. The review highlights the need for further research in this area to inform interventions.

The second part of the thesis contains a qualitative research study, which aimed to provide an understanding of how individuals with a mental illness described their experiences of being discharged from psychiatric inpatient stays. Suicide rates post-discharge remain high despite discharge planning and discharge interventions, yet little is known about why discharge can be so difficult for individuals. Interpretative Phenomenological Analysis (IPA) was used to analyse interviews from eight individuals who had been discharged within the last three years. The analysis highlighted five superordinate themes: the hospital experience, the experience of discharge, the outside world, the journey to health and self-beliefs/identity. The results are discussed in relation to previous findings and implications for future research and clinical practice.

Keywords: Narrative review, mental illness, stigma, coping, qualitative research, Interpretative Phenomenological Analysis, psychiatric discharge.

Table of Contents

Literature Review: How do people with a mental illness attempt to cope with stigma?

Table of Contents

Empirical Paper: What is the lived experience of being discharged from a psychiatric inpatient stay?

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I, Anna Redding, declare that the thesis entitled “what is the lived experience of being discharged from a psychiatric inpatient stay?” and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
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Signed: …………………………………………………………………………..

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Literature Review Paper

Literature Review: How do people with a mental illness attempt to cope with stigma?

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ABSTRACT

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WHAT IS THE LIVED EXPERIENCE OF BEING DISCHARGED FROM A PSYCHIATRIC INPATIENT STAY?

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This narrative literature review aims to provide an overview of the research relating to how people with a mental illness cope with stigma. It does this in an attempt to further understand what it is like for people to live with stigma related to their mental illness, and to explore what is known and what might be missing in the literature. Firstly, the review highlights what is understood by the term stigma, relating this to different theories. Secondly, the review considers what is understood to be coping. Thirdly, the review explores the impact that stigma has on individuals and what factors influence an individual's ability to cope with stigma. Fourthly, the review critically reviews these studies, focussing on methodological limitations and presenting implications for clinical practice.

Keywords: Narrative review, mental illness, stigma, coping

Introduction

Research into public attitudes towards mental illness began in earnest in the 1940s and 1950s. Early studies predominantly used attitude surveys and evaluations of efforts to educate the public about mental illness with the aim of enabling people with mental illness in hospital to return to the community without stigmatisation (Hinshaw, 2007). Most research into this area has focussed on the views of the public although more research appears to be emerging involving patient views (e.g. Corry, 2008; Green, Hayes, Dickinson, Whittaker, & Gilheany, 2003).

In 2004, a UK based Social Exclusion Unit (SEU) found that people with a mental illness are among the most excluded groups in society (Department of Health, DOH, 2009). Despite growing knowledge on how to diagnose and treat mental illness, myths and misperceptions persist, leading to discrimination and stigma (World Health Organisation, 2011). Campaigns aimed at addressing these myths have developed over the last two decades, yet people with mental illness continue to experience stigma (Suto, 2012), around the world (Lauber & Rössler, 2007). For example, people experience stigma resulting from diagnoses, particularly schizophrenia, being labelled dangerous due to media portrayal (Dinos, Stevens, Serfaty, Weich, & King, 2004), stigma in employment (Morgan, 2005) and family rejection (Lee, Chiu, Tsang, Chui, & Kleinman, 2006).

Traditionally, research examining stigma and mental illness has focussed on two main areas: (1) prejudice and discrimination against people with mental illness by society, and (2) the internalisation of these perspectives by individuals with mental illness, or self-stigma (Stier & Hinshaw, 2007). There is a wealth of research on the impact of stigma, but little on how people cope with that stigma, whether this differs depending on the type of stigma, personal traits and attributes of the individual and whether these strategies are effective (Stier

& Hinshaw, 2007). How people cope with stigma should be a key concern for professionals given the impact that it can have on an individual’s well-being and help-seeking behaviour (Thornicroft, Rose, & Kassam, 2007).

This narrative review will begin by examining what is meant by the term stigma and how it arises considering different models. The review will then consider the impact that stigma has on individuals, occupation and relationships. Next, the review will explore research examining how people cope with stigma. The research will be critically reviewed, focussing on methodological limitations. Conclusions will be drawn and suggestions for clinical implications regarding how people cope with stigma will be outlined. The term ‘patient’ will be used as this represents how individuals who have a mental illness prefer to be addressed (McGuire-Snieckus, McCabe, & Priebe, 2003; Simmons, Hawley, Gale, & Sivakumaran, 2010).

The databases Psychinfo, Medline and the British Library’s integrated catalogue were searched using the following terms: stigma or discrimination, mental disorders or mental illness, coping and/or coping behaviour/behavior and impact. Articles involving children and adolescents, siblings or carer’s experiences and stigma of physical illnesses were excluded. In addition, references gleaned from reading articles obtained from the main search were accessed.

There are different perspectives and realities of the experience of stigma; the patient, the professionals treating the patient, public attitudes, family and friends, and government all hold different viewpoints and have different experiences of mental illness and stigma (Gelb, 1980). This review will focus on the viewpoint of the patient, which may not represent the views of professionals, the public or friends and family (refer to Milliken & Northcott, 2003; Mordoch & Hall, 2008 for examples), however it is the truth as they perceive it.

What Do We Mean by Stigma, Mental Disorder and Coping?

Stigma

According to Simon (1992), the term stigma originated from the Greeks and referred to bodily marks that were burnt or cut into the body to expose something bad about the individual, for example that they were a slave, or a criminal. The dictionary definition of stigma is “a mark or sign of disgrace or discredit, regarded as impressed on or carried by a person or thing. A visible or apparent characteristic indicative of some (esp. undesirable or discreditable) quality, action, or circumstances” (Stevenson, 2007, p.3027). Goffman (1963) describes stigma as “an attribute that is deeply discrediting” (p.13). Stigma also signifies the social judgement and discrimination that the majority place on people who possess the ‘mark’, as well as the potential for internalising and shame on the individual. Stigma can be visible or invisible, controllable or not and linked to appearance (e.g. physical disfigurements), behaviour (e.g. child abuse), or group membership (e.g. homosexuality) (Hinshaw, 2007).

Stigma is believed by many to be a social construction that varies across time and cultures (Crocker, Major, & Steele, 1998; Jones et al., 1984). Stigma is “relationship- and context-specific; it does not reside in the person but in a social context” (Major & O'Brien, 2005, p.395). Therefore it might be argued that anyone can potentially be stigmatised in some context (Crocker, et al., 1998). Stigma of mental illness has persisted even when tolerance for other stigmatised groups has increased (Dubin & Fink; Stier & Hinshaw, 2007). Research indicates that stigma of patients remains prevalent, with a recent nationwide survey reporting nine out of ten patients (87%) stated it has a negative impact on their lives (Corry, 2008) and has not changed much in the last decade (Hinshaw, 2007; Lyons, Hopley, & Horrocks, 2009).

Three types of stigma have been proposed: public stigma, self-stigma, and label avoidance (Corrigan & Watson, 2002). Public and self-stigma involve the same three components: *stereotypes*, which refer to negative beliefs about a group, *prejudice* when the stereotype is agreed with, leading to the creation of a negative emotional response, and *discrimination* which refers to behavioural responses to prejudice. Public stigma refers to the public endorsing stereotypes about patients, and then acting negatively towards them. Even when people have not interacted with someone with a mental illness, the social meaning associated with the term can shape responses (Hinshaw, 2007). Self-stigma occurs when the patient internalises the stereotype resulting in low self-esteem and behavioural responses such as avoiding social situations, and failing to pursue goals. Label-avoidance describes individuals avoiding engaging with mental health services and interventions in order to avoid the stigmatising label (Corrigan, Markowitz, & Watson, 2004).

The media and language we use both help to maintain stereotypes of patients (Angermeyer & Schulze, 2001). News headlines often portray people with mental illness as more violent and dangerous than other offenders (Diefenbach, 1997). Terms such as ‘mental’ and ‘schizophrenic’ can lead to stereotypical images of mental illness associated with people like ‘The Yorkshire Ripper’ (serial murderer of women), (Green, et al., 2003). Despite recent moves to portray mental illness more positively using nationwide campaigns such as ‘Time to Change’ (Corry, 2008) and ‘Changing Minds: Every Family in the Land’, 1998-2003 (Crisp, 1998), the vast majority continue to depict an image of incompetence, violent and bizarre behaviour (Angermeyer & Schulze, 2001; Cloverdale, Nairn, & Claasen, 2002). Crisp (1998) reported that 70% of individuals believed people with schizophrenia, drug addiction and alcoholism were dangerous. This indicates that nationwide campaigns still have not yet fully addressed stereotypical views of mental illness.

Mental Illness

The Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, [APA], 2000) states that there is no definition that adequately specifies precisely what a ‘mental disorder’ covers. Furthermore, the term does not have a consistent operational definition that incorporates all situations. The International Classification of Disorders (ICD-10) states that “disorder” is not an exact term, but defines mental disorder as “the existence of a clinically recognizable set of symptoms or behaviour associated in most cases with distress and with interference with personal functions” (WHO, 2002, p.5).

The medical model promotes an ontological approach whereby mental illness is classified by observable phenomena and descriptions of symptoms. Therefore mental illness is classified into categories using set criteria, normal distribution curves, or cut-offs to diagnose conditions. Hinshaw (2007) argues that this highlights differences between ‘normal’ and ‘abnormal’ and only labels those with extremes of the condition. Definitions of what is normal, acceptable or labelled deviant or abnormal are socially constructed, therefore individuals who do not fit these norms are marked as differing from mainstream society. The medical model tends to diagnose people according to symptom clusters and does not account for individual differences or severity of illness.

According to the categorisation of mental illness in the DSM (APA, 2000), one would presume that two individual’s with the same disorder would show similar presentations, which is often not the case (Widiger & Sanderson, 1995). The medical model, possibly increases stigma because it allows the medical profession to categorise people with the same label and focusses on people’s difficulties and weaknesses. In addition, it does not allow for the patient’s perspective and therefore some feel it is inherently more stigmatising (Shah & Mountain, 2007).

Coping

This review aims to examine literature regarding how patients cope with stigma. It is therefore important to consider what we mean by coping; much of the existing research does not discuss this. Coping has been defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.141). This definition views coping independently of the outcome, so includes any strategy the person uses regardless of how effective. Other definitions of coping have been cited (e.g. Menninger, 1963; Vaillant, 1977), however, Lazarus and Folkman argue that their definition applies to all stressful encounters.

They perceive coping as a process, whereby coping methods can change depending on the situation and as the relationship between the individual and environment changes. They distinguish between coping directed at managing the problem causing distress (problem-focussed), and coping directed at regulating the emotional response to the problem (emotion-focussed), which can both facilitate and impede each other.

Models of Stigma

In order to consider how people cope with stigma, it is useful to explore models regarding how stigma arises in the first place. Theoretical models provide a way of understanding how people come to cope with stigma in the way that they do. There are several different theories and models that have been applied to stigma and mental illness; labelling theory, cognitive models, attributional theory, situational models and identity models. Some of these models will be discussed briefly. Social cognitive and attributional theories have not been empirically applied specifically to mental illness stigma or coping. Therefore these models will not be explored here (see Corrigan (2000) and Weiner, Perry and Magnusson, (1988) for an overview).

Labelling Theory

Categorical perception states that categorising people helps individuals make sense of the world (Harnad, 1987), and particularly the social world (Hewston & Jaspars, 1982). Stereotypes are an efficient way of categorising information about social groups by allowing the perceiver to rely on previously stored knowledge (Hilton & von Hippel, 1996). Scheff's (1966) formulation on labelling was based on the assumption that people learn and internalise cultural stereotypes of mental illness from childhood. These are continuously reaffirmed in the mass media and everyday conversations as well as from jokes and cartoons. For example, from a young age we are taught to avoid strangers, people who are different and have an instinct to protect ourselves (Houghton, 1980).

As early as 1934, the link between individuals' learning and internalising community beliefs was asserted (Mead, 1934). Using social theory, Link (1987) reported that conceptions about mental illness are used to form expectations about whether they believe people will reject and/or devalue patients. He claimed these beliefs have no real bearing on individuals unless they become patients themselves, whereby their beliefs about other's attitudes towards mental illness transform into an expectation of rejection. This can have negative connotations for the individual. Firstly, they may devalue themselves as they now belong to a group that they believe most people view negatively. Secondly, they believe they will be devalued and rejected by others and so engage in defensive mechanisms which lead to strained interactions with others and isolation. The first situation affects the self-esteem and self-concept of the individual as they internalise their perceived negative views of others. This theory highlights the importance of labelling as it is the official *label* of mental illness that makes perceived community attitudes become personally relevant. In addition, the beliefs develop early and have their source in culture, rather than developing from symptoms of mental illness.

Labelling theory suggests that people labelled with mental illness or who are observed to have such a label (from signals e.g. behaving bizarrely, or seeing a psychiatrist) are the object of stigma and discrimination (Link, 1987). In addition, bizarre behaviour can lead to public fear and therefore stigma. Bizarre behaviour can lead to more stigmatising reactions than labels alone (Rabkin, 1980).

The more a person believes they will be discriminated against and devalued, the more they feel threatened by interactions with others (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). This then leads the patient to adopt different strategies to cope with the perceived rejection, for example avoidance, secrecy or educating others. However, these strategies can lead to negative consequences for social networks, employment and self-esteem.

Situational Models

Corrigan and Watson (2002) proposed that not everyone labelled with a mental illness experiences low self-esteem as a result. Corrigan, Faber, Rashid and Leary (1999) claim that self-stigma and empowerment are on opposite poles of a continuum. Those who feel unable to overcome stigma fall in the negative end of self-stigma, resulting in low self-esteem and confidence in their future. At the other end are those who are energised by the stigma to experience righteous anger (Corrigan, et al., 1999) against those who have unjustly stigmatised them.

Self-esteem is affected when the person perceives the negative reactions to be valid. Those who view the reaction as unjust and not legitimate will keep their self-esteem intact. Some support for the model is demonstrated in literature from stigmatised groups indicating that some individuals do not show decline in self-esteem, for example black people (Porter & Washington, 1979), disabled people (Stager, Chassin, & Young, 1983) and people with mental illness (see Hayward & Bright, 1997, for a review). Additionally, Crocker, (1999) reported that a person's reactions to stigma may change throughout their life, and depending on the situation. The response of the individual depends on several factors: external attribution of negative feedback; protection from in-group comparisons, and having values that help protect against stigma (Crocker & Major, 1989).

Individuals who reject negative reactions of others, and align themselves with the stigmatised group experience righteous anger. On specific values relating to stigma, if they compare themselves to the general public, individuals are likely to lose self-esteem *(most people can live independently, there must be something wrong with me*). Therefore, comparing themselves with in-group members whose functional abilities tend to have less variation compared to the general public, helps protect their self-esteem (Crocker & Major, 1989). Those who do not identify with the group may be indifferent to self-stigma. Another mechanism that may offer some protection to self-esteem is attributing negative feedback to the prejudiced attitudes of others towards the individual’s group membership (Crocker & Major, 1989).

A study by Rüsch et al. (2009a) provides some support for these hypotheses. They reported stress appraisal was positively correlated with rejection sensitivity. Higher levels of perceived societal stigma and holding the group of patients in high regard independently predicted high stress appraisal. However, this study was a cross-sectional design and cannot infer causality. In addition, Corrigan and Watson (2002) claim that stigma related stress can be situation specific, which was not measured in Rüsch, et al’s. (2009) study.

Identity Threat Model

The identity threat model of stigma aims to bring together some of the theories regarding stigma (Major & O'Brien, 2005), integrating identity threat models of stigma (Major, Quinton, & McCoy, 2002) with models of stress and coping (Lazarus & Folkman, 1984). The model posits that possessing a devalued social identity (a stigma), increases the individual’s exposure to identity-threatening situations (Figure 1, see Appendix A for detailed explanation).

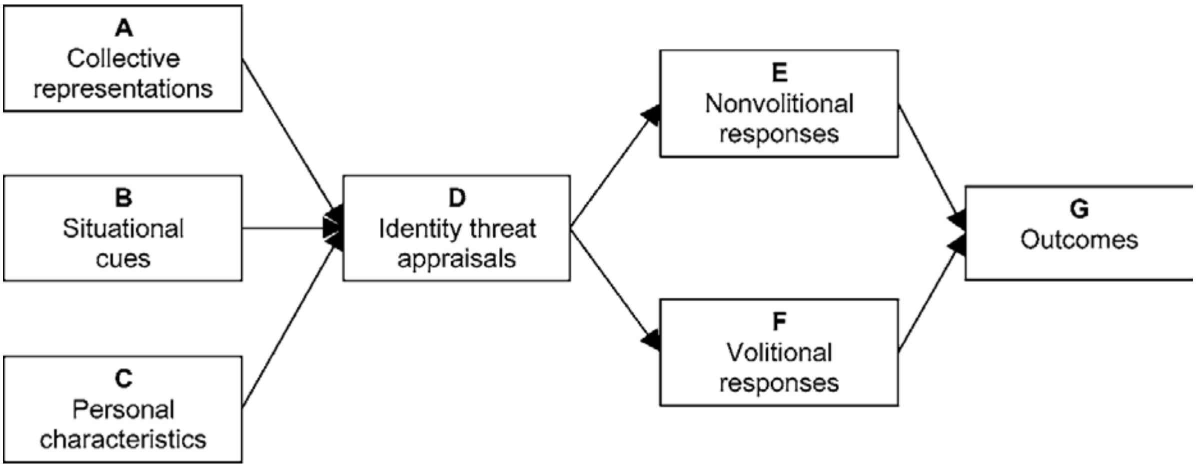

Figure 1. An identity threat model of stigma (Major & O'Brien, 2005).

Collective representations refer to the shared understandings of others about the stigmatised groups developed from experiences. They affect how stigmatised people appraise and perceive stigma-relevant situations, and help shape how individuals view stigma-related situations. Personal characteristics also affect how situations are perceived, for example, stigma sensitivity, goals and motives and group identification.

Stigma-induced identity threat results when the demands of a stigma-relevant stressor are appraised as harmful to their social identity and exceeding their coping resources. It is then assumed that if a stigma-related situation arises that the individual perceives they can cope with, the situation may not be perceived as a threat. Identity threat can cause automatic vigilance to threat-related stimuli; therefore previous experience may result in the individual being more alert to discrimination. However, this is not always the case; people who have lower prejudice expectations have been reported to screen out identity threat relevant information, particularly in identity-safe environments (Kaiser, Vick, & Major, 2006). This does not appear to have been directly studied in relation to mental illness stigma.

Summary.

There have been several proposed models of stigma of mental illness which are useful in understanding how stigma develops and is perceived. However, some appear to have a greater empirical base than others, particularly in relation to coping. Labelling theory (Link, 1987) appears to have been applied most frequently to stigma and coping in patients, followed by the identity threat model (Major & O'Brien, 2005). Situational models (Corrigan & Watson, 2002; Major, Kaiser, & McCoy, 2003; Weiner, et al., 1988) appear to have sound theoretical backgrounds, but do not appear to have been empirically tested in their application to coping with mental illness. Therefore, further investigation regarding the application of these theories to coping with stigma of mental illness would be beneficial to enhance our understanding.

The Impact of Stigma

In order to understand how people cope with stigma, it is important to consider how stigma impacts patients' lives. Stigma can emanate in three ways: overt discrimination, which may result in the individual being socially disadvantaged or excluded from activities; perception and fear of discrimination, which may lead to self-exclusion and withdrawal; and internalisation of the stigma, which may damage their self-worth (Green, et al., 2003).

Labelling theory advocates and its opponents have differing views of stigma and therefore differ in their opinions on the consequences it can have on patients. Labelling theory states that official marks, or labels such as being hospitalised, have negative consequences for the person. In contrast, critics of the theory state that stigma is relatively inconsequential (Rosenfield, 1997).

Proponents of research that indicates stigma is not a problem (Gove, 1980), claim that it is an individual's behaviour that is the problem not the label (Schwartz, Myers, & Astrachan, 1974). In 1980, a National Institute of Mental Health (NIMH) workshop of experts in the field decided not to use the term 'stigma' because it was: "too strong to describe the full range of negative reactions toward the mentally ill.…….using such an emotionally charged, strongly negative word to describe attitudes toward mental illness and the mentally ill does not encourage objective thinking about the problem" (Gelb, 1980, p.2). However, this raises the question of what word to use and whether not using the word further stigmatises the patient by avoiding the issue.

Jones et al. (1984) propose that once a person is linked to undesirable characteristics, rejection and isolation of the stigmatised person occurs. However, this may not always be the case, as a 'marked' person may not always be stigmatised (Jones, et al., 1984). Therefore, stigma could be viewed as a matter of degree, where the mark can vary regarding how much it sets the person apart from others, depending on how severe the link to undesirable characteristics are and how strong the rejection is. Therefore it might be argued that the impact stigma has on the individual may vary. This notion is hypothesised by Corrigan and Watson’s (2002) model which states that not everyone in a stigmatised group experiences negative effects from it.

Based on Major and O’Brien’s identity threat model (2005), greater perceived public stigma has been found to predict the appraisal of stigma as more stressful (Rüsch, et al., 2009a). Rüsch et al. reported that higher levels of rejection sensitivity and low perceived legitimacy of discrimination (perceiving the stigma as unfair), were associated with perceiving stigma as more harmful. In addition, poorer social cognition was associated with less rejection sensitivity, indicating that social cognitive deficits might reduce the level of stigma perceived by individuals, therefore indirectly reducing stress caused by stigma. As this was a cross-sectional design, causality cannot be inferred, however, it implies that personal characteristics of the individual can have an important bearing on the impact of stigma and might prove useful targets for intervention.

Labelling theory asserts that once labelled, patients are: “punished when they attempt to return to conventional roles” (Scheff, 1966, p.87). Despite being encouraged to rehabilitate back into the community following hospital discharge, patients are often discriminated against when trying to return to their old roles and in new ones such as relationships, social and occupational roles (Scheff, 1966).

Employment

Employment not only provides financial rewards, but also contributes to social identity and status and a sense of achievement and self-worth (Leete, 1992; Wahl, 1999; Warr, 1987).

Exclusion from the workforce can have implications for mental and physical health, resulting in a vicious circle (Lahelma, 1992). Less than four out of ten employers expressed a willingness to recruit patients (Department of Health, 2009).

Research indicates a range of negative beliefs regarding recruiting individuals with mental illness (Stuart, 2006). Three-quarters of employers expressed a belief that it would be difficult or impossible to employ someone with schizophrenia (Biggs, Hovey, Tyson, & MacDonald, 2010). Despite patients expressing a desire to work post-discharge from hospital, service providers believed that only 12% of patients were employable (Holley, Hidges, & Jeffers, 1998). Employers reported concerns regarding work performance including: absenteeism; the need for excess supervision and the ability to follow regulations; clinical factors such as relapse rates; severity of illness and how well controlled the illness is, and trusting the employee with information and safety of others (Biggs, et al., 2010). A scarcity of decent, well-paid jobs for people with mental illness helps maintain financial dependence (Thornicroft, 2006).

These findings suggest that more accurate knowledge on mental illness might be beneficial in helping employers with their lack of confidence in employing people. Biggs et al. (2010) claim that recruitment firms were generally more positive about putting forward people with mental illness for work positions, however, this might be due to the fact that they are not ultimately responsible for hiring the individual.

Research indicates that patients have experienced difficulties in securing jobs or have lost their job following disclosure of a mental illness (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Lyons, et al., 2009) and faced inappropriate questions during interviews such as: “how would you control your behaviour if challenged by work colleagues” (Lyons, et al., 2009, p.503). Returning to work after being ill can be a challenge (Houghton, 1980; Knight, Wykes, & Hayward, 2003) and patients reported being downgraded (Lyons, et al.,

2009) or advised to retire early (Leete, 1992; Lyons, et al., 2009). Treatment for mental illness has resulted in greater income loss and higher unemployment (Link, 1987). Patients have reported being treated differently in the workplace after disclosing a mental illness or an episode of illness. For example being treated as incompetent, people talking slower to them, being told to lower their expectations (Wahl, 1999), being avoided or talked about (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002).

Stigma by Professionals

Research indicates that health professionals also stigmatise patients, with people being told their physical illnesses are ‘in their mind’ (Lyons, et al., 2009), being on the receiving end of ‘jokes’ or being treated with a lack of respect (Wahl, 1999), being treated as “subhuman” (Herman, 1993, p.303) or being told to rethink their goals as they are now ‘ill’ (Katz, 2004). Patients have recounted not being taken seriously: “my depression is not taken seriously by some GPs, psychiatrists and CPNs, which makes it hard to get treatment. I felt like an impostor in psychiatric hospital” (Corry, 2008, p.10).

Relationships

Patients have reported being ‘dropped’ by friends, colleagues, and even family and their church after disclosing they have a mental illness (Houghton, 1980; Leete, 1992; Lyons, et al., 2009; Wahl, 1999). They also experienced being avoided (Link, et al., 1997), no longer being trusted (Rosenfield, 1997), people treating them with caution, being viewed as lazy or unmotivated (Wahl, 1999) and being taunted by neighbours (Green, et al., 2003). Patients have reported that family have lower expectations of them since their diagnosis, and believe that family are embarrassed of them (Corry, 2008). One patient recounted the impact a friend’s reactions can have: “keeping in touch with friends – reaction is usually one of shock, horror, followed by avoidance; most people have no idea how hard it is. This leaves me feeling very isolated and with low self-confidence” (Corry, 2008, p.4). Potentially the impact of stigma from family, friends and church might be more devastating than when received from strangers (Lyons, et al., 1999).

Patients have reported believing that people would no longer wish to marry them due to their mental illness (Link, et al., 1997). In addition strangers have been reported to shout abuse and derogatory statements to patients (Lyons, et al., 1999) or having their hospitalisation used to hurt their feelings (Link, et al., 1997). Landlords are less likely to rent out their properties to people with a mental illness (Houghton, 1980; Knight, et al., 2003; Link, et al., 1997; Page, 1977, 1995).

Linking to Link’s theory on perceptions of stigma (1987), studies have reported that patients’ perceptions of being devalued and discriminated against are high (Kleim et al., 2008; Link, et al., 1997). Link et al. (1997) reported 69% believed people would look down on them and 50% believed employers would refuse to hire them. Kleim et al. (2008) reported that 64% believed that psychiatric hospitalisation would be seen as a failure.

In fact, the more the patient believes that people with a mental illness will be rejected, devalued and discriminated against, the more likely they are to have low incomes, feel demoralised, have social networks that consist mainly of household members and be rejected by others (Link, 1987; Link, et al., 1989; Wright, Gronfein, & Owens, 2000).

The Equality Act (1998; Equality Act, 2010) states that it is unlawful for employers, landlords, education to discriminate on the grounds of disability. Current research is needed to see if this has had any impact.

Impact to Self

Personal accounts of stigma reveal the negative impact it can have;

> It has been my experience that there is nothing more devastating, discrediting, and disabling to an individual recovering from mental illness than stigma…….it signifies that an individual is different, someone to be avoided. Such a tainted person is seen as unbelievable and therefore untrustworthy. And persons who cannot be trusted must be feared. (Leete, 1992, p.18).

Perceived stigma has been associated with greater demoralisation among patients than in non-labelled patients (Link, 1987) and contributed to negative emotions (Eagles, Carson, Begg, & Naji, 2003). Rosenfield (1997) claimed that as the stigma becomes internalised, it changes how the person views themselves. They begin to evaluate themselves in terms of what they cannot do and what they are not, rather than what they are (Jones, et al., 1984). In addition, the individual may face the loss of their 'future-self' and the life they had planned for themselves as a result of stigma as well as from the limitations placed on them by their mental illness. This can result in a sense of loss of the characteristics they valued in themselves and of their life goals (Rosenfield, 1997), which can form the basis of demoralisation (Link, 1987).

The importance of 'reflected appraisals' have been emphasised in the development of the self-concept (Mead, 1934). According to this view, our self-concept develops through our interactions with others and is a reflection of others' appraisals of ourselves (Crocker & Major, 1989). Crocker & Major (1989) argue that people, who know they belong to a stigmatised group that is viewed negatively, will incorporate those negative attitudes into their self-concept and therefore have lower self-esteem. The impact that stigma can have on an individual's self-concept and self-esteem may in part depend on what part of their self-concept is important to them (Jones, et al., 1984). However, Jones et al., (1984) also argue that in the case of mental illness, stigma is likely to affect all aspects of the self.

Corrigan (2000) states that research into treatments and rehabilitation of mental illness are not enough to improve the course of severe mental illness; stigma and discrimination must also be addressed. In addition, Link, et al's. study (1997) reported lasting effects of stigma, with patient's beliefs regarding perceived devaluation and discrimination (PDD) not changing over a one year period even after engaging in a treatment which indicated significant improvements in psychiatric symptoms. This casts doubt on claims regarding the association between symptoms and stigma whereby symptoms such as depression or paranoia influence perceptions of stigma. Depressive symptoms were found to be significantly related to beliefs of PDD whereas coping styles were not, indicating the lasting effect of stigma.

Considering these findings, the question as to why stigma effects endure is raised. Is it because public rejection continues? Or rather that it is difficult for the individual to overcome the personal meanings attached to the label and the trauma of the rejection they experienced? (Link, et al., 1997). If this second notion is a causal factor then even if public attitudes changed, patients still might perceive that they will be stigmatised and therefore the negative impact of stigma will remain. Furthermore, the notion of the self-fulfilling prophecy (Merton, 1957) has a role to play here whereby the expectations of both the stigmatised and the stigmatiser cause the other to act in ways that confirm their false beliefs (Jones, et al., 1984). For example, the Changing Minds campaign research found that people with mental disorders were perceived by the public to be hard to talk to (Crisp, 1998). This may be as a result of direct stigma, or as a result of awkward interactions they have had with a person who has a mental illness and is expecting rejection. Therefore, perhaps the focus also needs to be on addressing how patients perceive themselves, increasing self-esteem and education around how to cope with stigma. This is echoed by Leete (1992) who stated that overcoming self-stigma is the first step towards recovery.

Despite research indicating the impact that stigma can have, as mentioned earlier, there remain some for whom stigma does not appear to have an impact, their self-esteem appearing to be unaffected (Crocker & Major, 1989). Research on this has mainly been done with other stigmatised groups, however, the principles may be applied to patients as well. Crocker and Major (1989) argue that the impact of stigma can depend on who it is that holds the negative attitudes. If significant others in the patient's life continue to value them as a person, the self-esteem of the individual may be somewhat protected. However, significant others who are members of non-stigmatised groups may also hold prejudiced attitudes, for example peers, co-workers and teachers. In addition, personal traits of individual's may also buffer the self-esteem of stigmatised individuals (see also situational models section).

The time since acquiring the stigma and how concealable it is may influence the use of self-protective strategies. It has been argued that those who have been stigmatised more recently will lack the strategies to protect their self-esteem and may need time to learn them (Crocker & Major, 1989). In other words, it may take time for the individual to adjust and accept their new stigma. In addition, the impact of stigma on the individual may depend on the controllability and responsibility for the condition (Corrigan, 2000). It is difficult to ascertain the impact of stigma directly on people. It may be that patients become depressed if they cannot get a job, but it is difficult to ascertain whether they cannot get a job because of stigma or because their symptoms are making it impossible. However, all of these factors will influence how a person then copes with stigma.

Factors That Influence How People Cope with Stigma

Given the pervasive negative impact that stigma has on patients, individuals have to learn ways to cope with it. Little research has explored how patients cope with labelling and stigma and none have evaluated the effectiveness of such strategies, (Link, Mirotznik, & Cullen, 1991) particularly in relation to which strategies might be helpful or cause more harm and indeed exacerbate the problem (Hinshaw, 2007). It is also unclear as to why some people experience stigma as stressful and become demoralised while others seem to be relatively unaffected (Corrigan & Watson, 2002). Further research addressing these factors will help to develop more effective interventions to help patients to cope more effectively with it and potentially improve quality of life.

According to labelling theory, the expectation and actual experiences of rejection lead people to seek ways of coping with the threat of rejection (Link, et al., 1997). This also leads to defence mechanisms which can have negative effects. Reactions to stigma stress can explain why individuals cope more or less successfully with stigma (Rusch et al., 2009b). However, Major and O’Brien (2005) claim that no coping strategy is universally better or worse, as one response may be effective in one situation but harmful in another. Different studies have explored different types of coping strategies that are claimed to be commonly used amongst patients. For example, studies utilising Lazarus and Folkman’s (1984) model of; problem-focused and emotion-focused coping indicate that the strategies adopted by patients to cope with stigma tend to be more emotion-focused, for example avoidance, reappraisal, self-blame, distancing, making comparisons and seeking support (e.g. Green, et al., 2003; Herman, 1993; Rʋsch, et al., 2009b).

Using an adapted version of the identity threat model proposed by Major and O’Brien (2005), Rüsch et al. (2009b) identified two sets of responses caused by stress-appraisal; involuntary emotional reactions; anxiety and shame, and three deliberate cognitive coping responses. Firstly, blaming discrimination versus blaming the self whereby blaming stigma on discrimination shifts the blame to an external cause – other people’s prejudice, which protects self-esteem (Major, et al., 2003). Secondly, devaluing domains which their group typically performs poorly in (Rʋsch, et al., 2009b). Major and O’Brien (2005) discuss this in terms of disengagement versus striving whereby the individual either disengages their self-esteem from areas where they fear discrimination or alternatively, strive to overcome obstacles. Disidentifying in areas where the individual is stereotyped over time, results in their performance in this domain becoming less important to their self-esteem (Steele, 1997). However, Steele argues that this might also have detrimental effects on their success within that domain, for example education. Thirdly, group identification versus disidentification whereby the individual either copes by identifying with their group and making in-group comparisons, or may choose to distance themselves from it (Major & O'Brien, 2005; Rʋsch, et al., 2009b).

Rüsch et al. (2009b) reported that high stigma stress was associated with increased social anxiety and shame, which in turn predicted increased hopelessness in patients. Hopelessness was significantly associated with adopting coping mechanisms of devaluing work/education and blaming discrimination for failures. Coping by use of in-group comparisons (e.g. comparing themselves with other patients) were strongly linked to poorer social performance. They also reported a significantly higher use of in-group comparisons by people with schizophrenia compared with individuals with bipolar disorders. However, this study used a cross-sectional design, therefore causality cannot be inferred; it might be that the coping mechanisms create hopelessness rather than the other way around. Additionally, they state that stigma stress responses are often related to threatening situations which were not measured. Other coping mechanisms that were not measured in this study, for example active coping, withdrawing and acceptance (Roe & Chopra, 2003) need further research.

Research indicates that group identification can be both helpful and harmful at the same time. The ‘minimal group paradigm’ has shown that social categorisation leads to intergroup behaviour whereby the ‘ingroup’ is favoured and the ‘outgroup’ discriminated against (Tajfel, 1970). Associating with ‘the own’ (people who are similarly stigmatised) (Goffman, 1963) can be a comfort, being around people who are accepting and have shared experiences (Knight, et al., 2003). Group identification has been linked to more perceived coping resources (Rüsch, et al., 2009a). Unfortunately, this study did not use measures that identified what these were.

Goffman stated that for some, identifying with their stigmatised group can provide a new role or career, that of representing their group. This also resulted in them associating with people outside of the group rather than only spending time with “the own” (p.31). On the other hand, group identification can elicit a push-pull factor where people value the sense of belonging and solidarity that comes with being associated with a group but also wanting to be seen as separate and as part of ‘normal’ society (Knight, et al., 2003). Rüsch, et al. (2009c) reported that group identification was also associated with perceiving stigma as more harmful. Therefore, if the group value is low, associating with such a group could be a source of threat.

Link et al. (1991) consider three responses to coping with stigma. Firstly, secrecy whereby the person may choose to conceal their illness and/or treatment history from employers, relatives, potential partners to protect against rejection (Jones, et al., 1984). Secondly, avoidance-withdrawal where people limit their interactions with others to avoid rejection. Thirdly, education or ‘preventive telling’ in the hope of educating others to ward off negative attitudes (Schneider & Conrad, 1980). Link et al. (1989) developed measures of these coping orientations and report that patients endorse these as a way of adapting to stigma with high frequency. However, these researchers did not explore other types of coping that have been cited in the literature, for example help-seeking behaviour, psychological resources, faith-seeking and education. These coping strategies will now be discussed.

Secrecy

Goffman (1963) distinguished between ‘passing,’ which refers to deliberate concealment of the mark and ‘covering,’ using subtle strategies to keep the stigma more discrete. Passing appears to be more the rule in situations where stigma attached to the mark is great and if the mark is easily concealed, for example being a former mental patient (Jones, et al., 1984). This comes with daily challenges in trying to maintain the concealment, keeping up with lies and living with the fear of discovery (Morgan, 2005). Patients must face the reality that if and when the mark is revealed to others, they may feel resentment that they have been deceived, or indeed face consequences such as losing their job (Morgan, 2005). Consideration of the possible pros (increased self-esteem, improved relationships and support) and cons (avoidance by others, rejection, self-fulfilling prophecies) is needed (Corrigan & Matthews, 2003).

Wegner and Lane, (1995) proposed a ‘secrecy cycle’ where secrecy can lead to obsessive preoccupation with the secret causing stress. Some people may choose different levels of disclosure, including selective disclosure where individuals monitor how much to disclose and to who based on experience and how ‘trustworthy’ or ‘risky’ people were perceived to be (Herman, 1993). Herman’s study reported strategies patients used to help maintain their secret, for example avoidance of selected ‘normals’, redirecting conversations, withdrawal and even making jokes about mental illness in front of ‘normals.’ Others used a strategy of ‘preventive disclosure’ preferring to tell people straight away in a relationship to prevent being ‘dropped’ later on once they were more invested. However, some patients have described the act of finally disclosing to someone as cathartic and as though a burden had been lifted, even in cases where it resulted in negative responses. Although some reported playing down their illness or emphasising it is as a medical cause, that it is ‘not their fault’ when they do disclose (Herman, 1993).

The vast majority of patients reported non-disclosure as a strategy they indorsed due to fear of being stigmatised (Green, et al., 2003; Peterson, Currey, & Collings, 2011). High levels of PDD have been associated with high levels of secrecy (Kleim, et al., 2008). One patient recounted their feelings about disclosing their mental illness, “stigma makes me afraid of telling my work colleagues, telling my fellow volunteer colleagues, telling certain friends as I am uncertain of their reaction” (Corry, 2008, p.5). According to a study of 84 men with mental illness by Link, et al. (1997), 57% believed it was a good idea to keep their history of hospitalisation a secret and 75% would not tell a prospective employer. Patients have denied any mental illness on health-related questions on job applications, despite the possibility of dismissal if discovered (Peterson, et al., 2011). In contrast, others viewed mental illness as part of their identity, and believed it was important that people knew the “real person” (Peterson, et al., 2011, p.146).

Deciding whether to disclose might also depend on a patient’s culture. One lady described how she would never tell her community in Ghana, as in their culture she would no longer be seen as a “credible” person (Thornicroft, et al., 2007).

Withdrawal and Avoidance

Jones et al. (1984) claimed that often the most appropriate way for people to cope with the discomfort or hostility they felt towards stigmatised groups was to minimise interactions with them. This resulted in the stigmatised individual experiencing rejection or negative reactions from others and so sought to avoid such situations. High levels of PDD have been associated with low self-efficacy and withdrawal strategies (Kleim, et al., 2008).

The Time to Change (Corry, 2008) campaign survey reported that perceived and experienced stigma stopped patients doing things (10%), or made them avoid things such as making new friends (33% experienced actual stigma), seeking employment (49% actual stigma). People may avoid places where they feel they cannot pass as ‘normal’ or feel that they are not worthy of taking part (Green, et al., 2003).

Individuals may seek the company of similarly stigmatised others in order to be amongst those who understand and can be more favourably compared with (Estroff, 1981; Jones, et al., 1984). This in turn may help to limit the opportunities they have to be rejected (Braginsky, Braginsky, & Ring, 1969).

Education and Political Activism

Some people may choose to become more involved in advocacy and educating others about mental illness as a way of coping with stigma. Becoming involved in advocacy and speaking out about stigma has helped patients cope (Wahl, 1999). Providing information to others about stigma and what it means for the individual can help alleviate people worrying about what patients’ capabilities are and help interactions become more relaxed (Jones, et al., 1984). Some patients have reported a desire to tell people the ‘truth’ about mental illness and have felt “more highly of myself” when they have a “breakthrough” (Herman, 1993, p.316). However, this is sometimes done on a selective basis “there are some that these efforts would be fatal and fruitless” (p.316).

Political activism serves several functions for patients: rejects standards of normalcy and the deviant labels placed on them, increased self-respect and sense of purpose and projecting this image to the public (Herman, 1993). Providing the public with more contact with patients can help break down stereotypes (Corrigan & Penn, 1999). A meta-analysis of 35 studies examining the effect of contact with patients on attitudes of mental health employees and students indicated reported a greater acceptance of patients (Kolodziej & Johnson, 1996). However, the type of contact was not discussed, so further research into the type of contact that is effective and examining effects of contact with the public is needed.

Psychological Resources

Psychological resources might have beneficial effects on health by decreasing social identity threat. Optimistic women have been shown to be less threatened and have less negative emotional reactions to prejudice (Kaiser, et al., 2006). Awareness of prejudice such as sexism has been shown to protect self-esteem due to reduced self-blame compared with people who were not aware of prejudice (Major, et al., 2003). However, this has not been researched with patients.

Humour can be a useful way of breaking barriers, by indicating to others that they are comfortable with their disability (Jones, et al., 1984). However, this can also lead to the ‘normal’ person feeling uncomfortable and place further strain on relationships. Highlighting values, interests and talents that have nothing to do with the stigma may help to reduce the focus on the stigma and help normalise interactions (Jones, et al., 1984).

Individuals who perceived that they had more coping resources to manage stigma were found to have decreased social anxiety (Rʋsch, et al., 2009b). Furthermore, self-esteem is strongly related to coping (Jones, et al., 1984). Some people view their mental illness as an opportunity to re-evaluate their lives (Knight, et al., 2003). However, the mechanisms by which someone accepts their stigma or remove or dissociate themselves from it are not well understood.

Additionally, there is some evidence that stigma-resistance (SR), an individual’s ability to counteract stigma, is positively correlated with self-esteem, empowerment and quality of life (Sibitz, Unger, Woppmann, Zidek, & Amering, 2011). A social network and receiving outpatient treatment was also associated with higher SR. However, a more robust measure of SR and further research exploring the impact of SR in other diagnostic groups is needed.

Help-Seeking

Evidence suggests patients will avoid seeking treatment for mental illness due to fear of stigma from health professionals and employers, resulting in them not always receiving the help they need (Keating & Robertson, 2004; Stuart, 2004; Wrigley, Jackson, Judd, & Komiti, 2005). In the extreme, people may opt to avoid stigma altogether by avoiding any institution that might mark them including mental health care and treatment programmes (Corrigan, 2004). Corrigan reports that both public and self-stigma may result in a person not seeking or completing treatment.

Those who internalise perceived stigma views are likely to suffer low self-esteem and devalue themselves (Link, 1987; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001) and therefore feel they are undeserving of treatment, or that treatment is pointless (Corrigan, 2004). In addition, perceiving stigma as more harmful has been associated with higher levels of shame in patients (Rυsch, et al., 2009b), which has been linked to people being less likely to seek treatment (Sirey et al., 2001).

One study reported that the time from the point patients realised there was a problem to seeking help ranged from one to fourteen years, with a median of five years (Hines-Martin, Malone, Kim, & Brown-Piper, 2003). Patients reported believing that they weren't "crazy" and therefore did not need treatment (Hines-Martin, et al., 2003, p.246) and have refused treatment for fear of being labelled as such (Dinos, et al., 2004).

Combat veterans have reported not seeking help for post-traumatic stress disorder (PTSD) due to fear of stigma (Hoge et al., 2004), being labelled "crazy" and the impact of this on their career (Stecker, Fortney, Hamilton, & Ajzen, 2007). Although 80% (n=20) reported getting better as a primary advantage of seeking help and 30% felt treatment was a means to return to "normal" (Stecker, et al., 2007). Strong family encouragement to seek assessment has been effective (Link, et al., 1989).

Paradoxically, one factor that resulted in patients attempting to cope without seeking treatment is a belief that people should solve their own problems (Kessler et al., 2001). One study reported that perceived stigma was unrelated to help-seeking behaviours in people with depression, but self-stigmatisation resulting in feelings of shame hindered help-seeking (Schomerus, Matschinger, & Angermeyer, 2009). This was replicated in a study of American-Asian students (Loya, Reddy, & Hinshaw, 2010). Maintenance of roles in daily life that were central to an individual's self-image and the need to be "strong" acted as a barrier to help-seeking (Hines-Martin, et al., 2003).

A study exploring coping strategies amongst African-American women found that they endorsed treatment-seeking and reported low levels of stigma associated with seeking treatment (Ward & Heidrich, 2009). They reported that older women were also more likely to report using treatment-seeking as a preferred coping strategy and less likely to endorse avoidance compared to young women. However, the study did not include definitions of treatment so it is unclear as to what this referred to.

Resources, Constraints and Level of Threat

An individual’s resources can help them cope with stresses (Lazarus & Folkman, 1984). For example, social skills, problem-solving skills, social support, personal attributes such as positivism and material resources can be drawn on by the individual to help them cope with a given situation. According to the identity threat model, (Major & O'Brien, 2005), threats to self and stress occur when the individual perceives the potential harm as exceeding their resources to cope. Whilst an individual may have the resources to cope with a problem, there may also be constraints that prevent them being used, for example personal constraints (e.g. guilt, cultural values) and environmental constraints (e.g. competing demands for resources) (Lazarus & Folkman, 1984). Level of threat can determine how coping resources are perceived and how they can be used. The greater the threat, the more primitive, desperate and regressive emotion-focused forms of coping become. Therefore, it might be that an individual has the resources to cope, but they are useless if they situation is deemed harmful as may be the case regarding stigma.

Impact of Coping Strategies

It is important to consider the impact of adopting these coping mechanisms to the individual, although there appears to be little empirical data exploring this. Adopted as a way of protecting themselves, strategies sometimes serve to further alienate patients and ultimately reinforce their beliefs that they are flawed (Link, et al., 1991; Wright, et al., 2000). Individuals may inadvertently cause people to react to them in negative ways due to expectations of being stigmatised.

Link et al. (1991) measured levels of demoralisation and unemployment in labelled patients and non-labelled community residents to identify the gap between them. Findings indicated that none of the coping strategies were helpful in reducing labelling effects or psychological distress and in fact are more harmful, with withdrawal/avoidance having a significantly harmful effect. It is worth noting however that combinations of coping strategies and other strategies such as cognitive reframing were not examined. In addition, ordering effects and causality is difficult to determine. It might be that demoralisation and unemployment effect coping mechanisms and PDD rather than the other way around (Link, et al., 1991). Whilst they had mechanisms in place to limit this as a possibility, longitudinal data to measure one factor before another would be preferable. Current research is needed to examine the impact of coping strategies.

Methodological Issues

Much of the research exploring stigma and mental illness implemented cross-sectional designs (e.g.Kleim, et al., 2008; Rosenfield, 1997; Rʊsch, et al., 2009b; Rüsch, et al., 2009a). Longitudinal or experimental methods would be useful to attempt to define causal relationships. Perceived stigma and the impact it has on an individual can be situation and time specific (Corrigan & Watson, 2002). However, cross-sectional design studies only examine a snap-shot of a person's experience. Research involving longitudinal designs or qualitative research exploring people's experiences over time may provide more insight regarding how people's views of stigma and how they cope with it changes.

Research into patients' opinions of stigma are often survey driven (e.g. Dickerson, et al., 2002; Link, et al., 1997). One major limitation of this approach is that participants have little control over what they are asked about and their answers are restricted. Studies examining stigma often used fake situations e.g. case studies and questionnaires which may not relate to real-life behaviour (Page, 1977). Typical questionnaire measures of attitudes to mental illness are prone to socially desirable responses (Link & Cullen, 1983). Considering that it is no longer acceptable to express prejudice views, individuals with negative views may respond in a socially desirable way on explicit measures of stigma (Stier & Hinshaw, 2007).

Therefore, more recent measures have assessed implicit attitudes of stigma (Stier & Hinshaw, 2007). Stier and Hinshaw (2007) report that such measures assess more automatic behaviour so giving participants less control in their responses, resulting in more accurate depictions of their attitudes. Teachman, Wilson and Kormarovskaya (2006) found that explicit reports of attitudes towards mental illness were neutral, whereas implicit reports revealed higher negative attitudes. It is important to consider such findings when applying measures of stigma to interventions aimed at reducing stigma. Explicit measures may reveal a positive reduction in stigma attitudes that do not reflect levels of deep attitude change or reduction in discriminatory behaviours (Stier & Hinshaw, 2007).

Some studies are based on opportunity samples or not randomly selected (e.g. Crisp, 1998; Green, et al., 2003; Knight, et al., 2003; Ward & Heidrich, 2009). Therefore participants may feel as though they have ‘something to say’ about stigma and be over-represented in results. Those who have not experienced stigma, are unwell or more ‘hard to reach’ populations may be under-represented. In addition, those who chose not to participate may have felt more shame about their mental illness and more fearful of encountering stigma (Green, et al., 2003). However, some studies have attempted to overcome this by persisting with hard to reach populations to encourage them to take part or ensuring anonymity (e.g. Link, 1987; Link, et al., 1991).

Many studies examined *perceived* and not *actual* stigmatising experiences (e.g. Biggs, et al., 2010; Link, et al., 1997; Rosenfield, 1997). However, it seems that perceived stigma alone is enough to impact patient’s lives quite dramatically. In addition, it may indicate that clinicians need to address patient’s perceptions of stigma whilst validating that these perceptions and fears are justified given the research findings that examine actual experiences.

Time since diagnosis and length of time an individual has been exposed to stigma are important factors to consider (Corrigan & Watson, 2002). A person who has had a longer time to be exposed to stigma may have had more time to develop effective coping strategies and support. On the other hand, they may have had more negative experiences compared with someone newly labelled. Some studies have attempted to address this problem by including participants at different stages of being labelled (e.g. Link, et al., 1991).

Unlike some other stigmatised groups, low self-esteem is intrinsic to the definition of some mental illnesses (APA, 2000). Therefore, research needs to distinguish between problems with self-esteem related to diagnosis and those arising from stigma (Corrigan & Watson, 2002).

Studies have also tended not to distinguish between diagnoses, rather preferring to focus on the general experience. However, this means that little is known about which mental illnesses, if any are subject to worse or more stigma than others, which might help campaigns know which groups need targeting. Campaigns so far seem to have thought about who to target (e.g. the local community and family) and where to target rather than which patients need more focus (Corry, 2008). However, this might serve to further alienate these groups, rather than the inclusive nature of ‘mental illness’ campaigns.

Few studies have explored the impact of different coping strategies on patients. Little is known about why people disengage or do not attend appointments from the perspective of the patient. This would help clinicians understand the possible role that stigma and discrimination play in treatment decisions (Thornicroft, et al., 2007). Some research has used vignettes with the general population to explore stigma and help-seeking intentions and therefore not explored actual behaviours of patients (Schomerus, et al., 2009). Studies have not always explored every possible coping strategy, for example not examining education or cognitive approaches (cf. Link, et al., 1991). Therefore there may still be coping strategies that patients use that remain unknown. Research exploring the links between stigma experiences, adopted coping strategies and their impact on individuals may provide some insight into how to support patients.

Black and ethnic minorities (BME) have not always been equally represented in research, with some samples being predominantly Caucasian (e.g. Green, et al., 2003; Kaiser, et al., 2006; Suto, 2012), despite BME groups having higher than average rates of detention under the Mental Health Act (Quality Care Comission, 2011). The Time to Change campaign received 21% of responses from ethnic minorities, who also reported higher levels of discrimination (Corry, 2008). Some studies however, have attempted to sample equal proportions of ethnic origins (Link, et al., 1989; Rüsch, et al., 2009a).

Implications for Clinical Practice and Further Considerations

The research presented here highlights a role for clinicians to be more aware of the impact of perceived stigma by patients and to enable them to explore effective ways of coping. In addition, interventions to increase SR to reduce the impact of stigma may be beneficial (Sibitz, et al., 2011).

Research also indicates that some patients do not believe that patients are stigmatised (Rosenfield, 1997), and a small number (6%) reported never having experienced stigma as a result of their mental illness (Link, et al., 1997). The reasons for this are unclear. Further research may help clinicians better understand these experiences and possibly enable other patients to learn more effective coping strategies and/or lessen the impact that stigma can have.

Personal characteristics that may lead individuals to adopt certain coping strategies need further exploration to help develop interventions to build personal resources to manage stigma. However, there is some empirical data to suggest that the course of how stigmatising experiences are understood and translate to coping strategies may change as the patient becomes a more experienced stigmatised person (Wright, et al., 2000). However, more research is needed with larger samples and at different stages of the illness career to further understand this.

Corrigan and Penn (1999), propose three methods of combating public stigma; protest, education and contact. However, in some cases protest has been found to make things worse (Corrigan et al., 2001). Therefore perhaps the nationwide campaigns such as Rethink might be more effective. Corrigan and Matthews (2003) state that prejudicial attitudes and discriminatory behaviour are more likely to abate if people have more contact with patients. However, given that most patients are fearful of disclosing, it might be useful for research to examine ways in which they can be helped to 'come out.' It has been proposed that literature examining how the homosexual community addressed this difficulty might have some use here (Corrigan & Matthews, 2003).

Further research exploring the impact of adopting particular coping strategies would be beneficial in attempting to understand any advantages certain strategies might have. For example, further exploration of the impact of stigma-resisting beliefs may help develop interventions in order to enhance SR in patients to enable greater quality of life despite stigma (Sibitz, et al., 2011). In addition, understanding the impact of coping strategies may also offer thoughts regarding how to address these issues and developing treatment strategies. For example, veterans had reported not wishing to seek help for mental illness for fear they would be seen as incompetent (Stecker, et al., 2007). However, literature also states that PTSD in soldiers is linked to high levels of functional impairment and comorbid difficulties, for example substance misuse and aggression, which might impact on their ability to be redeployed (Thomas et al., 2010). Therefore, cognitive-behavioural therapy to address soldiers beliefs regarding help-seeking might be of benefit (Stecker, et al., 2007).

Increasing patient's beliefs in biological attributions of mental illness increased help-seeking behaviour, whereas destigmatising education did not (Han, Chen, Hwang, & Wei, 2006). Therefore, interventions could focus on educating patients beliefs about the causes of mental illness (Schomerus & Angermeyer, 2008).

Conclusion

This review examined the literature regarding coping with mental illness stigma. It highlighted that most of the research has explored the impact of stigma on individuals' lives in relation to models and theories of stigma. The impact of stigma on patients' lives is pervasive, impacting on work, housing, and relationships. Perceived stigma has been associated with lower levels of self-efficacy (Kleim, et al., 2008), and higher levels of anxiety and shame (Rʋsch, et al., 2009b).

The impact of stigma then leads individuals to endorse negative coping strategies, such as withdrawing, avoiding and secrecy. Research suggests these are not overly effective (Link, et al., 1991; Rʋsch, et al., 2009b). On the other hand, it seems that actively speaking out about stigma and being part of a support group can be somewhat protective to self-esteem (Green, et al., 2003; Ward & Heidrich, 2009).

Despite government campaigns aimed at addressing stigma of mental illness, patients continue to report perceived and actual stigma. Further research regarding individual differences in coping with stigma is needed to ascertain why some people adopt more effective coping strategies, and why some people report not experiencing stigma in order for interventions to be devised to help people overcome stigma and cope more effectively with it.

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Empirical paper

What is the lived experience of being discharged from a psychiatric inpatient stay?

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ABSTRACT

FACULTY OF SOCIAL AND HUMAN SCIENCES

Psychology

Doctor of Clinical Psychology

WHAT IS THE LIVED EXPERIENCE OF BEING DISCHARGED FROM A PSYCHIATRIC INPATIENT STAY?

By Anna Redding

This qualitative study used semi-structured interviews and Interpretative Phenomenological Analysis (IPA) in an attempt to understand the lived experience of being discharged from psychiatric inpatient stays. Psychiatric patients encounter many difficulties post-discharge and suicide rates are high, particularly within the first three months. However, to date most research has used quantitative methods to examine these difficulties and the effectiveness of discharge interventions. Therefore, little is known about why discharge is so difficult for people with mental illness. Eight participants who had been discharged from psychiatric hospital within the last three years were interviewed to explore their experiences of discharge. Five superordinate themes emerged from the data. These are discussed along with clinical implications and suggestions for further research.

Keywords: Interpretative Phenomenological Analysis, mental illness, psychiatric discharge.

Introduction

Deinstitutionalisation began in the 1950’s to increase treatment in the community. Reintegration after hospital has been problematic due to a lack of coordination between funding sources and implementation services (Talbot, 1981) and patients struggled to cope (Farina, Fisher, & Fischer, 1991), particularly as they required more support than just symptom relief (Anthony, 1993a). Farina et al. (1991) stated that readjustment is harder, in part, due to the stigma faced by people with mental illness.

Risks of adverse outcomes are not constant over time and fluctuate particularly in relation to “landmarks in the course of illness” such as discharge from hospital (Thornicroft & Susser, 2001, p.3). The immediate post-discharge phase is critical for psychiatric patients (Talbot, 1981) particularly for long-term adaptation to the community (Bruffaerts, Sabbe, & Demyttenaere, 2004). Reasons for this are unclear, but may be related to stressors associated with re-entry to the community following intensive inpatient treatment (Gerson & Rose, in press). They are at risk of homelessness (Forchuk, Russell, Kingston-Macclure, Turner, & Dill, 2006; Johnstone, Owens, Gold, Crow, & Macmillan, 1984), stigma (Farina, et al., 1991) violence (Steadman et al., 1998) and suicide (Gunnell et al., 2008) post-discharge.

Over a seven year period, 73% of patients discharged from psychiatric units in America were re-hospitalised to psychiatric inpatient units within one year of discharge (Irmiter, McCarthy, Barry, Soliman, & Blow, 2007). In Belgium, one in three patients visited the psychiatric emergency room within 30 days of discharge, which was more likely if they did not have an after-care plan or had a short hospitalisation (Bruffaerts, et al., 2004). Illness-related needs remained unchanged four weeks post-discharge (Gerson & Rose, in press).

Close social networks are smaller compared to the general population and often limited to staff or other patients (Forrester-Jones et al., 2012). Patients have reported loneliness and difficulties attending appointments due to lack of transport as problems (Beebe, 2010). Even for individuals who were deemed to function well in the community after leaving hospital, there was little difference in their level of morale following discharge, even after two years (Donnelly et al., 1996).

Patients encounter many difficulties post-discharge. For some, their difficulties coping post-discharge result in them attempting and completing suicide, yet little is known about why discharge is so challenging. It could be argued that suicide post-discharge is the most extreme indication that discharge is a traumatic experience. It has also received the most research; therefore an overview of this literature will be presented. Discharge planning (DP) and interventions post-discharge will then be discussed to provide an overview of what is in place for people being discharged and what, if anything, is effective in reducing the risk of suicide. Methodological considerations and justifications for the current study, will be explored.

Suicide Post-Discharge

Suicide rates are higher amongst psychiatric patients than the general population (Barraclough, Bunch, Nelosn, & Sainsbury, 1974). Following discharge, patients are at high risk of self-harm and suicide, with many incidents occurring in the first two weeks (Gunnell, et al., 2008; Morgan & Priest, 1991), most within three months (McKenzie & Wurr, 2001) and 40% occurring before the first community follow-up (Meehan et al., 2006).

Risk factors for self-harm and suicides include previous history of attempts, substance misuse, unemployment, living alone and homelessness (Gunnel et al, 2008; Meehan et al., 2006). Additionally, studies report that men had higher rates of suicide post-discharge than women (Goldacre, Seagroatt, & Hawton, 1993; McKenzie & Wurr, 2001). Furthermore, patients whose discharge was unplanned or had their significant care professional absent were more at risk, whereas continuity of care throughout the discharge process appears to reduce risk of suicide (King et al., 2001).

The period of highest risk of suicide appears to be within the first few weeks of discharge, suggesting that discharge itself may increase vulnerability to suicide for some (Goldacre, et al., 1993). Duration of hospital stay was not particularly long for these patients, averaging from 14 days (Goldacre, et al., 1993) to 31 days (Moore, 1998). One thought is that discharge that occurs too early during an individual’s stage of recovery might exacerbate feelings of hopelessness and therefore increase risk of suicide (Appleby, 1992).

High rates of suicide post-discharge have been noted in the literature for decades. Flood and Seager (1968) reported that of all the psychiatric suicides recorded, more than half occurred within three months of discharge and typically involved shorter hospital stays. A study exploring trends of suicide within 28 days of discharge in Scotland reported that suicide rates in females increased during the period 1968 to 1992, whereas suicide in males decreased (Geddes & Juszczak, 1995). Geddes and Juszczak (1995) suggest that recent government moves to reduce hospital beds and have shorter inpatient stays may be responsible for these trends. They posit that males might be less affected by the changes, given the decrease in male suicides compared with the increase for females. In addition, males are less likely than females to be in contact with health services before suicide (Vassilas & Morgan, 1993).

Statistics from the National Confidential Inquiry (NCI, 2011) in England (1997-2008) reported that suicide by patients who had been in contact with services in the last 12 months accounted for 26% (14,654/56,091) of all suicides in the general population. Data between

2000-2004 in England and Wales indicates that of all the post-discharge suicides, 15% occurred in the first week, 22% occurred before the first community follow-up appointment and 34% (292/856) of in-patient suicides occurred during the period of DP prior to admission (NCI, 2006). In total 1,563 suicides occurred during the transition from the ward to the community, indicating this is the maximum risk period.

Recommendations from the report to address risk of suicide included telephone calls immediately following discharge for high risk patients and face to face contact within a week, patients to have contacts for services if in crisis, regular risk assessments throughout the transition period and agreed plans to address stressors. These are similar to recommendations made decades earlier such as services maintaining contact with patients and to inform relatives of their discharge (cf. Flood & Seager, 1968). The research examining the implementation of such strategies has tended to be limited and lacks evidence to suggest they have been successful.

Psychological Theory

There is no research to date that explores psychological theory in relation to the difficulties patients face upon discharge. However, several might be proposed to be relevant including theories of attachment and loss, life transition and recovery.

Bowlby (1969) has highlighted the anxiety-buffering and protection functions of close relationships. In a more recent model that integrates findings with earlier works on attachment, including the work of Bowlby (1969) and Ainsworth (1991), Shaver and Mikulincer, (2002) claim that during times of threat the attachment system is activated and we seek proximity to our attachment figure. If there is not one available, we seek to find one.

People who have developed secure attachments learn that displays of distress elicits support from others and that this enhances coping (Mikulincer, Shaver, & Pereg, 2003). It might be suggested that patients in acute care have not developed secure attachments and therefore may not seek them (avoidant) or desperately seek them (anxious) in times of stress. Regarding discharge, it might be posited that leaving hospital activates the attachment system, but without available attachments for support, patients resort to maladaptive coping styles such as self-harm or suicide.

Bowlby (1969) further claimed that the intensity of grief is influenced by the type of attachment the person had to the deceased. Although patients leaving hospital have not experienced the loss of a loved one, it is possible that they might experience loss and therefore something akin to grief when they leave hospital. For example, Bowlby discusses feeling a loss of security following bereavement. Patients have described feeling safe and secure in hospital (from themselves) and receiving mutual support from other patients (Johnson et al., 2004). However, some patients reported that staff were uncaring and did not have enough time for them (Foss, 2002) and others stated that they developed supportive relationships with other patients (Shattell, Andes, & Thomas, 2008). Therefore, it might seem reasonable to suggest that patients leaving the hospital environment might feel a sense of loss. In a similar vein, Linehan’s (1993) model of Dialectical Behaviour Therapy (DBT) states that patients who are emotionally vulnerable fear abandonment of others and that self-harm behaviours or suicide are the patient’s attempt to solve the problem of overwhelming emotions. Therefore, when leaving hospital, a lack of support might elicit behaviours that patients have learnt elicit care from others; referred to as “active passivity” by Linehan (p.78).

Models of transition originated from work on bereavement, family crisis and depression and aimed to explain how individuals respond to change, either in their own lives or the environment (Williams, 1999). Most transitions are associated with significant life events and the process takes between 6-12 months. Following a negative life event, the individual moves through five main stages: initial shock, characterised by feelings of numbness; provisional adjustment, minimisation or denial; inner contradictions, such as uncertainty, loss of confidence and depression; inner crisis and finally re-construction and recovery whereby the individual begins to accept the change and experiences recovery, or does not accept the change leading to extended crisis (Williams, 1999). Given that both admission and discharge from hospital constitute major life events, it might seem likely that patients experience similar stages of transition.

Models of recovery may have some relevance to people’s experience of discharge. Recovery has been defined as: “the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (Anthony, 1993, p.11). Andreson, Caputi and Oades (2003) suggest five stages to recovery: moratorium, a period of withdrawal characterised by feelings of loss and hopelessness; awareness, realising that a life worth living is possible; preparation, understanding their strengths and weaknesses regarding recovery and developing recovery skills; rebuilding, actively working towards goals and taking control of one’s life and finally; growth, living a meaningful life by self-management of the illness. As their model is based on extensive interviews with patients, it is possible that it may relate to people’s experience of discharge.

Linking Inpatient Care to the Community

Given that the research indicates that discharge is problematic, it is important to consider what services are available to support the transition between hospital and the community. The Care Programme Approach (CPA) came into effect in 1991 to ensure that all patients had a named key worker and documented care plan accessible to all services to enable coordinated care (Moore, 1998). Discharge is also discussed in CPA meetings, however one study in London reported that less than half of patients had complete CPA plans upon discharge despite being eligible (Minghella & Ford, 1997). They reported 28% of patients who committed suicide were not subject to enhanced CPA despite having a serious mental illness and previous self-harm or admission under the Mental Health Act. Sixty eight patients who committed suicide while under enhanced CPA did not receive the intensive care they were meant to. For example, there was not an adequate attempt to re-establish care and treatment following noncompliance by the patient (NCI, 2006). Patients should receive a level of aftercare ranging from minimal to intensive support following a CPA. However, this does not always occur and some assumed that minimal aftercare would be adequate (SCMH, 1998). Despite this, most patients received some kind of follow-up post-discharge.

DP aims to ease the transition between hospital stays and the community by improving the co-ordination of services, and therefore reduce length of hospital stay, readmission rates and costs (Sheppard et al., 2010; Steffen, Kösters, Becker, & Puschner, 2009). The Department of Health (DOH) in its best practice guidance for discharge outlines several recommendations for discharge from hospital (2003). The paper recommends a “whole systems approach” (p.15) utilising a mixture of professionals and services and viewing the patient and carer as the “experts” on their condition and needs (p.8). Therefore, both patient and carer should be involved in the DP process. DP should begin prior to admission, or at admission where hospitalisation is unplanned. The paper advocates multi-agency working in order for the discharge coordinator to be aware of community and hospital services available.

There appears to be little research exploring whether these recommendations are routinely put into practice or the effectiveness of DP with psychiatric patients. A systematic review revealed relatively small effects for DP on readmission rates, costs and length of hospital stay (Sheppard, et al., 2010). However, only one study involved discharge of psychiatric patients. A less rigorous review of seven studies between 1981 and 1998 examining the effect of DP with psychiatric patients reported the evidence to be too low to conclude whether DP reduces readmission rates (Missio, 2002). A meta-analysis conducted on eleven studies reported readmission rates ranging from 15–46% in control groups, and 7%-25% in the intervention groups (Steffen, et al., 2009). Heterogeneity was low[1] ($I^2 = 0\%$) (Higgins & Thompson, 2002) thus, the relative risk reduction was 35% in favour of the intervention group. There was no significant effect of DP on quality of life or costs.

Effective discharge is collaborative and involves the patient, members of their family and community services (Altman, 1983; Batey & Ledbetter, 1981; Rock, 1987). Furthermore, DP should incorporate educating patients and their families about the diagnosis, the importance of compliance with treatment and encouraging education and social activities post-discharge (Buckwalter, 1982). DP meetings should include community staff, carers and relatives (who are not present at wards rounds) and aim to discuss any issues around discharge with the patient, for example needs and aftercare (Moore, 1998).

Despite this knowledge about best practice, discharge from hospital is often unplanned, with community services and carers not being informed of discharge plans (Sainsbury Centre for Mental Health, (SCMH), 1998). Additionally, they reported community psychiatric nurses attended less than half of the DP meetings that were formally arranged, despite their role in patients' aftercare. Frequently, family and carers were not invited to these meetings. Only 14% of patients received a formally organised DP meeting, with discharge often being discussed during ward round (Moore, 1998). Delayed discharge is

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[1] The I^2 statistic gives an indicator of heterogeneity of effects between studies. Low heterogeneity is associated with an I value of up to 25%, high heterogeneity with an I value above 75%.

not uncommon and is often due to lack of suitable accommodation (Shepherd, Beadsmoore, Moore, Hardy, & Muijen, 1997). Kelly, Watson, Rabound and Bilsker, (1998) reported that patients with delayed discharge have shown increased hallucinations, disorientation, conceptual disorganisation and active symptoms.

Large numbers of patients are discharged without successful links to outpatient services (Boyer, McAlpine, Pottick, & Olfson, 2000), which can negatively impact readmission rates (Rosenfield, Caton, Nachumi, & Robbins, 1986) and quality of life (Boyer, et al., 2000). Substantial delays between discharge and a patient's first community appointment can occur (Saarento et al., 1998). This is particularly alarming given the aforementioned research regarding self-harm and suicide rates during this period indicating that it is a critical time.

Interventions at Discharge

Strategies that bridge the gap between discharge and community care are needed (Dixon et al., 2009). Mistiaen, Francke and Poot, (2007) classify discharge interventions into two groups. Firstly, discharge preparation, which predominantly takes place within hospital, aims to reduce hospital stay, ensure the patient is well enough to be discharged home and to highlight needs to services post-discharge. Secondly, discharge aftercare, which occurs post-discharge to reduce and prevent readmission and promote well-being.

Specific interventions that have attempted to address difficulties in continuity of care are rare (Puschner et al., 2011), and have had limited success (Walker & Eagles, 2002). A multi-centre RCT examining the effects of a needs-orientated DP for high utilisers[2] of

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[2] Defined as: during a 24-monthperiod prior to admission: a) has been psychiatrically hospitalised at least twice with a cumulative length of stay (LOS) exceeding 30 days or b) has been psychiatric hospitalised at least once with a cumulative psychiatric LOS of more than 50 days.

inpatient care (Puschner et al., 2008) reported no significant effect on number of inpatient episodes, quality of life, depression and use of outpatient services (Puschner, et al., 2011).

A discharge preparation group aimed at helping patients address difficulties associated with discharge reported some success in supporting the discharge of patients deemed “resistant” to discharge (Patrick, Smith, Schleifer, Morris, & McLennon, 2006). However long-term effects were not measured. Implementing dedicated discharge coordinators improved the DP process and reduced problems post-discharge, for example not receiving prescribed treatment (Houghton, Bowling, Clarke, Hopkins, & Jones, 1996).

Contact between inpatient and outpatient staff prior to discharge can significantly increase the likelihood of the patient attending outpatient appointments (Olfson, Mechanic, Boyer, & Hansell, 1998), reduce readmission (Reynolds et al., 2004), and understanding of their medication (Dudas, Bookwalter, Kerr, & Pantilat, 2001). This is particularly important given that staff can overestimate a patients understanding of their DP (Calkins et al., 1997). However, more than one-third of discharge plans were not discussed with providers. Strategies such as reminders for appointments and arranging transport for patients to attend outpatient appointments were used infrequently. Providing GPs with information about upcoming discharges did not reduce the time between discharge and first community appointment (Naji, 1999). Naji reported a trend for fewer readmissions in their treatment trial although this was not significant. This study did not include people who did not have a registered GP, or those who were discharged quickly.

Implementing critically-timed interventions (CTI) have been studied across different transitions (Thornicroft & Susser, 2001). CTIs aim to enhance continuity of care whereby an allocated worker provides support throughout the transition, devises an individualised plan (with the client) prior to discharge for transferring care to the community and identifies potential barriers (Dixon, et al., 2009; Susser et al., 1997). CTI's have resulted in a threefold reduction in homelessness (maintained at follow-up) (Susser, et al., 1997), and significantly fewer days between discharge and first contact when compared to treatment as usual[3] (Dixon, et al., 2009). However, overall satisfaction and quality of life did not improve (Dixon, et al., 2009; Reynolds, et al., 2004).

Crisis Resolution/Home Treatment

Crisis Resolution/Home Treatment (CRHT) teams were implemented to help reduce the need for hospital admission by providing 24 hour support seven days a week to those with severe mental illness who were in an acute phase of crisis (DOH, 2001). CRHT is recommended by the DOH in its best practice and policy guides (2001, 2002, 2007). A key function of the CRHT is involvement in DP and linking with assertive outreach teams (AOT) and early intervention teams (EIT) who may not provide 24 hour support (DOH, 2001).

Studies of CRHT have reported significantly reduced admission rates and length of hospital stay particularly where they provided 24 hour care (Glover, Arts, & Babu, 2006; Johnson et al., 2005). However, another study reported readmission rates remained stable (Barker, Taylor, Kader, Stewart, & Le Fevre, 2011). These studies have not explicitly explored the impact of CRHT on discharge from hospital. However, Barker et al's. study (2011) claimed that 31% of participants reported feeling fully recovered and 78% felt ready to move one at the time they were discharged from CRHT.

Whilst some patients found the CRHT teams to be invaluable, others (staff and patients) felt that they were underfunded, under resourced and that the threshold for eligibility

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[3] Treatment as usual involved referral to outpatient treatment, partial hospitalisation or substance abuse treatment depending on the unit's usual practice. There was no formal care coordination beyond referral.

was too high (Mind, 2011). A national survey of CRHT in 2006 reported that many were under resourced to meet the demands of out of hours assessments and just over half offered out of hours services and only 8% of teams had a psychologist despite these being national guidelines (Onyett et al., 2008).

Methodological Issues

Most of the studies exploring suicide, DP and interventions for patients leaving hospital have been quantitative (e.g. Donnelly, et al., 1996; Glover, et al., 2006; Meehan, et al., 2006; Naji, 1999). Therefore, whilst there is a wealth of knowledge regarding the risk factors post-discharge, little is known about why the transition is so difficult in order to gear interventions to their needs. Additionally, research suggests that patients express clear views regarding their care when asked and that their preferences often differ from the views of family or care providers (Holley, et al., 1998).

Studies such as Mind (2011), and Fallon (2003) have qualitatively explored patients' views, but not specifically their discharge experience. Suicide studies do not always include patients who have discharged themselves from hospital (e.g. Goldacre, et al., 1993). Some studies exploring patients' experiences of being in the community have not examined cause of death in those who have died at follow-up, therefore those that may have committed suicide are unknown (e.g. Donnelly, et al., 1996).

Studies that have examined DP, are often more than 10 years old and have methodological flaws, for example small samples (cf. Altman, 1983) and do not include the viewpoint of the patient (e.g. Buckwalter, 1982; Cohen, Gantt, & Sainz, 1997; Rock, 1987). Measuring the quality of DP interventions appears to be complex. The definition of DP, what it entails and exactly when DP concludes and after-care begins is difficult to determine and can differ across studies (Steffen, et al., 2009). Studies that do not distinguish between diagnoses (e.g. Orlosky, Caiati, Hadad, Arnold, & Camarro, 2007) mean it is difficult to ascertain whether particular strategies are effective, given the heterogeneity of needs within a clinical population. Research examining continuity of care post-discharge, particularly whether patients have been involved in DP, have an allocated key worker and the time between discharge and outpatient appointments is needed to identify any improvements.

Some patients do not receive adequate post-discharge input from services, the reasons for which are not entirely known. Individual differences in patients who are not adequately ‘linked’ to services are not known (Boyer, et al., 2000). Studies exploring the impact of CRHT have had small response rates (e.g. Barker, et al., 2011; Johnson, et al., 2005). Those who have had less positive experiences with services and who remain unwell might be less likely to participate (Barker, et al., 2011). In addition, Johnson, et al. (2005) asked participants about their views on the CRHT after only one episode of care. Many studies have not examined differences in suicide rates since the implementation of CRHT teams. Johnson et al. (2005) noted that although lacking power to examine suicide attempts, they appeared to decrease (23-15%). However, of the four deaths by suicide one of these occurred soon after discharge from hospital without referral to CRHT, one committed suicide after discharging himself from hospital, one committed suicide whilst receiving care from CRHT but again, why this occurs is not explored.

Relevance of Research

Although suicide and readmission rates are high post-discharge, little is known about why discharge is so difficult for some people. Existing research into psychiatric discharge has typically used quantitative methods to examine rates of suicide (e.g. Kao & Liu, 2010; Meehan, et al., 2006) or has explored the effectiveness of discharge interventions (e.g. Johnson, et al., 2005; Patrick, et al., 2006; Puschner, et al., 2011). However, what the actual discharge is like for patients has not been explored. It seems discharge interventions have been implemented to reduce readmission and suicide, with little understanding of why discharge can be so traumatic. Therefore, this study used qualitative methods to gain insight into why discharge can be so challenging, with the hope that more can be learned about what works and where improvements could be made. In addition it may help inform the development of quantitative measures to assess satisfaction post-discharge and risk.

Chosen Qualitative Methodology

Research has indicated that talking about traumatic and difficult past experiences can be beneficial (Donnelly & Murray, 1991; Pennebaker & Seagal, 1999), including experiences related to mental health (Seebold, 2007). A method particularly suited to understanding the lived experience of an individual is Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009).

IPA has its origins in phenomenology and symbolic interactionism, which state that individuals are not passive receivers of an objective reality, but that they understand and interpret their world by forming narratives that make sense to them. IPA seeks to understand the participant’s view of the world by enabling them to share their experience.

It was felt that IPA was the most appropriate method for this study given its focus on the lived experience and idiographic nature. Given that little research has explored this area, it was felt that trying to understand what discharge is like for patients and IPA’s focus on detail would be beneficial in understanding why it can be so challenging. Thematic analysis focuses on general themes (Willig, 2008) and therefore the richness of the experience might have been lost; IPA explores both convergence and divergence across transcripts and moves beyond the surface (Smith et al. 2009). Traditionally grounded theory has been used to explore social processes and aims to identify theories relating to the research question (Willig, 2008), whereas IPA is concerned with exploring the lived experience of the individual. Additionally, the focus of the research was to understand the patient’s experience of discharge rather than focus on theories related to discharge, although this might be a useful next step. Finally, narrative approaches also explore the meanings people ascribe to events, however, there are no overall rules to narrative approaches (Andrews, Squire, & Tamboukou, 2008), and so it can be difficult to follow a particular set of guidelines regarding analysis.

IPA has successfully been used to explore a variety of illnesses such as chronic fatigue (Arroll & Senior, 2008), multiple sclerosis (Borkoles, Nicholls, Bell, Butterly, & Polman, 2008) and mental health (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007).

Method

Participants

Recruitment.

Participants were recruited through the NHS and therefore ethics approval was obtained from the Isle of Wight, Portsmouth and South East Hampshire research ethics committee in addition to approval from the University Of Southampton School Of Psychology Ethics prior to recruiting (Appendix B, C).

Participants were recruited through three local Community Mental Health Teams (CMHTs), the local AOT and CAST (a service user Consultancy And Support Team recruited and supported through the NHS and trained by a Consultant Psychologist).

Inclusion and exclusion criteria.

Principal inclusion criteria:

i. Discharge from an inpatient psychiatric stay within the last 3 years
ii. Any diagnosis of mental illness or personality disorder
iii. Ability to give informed consent
iv. Aged 18 years or above

Principal exclusion criteria:

i. Current psychotic symptoms that might impair capacity to give informed consent, or to take part in an interview.
ii. Learning disability

iii. Other organic disorder that might impair capacity to give informed consent, or to hold a conversation during the interview.

iv. Discharge having occurred within the previous 6 months of the interview due to possible distress that this may cause.

Sample size and characteristics.

As an idiographic approach a small sample size in IPA is the norm (Brocki & Wearden, 2006). Eight individuals (five females, three males) were recruited in total. No new themes emerged after seven interviews; therefore an additional interview was conducted to check for possible saturation (Chamberlain, Camic, & Yardley, 2004). No new themes emerged and therefore recruiting ceased.

Ages ranged from 26 to 65 years, with a mean of 46 years. Seven participants were white, one was Asian. Time since discharge (to when they were interviewed) ranged between 6 months to 2.5 years, with a mean time of 1 year and 8 months. Data on diagnosis was not collected as this was not deemed relevant to the individual’s experience.

Procedure

The researcher attended an area meeting with the CMHT lead and individual managers for the individual CMHTs to discuss the study. This information was then disseminated by the CMHT managers to individual care coordinators. The researcher also attended business meetings in two of the CMHTs to inform them of the research due to difficulties recruiting.

An ex-service user and member of CAST, was consulted on the information sheets and consent forms (Appendix D, E). Care co-ordinators passed on information about the study and opt-in forms to patients that met the criteria. Participants were only contacted by the researcher after they completed the opt-in form (Appendix F), which was stored in locked cabinets at the CMHT for the researcher to collect.

The researcher contacted potential participants by telephone to discuss the study, answer any queries and arrange an interview date. Written consent was obtained before the commencement of the interview. Participants were informed prior to the interview that their participation was voluntary, that they had the right to withdraw at any time and that their routine care and treatment would not be affected in any way. Participants were informed that if the researcher became concerned about their distress or if they disclosed that they wished to harm themselves or others, their care co-ordinator would be informed. Contact details for the CMHT duty desk and help lines such as Samaritans and MIND were given to all participants.

The care co-ordinator would inform the researcher if they had any concerns regarding the mental well-being of the participant throughout the study and if, in their opinion, the participant's mental health deteriorated before their interview to the extent that they believed they were no longer able to provide informed consent or were well enough to take part in the study.

Interviews were held at the participant's local CMHT. Participant's travel expenses were reimbursed. Interviews were digitally recorded and lasted between 35 to 80 minutes. Participants were given the opportunity to request a summary of the researcher's interpretations of the themes elicited from the interviews and given the opportunity to provide any comments should they wish to, which they all requested.

Measures

A semi-structured interview schedule was used to elicit an account of the participants' experiences of being discharged (Appendix G). Questions were deliberately open ended in order to facilitate the participants' ability to tell their story in their own words, a central premise of IPA (Smith, Flowers, & Osborn, 1997). Questions were phrased so as not to be leading or to make assumptions about the participant's experience or beliefs. The schedule included eight main questions with follow-up prompts where necessary. These were open and aimed to elicit more detailed information, such as "*could you tell me more about that?"* (Smith & Osborn, 2003). The research team devised the schedule by considering topic areas that the researcher would need to cover in the interview that, once answered, would provide the researcher with the information to answer the research question (Smith, et al., 2009). The interview questions were based on questions used in a similar interview exploring patient experiences of being sectioned (Seebold, 2007). An ex-service user from CAST was consulted to ensure they were appropriate.

A "scene-setting" (Smith, et al., 2009, p.61) question asking the participant why they were interested in taking part was used to help establish rapport before asking them about their experiences. Participants were offered the opportunity to add anything they felt was important at the end of the interview and asked how they had found the experience. Where participants reported feeling upset by discussing their experience, the ethics protocol was followed, for example using distraction techniques, (e.g. asking them what they had planned for the day, how they were getting home).

Data Management and Analysis

Transcription.

Interviews were transcribed by the researcher following Thornhill's (2002) format. To ensure confidentiality, names of people and places were omitted and replaced with (X) or (title). Italics and question or exclamation marks were used to indicate emphasis. Para-verbal features were placed in brackets, for example (sighs). Pauses were indicated by (pause), and (?) refers to words which were inaudible.

Data Analysis.

IPA involves the researcher trying to make sense of the participant's experience (Smith, 2011) and therefore, acknowledges that claims are tentative and subjective (Smith, et al., 2009).

Each participant is situated in their particular context and each case is explored individually before moving onto the next. The interpretation of the data emerges from the participant's words. In this sense the analysis follows the hermeneutic circle, moving from the particular to the shared and from description to interpretation. The focus being on understanding the participant's experience within the context of the interview, but the end result is an account of the analyst's beliefs about what the participants' lived experience is (i.e. the double hermeneutic circle). IPA starts with, but should go beyond, a standard thematic analysis (Brocki & Wearden, 2006).

The data were analysed using procedures outlined by Smith, et al. (2009), Smith and Osborn (2003) and Smith (2011). The aim was to create a comprehensive account of themes, which were pertinent in the original text. Therefore links are made from the original dialogue and not a pre-existing theoretical position. The authors pre-existing thoughts were considered and noted within a reflective diary (see Appendix H for excerpts).

The first stage in the analysis is to immerse in the data. The interview recording was listened to again in order to help the researcher imagine the voice of the participant in subsequent readings of the transcript. The transcript was then re-read several times to help engage with the data. Initial ideas or possible connections were noted in the reflective diary in order to help the focus remain with the participant’s words.

The second stage of the analysis involves initial noting; the first level of analysis in IPA. The researcher notes in the right-hand margin anything of interest within the transcript. Three different exploratory comments are noted at this stage: descriptive comments focussing key phrases; linguistic comments noting explicit use of language by the participant and; conceptual comments which are more interpretive and involve noting any initial concepts, reflections or questions. Each transcript was then re-read to check initial noting and to ensure nothing was overlooked from the data.

The third stage involves identifying emerging themes. The comments from the initial noting stage (which are closely tied to the data) are used to produce a concise statement or phrase to capture what was important in a piece of transcript. These statements are grounded within the data, but also begin to become more abstract and conceptual. Emerging themes were established for each transcript and checked by reading through the transcript again.

Stage four involves searching for connections across emergent themes. Clusters of themes are developed to produce subordinate themes. A table of themes for each participant was created along with the corresponding text extracts, noting page and line numbers.

Once this was achieved, the next interview was analysed in the same way. Although IPA recognises that the researcher will be influenced by the previous interview, it stresses the importance of, as far as possible, putting these thoughts to one side and analysing each interview as individual to keep with the idiographic commitment. Each interview was transcribed fully (but not analysed) before moving on to interview the next participant, with any thoughts noted in the reflective diary. This enabled the researcher to "bracket off" any preconceptions and to reduce the influence of previous interviews.

Once all interviews were analysed individually, patterns were established across all cases. Subordinate themes that cluster together emerge as superordinate themes. Where new themes emerged, earlier transcripts were reviewed and any instances of the new superordinate theme were included in the on-going analysis. In larger samples, measuring recurrence of themes across cases is important. However, Smith et al. (2009) also stress that frequency of themes is not the only indicator of its importance: "other factors, including the richness of the particular passages which highlight the themes, and how the theme helps illuminate other aspects of the account, are also taken into account" (Smith et al., 1999, p. 226). Different levels of recurrence were identified (see Table 1).

Validity

Credibility checks in line with guidelines for good practice were utilised throughout the process of data collection and analysis (Smith, 2003, 2011; Yardley, 2000). Yardley's (2000) principles for assessing the quality of qualitative research were followed (see Appendix I for further detail):

- *Sensitivity to context: knowledge of the empirical literature surrounding the topic under investigation*. The relationship between participant and researcher was considered. Participant involvement was included in the design stages of the study.

- *Commitment and rigour*: Yardley (2000) argues that reliability may be inappropriate criteria against which to measure qualitative research if the purpose of the research is to offer just one of many possible interpretations. However, rigour refers to the completeness of data collection and analysis.

- *Transparency and coherence*: Participants were provided with the opportunity to receive a summary of findings and to comment on them should they wish to in order to involve them in the analysis (DOH, 2005), provide ‘member checks’ (Russell & Gregory, 2003) and ‘testimonial validity’ (Stiles, 1999). A paper trail of the progression of analysis has been verified by the researcher’s supervisors to check transparency of the findings.

- *Impact and importance*: the current study aims to explore an area that has as yet not been explored.

Additionally, measuring recurrence across cases enhances the validity of findings (Smith, et al., 2009) and is a criteria Smith (2011) uses to measure “good” quality IPA research. This study measured several levels of recurrence.

Reflexivity

Qualitative researchers emphasise the importance of reflexivity in qualitative research, which is the process of examining one’s effect as a researcher in the research process (Elliott, Fischer, & Rennie, 1999; Stiles, 1999; Yardley, 2000). Although they may be firmly committed to honouring the data, no researchers are without bias. Therefore, values, beliefs and assumptions were acknowledged at the outset of the study and were ‘bracketed’ during analysis (Elliott, et al., 1999), (see Appendix H).

Following each interview, the researcher reflected on her emotional responses and tentative ideas that emerged from the interview. These were noted in the reflective journal.

Results

This study used IPA to explore the following research question: *What is the lived experience of being discharged from a psychiatric inpatient stay?*

Participants' accounts were detailed and provided a rich description of what it is like to be discharge from psychiatric hospital. They described their experiences in depth and demonstrated insight of both challenging and positive experiences. Participants' experiences of discharge revealed a timeline, beginning with their hospital stay, through to leaving hospital and their continued journey to recovery in the outside world. Discharge appeared to be viewed as a process that was part of their journey to recovery from mental illness rather than a discrete event. Throughout this journey, participants disclosed feeling 'not normal', experiences of stigma associated with their mental illness and a sense of not belonging. Relationships to others appeared to be key in helping participants progress and could impact on their experiences. A letter and summary of the results were sent to participants (Appendix J and K).

Description of themes

Five superordinate themes emerged from the analysis: (1) the hospital experience; (2) experience of discharge; (3) the outside world; (4) the journey to health, and (5) self-beliefs/identity. The structure for each superordinate theme and their subordinate themes are represented in Table 1. Support for all of these superordinate themes was demonstrated in transcripts from all participants. The frequency within which each superordinate and subordinate theme appeared in the transcripts is listed in Table 1 using methods reported used in other IPA studies (Bottrill, Pistrang, Barker, & Worrell, 2010; Rhodes, Hill, Thompson, & Elliott, 1994). Support for subthemes is considered here, but not separately in terms of those subthemes. These details can be found in Appendix L.

Table 1
Master Table of Themes

Superordinate	**Subtheme**	**Frequency[a]**
1.The hospital experience		General
	1.1 Becoming institutionalised	Typical
	1.2 Sense of being locked up	Typical
	1.3 Hospital as a break from	Variant
	real world	Variant
	1.4 Vicious circle	General
	1.5 Hospital as a haven	General
	1.6 Experience as negative	Typical
	1.7 The ‘system’	Variant
	1.8 Challenges for staff	
2.Experience of discharge		General
	2.1 Meaning of discharge	Typical
	2.2 Emotions on discharge	General
	2.3 Experience of returning home	Variant
	2.4 Discharge as impersonal	Typical
	2.5 Discharge as collaborative	Variant
	2.6 Support on discharge	General
	2.7 Discharge as a process	Typical
	2.8 Graded support	Typical
3)The outside world		General
	3.1 Adapting to life outside	General
	3.2 The real world is scary	Typical
	3.3 Return to old life	Variant
	3.4 Process of adapting as gradual	Variant
	3.5 Coping with life outside	Typical
	3.6 Feelings	Typical
	3.7 Regaining independence	General
4) The journey to health		General
	4.1 Health on a continuum	Variant
	4.2 Role of medication	Variant
	4.3 Recovery as fragile	Variant
	4.4 There is no magic wand!	Variant
	4.5 Recovery as a journey	Typical
	4.6 Readiness to change	Typical
	4.7 Change as a challenge	Variant
	4.8 Feelings about the future	Typical
	4.9 The journey continues	Variant

5) Self-beliefs/ Identity		General
	5.1 Understanding/attitudes to mental illness	Typical
	5.2 Sense of self with mental illness	Typical
	5.3 Feeling Valued	General
	5.4 Being different	Typical
	5.5 Asking for/Accepting help as difficult	Typical
	5.6 Staff genuineness	Variant
	5.7 Building relationships as important	Typical
	5.8 Support as a privilege	Typical
	5.9 Importance of support	General
	5.10 Support needed	Variant
	5.11 Self & others	Typical

Note:[a] General_theme/subtheme applies to all or all but one of the participants; typical_theme/subtheme applies to more than half of the participants; variant_theme/subtheme applies to up to half of the participants; rare_theme/subtheme applies to one or two participants.

1) The hospital experience.

Participants' provided rich accounts of their hospital experience. Subthemes about the hospital being both positive and negative arose. For everyone, the hospital was, at times quite a frightening place. Despite feeling threatened, Marie[4] still seems keen not to offend: "we had to have a lady on our, sort of from the ward who was very violent, very I mean I know she was unwell I'm not blaming her but she was really frightening" (Marie, 4, 11-13). Some felt that they did not belong: "the first few days in hospital I hated, I thought "god they're all lunatics in here! (laughs)" (Gill, 3, 13-14). However, it did not take them long to adapt: "over time you get used to people shouting and you see people being aggressive and it becomes the norm almost" (Sally,3, 4-5).

There was a shared experience of the hospital environment feeling quite confined, with little space for patients to have some time to themselves or escape the difficulties of

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[4] All names have been changed to protect confidentiality.

other patients: “at night when you can’t get to sleep and you need a cigarette, and the doors are all locked and you can’t go out for a cigarette” (Dan, 8, 28-29). The lack of freedom made them feel as though they were locked up. Marie reported: “it almost feels like a prison, like you’ve done something wrong, you know? The locked doors where you can’t do this, you can’t do that” (2, 26-28). There was a notion of having ‘controlled freedom’ where some participants were allowed to leave the hospital for short periods but were required to sign out, but: “times up, you’ve got to go back!” (Mina, 15,32).

Most of the participants’ spoke about the lack of responsibility in hospital, which at times was a release from the stress of everyday life: “I didn’t mind the restrictions that were put, piled upon me, because it gave me boundaries and I knew what I could and couldn’t do. And it was just like being in a safe little cocoon really” (Gill, 16, 14-17). Despite the sense of being overloaded with rules, Gill’s description of being cocooned also gives the sense of being contained and protected. It could possibly be interpreted as being similar to a mother swaddling a baby tightly to both restrict them but help them feel protected.

Some participants spoke about the hospital as a ‘system’ where they felt treatment was manualised rather than tailored to their individual needs. At times, their descriptions have a sense of their experience being quite de-humanising: “as I was getting moved along, the er, sort of like the um, erm, (pause) almost like a production line, you know?” (Gary, 2, 10-12). It gives the impression of patients on a conveyor belt.

They felt that resources were lacking and resulted in some people not getting beds or the treatment they needed. Marie felt frustrated that often people who needed therapy did not get it due to lack of resources: “I came across quite a few patients who I feel got lost in the system” (1, 32-33). The challenges placed on staff were acknowledged. Communication across teams, particularly different systems in different hospitals, and between hospital and community staff was deemed to be a problem: “(the) psychiatrist that’s discharging you from hospital should speak, somehow speak to the one on the community. Erm, and they should be singing from the same hymn sheet really (laughs). You know, not giving you mixed messages” (Sally, 21, 7-11).

2) The experience of discharge.

Discharge was viewed as a process. This theme highlights participants’ experiences of what leaving hospital was like for them.

There was a shared experience regarding the meaning of discharge. Participants’ viewed this as something that happened when you no longer needed hospital but did not mean you were ‘cured’: “discharge to me is when you’re, they feel, everyone feels you’re well enough to leave hospital, but that doesn’t mean that you’re better. It just means you’re well enough not to be there” (Marie, 2, 5-7). Marie’s change of words here possibly implies she is unsure as to who decides whether you are well enough for discharge.

Discharge from hospital raised a mixture of emotions ranging from joy and relief, to anxiety and fear that they could not cope. Sally experienced different emotions about her discharge, which changed from before leaving: “absolute joy going home, erm, thinking things are going to be different. You know, I’m going to make a huge effort, it’s going to be all different from now on” (Sally, 9, 4-6). To actually being home:

> The first time I was discharged it was awful, I felt so alone. Because my husband was gone off to work, my children were gone off to school and college, I was alone in the house every day. And I was totally lost. (Sally, 8, 17-20).

This description gives the impression of people leaving her and Sally not knowing what to do with herself, perhaps due to having lost the role she had before admission. Participants reported feeling all of these emotions in one discharge, but they also seemed to differ across discharges (where they experienced multiple), possibly depending on the circumstances.

These feelings also surfaced as a result of returning home. The act of putting the key in the door for some was anxiety provoking: “very strange. It was almost like going into (long pause), letting yourself into somebody else’s house, almost. It, it didn’t feel like I was letting myself home” (Gill, 5, 30-32).

Two people described returning home alone to find everything as they had left it before their admission:

> Everything was just the way it was and for example, I had a take away before I went into hospital and that was still on the bed, yeah and then I thought it was poison when I came back. That put me off food again. (Mina, 4, 8-12).

For Mina, this resurfaced her beliefs that the food was poisoned, she felt unable to cope and resorted to throwing all of her sheets away. She spoke about having only a “small piece of cheese” in her fridge and feeling “disheartened”. For others, this was not perceived as a problem: “yeah it was fine yeah, you know my room was such a mess when I got home it was like a bomb site” (5, 26-29) and referred to it as “home sweet home” (Dan, 11, 3).

As noted earlier discharge was viewed as a process rather than a discrete event. For some, discharge began weeks before they left hospital, gradually building up to it with day release, visits home and continued with community support.

> I had, had a series of phased discharges home I think it was type thing, I had a series of erm (pause) nights home, so I'd go home for a day and night and then go back and then I'd go home for two nights, then I went home for 3 nights, then I went home for a few nights before the day of the discharge and things. So it was gradually built up. (Gill,16, 31-36).

This appears to be in line with DP guidelines (DOH, 2003) that state discharge should be a collaborative process, whereby a strategy for discharge is planned, beginning from when the patient is admitted. Participants' had mixed experiences in relation to their involvement in their discharge plan. Some spoke about a collaborative approach where they felt involved in decisions about their treatment and felt they left hospital when they were ready. Gill was informed by her key nurse: "if it (discharge plan) needs to be adapted at any time then that can be changed. So if it needed to be lengthened or shortened you could do it" (19, 13-15) and she felt that things were moving at a pace that she was in control of, which she found helpful:

> (it) felt like I was partially in control helped. Because I wasn't being told, you are ready to go, we think we need to talk about a discharge you know let's do, we'll do it this way. So it was all part of, I was part, I felt I was part of the whole thing. So I wasn't just being told. (23, 17-21).

Gill laughed at her thought that she was partially in control of the process. One interpretation of this might be that, having said it, she wondered if it was presumptuous to think such a thing. It possibly indicates some doubt that she was able to have such an input within the system and that her view was powerful enough to change things.

At other times, participants were told they were leaving, with little preparation: “I saw the doctor and I was basically told I was being discharged that day. It wasn’t like ‘how do you feel about being discharged?’” (Mark, 8, 7-9). Despite not feeling ready to be discharged, it seems Mark did not feel he was qualified to be involved in decisions about his care: “I just thought to myself, who was I to argue with the doctor you know?” (8, 17-19). Mark said he was readmitted to hospital a few weeks later.

There were shared experiences that support upon discharge varied, with little consistency, with some receiving no support: “no, none whatsoever. There was erm, (pause) they, no, no they…. Erm, no I, I had no home treatment, I had, nothing except a prescription” (Marie, 6, 12 & 16-17). This description gives an impression of support being a piece of paper: thin and flimsy but all she had to rely on.

3) The outside world.

Participants spoke about their experiences of the community after having been in hospital. They shared a mixture of feelings and struggled to return to their old lives. The process of adaptation took time, and many found it difficult to accept the support they needed.

There was a sense that the community felt like a totally different world after people had been in hospital. Having adapted to life in hospital, they now had to re-learn how to live in the community. This for many was a scary prospect and they described having to “fend for themselves” (Gwen) and “face life” (Gary). Words such as ‘fend’ perhaps give the impression of fighting for survival in the world they had experienced difficulties living in. Gary described what it felt like to be part of the real world again: “it’s just with stepping through your front door and into the big bad world and erm, for me it felt, you know erm, there wasn't any safety net you know?" (3, 35-36).

Stepping into the "big bad world" gives an image of their homes being separate from this scary outside world, where if they stayed inside, they wouldn't have to face it. Merely walking out the front door was a challenge. One interpretation might be that patients had become institutionalised and therefore were questioning whether they could be independent again. It almost gives the feeling of being introduced to the world for the very first time.

Participants spoke of how alone they felt at times post-discharge:

> You know, it's like 4 o'clock in the morning and all your family's asleep, you're on your own, you're depressed, you may be suicidal, you're thinking, my first thought is I could do something now and no one could stop me. (Marie, 7, 31-34).

This feeling seemed to occur particularly when there was no support and in the first few days post-discharge when there was pressure, both from themselves and family, for life to return to normal. Participants' adopted different ways of coping. Sally described feeling alone and unable to cope during the first few days, which resulted in her drinking or attempting suicide, which impacted on her view of herself: "absolutely hated myself with a vengeance, really really hated myself" (12, 7-8) and "when I drank to cope with life there was such shame in that, oh it was absolute, I couldn't handle the shame at all" (12, 15-17). The repetition of words and use of "absolute" gives real emphasis to her feelings, it gives the impression of it being all encompassing.

It would be no surprise then that participants might seek ways to avoid their feelings: "I don't recall allowing myself to sit very much" (Gill, 25, 27). Mina spoke of using medication to help block the thoughts and voices she was hearing: "to forget about what was going on in my head and just to block it out and go to sleep" (16, 26-27). This seems to be a way for Mina to not only avoid her distress but gain some relief from it, possibly hoping that when she woke it would feel easier.

Some had hopes and expectations that their lives would return to how they had been prior to their admission. Dan's description of people leaving hospital assumed a return to life as it had been: "back to your old friends, back to neighbours and back to your old neighbourhood. Erm, or if you're working you can get back on with your life you know" (3, 2-4).

Others did not share this view and it seems life did not return to 'normal': "er, I was quite a high achiever getting all those bonuses all the time……so erm I've tried to get that thing back in my life again and try and go for different jobs and never found it" (Mina, 9, 8-12). Mina's words give the impression of searching for something, possibly searching for her old life and the desire to recapture her successes at work. It seems work was something Mina valued and took pride in, for example once she found out she had lost her job, she stated that she no longer wanted to be discharged.

For some, the process of adapting to life outside was slow and one that continues. Gary spoke about "the gradual exposure to the um community" (2, 14-15), which sounds similar to phobia work. In a similar thread, Sally stated the support helped "ease" her back into "normal" life. It sounds as though returning to normal living was something that needed to be handled delicately.

4) The journey to health.

This theme related to people's experiences of recovery, what they found challenging and what helped. Health and illness were not viewed as dichotomous states but on a continuum: "meeting new people who were, um, slightly more ill than myself" (Gary, 2, 25-26). Some participants spoke of the role of medication in their recovery. For some, it helped them manage their symptoms:

> The medication is one area that is another safety net, for many years I was on several different types of depo injection, which erm didn't help at all. Again I was anti-psychotics like Amisulpride, Olazapine, but the one I've been on currently for about 4-5 years now is Clozaril and it's a miracle what it's done in my life……(Gary, 9, 17-21).

For others, it did not help them address their difficulties.

> Everyone wants the easy option and the drugs are the easy, they blank things but they're not a long-term solution. I, I mean I'm not against drugs in the short-term, very short-term to get you over extreme anxiety or something like that maybe when you're in hospital but they need to start taking you off them gradually as you come out. That would have helped as well, if they'd just didn't stick you on this medication and keep you drugged up like that. I mean I wouldn't have been able to go back to work if they kept me on that Olanzapine. (Sally, 18, 6-14).

Sally's use of the word 'blank' appears to imply that medication helps to make problems invisible. Her words here suggest that medication is not only an easy option for the patient in order to forget their difficulties, but also for the staff. It also seems to dehumanise the patient; to "stick" something and "keep you drugged up" almost gives the impression of something that is done *to* the person, so they don't have to do anything else with you. Sally seems to imply here that medication is a short-term solution and that something else is needed for people to recover. For some, medication was not the solution: "I know doctors rely very heavily on, on meds but, I believe there's a lot of people like me where they don't make a huge difference you know" (Marie, 10, 16-18).

Models of change (Prochaska & DiClemente, 1982; 1983) discuss stages people take before embarking on changing something. Participants discussed recovering from mental illness in similar terms, beginning with pre-contemplation: "erm, in the past I blamed everyone for my troubles other than, mm I shouldn't blame me as such but I took no responsibility at all for any change, I expected other people to do it for me" (Sally, 13, 11-13). Participants recognised that there was no magic wand and at some point they realised that they had to take responsibility for their recovery: "you've got to do a lot yourself erm, it's got to come from you really. You've got to want to get better, it's got to come from you." (Gwen, 15, 34-36).

This came with challenges and it was acknowledged that change was difficult. For some, it seemed that mental illness was something that they needed to fight and battle with to overcome: "to me, you have to, (sighs) I don't know if fight is the right word, but you have to think right, I'm gonna take this on and I'm gonna win when you're thinking about the illness." (Marie, 10, 27-30). To "take it on" implies that it is something tough and mean to overcome. The need to remain positive in order for it not to get the better of you is highlighted. Gary's use of words here give the image of defeating and gaining control over the illness: "to see if um I can conquer these feelings you know, about apprehension, about stepping out" (Gary, 9, 30-31).

People worried about returning to hospital, almost as though their mental illness was something that was always lurking in the background: “maybe I, maybe that erm, I the hospital hasn’t seen the last of me you know?” (Dan, 3, 35). It seemed that being well was something precious: “the best gift I could ever have is being well and being stable for a long time” (Gary, 9, 16-17).

Many felt that their journey to recovery continued: “I still feel as if I’m withdrawn a lot now but erm, it’s getting a little bit easier for me to talk now” (Gwen, 19, 19-20) but they were hopeful: “that’s what I am now you know instead of attending a therapist I am my own one” (Sally, 25, 23-25).

5) Self-belief/ identity.

The theme of self-belief and identity emerged as an over-arching theme covering issues relating to their identity with a mental illness. This theme infiltrated the other superordinate themes throughout their journey.

The notion of normality emerged frequently throughout the transcripts, regarding how participants’ felt, what they perceived as normal and other people’s expectations: “certainly if you’ve children or teenagers, erm, they just want life to be back to normal. And they treat you as normal” (Sally, 20, 3-6). What was ‘normal’ was questioned and changed throughout their journey. The sense of not being a normal person is highlighted in Sally’s description of being on medication: “you don’t care about anything, er, going around like a zombie, you can’t feel anything, you’re totally out of it” (Sally, 7, 23-25). We tend to view zombie’s as dead, unfeeling, non-human creatures; therefore Sally’s use of it here is quite poignant.

Participants felt that mental illness could not be fully appreciated unless a person had experienced it. Gwen stressed how different it was: “cos that’s natural isn’t it you have your off days then, but when you’re depressed it’s er, it’s a bit more of a deal and that it’s a bigger thing really” (16, 27-29).

Other people’s lack of understanding has been cited as one of the reasons for stigma around mental illness (Jorm, 2000). Participants spoke about being judged and labelled due to having a mental illness:

> It was with er, my workplace, as soon as they found out I was schizophrenic, they dropped me like a ton of bricks. Erm, my manager got scared of me, she was scared that I might follow her, which I’d never done before. (Mina, 18, 25-29).

Mina’s use of words here gives a sense of rejection. The “ton of bricks” gives the sense of weight, as though she is a burden for others. Mina described how she had to be careful what she said within her community due to stigma. She reported their assumption that “you don’t know what you’re talking about” (19, 18-19) because you have a mental illness, therefore in their eyes, she counted for nothing. Mina coped with this by telling people she had depression as this was less stigmatising than revealing she had schizophrenia.

However, those with a mental illness have also made judgements about others. Gary spoke about being fearful in the community he lived in:

> Just walking down the street is a challenge you know because you know, you tend to find, especially in the area that I live XX you tend to find a lot of people there are on the corners drinking, there’s a lot of people around that area that are either using or have been using psychiatric services. There’s a few erm, houses along the street I live

> that are dry house for alcoholics and drug addicts so the area is quite a um, colourful mix of people. (9, 32-38).

Gary's use of 'colourful' implies a range of people from all cultures and different walks of life. However, given that he seems to be making the assumption that they are people to be wary of, 'colourful' could possibly mean that they are intimidating.

Mental illness resulted in some people questioning their identity and their roles:

> I'd been questioning what sort of wife was I, what sort of mother am I, what sort of grandmother am I, I keep questioning myself cos I say my self-esteem is so low. I can't understand why people would want to be with me at the moment. (Gwen, 16, 12-14).

It seems that Gwen is questioning who she is as a person and whether she can fulfil her roles as well as she used to. Participants questioned whether they were 'mad', believing there was something wrong with them. They assumed an identity of being 'ill': "I'm thinking 'no I can't I'm ill!'" (Sally, 4, 26), but at the same time rejecting it: "what am I doing here? I'm not (whispers) really ill" (Gill, 3, 18). The language used also helped to reinforce this: "now that I'm *out*, 'out' sounds as if I'm mad" (Gwen, 9, 2).

A sense of not being valued as a person appeared to be a shared experience. Participants described times when their calls to services were not returned, or they were made to feel as though they were a drain on services: "I remember the doctor saying to me once you know, do you realise how expensive hospital is and how much it costs a week for us to keep you in here" (Marie, 3, 23-26).

Receiving support from someone genuine and who had time for them was highly valued by participants:

> Oh it was absolutely amazing, it was such an appreciated feeling, it was such a warm feeling and it felt like somebody was there for you, that you weren't alone, neglected and a just, abandoned, by everybody you know you felt that you had somebody there for you. (Mina, 4, 29-32)

Their accounts highlighted how important it was for them to have even one significant person to support them, whether it was family or staff. It took time for them to build relationships with people. Sally highlighted that for some people, receiving twelve weeks of therapy would not be beneficial:

> What's very important is building up a relationship with the therapist where you can trust them so much. I mean I was able to go in and say to her (therapist) I would, that I felt suicidal and I knew I wouldn't get detained. Whereas I would go, I wouldn't dream of saying that to the, my psychiatrist cos he'd have me in hospital! And erm, so this idea 12 weeks, it's, I don't think you can build up a relationship with people over that period of time. (Sally, 22-23, 39-5).

Changes in staff were difficult to cope with, almost like bereavement:

> Being introduced to (discharge coordinator) and then I had to say goodbye to (DC) and be introduced to somebody else. And each time it was, it got, each time it got more difficult really I was losing my circle of support (10, 31-34).

Some support was time limited: "the emergency number I had, I knew that was only good for like, till the end of the week" (Marie, 16, 33-34). Whilst services may have no choice but to have time restrictions, the fact that the number was ‘good’ for a limited time gives the impression that there is a best before date, where patients must be ‘well’ before this time, otherwise they run out of support. Participants viewed support and treatment as a privilege, stating that they felt “lucky”. It felt as though they believed they did not deserve the help. This is emphasised by the difficulties participants had in asking for help, sometimes waiting until they were at crisis point before they contacted services:

> I used to let myself get really ill and then access the services and it used to frustrate X (care coordinator) a lot, she used to say you know (laughs slightly) ‘just pick the phone up, you don’t have to wait until you needed admission into hospital before you access the services’ but I used to think no no I’m not unwell enough yet! (Mark, 15, 12-16).

It emerged that staff needed to repeatedly encourage participants to call them, make it part of their treatment, or contact them rather than relying on participants to call. Gill would create ways for staff to call her: “couldn’t settle, couldn’t stop crying, was real, so I sent them a text so the phone call came from them, which then made it easier to talk to them, if that makes sense” (21, 27-28). The very act of someone else calling her, made it easier for Gill to accept the support she needed.

Summary.

Participants’ provided detailed accounts of their experience of discharge. Whilst there were shared experiences, there were also individual differences. Participants’ viewed their discharge as a process and a journey that began whilst they were in hospital and continued long after they left. The difficulties with adapting to life outside and learning ways to cope were highlighted. Support from at least one person was crucial in helping people feel valued, however they expressed difficulties in asking for the help they needed. It emerged that they viewed their support as a privilege and something that was not consistent.

Discussion

This study aimed to gain insight into the experience of being discharged from psychiatric hospital. The study highlighted common themes between participants' accounts as well the differences between their individual experiences. Common themes included the hospital experience, perceiving discharge as a process, readiness to change, the difficulties with adapting to the community, the importance of support on discharge and the impact of having a mental illness on their self-beliefs. Individual differences were apparent in their emotions and perceptions of their journey through hospital and discharge to the community. The reasons for these differences were not explored in this study but may be linked to stages of change, personality, environment and past experiences.

Summary of Findings

Five superordinate themes of participants' experience of being discharged from psychiatric hospital were identified. These themes are comprised of numerous subthemes. These themes are intrinsically linked, for example it is impossible to separate an individual's experience of discharge from their self-beliefs. Furthermore, whilst causality is not the focus of this study, it is plausible that an individuals' experience of hospital and subsequent discharge will impact on their adaptation to the community and continued recovery. However, it is important to note that individual differences were identified throughout the transcripts.

IPA involves a double hermeneutic whereby the researcher is attempting to make sense of the participant's account, who is also trying to make sense of their own experience (Smith, et al., 2009). This requires interpretation by the researcher. Therefore, the researcher chose themes which stood out most in helping her understand the individual's lived experience. It is acknowledged that there are other themes that could be presented. The themes highlighted here reflect the journey of the discharge experience undertaken by participants, beginning with their hospital experience and continuing with the point of leaving hospital, their adaptation to the community and their journey to recovery. Throughout, this journey is underpinned by the impact of their experiences on their self-beliefs with a mental illness, how they were treated by others and the support they received from services, staff and family.

Links to Previous Research

The themes from this study relate to findings of previous research exploring mental illness. For example, this study identified that hospital provides respite from problems and offers a place of safety, but also a place of boundaries and paradoxically can be frightening (Johnson, et al., 2004; Samuelsson, Wiklander, Asberg, & Saveman, 2000; The Sainsbury Centre for Mental Health, 1998).

The subtheme of mental health being on a continuum emerged from the data, with participants talking about their illness with regards to being “well enough” but not “cured”. This appears to be in contrast with research where patients have viewed mental health and illness as dichotomous states (Hines-Martin, et al., 2003), but in line with research reporting that there is not a clear divide between illness and health (Bentall, 2004; Roe & Chopra, 2003). This provides some evidence that the medical model’s criteria and cut-off’s for diagnosis of mental illness are not supported by patients who view their illness as graded in terms of severity.

Despite the implementation of DP and CRHT teams it seems that many people still do not receive the support they feel they need post-discharge (Gerson & Rose, in press). The amount of support people receive is variable (Mind, 2011) and patients find it difficult to cope when support stops abruptly (Larivière, Desrosiers, Tousignant, & Boyer, 2010).

Participants in this study spoke of similar experiences, with amount, type and length of support varying greatly across discharges. A number of voluntary sector crisis provisions have been established by patients who were dissatisfied with NHS services in order to provide further support (Mind, 2011). Although it did not emerge from the data, this might relate to a need for attachment figures to help support patients in times of crisis and the need for continuity of the relationship. It might be that the abrupt end of the relationship leads to feelings of loss, similar to that explored in models of grief. However, this would need further exploration to examine these links.

Boyer et al. (2000) reported that many patients do not attend follow-up appointments in the community, often due to lack of transport (Beebe, 2010). However, participants in this study spoke about the difficulties in adapting to life in the community, experiencing a variety of emotions and stresses, and generally struggling to cope at times. This may offer reasons as to why it is difficult to attend appointments. Some patients require more effort from staff to ensure effective linking between hospital and the community. Discussion of the DP protocol between inpatient and community staff was found to increase attendance at outpatient appointments (Boyer, et al., 2000). This is something that participants felt did not always occur, which is consistent with research findings (cf. Boyer et al., 2000).

Participants also mentioned that it would have eased their anxiety if they had had an opportunity to meet their community care coordinator prior to discharge. On the occasion where this did happen, they discussed how helpful this was. Linking community staff with inpatients has been recommended in the literature as important for successful discharge (Moore, 1998) but the current study reveals that this does not consistently occur. Research states that families, the community and the patient should be involved in DP (Moore, 1998). In addition, that families and the patient should be educated regarding their diagnosis and informed of the importance of social activities post discharge (Buckwalter, 1982). This was something that Sally in particular raised; expressing that she felt this would help reduce the expectations family had of her returning to “normal” post-discharge and therefore reduce the stress she was under. In addition, some spoke of not feeling included in decisions made about their care and a lack of family involvement, which has also been reported (cf. Howard, El-Mallakh, Kay Rayens, & Clark, 2003).

The experience of difficulties adapting post-discharge and searching for what is “normal” might relate to models of transition as suggested earlier (Williams, 1999). Patients spoke about experiencing a range of emotions and struggling to cope at times. They spoke about the difficulties with arriving home and having to adapt to the change, having been used to little or no responsibility in hospital, they now had to resume coping by themselves. It seems that these experiences are similar to the stages in the transition model; experiencing uncertainty, confusion and at times, depression. However, in contrast to the model, participants did not describe feelings of shock of numbness in relation to the first stage of the model.

The National Confidentiality Inquiry (2006) recommended that patients who are at high risk of suicide following discharge from in-patient stays should have ways of contacting services if they are in crisis. However, participants reported not feeling able to ask for help for various reasons, for example believing they do not deserve help, an issue that other patients have reported elsewhere (Mind, 2011). In addition, it seems from this study that sometimes telephone numbers provided from services such as CRHT and AOT are only valid for a limited time. Given that risk of suicide post-discharge is high for the first three months (Meehan, et al., 2006), it seems that there needs to be some way that patients can contact services anytime. Services may need to be more proactive about contacting patients during high risk periods (e.g. during transition times and up to three months post-discharge).

Although not asked directly, three participants in this study did talk about their attempts at suicide following discharge. This appeared to be in relation to feeling hopeless, depressed and alone (e.g. Mark). In addition, hospital had helped to keep them safe (e.g. from harming themselves) and so being discharge resulted in some participants feeling terrified of what they might do (e.g. Marie). In addition, Sally described the shame of being a mental patient, struggling to cope with life and so using alcohol as a way of coping. This caused her to feel more shame, which resulted in her attempting to take her own life with the belief that her family would be better off without her. Marie also talked about her feelings of guilt about being a mental patient and the burden on her partner of having to look after her. In addition, she spoke about the stigma of having been in hospital and this causing further stress, all of which led her to believe that life was not worth living.

Participants spoke about the importance of having someone there to talk to in the immediate days following their discharge, particularly in relation to keeping them safe and helping them to cope with life outside hospital. They experienced a multitude of emotions and knowing that someone was coming to see them appeared to help them get through the day. Studies suggest that this contact can help prevent crisis and admissions (Fallon, 2003; Mind, 2011). However, research indicates that support is not always consistent and some patients experience a delay between discharge and their first appointment (Saarento, et al., 1998), something that participants here found difficult to cope with. Findings here support research stating that failure to link patients with community services post-discharge increases the risk of readmission, relapse and lowers quality of life (Rosenfield, et al., 1986). Again, this might link to theories of attachment and the importance of having an attachment figure in times of crisis. With little staff continuity, it might be that patients cannot establish a secure attachment.

Participants spoke of the difficulties associated with not having the same staff member coming to see them when involved with CRHT teams. Whilst it is acknowledged that this is inherent in many 24/7 teams (Glover, et al., 2006), solutions such as providing the patient with information about the whole team, ensuring that information about patients is shared amongst the team and reducing the need for multiple assessments is recommended (Mind, 2011).

Despite many clinical guidelines regarding services, there are few studies on how to put those guidelines into practice. This makes implementation of evidence-based interventions such as CRHT difficult (Barker, et al., 2011). It seems that despite these guidelines and the implementations of CRHT, the input people receive from CRHT remains inconsistent as evidenced by the experiences of the people in this study. For example, some (e.g. Marie, Sally, Mark) did not receive input from the CRHT team when discharged and did not receive the referrals recommended by guidance (DOH, 2001) despite high risk of relapse.

It seems that some CRHT teams continue to be under resourced in order to provide services that adhere to the model suggested by the DOH, for example providing out of hours support (Onyett, et al., 2008). In view of the nature of these people’s difficulties, they need someone to turn to when difficulties arise, particularly at night when they feel most alone (Bridgett et al., 2006) as voiced by Marie talking about how desperate she felt at night. Just knowing that someone was there if they needed was highlighted by many participants as being enough, therefore many difficulties could perhaps be solved by knowing there is a team available at any time, or by telephone response (Bridgett, et al., 2006).

However, it might be that some of the participants in this study may not have met criteria for being in ‘crisis’ to qualify for input by the CRHT teams, which suggests there is a gap in services for those that need support, but are not deemed unwell enough to require input from services, something that was also voiced by service users in the Mind survey (2011). Additionally, CRHT's role is to stay involved until the crisis has resolved and then refer the client back to the CMHT (DOH, 2001), although large numbers of patients reported delays in being picked up again (Onyett, et al., 2008).

For some participants in the study, discharge from CRHT could be just as difficult as being discharged from hospital and evoked feelings of being alone (e.g. Sally). For others, they felt that they received input until they were ready for discharge (e.g. Gill, Gwen). This might suggest that involvement of the CRHT is inconsistent, or that there are discrepancies between the views of the client and the CRHT regarding their needs. Reports suggest that this phase should be handled sensitively and gradually as rapid discharge and referrals to other services can result in return to crisis (Bridgett, et al., 2006). Participants in this study echoed the need for services to withdraw gradually (e.g. Gill, Marie, Mark, Sally).

Mind's (2011) inquiry into experiences of acute care reported patients' wishes for more peer support, greater choice over their care, individualised treatment and access to services when they needed support to prevent relapses. These findings were replicated in this study. Participants felt that care was depersonalised, with a focus on medication, where the illness or crisis was treated rather than helping them as individuals. Participants spoke about how they felt they were labelled and that their treatment was manualised. One thought might be that this is a reflection of services following the medical model and so prioritising medical treatment and focussing on diagnostic labels to treat the illness rather than the person. This is inherently more stigmatising given that the patient's did not feel they had much input into their care and at times felt that their opinion was not heard (e.g. Sally trying to explain that her early morning waking was not depression but something she had always done). Although the medical model has its place, it seems patients are calling for more balance (Mind, 2011).

The Sainsbury report highlights the importance of working not only with evidence-based practice but also value-based practice (Bridgett, et al., 2006). A full description of values-based practice can be found in Woodbridge and Fulford's book (2004).

This study supports findings from previous research where patients have viewed their experience of services as a journey (Fallon, 2003) and that recovery from mental health is also a dynamic process (Pitt, et al., 2007). This study suggests that discharge is not a discrete concept, but one that involves overcoming milestones along the way. This provides some support for models of recovery and the five stages proposed by (Andresen, et al., 2003). For example, participants spoke about their feelings of despair when leaving hospital and thinking that therapy was "too hard" and wanting to give up (possibly stage 1: moratorium). At some point, they realised they had to "fight" their illness and began to work towards recovery, which might be similar to stage 2; awareness. Participants also spoke of what Andresen et al. label "rebuilding" (stage 4) where they began to work towards goals of independence and returning to work. One participant, Sally, then spoke of her growth (stage 5) in terms of becoming her own therapist. However, further exploration of the stages of their journey, possibly within a grounded theory approach is needed to see how well the stages of recovery map onto patients' experiences.

The findings of this study also reflect a lot of the experiences cited in the literature regarding stigma and identity. Participants appeared to view themselves as an "ill" person and that their illness was something that they had to overcome and "fight." For example, Sally spoke about not being able to engage in therapy because she was "ill" and wondering what "normal" was. Three participants in particular spoke about their experiences of stigma and the impact that this has had on their lives. For example, Mina spoke about the stigma she received when her employers found out she had schizophrenia and the assumptions they made about her. Experiences like this result in people then not wanting to disclose their mental illness; Mina would only tell her family she had depression for fear of being ostracised in the community. Gary refused to disclose his health history to possible employers for fear of being stigmatised. These experiences are not uncommon and have been cited elsewhere in the literature where people have experienced stigma particularly in relation to the community, family (cf. Dinos, et al., 2004) and employment (Department of Health, 2009; Stuart, 2006).

The study also raised issues that do not appear to have received as much attention in the literature, perhaps because the predominant use of quantitative methods has not highlighted them. These relate to the detailed descriptions of difficulties in adapting to life outside hospital. Participants seemed to experience hospital and the community as two separate worlds and highlighted the difficulties of re-entering the “real world” which had become scary and unfamiliar. Simple everyday tasks had, for some, become a challenge, for example going shopping. Expectations of returning to “normal” were mentioned as was struggling to define what this meant for them.

Theories of life transition and roles might be relevant here. Life transition has been defined as: “sharp discontinuity with previous life events” (Brammer, 1992, p.239). Typically, life transitions are predictable in their occurrence and timing. In addition, socialisation provides individuals with the skills needed to master new roles and cope with transitions (George, 1993). However, Brammer (1992) claims that most transitions are experienced with loss as any change places demands on the individual and requires a period of adjustment, particularly in transitions that are not wanted, unexpected, uncontrollable or for those with fewer coping resources.

The findings in this study may indicate some support for this model. Participants found the transition between hospital and home, and between community support and coping alone challenging, evoking feelings of loss and anxiety. Participants spoke about feeling as though they had no control and were not involved in their discharge process. Their descriptions of support on discharge being a “lottery” (Marie) may serve to exacerbate the difficulties associated with the transition. They spoke of the time it took to adjust to their new situation, which may be linked to grieving models that have been applied to life transitions (Hopson, 1981). However, this would need further research regarding links to mental health transitions. A key point of relevance is that during the first stage of adjusting to a transition the critical strategy to help an individual is support (Brammer, 1992).

Limitations of Research

The interviews reflect the experiences of eight participants as they recalled them in the moment and how their accounts were interpreted by the researcher. As such, the interpretations made are subjective and may not be generalizable. This study had a small sample in research terms and therefore the findings may not represent the views of others. In addition, IPA recommends recruiting a homogenous sample to reduce variation. The sample in this study varied in age, gender and ethnicity. However, they all shared the experience of having a mental illness that was severe enough to result in hospitalisation. In addition, recruiting a totally homogenous sample would be impossible. However, it seems that many of the themes that arose from this study have been supported by previous research. In addition, the size reflects other studies that have used similar methodology (cf. Arroll & Senior, 2008).

The participants who engaged in the research may be considered as being more motivated, representing those who had more negative experiences, or those who are more confident in sharing their experiences. Given the selection criteria, only patients who were deemed mentally well enough to take part were given information regarding the study. The views of those who were not sufficiently well may have a different experience. However, those who were interviewed had all been ill enough to be in hospital at some point.

The research denotes the views of individuals recounting their experiences as they remember it, which represents a snapshot in time. Provision of care within the NHS is changing and may vary across the country. For example, Hampshire CRHT teams are being replaced by 'hospital at home' teams. Therefore, it is acknowledged that the experiences may change as services change.

Despite these limitations, this study gave patients a voice that has previously been unheard in relation to their discharge experiences. It has highlighted significant issues relating to discharge, which will provide important information regarding future research and clinical practice.

Implications for Future Research

The reasons for individual differences were not explored in this study, but may be linked to stages of change, personality, environment and past experiences. Further research examining these factors might provide useful information regarding their relationship. Further research needs to explore the relationship between the themes identified in this study and suicide, readmission and self-harm post-discharge in order to highlight possible risks. This information could be used to inform quantitative measures examining satisfaction on discharge.

Despite the implementation of services such as CRHT teams it seems that some people still do not receive the support they feel they need when they are discharged from hospital (Royal College of Psychiatrists, 2011). It seems that guidance regarding how to cost effectively implement these services is lacking (Barker, et al., 2011) and communication between inpatient and community services is inadequate (RCP, 2011). Further guidance regarding how to implement strategies would be of benefit. In addition, it seems that the process of discharge and the level of support regarding discharge both when in hospital and in the community greatly varies. Further research examining the frequency of use of DP strategies might identify whether these people's experiences are the norm or the exception.

Only one person of ethnic minority was interviewed, therefore further research examining the experiences of discharge with black and minority ethnic groups is warranted to ensure that the stories of patients reflect our multi-cultural NHS users. Particularly as in the UK, black and mixed-race individuals are between two and six times more likely to be admitted to psychiatric hospital compared to the average (Care Quality Commission, 2011).

Clinical Implications

This study replicates others' findings that one of the key things patients' value is the relationship with staff (Fallon, 2003; Mind, 2011). Often at the point of crisis, it is having someone familiar to talk to that helps alleviate that crisis and prevent admission.

Participants spoke of wanting individualised care that was not manualised or medicalised. Around half of the participants spoke about medication being a short-term solution and identified that psychological therapy helped them learn the skills they needed in order to remain out of hospital. This supports findings from the literature that patients have felt that treatment needed to be less focussed on the medical model (Mind, 2011) and the value of intensive specialist psychological input (Fallon, 2003). This also provides support for the notion of utilising value-based practice as well as evidence-based practice in our work with patients as recommended in the Sainsbury report (Bridgett, et al., 2006).

The psychological implications of discharge on patients can be profound. For some, leaving hospital resulted in feelings of loss and hopelessness about the future. Whilst in hospital participants established relationships with staff and/or patients, felt safe and had little or no responsibility. Therefore, leaving hospital and finding they had little or no support in the community resulted in a sense of abandonment and fear. Some struggled to cope without the support and to control their feelings of anxiety, feeling alone. This research might offer some explanation as to why some patients resort to self-harm or suicide as a way of coping with their emotions and/or an attempt to elicit help from others as proposed by the DBT model (Linehan, 1993). Therefore, perhaps working within a DBT framework with patients upon discharge might reduce their feelings of abandonment and offer alternative ways of coping.

Participants spoke about how difficult it was to ask for help and needed several prompts by staff to utilise services and out of hour’s numbers. Fear of being a burden, feeling undeserving of input and fear of being laughed at were highlighted as reasons why this was difficult. Participants tended to contact services once they had reached crisis point, which has also been noted elsewhere in the literature (Fallon, 2003). Therefore, community services need to be more proactive in contacting patients who have been recently discharged or who are risk of crisis in order to prevent further crisis. CTIs to link inpatient and community have shown to have some benefit reducing readmissions and patients attending appointments, (Dixon, et al., 2009) and so similar models might be worth implementing.

Participants spoke of the difficulties in coping with different staff, both between inpatient and the community and within community teams. It was hard to “relive” their experiences repeatedly to different staff and to have to build up new relationships, which they reported took them time. Although consistency at times can be a challenge in community teams, having a significant person who valued them appeared to have a large impact on the participant’s recovery in this study.

Conclusion

This study set out to increase understanding of the lived experience of being discharged from psychiatric hospital. To date, most research regarding discharge has focussed on quantitative methods examining suicide and readmission rates, risk factors and DP. This is the first study to use qualitative methods to examine what it is like to be discharged from hospital.

The study identified five superordinate themes relating to peoples' experiences. These themes highlighted discharge as a process that begins in hospital and continues in the community. Participants discussed difficulties with adapting to both being in hospital and living in the community post-discharge. Their experiences emerged as a journey to recovery, highlighting the need for graded discharge, the importance of collaborative, individualised interventions and the importance of support from staff throughout. Inconsistencies regarding support on discharge and the process they experienced were identified.

The findings could be used to inform further research exploring the relationship between these themes and to risk factors for suicide and readmission. These themes could also inform quantitative measures on satisfaction post-discharge.

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List of Appendices

Appendix A: Identity Threat Model of Stigma

Collective representation (A), immediate situational cues (B) and personal characteristics affect the individual's appraisal of the significance of the situations for their well-being. Identity threat (D) occurs when the stigma-related stressor is perceived as potentially harmful and exceeds their resources to cope with the stressor. Responses to the stress can then be involuntary (e.g. anxiety, increased vigilance, and working memory load) (E) or voluntary (e.g. coping efforts) (F). Involuntary responses refer to emotional, cognitive, behavioural and physiological responses that do not serve to modify or regulate stressful experiences. Voluntary responses or coping, refer to conscious efforts to regulate the environment, cognitive, emotional, behavioural and physiological responses to the situation perceived as stressful. Outcomes (G) can refer to things such as self- esteem, achievements and health. This model is recursive, therefore responses and their outcomes may exacerbate or lessen the effects of stigma.

Appendix B: University of Southampton Ethics Approval Email

Submission Number 127:

Submission Name What is the lived experience of being discharged from a psychiatric inpatient ward?:

This is email is to let you know your submission was approved by the Ethics Committee.

Comments

1.

2.

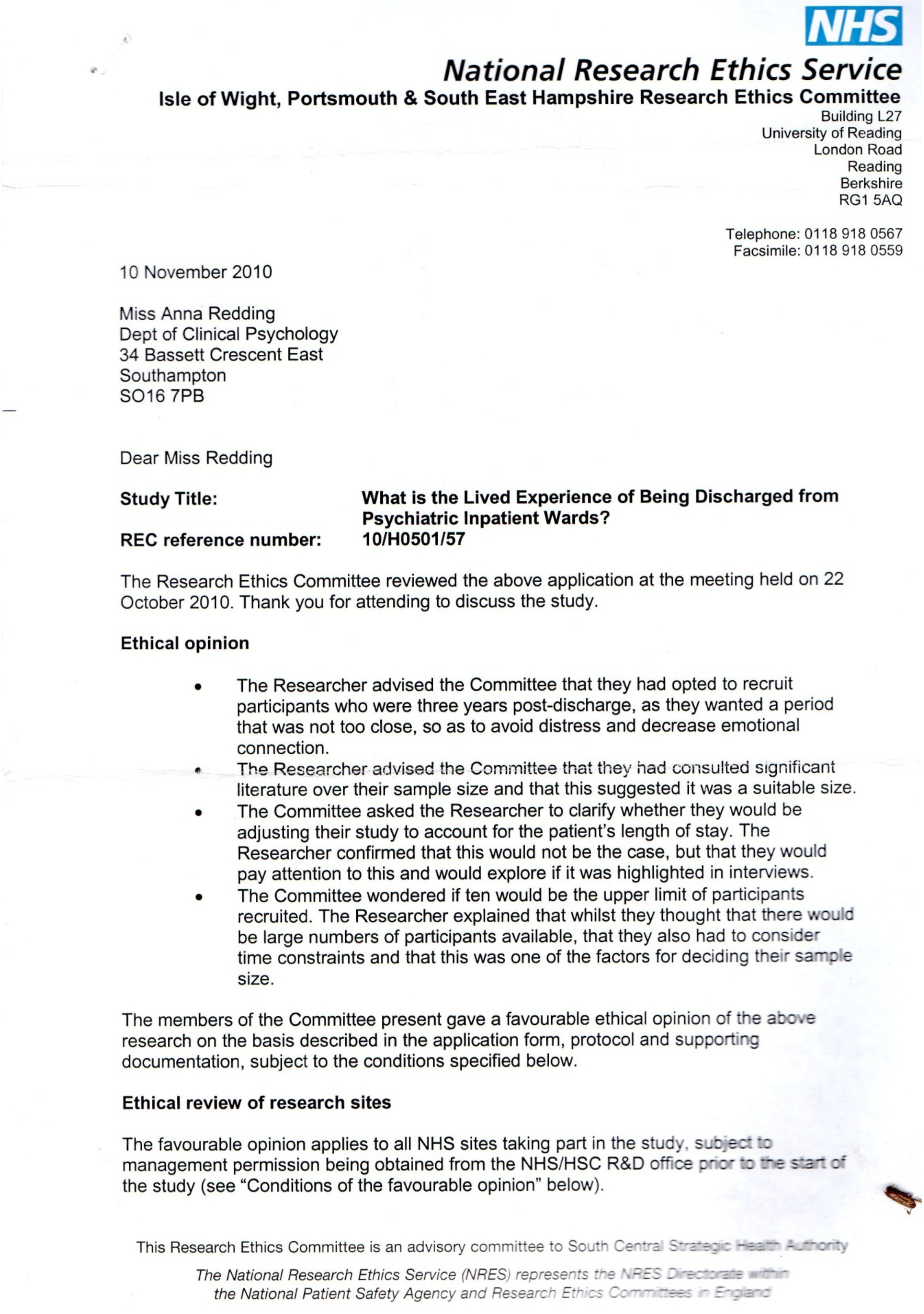
Click here to view your submission

ERGO : Ethics and Research Governance Online

http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

Appendix C: NHS Ethics Approval



NHS
National Research Ethics Service
Isle of Wight, Portsmouth & South East Hampshire Research Ethics Committee
Building L27
University of Reading
London Road
Reading
Berkshire
RG1 5AQ

Telephone: 0118 918 0567
Facsimile: 0118 918 0559

10 November 2010

Miss Anna Redding
Dept of Clinical Psychology
34 Bassett Crescent East
Southampton
SO16 7PB

Dear Miss Redding

Study Title: **What is the Lived Experience of Being Discharged from Psychiatric Inpatient Wards?**
REC reference number: **10/H0501/57**

The Research Ethics Committee reviewed the above application at the meeting held on 22 October 2010. Thank you for attending to discuss the study.

Ethical opinion

- The Researcher advised the Committee that they had opted to recruit participants who were three years post-discharge, as they wanted a period that was not too close, so as to avoid distress and decrease emotional connection.
- The Researcher advised the Committee that they had consulted significant literature over their sample size and that this suggested it was a suitable size.
- The Committee asked the Researcher to clarify whether they would be adjusting their study to account for the patient's length of stay. The Researcher confirmed that this would not be the case, but that they would pay attention to this and would explore if it was highlighted in interviews.
- The Committee wondered if ten would be the upper limit of participants recruited. The Researcher explained that whilst they thought that there would be large numbers of participants available, that they also had to consider time constraints and that this was one of the factors for deciding their sample size.

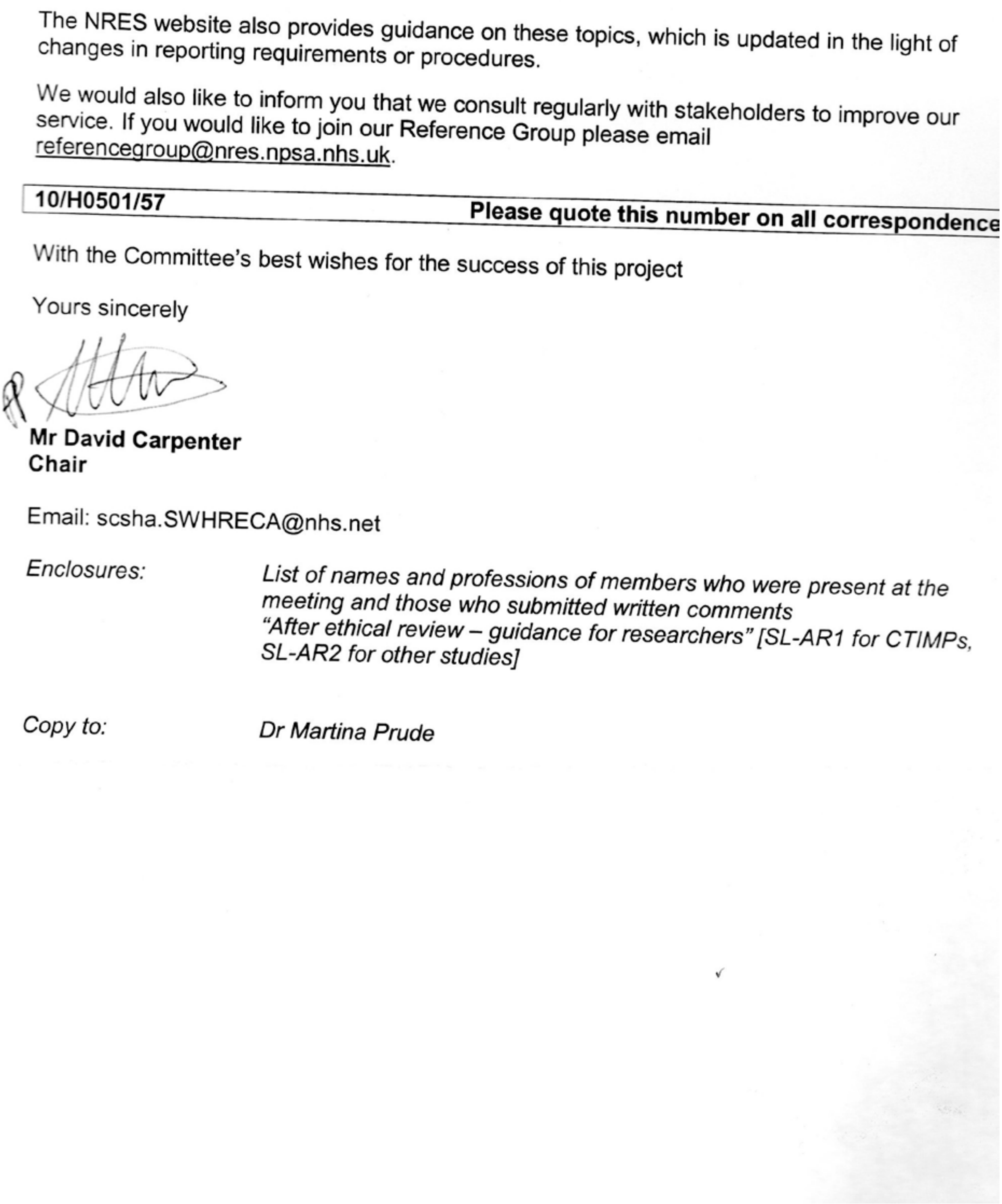
The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

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

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0501/57	**Please quote this number on all correspondence**

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

Yours sincerely

Mr David Carpenter
Chair

Email: scsha.SWHRECA@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers" [SL-AR1 for CTIMPs, SL-AR2 for other studies]

Copy to: *Dr Martina Prude*

Appendix D: Participant Invitation

Research Study into "What is the Lived Experience of Being Discharged from Psychiatric Inpatient Wards?"

Have you been discharged from an inpatient stay in a psychiatric hospital in the last 3 years? If you have I would like to find out more about what this was like for you.

Hi, my name is Anna Redding and I am a Trainee Clinical Psychologist at the University of Southampton. I am doing a study looking at how people feel about their discharge from hospital, so that it can help professionals understand what this is like and how people feel about it. With a better understanding, we hope we can reduce any distress people experienced.

If you would like to take part, you will need to meet me for an interview at your community mental health team base. The interview should last about 1 hour, but we can meet on two occasions if this is more convenient for you.

I understand that being discharged from hospital is a very personal experience, so want to let you know that any personal information will not be passed on to anyone. Any names or personal information will be changed so that you can not be identified in the written report of the study.

If you are interested in taking part, please speak to your care coordinator who will contact me. I will then contact you to arrange to meet so that we can discuss the study further and answer any questions or concerns you might have.

Thank you for your time, Anna Redding (Trainee Clinical Psychologist)

TAKING PART IN RESEARCH

What is the Lived Experience of being Discharged from Psychiatric Inpatient Wards? ***Rec No:10/H0501/57***

We are asking if you would like to join in a research project exploring people's experiences of being discharged from psychiatric inpatient wards. Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you.

Please consider this leaflet carefully. Talk to your family, friends, doctor or nurse if you want to.

What is the Lived Experience of being Discharged from Psychiatric Inpatient Wards?

Information for Participants.

Date : September 2010
Version : AR1

1. *What is the Lived Experience of being Discharged from Psychiatric Inpatient Wards?*

In this research we would like to find out more about people's experiences of being discharged from a psychiatric hospital stay. Research indicates that people's experiences of being an inpatient in a psychiatric hospital varies, with some people finding this a good experience and other people finding it very distressing. Research also shows that self-harm and suicide rates are high following discharge from psychiatric hospital. However, little is known about why this is. This study aims to find out about people's experience of discharge with the hope that with better understanding of what is beneficial (or not) and what makes it distressing we can learn to improve the experience.

2. What is the purpose of this study?

There is limited research looking at what being discharged from a psychiatric hospital is like for the individual. Everyone has different experiences of being discharged, so it would be helpful to professionals to understand how people feel about it. This study aims to gain a better understanding of what it is like to be discharged in the hope that we can increase our knowledge about what is helpful or unhelpful.

3. Why have I been chosen?

You have been asked to take part because you have been identified by your care coordinator as someone who has been a patient in a psychiatric hospital and therefore experienced being discharged. We will be asking approximately 10 people to take part in the study.

4. Who is organising the study?

This study has been organised by Anna Redding who is a Trainee Clinical Psychologist currently studying at Southampton University.

5. What will happen to me if I take part?

You will be provided with information about the study by your care coordinator and given a form to sign if you are interested. You will then be invited to meet with Anna Redding, a Trainee Clinical Psychologist at the University of Southampton who is involved in the project. You will be able to ask any questions you have or discuss concerns before you decide if you want to take part.

If you decide to take part, Anna Redding, Trainee Clinical Psychologist will ask you some questions by about your experiences of being discharged from hospital and what that was like for you. This will take place within the Community Mental Health Team site and will take approximately 1 hour. Your answers will be recorded to help Anna remember what you have said and to be used in the report. Your personal information will not be given to anyone. Any names or personal information will be changed so that you can not be identified in the written report of the study. The recording will be destroyed once the study has finished.

6. What are the possible risks of taking part?

Some people find discussing coping with difficult things in their life distressing. Anna will be very sensitive towards this and will contact your care co-ordinator if you feel that you require additional support. You may also request a break at any time, and if you wish to end the session at any point, nobody will mind.

7. What are the possible benefits of taking part?

Many people have valued the opportunity to talk about their experiences and so we hope you will too. Although you may not benefit directly from talking about your experiences, it is hoped that if we can understand better what this experience is like for people, we can help improve the process for other people.

8. What if something goes wrong?

It is highly unlikely that taking part in this study could harm you. However, there are no special compensation arrangements. If you are harmed due to someone’s negligence then you may have grounds for legal action. Regardless of this, if you have any grounds to complain about any aspect of the way you have been approached or treated during the course of this study, you can contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ, Telephone: 02380 593995.

9. Confidentiality – Who will know that I am taking part in this study?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you, will be anonymous (your name will be changed), so you cannot be recognised from it. Relevant sections of the research data may be looked at by The University of Southampton, from regulatory authorities, where it is relevant to my taking part in the research.

10. Ethical Approval

This study has been approved as ethical by the Isle of Wight, Portsmouth and South East Hampshire Research Ethics Committee.

11. What will happen to the results of this study?

The results of the study will be written-up into a report that will be available to staff at the University, your name will appear nowhere in the report and you will not be recognisable. If you want to receive a copy of the completed report, this can be arranged through Anna. If the report is published in an academic or practice based journal, as before, your name will appear nowhere in the text and you will not be recognisable.

12. For further information

Further information about this study can be obtained from Anna Redding, who will be carrying out the research. Anna can be contacted on email: *ar5g09@soton.ac.uk* or through your care coordinator.

13. Contact for further information.

If you wish to talk to an independent person about this study and its implications for you, you can contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ, Telephone: 02380 593995. Additionally your care coordinator would be happy to speak to you in more detail about the study.

Appendix E: Consent Form

Southern Health NHS
NHS Foundation Trust

UNIVERSITY OF Southampton
School of Psychology

Department of Clinical Psychology
34 Bassett Crescent East
Southampton
SO16 7PB
Tel: 02380 59 5320

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Experiences of Psychiatric Discharge, Rec No: 10/H0501/57

Name of Researcher: Anna Redding

Version: AR1

Please initial each box

1.	I confirm that I have read and understand the information sheet dated May 2010 (version AR1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected	
3.	I understand that data collected throughout this study may be looked at by members of Anna Redding's research team. I give permission for these individuals to have access to the data collected from this study, to store and to process it. I understand that relevant sections of data collected during the study may be looked at by individuals from The University of Southampton, regulatory authorities, where it is relevant to my taking part in this research. I give permission for these people to have access to the research data.	

4.	I agree that in order for me to participate in the study, members of Anna Redding's research team may have access to my contact details, which will be stored securely on an NHS, password-protected computer or locked in an NHS filing cabinet or in a locked cabinet at Southampton University.	
5.	I agree to my care-coordinator being informed of my participation in the study and to be contacted if the researcher is concerned about my emotional well-being after the interview. This will allow my care coordinator to offer me further support if necessary.	
6.	I give my consent for the interview to be audio-taped.	
7.	I understand that this tape will be destroyed once the study has finished.	
8.	I give my consent for the researcher to use the words I have said in the interview as an example of my experiences in the written report. I understand that any personal information will be changed to protect my identity.	
9.	I agree that data obtained from this research can be used, in anonymous form, for publication.	
10.	I would like a summary of the findings after the study ends.	

______________________ _________________ ______________________

Participant name Date Signature

______________________ _________________ ______________________

Researcher name Date Signature

Appendix F: Opt-in Sheet

Participant Opt In Record

I have been informed about the study exploring people's experiences of discharge from a psychiatric inpatient stay and would like to know more about this study.

Name………………………………………………………………………

Contact Details (email/ phone number)

…………………………………………………………………………………

……………………………………………………………………………………………………

…………………………………………………………………

Care Co-ordinator

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

………………………

Please note, completing this form does NOT in any way mean that you have to take part in the study, this form just allows the researcher, Anna Redding to contact you to give you more details about the study. You can decide you do not want to take part at any time.

Appendix G: Interview Schedule

Opening statement: Thanks for coming along today, as you know I'd like to speak to you today about your experiences of being discharged from hospital and what that was like for you. Firstly, I'd be really interested in hearing something about yourself and why you were interested in taking part today…….

- What do you understand by discharge?

- Tell me about your experiences of being discharged from hospital
    - Can you remember the day you left hospital?
    - where there are multiple admissions were there any differences or similarities between them?
    - Is there one that stands out for you?
    - Is there another that had a different impact?

- What was being discharged like for you?
    - What made it a good/bad *(use participants words)* experience?
    - How did you feel about being readmitted (if they were)

- What was your experience of preparing for discharge?
    - Can you tell me about anything that was helpful/not helpful?
    - Is there anything that the service/staff did or didn't do?

- What were the circumstances surrounding your discharge?
    - Can you remember when discharged was first mentioned?
        - Then what happened?
    - How did you feel being discharged to…?
        - Tell me about any pre or post discharge support you received.

- Is there anything that I have not asked about your experience that you feel is important?

- Id be interested in hearing about how this experience has been for you and how you found talking about your experiences with me today.

Appendix H: Summary of Main Points in Reflective Journal

The researcher kept a reflective journal throughout the research process. Some of the key areas covered by the journal are listed below.

The researcher had the following beliefs; that understanding discharge experiences was essential to help professionals fully empathise with service users and necessary to improve services. The researcher had the assumptions that; participants would provide meaningful accounts of their experiences and that several participants would describe difficult discharge experiences.

Reflection on a service user's disclosure of a negative experience of discharge during a teaching day and how this motivated the researcher to explore this issue further. Reflection on whether this was an isolated incident or whether other people had shared similar experience. This led to wanting to complete research in this area in order to attempt to highlight what people's experiences are and possibly highlight ways in which services could be improved.

Reflection on choosing supervisors and concerns regarding finding a qualitative supervisor. Reflections on the researcher's excitement at having supervisors who were equally passionate about the project.

Reflection on the difficulty of recruiting through community mental health teams.

- Wondering why people are so hard to contact. What other ways can I try to get people interested, or make it easier for them to find participants.
- Could I attend their meetings? Is there anyone who is interested that could help spread the word?
- Are there any charities I could recruit from? Might this add to the richness of the data as I will have a combination of NHS and non, but then this would increase the heterogeneity of the sample, which doesn't fit IPA.

Reflection on the feelings evoked by the interviews, in particular, those who described distressing discharge experiences and those who described what the researcher felt were challenging situations, but participants described feeling OK about it. Reflection on the images that the stories participants told conjured up for the researcher. Reflection on how these feeling re-emerged during the transcription of the interviews.

- Interview 1: I feel worried that I was repeating myself in the interview, was I getting to the 'real' experience, is the data rich enough?
- Interview 2: He wasn't very talkative, was there something else I could have done to help him open up?
- Interview 5: I felt as though I was more "in the room" with her. I can really imagine/visualise her putting the key in the door for the first time, how anxious and scary, how alone I would feel. Supermarkets being scary, reminds me of when I returned home from travelling; I'd spent the last four months with no real traffic in Asia, so huge supermarkets in London were daunting, so I can imagine what it might have been like for her.
- Interview 6:She seemed really anxious, she had her toes curled and wringing her hands. I feel a bit guilty putting her through that, yet she said how important it was to her to be able to do it.
- I'm noticing the difficulties between being an interviewer/researcher and separating this from being a clinician and the questions I might ask if it was a client. Also, difficulties with wanting to validate, but not wanting to lead them!

Reflection on the analysis and interpretation stages of the research and the desire to portray participants' experiences accurately. In addition, reflecting on using IPA methods for the first time and learning to use the methods. Reflection on the different levels of interpretation.

- Really feeling quite pressured to do a "good job" and feeling as though I don't know what I'm doing. Is what I'm doing right? Do these themes fits? Have I missed anything?
- Is my interpretation "deep" enough?
- I really want my research to be good quality. These people took the time to speak to me, it feels really important to do their experiences justice.

Reflection on what I have gained from the interviews and the process of completing a thesis. Reflection on the mixed emotion this has brought, for example a feeling of pressure to give the participants a voice and to do their stories justice as well as feeling privileged to have been trusted with their experience.

Appendix I: Credibility Checks

- *Sensitivity to context: knowledge of the empirical literature surrounding the topic under investigation*. The current study aimed to explore a gap in the literature. The relationship between participant and researcher was also considered, for example her status as a health professional may have resulted in participants associating the researcher with their treatment and impacted on their willingness to share their experiences. In addition, it might add to the power imbalance of the relationship. To this end, participant involvement was included in the design stages of the study.

- *Commitment and rigour*: Yardley (2000) argues that reliability may be inappropriate criteria against which to measure qualitative research if the purpose of the research is to offer just one of many possible interpretations. However, rigour refers to the completeness of data collection and analysis. IPA seeks to produce in-depth analyses not representative samples or generalisable results and therefore has smaller samples. In order to ensure completeness of analysis, IPA utilises several levels of analysis and repeated checking of the data.

- *Transparency and coherence*: Repeated checking also ensures themes and interpretations are transparent and grounded in the data (Smith, et al., 2009), evidenced by including adequate excerpts of text in the write up (Smith, 2011). The researcher’s supervisors were involved in verification checks of the data. Participants were provided with the opportunity to receive a summary of findings and to comment on them should they wish to in order to involve them in the analysis (DOH, 2005), provide ‘member checks’ (Russell & Gregory, 2003) and ‘testimonial validity’ (Stiles, 1999). This allowed the researcher to check whether the interpretation made sense to the participants. A paper trail of the progression of analysis has been verified by the researcher's supervisors to check transparency of the findings. However, this is different to inter-rater reliability in that qualitative research does not aim to provide the 'truth' or a definitive account, it merely provides one perspective, in this case that of the researcher (Smith, 2003).

- *Impact and importance*: the current study aims to explore an area that has as yet not been explored.

Appendix J: Summary of Results Letter to Participants

Address

Dear X,

I am writing to firstly say thank you for meeting with me last summer and sharing your experiences of being discharged from hospital with me. I feel very privileged to have been able to hear about your experience.

As part of my research, I interviewed seven other people who had also been discharged from a psychiatric hospital. I have now gathered all of the information from all of the interviews and am writing to provide you with a summary of the findings. As I was reading through the interviews I was struck by the similarities and differences between all of your experiences.

I was interested to know whether these findings make sense to you and if it reflects your experience. I have included a sheet for you to provide any feedback about the interview or the findings should you wish to (you do not have to do this if you do not want to). If you wish to do so, I would be really grateful if you could return any comments in the envelope provided to me by DATE. However, any time that is convenient would be valuable.

I would like to thank you again for taking part and taking the time to share some truly personal experiences with me. I very much appreciated the opportunity to listen to your story and hope to do that story justice within my research.

I wish you well for the future and your continued journey to recovery,

With warmest wishes

Anna Redding

Please write any comments about the interview or the summary of results and return in the envelope provided.

Appendix K: Summary of Findings

Eight people (5 female and 3 male) who had all experienced at least one discharge from a psychiatric inpatient stay took part in the research. Five main themes were concluded from those interviews:

(1) The hospital experience;
(2) experience of discharge;
(3) The outside world;
(4) The journey to health, and
(5) Sense of self/identity.

Your experiences of discharge revealed a timeline, beginning with your hospital admission, through to leaving hospital and your continued journey to recovery outside hospital.

The **first** theme that emerged was about your experiences of being in hospital. Some of you described hospital as a safe place to be, somewhere you could escape from the difficulties you were experiencing in your lives. On the other hand, being in hospital was quite frightening. It seems you quickly adapted to life in hospital and discussed becoming ‘institutionalised’, for example not having any responsibility and having everything done for you. Some of you seemed to feel as though you had little control over your care and that the treatment you received was dependent upon staff’s perceptions of the support you needed. You also recognised that staff numbers were often low and that communication between different professionals and the hospital and the community were not always as good as they could have been.

The **second** theme involved people’s experiences of being discharged. It appeared that you saw discharge as a process that did not just involve leaving hospital, but included the care you received afterwards. The word discharge for most of you meant that you were well enough to leave hospital but that you were not ‘cured’. There were many mixed emotions about being discharged, for example scared, happy, relieved and feeling alone. The actual moment of entering your homes again could be a daunting one.

You all had both similarities and differences within your experience of the support received when you were discharged. Some had a discharge plan put into place with gradually more community leave to help you adapt to being in the community, others were discharged without this. Some of you received intensive support to begin with that gradually declined as your health improved. Others had no support at all when they were discharged. It seems that for those who had more than one hospital admission, you experienced different levels of support each time you were discharged. Some of you mentioned that it was ‘luck’ as to what support you received. Sometimes you felt you had a say in what you needed, whereas other times it seemed you were discharged when the professionals felt you were ready, with you having little say in the decisions they made about your care.

The **third** theme was about your experiences of adapting to being outside hospital. Some of you referred to the community as the ‘big bad world’ or the ‘real world’. It seemed that hospital was viewed as being cut off from the rest of the world and so returning to the community was frightening for many of you. You spoke about having to adapt to real life again and learn to cope with everyday tasks. Returning to your old life and having your independence back was something that many of you desired, but found difficult at the same time.

The **fourth** theme that emerged from the interviews was about your journeys to recovery. It seems that recovery is something that takes time and hard work: change was particularly difficult. It seemed that most of you felt there was a ‘right time’ when you felt ready to make the changes necessary in your lives in order to get better and stay well. It seems that it is not as simple as being ‘ill’ or ‘well’ but that there are stages in between these, for example being well enough to leave hospital but still needing support. Many of you felt a mixture of hope and anxiety about the future and worried about your health deteriorating in the future. Despite being out of hospital, the journey to recovery seems to be a continuing one for many of you.

The **fifth** theme that emerged was about how you viewed yourselves and how you felt others treated you as someone with a mental health difficulty. You felt many people did not understand what it was like to have a mental illness and some of you experienced stigma because of it. The question of what is ‘normal’ was raised within interviews: you questioned whether you were ‘mad’. The sense of not being a normal person was discussed: some of you felt that medication left you feeling as though you were not a real person. Most of you at some time had felt you were not valued as a person, for example when your problems were trivialised, or when people did not return your calls. Having staff that treated you with compassion, respect and were reliable made you feel more valued as individuals rather than as a mental patient.

Despite recognising you needed support, many of you spoke about how difficult it was to ask for help or accept it if it was offered. You needed encouragement to ask for help or for staff to come to you first. The relationship with staff appeared to be important in your journeys. Staff that challenged you, but at the same time were caring and trustworthy was important. Building a relationship with someone was important as you learned to trust them and had someone who knew you. However, you recognised that this can take time and found it difficult when staff changed.

Although your experiences of being discharged from hospital are different and unique, they share striking similarities to others. It seems that a support plan that begins in hospital and continues into the community, with a skilled professional who cares is important. This needs to be tailored to your individual needs, which may change as your lives change. It seems that many of you believe there is hope for your future, but that the road to recovery can be a long and difficult one.

Appendix L: Extended Results

Additional excerpts from the transcripts and their interpretations have been included here to provide a more in-depth overview of the themes. Subheadings for each sub-theme have been used. However, subthemes for which there are no additional comments from the empirical paper are not repeated here.

1) The hospital experience.

1.1 Becoming institutionalised.

Participants described it not taking very long for them to feel institutionalised: “the longest I’ve been in hospital was about 4 weeks and I felt really really institutionalised after that” (Sally, 3, 6-7). Sally’s repetition of ‘really’ emphasises just how institutionalised she felt. Additionally it seems that there is some adjustment to hospital life. The researcher gained a sense that patients in hospital had little responsibility and participants’ described feeling “hospitalised:” “you know where everything is done for you, you’ve not got to think for yourself really” (Gwen, 8, 17-18). Gwen’s description indicates a loss of independence, that someone else is doing the thinking for her.

The meaning of what constituted ‘normal’ appeared to change for participants whereby hospital life became normal, which created difficulties. For example, feeling fearful; “it was horrible really in some ways you didn’t know how to cope when you went out” (Sally, 3, 9-10), and communicating with others; “because you’ve just forgotten how to act with other people and how to behave with other people and everything yeah” (Mina, 7, 1-2). It seems that Mina has lost what it means to be a social person. Her description here implies that she needs to relearn how to interact with others.

Gary’s repetition of the word ‘never’ helps emphasise the enormity of leaving hospital: “being out late at night say after half seven in the evening. I had never never been out at that time of the evening for the best part of 15 years” (4, 5-6).

1.2 Sense of being locked up.

The confined space meant that patients struggled to get any peace:

> it’s such an enclosed area, that the slightest, if your caught in, if two people are arguing you’re automatically involved in it because it’s a small unit, and over weeks if left to simmer, the whole atmosphere in the ward is affected you know? (Gary, 6, 30-34)

At times there was a sense of not having any control or freedom, for example it feels as though they are prisoners being allowed to leave: “and er, then (psychiatrist) let me have a week off to see how I got on and they give you a week off and they give you (?) time off” (13, 30-32).

1.3 Hospital as a break from the real world.

They no longer had people making “demands” (Sally, 2,30) on them and had staff to help them solve the problems in the “outside world” (Gill, 3,23) causing them stress such as bills, or the things they were struggling with on the own such as poor diet. Gary spoke about having to “face life” (4,1) when he was discharged. This gave a real sense of the hospital world being completely separate from life outside as though they were closed off from it.

1.4 Vicious circle.

Three women spoke about their experiences of multiple admissions to hospital. They expressed feeling confident or happy about leaving hospital but then being unable to cope with daily life once they were discharged:

> You come out full of erm, you know “I’m going to make every effort now to be normal, to get on and everything’s going to be fine”. Within days you find actually, nothing has changed and pressure build and build again and one time I was discharged I ended up back up in there within three weeks. (Sally, 3, 31-35).

Support appeared to be important in helping individual’s remain out of hospital “I think with me it was in and out of hospital until I had support from the X support outreach team” (Mina, 2, 12-13). Attempting to cope on their own proved challenging: “you go back to an empty flat, and the way you left it, everything is still being in the same place. It all starts the episode all over again” (Mina, 2, 24-26). Mina’s description of returning to her flat seems almost eerie, as though time has stood still while she was in hospital. Addressing underlying causes for a person’s difficulties were deemed crucial in helping people stay well and out of hospital. It seemed as though mental illness was perceived as something nasty, lurking in the background ready to strike:

> if you’re not dealing with the underlying causes of what’s making you so depressed then, you just, you never get rid of it, it’s always in the background and it will always come back and bite you on the bum when you least expect it. (Marie, 6, 4-8).

1.5 Hospital as a haven.

At the same time as finding hospital a negative experience, people also felt safe: “you’ve got a roof over your head, people around you that care and so, it’s such a comforting feeling that you’re being looked after” (Mina, 15, 4-6). Even sitting on a chair all day without a room provided more comfort than the prospect of the outside: “I was quite pleased that I had been there all day (laughs) even though I no longer had my room, I was just sat there on a chair I was still in a safe place” (Gill, 4, 7-9).

The staff and patients had a role to play in making hospital a more enjoyable experience:

> there was a group of patients there that I got on with, so that made a big difference, the people that were in there with ya and the staff as well, it was very good staff there at the X (Mark, 11, 24-26).

It was important for participants' to feel they had someone to talk to: "yeah, yeah they're always there and at the end of each shift they talk to you, what sort of day have you had you know and erm, so they, they were always there to talk to yes" (Gwen, 6, 3-5). On the other hand, time to themselves was also appreciated: "I suppose for me it felt like I had, peace I could be on my own" (Sally, 2,29).

1.6 Experience as negative.

All but one participant had negative experiences whilst in hospital. Initially, most participants expressed fear of being in hospital: "when you go into hospital first you, I was very frightened, very, very frightened of er the other patients" (Sally, 3,2-3).

Others reported feeling alone: "at X you were basically left to "get on with it" yourself" (Mark, 12, 5-6), as though they did not matter or that they did not belong: "the first few days in hospital I hated, I thought "god they're all lunatics in here" (laughs) (Gill, 3, 13-14). It seems that Gill was making comparisons to other patients, believing that she could not possibly be like them, perhaps indicating some preconceived views regarding patients and not wanting to be associated with them.

There were reported episodes of aggression from patients: "there's always other patients around you, and people with problems and stuff, you know and they get a bit aggressive and that" (Dan,13, 29-31). Gary, who was in hospital for many years questioned how he coped and almost seems surprised at his own resilience: “I don’t know, it’s just, I don’t know how I’ve done 18 years, I don’t know how I’ve done it” (14, 30-31).

1.7 The ‘system’.

Staff were reported to have to follow procedures, with treatment not feeling individualised: “guess all through hospital my experience has been that the staff erm, (pause) just follow textbook procedures, you know?” (Gary, 17, 19-20).

The discharge package that participants received was viewed to be dependent on staff perceptions: “it depends on how they perceive you, what’s available, what they think you need and everything” (Gill, 14, 31-33). Marie felt frustrated that often people who needed therapy did not get it due to lack of resources:

> I would just so love to talk, sit down with the doctor and say look, you would save money! If you put money into therapy you would save a fortune in the long run! (11, 27-30).

1.8 Challenges for staff.

Marie felt quite strongly that more therapy was needed: “but there aren’t enough therapists, there, those therapists don’t have enough time to take anyone else on” (3, 14-16). Lack of staffing led participants to feel: “they do their jobs properly but because they’re sort of limited on staff, they can’t spend that time with you. So there’s no one to talk to really about what’s going on in your head” (Mina, 3, 24-27).

Differences across disciplines, particularly psychology and psychiatry was mentioned by a few participants as being a problem, for example: “I suppose there’s two very different sort of disciplines and in a way they're at logger heads with each other you know? Erm, but it's not helpful for the patient. Work together I say (laughs)" (Sally, 26, 15-18) and: "so you're totally confused as a patient and you don't know who to listen to you know?" (Sally, 18, 4-5).

2) The Experience of Discharge.

2.1 Meaning of discharge.

Most participants viewed the word discharge to mean that they were well enough to go home: "I think that sort of indicates that you've got a lot better you know, mentally wise, they feel they need to discharge you then, you've got a lot better" (Dan, 2, 21-23). It raises the question of what 'well enough' or 'better' is and who decides when a person has achieved them? Others added that discharge meant being "safe" (from yourself, researcher insertion) (Sally, 1, 36) and "freedom" (Mina, 8, 10).

2.2 Emotions on discharge.

Sally experienced different emotions about her discharged, which changed from before leaving: "absolute joy going home, erm, thinking things are going to be different. You know, I'm going to make a huge effort, it's going to be all different from now on" (Sally, 9, 4-6). It could be interpreted that Sally believed it would all be OK that she was going to put in the effort and everything would be just fine. Almost as though she is convincing herself that all she has to do is try.

Mark struggled to explain what it was like for him: “I wouldn’t say it was none too pleasant but it was a bit er, I wouldn’t even say it was unnerving it just felt, I dunno it just felt a bit er it felt a bit odd really” (Mark, 3, 28-30).

Marie was informed by the doctors that her safety following an incident where she was threatened and assaulted by another patient on the ward, could not be guaranteed. She described ‘having’ to go home:

> I was faced with the prospect of having to go home, having these bad thoughts and feelings, and knowing that somehow I had to pull myself through it because no one else was going to be able to, you know watch me 24/7. Yeah, it was terrifying. (Marie, 5, 18-22).

Marie’s words about having to rely on herself and “pull myself through” gives the reader a sense of the struggle and enormity of this task.

The word discharge often led participants to experience negative thoughts and feelings: “I was panicking and thinking “I don’t want to go I’m not ready! I don’t wanna go, I don’t wanna go!” because it was, it was safe!” (Gill, 16, 20-22). Gill’s repetition here appears almost childlike in her desire to stay somewhere safe and not have to leave. Interestingly, this was what she described thinking, but did not say anything to the staff. Some reactions arose from misunderstandings about discharge: “(I thought), “Oh god you’re going to send me home tomorrow,” you know, cos discharge means going home so you just assume, right, “you’re alright you can go now” (Gill, 19, 9-11).

2.4 Discharge as impersonal.

Some of the participants spoke about discharge as something that was ‘done to them’, where they were told about decisions rather than included in discussions. At times it seemed as though they were not valued enough to be included and the whole process felt quite impersonal: “(I was) making enough progress to have them make plans for me” (Gary, 6, 7). This gives the impression that patients are not always consulted about their care and seems a manualised system such that, once you have made the right amount of progress, plans are made on your behalf regarding what happens next. It seemed that participants at times felt they had no choice or say in their discharge: “I don’t think I felt I was ready for discharge but er, I went along with it then put it that way. Cos I knew it was going to happen you know” (Gwen, 14, 18-19).

2.5 Discharge as collaborative.

Having experienced being discharged before he felt he was ready, Mark felt the doctor was “doing his job properly” (11, 1-2) when “I was actually asked that time if I felt ready for discharge and at the time I was asked I didn’t and they were absolutely fine about that” (10, 20-22). It appeared that having some control over and being included in the decisions around their discharge was important.

Involving family and partners in the discharge process was viewed by Sally as something that would have been beneficial:

> I think, maybe there should be a discussion with the family as well before you’re discharged. To help you know? To make them maybe aware that you know, you, this person may face a bit of difficulty adapting to the home again when they come out (20, 3-6).

However, Sally also acknowledged that this was something she probably would not have wanted at the time, but on reflection, she felt it would have been beneficial for both her and her family.

2.6 Support on discharge.

Participants spoke about having to adjust to different levels of support from leaving hospital where they had a lot of support to having less when they returned to the community. It appeared that this could happen quite quickly: "Cos there you are, you've been in hospital and then the next minute you're discharged (pause) you're just going out to, going out to nothing basically" (Mark, 3,30-32). They felt unprepared without any support "because there's no preparation. And there's no one, there's nothing" (Mina, 16, 4-5).

It was noted that their experiences might also be different to other patients:

> her experience was the complete opposite of mine and I mean the complete opposite. And she had a break down again and has, it wasn't until after that that she got some more help, so now she's doing better but she never had the support I had after discharge and I, I think if she had had what I had, she wouldn't have had that second break down. (Gill, 14, 22-27).

One participant felt that the regulations for the amount of support were too strict:

> the system with home treatment team is, it seems to be very strict. They only see certain people at certain times….Like they can see you on discharge but for a certain amount of time and then they go. (Marie, 16, 26-27, 31-32).

It seemed that patients have to fit the system in order to get help. In addition, a few participants talked about support not being in place following their discharge, ranging from a few days to waiting a whole week for their first visit, or having to travel: “it wasn’t too, it wasn’t too good actually, cos as I say I was living over at, still over at XX at the time. And by that stage I had no care coordinator” (Mark, 5, 3-6).

The type of support was raised as an important issue. Some felt that it was enough to know someone was there, others felt that matching coordinators to patients would be helpful:

> maybe matching people, I suppose those resources aren’t there, but you know, like I had a care coordinator that didn’t know anything about DBT, would be useful that I was matched up with someone that was DBT trained and that would then remind me. I mean that’s what the visits should then be about. (Sally, 27, 19-24).

Sally appears to be talking about care being more personalised to the individual and tailored to their needs.

2.7 Discharge as a process

Mina described how her DP began whilst she was in hospital: “they were very good they said what I needed to do was come out of intensive, go back to acute ward and then get discharged” (13, 10-12). For some, the discharge process involved a gradual progression towards leaving hospital: “I had worked up to the stage where I was out most days, I had er, I can’t remember what it was called, community leave I believe, and erm, I used to go into the local town” (Gary, 7, 17-19).

On some occasions support was more intensive during the first few weeks and gradually reduced as they adapted to life in the community. For example:

> I was having somebody visit a day to start with, then it becomes every other day then it becomes phone calls and its sort of, you’re working at your own pace sort of, so it’s

> a combination of visits every day and every other day, once a week, phone calls in between times. (Gill, 24, 10-14).

However, in other circumstances, the support stopped suddenly:

> What they did was came around every single day for two weeks and that was it then. But it would have been better I think if they eased me off a bit gradually. If they skipped a day and then went to 3 days or something like that cos again you're going from them every day down to nothing. (Sally, 14, 31-35).

It seemed that there was no real consistency to what support people received once they were discharged. Some received support that was gradually tapered whilst for others, it was stopped suddenly, which participants found difficult.

3) The Outside World.

3.1 Adapting to life outside.

Participants struggled to adapt to life outside. Marie worried about her safety: "around your home, there are so many things that you could seriously hurt yourself with (laughs) and, and then obviously when you're discharged you have to accept that you're surrounded by those things" (14, 3-6). Gary felt anxious about new situations, particularly things he had not had to do for years: "I've still got anxiety issues erm, new situations that I have to deal with like being out late at night, half seven/eight, and especially when it gets quite dark" (9, 27-29). Daily tasks were now a challenge:

> I think it was just the space, cos I hadn't, for three months I'd erm (pause) 3 months I hadn't had to go anywhere. I hadn't had to do any shopping, or erm unless I chose to go into (town). (Gill, 15, 12-15).

Attempting to build a routine again after having everything done for them when in hospital was difficult:

> I mean I'm still struggling to build a routine in my life now. I've tried several jobs but I haven't been able to cope with them. And the SOT team thinks it's going to be about 6 months before I can get back into work again. (Mina, 8, 32-35).

It seemed that for some, just being outside the hospital was difficult: "so it could have just been everything really when I first came out it was quite stressful just being out was quite stressful" (Gwen, 9, 14-16). Hospital admission could lead to a loss in confidence in interacting with society, for example Mina felt that she questioned how to interact with others: "it just feels as though you gotta watch whatever you're saying and doing you know. Yeah yeah, and ah yeah, it's difficult, it's very difficult" (7, 10-11).

These excerpts give the sense that home for many of us is a safe, comforting place and going about our daily lives is something we take for granted. However, for patients leaving hospital, these things can be daunting, challenging and something they have to actively think about. It highlights how difficult the transition from living in a small, confined space to the community is.

3.2 The real world is scary.

Daily activities that they had never given a thought to before their admission were now a cause for anxiety: "for the first, short peri, the first week or so all I did was Tesco express type shopping, the thought of having to go round a big supermarket (laughs), it was ooh a bit scary" (Gill, 6, 14-16).

Many people referred to the community as the 'real world' as though it was something totally separate from the hospital world. This 'real world' was now a scary place at times. Most participants had reported feeling safe in hospital and for some, their home became their new sanctuary:

> So some days I can't wait to get back to the flat to get back inside its actually safe in there, I think its security feeling to close the door and think I haven't got to go out again today now. I've done my bit for the day kind of thing. (Gwen, 10, 14-17).

Participants spoke about how frightening the community could be: "in a small way, small drop of water in a big sea sort of thing" (Gary, 20, 33). This imagery may be interpreted as Gary feeling quite overwhelmed and lost. The sea is a vast place that is hugely powerful and can be turbulent, which may be how Gary was feeling about being in the community.

The thought that they were now responsible for themselves, their daily activities and their own safety was also a concern:

> I was, at one point I was frightened to go round the shops because I thought, If a lorry comes I could just step in front of it, whoompf I'd be gone, you go out the kitchen there are knives in the draw, you think I could do, I could hurt myself (laughs) whereas you, you go in hospital obviously you don't worry about those things. (Marie, 13, 30-34).

In addition, it seemed that the unpredictable nature of life caused people to feel anxiety: "it makes you feel a bit vulnerable, cos you wonder what's going to happen then when you get out" (Mark, 8, 26-27). They became used to living in a world where everything was “regimented” and then were exposed to the “big bad world” that did not have those boundaries. The fear of the unknown was a very realistic notion:

> What’s going to happen when I go out there. Nothing’s going to happen I know, but it’s the way that I feel. If I go on a bus with somebody I know come up and talk to me or I don’t want them to talk to me kind of thing. How would I react to that you know? (Gwen, 11, 17-23).

3.3 Return to old life.

Half of the participants referred to their lives before their admission to hospital and expressed a wish for their lives to return to how they had been. Others did not share this view and it seems life did not return to ‘normal’: “when I was being discharged and erm, in many ways looking back, I suppose I thought life should go back to normal” (Sally, 2, 42-45). The notion of what was ‘normal’ was something that Gwen appeared to feel was expected: “that’s sort of things you have to do isn’t it to get back to normal really, normal living that’s part of a normal life isn’t it to go shopping?” (8, 34-36).

3.4 Process of adapting as gradual.

Adjusting to life outside hospital emerged as a gradual process. It seems it is not as easy as being discharged and life returns to normal as noted in the previous theme. For some, adapting has been a long process:

> gradually doing it, gradually doing a little bit more now. Even though I’d like to be doing more they said it takes time so I’ve just gotta erm, gotta, take things days by day really. You know take every day as it comes. (Gwen, 9, 19-22).

3.5 Coping with life outside.

Given the difficulties with being discharged from hospital and returning the "big bad world," it was not surprising that how people coped emerged as a typical theme. Participants spoke of various ways of coping with life, from drinking, using medication, avoidance and having to learn new skills in order to cope more effectively. Participants spoke of not having the skills to cope effectively with life:

> And I just didn't, I didn't know how to cope, I really didn't. And of course I was ruminating on what I had done…... It was awful, and I decided then of course with all too much time sitting down thinking, decided to kill myself again. (Sally, 8, 22-26).

Learning different skills to cope appeared to be important in helping people stay well:

> I mean I've the same family, same job, same pressures, but it's getting up in the morning and knowing no matter what life throws at you that you can cope. That's to me, joy, you know, knowing that *I'm* in control of my own life and, you know I can handle it. (Sally, 13, 3-7).

Gwen also found relief in avoiding facing tasks she found difficult: "sounds silly you know but er, if I give in to it and say that I won't go out today then I sort of (takes a deep breath and sighs) 'oh thank goodness for that!'" (18, 16-18), but acknowledged that if she kept putting it off, she would not get "better" (18, 24).

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> me, joy, you know, knowing that *I'm* in control of my own life and, you know I can handle it. (Sally, 13, 3-7).

> I've had a panic attack I do my breathing exercises like what they taught me to do you know and try and sort it out, try and de-stress myself really. I'm always doing my exercises and I manage to de stress myself. (Gwen, 8, 29-31).

Routine and keeping busy were noted as strategies to help rumination on the past: "If I'm busy, I don't have to sit and think" (Gill, 25, 31). However, Gary highlighted: "then again you know, there is always something you know, you have to deal with that may be a bit unpleasant" (10, 24-25).

3.6 Feelings.

Participants described many emotions at different stages of their experience of discharge. These appeared to be different both across participants and within their daily lives. In particular, was the sense of feeling alone that participants felt particularly when they were first discharged from hospital:

> you know it's like 4 o'clock in the morning and all your family's asleep, you're on your own, your depressed, you may be suicidal, you're thinking, my first thought is I could do something now and no one could stop me. (Marie, 7, 31-34).

This extract gives a real sense of what it might be like to be Marie in this situation. In addition to an overwhelming feeling of being alone, it also gives a sense of control and power, whereby Marie could harm herself and no one could intervene.

Gwen suffered from anxiety on a daily basis: "I can feel myself getting anxious as soon as I wake up in the morning and sort of then your heart pounds and start to feel sick and you get, I get a bit panicky, think ‘what’s going to happen today’ you know ‘where have I got to go today?’” (17, 15-18).

3.7 Regaining independence.

Seven of the participants spoke about wanting to regain their independence. This seemed to have different meanings for participants. Dan felt a sense of independence in his own home: “I think I had a couple of pints of beer in my living room, you know cans, and er I just watched er my soaps and that” (5, 13-15), enjoying doing things he had been unable to do whilst in hospital. Independence often involved everyday activities that many people take for granted: “go into the local community, you got on a local bus and looking round the shops having a meal in one of the pubs, I could have a drink if I wanted to” (Gary, 7, 28-30).

For Sally, independence appeared to mean not being “dependent” on others: “and that’s what I want (independence), I feel totally self-sufficient now” (25, 27). Sally had worried that although she needed support both in hospital and when she was discharged, she was beginning to rely on it:

> at the same time there was a niggle in the back of my mind that I was becoming totally dependent on these services. And I don’t know, I had something in my head that erm, I needed to be totally independent. (11, 26-29).

Independence caused anxiety for some participants: “I wasn’t going out much then. My daughter was taking me shopping, but now I do go shopping now, even though I dread it” (Gwen, 8, 32-34). Gill’s use of metaphor aptly describes her feelings about regaining independence: “by the time she discharged me I was more than ready I think to go and spread my wings on my own” (12, 9-10). It gives a real sense of freedom and feeling light.

4) The Journey to Health.

4.1 Health on a continuum.

Half of the participants spoke about the difference between being ‘ill’, being well enough to leave hospital and being ‘better’. Many believed discharge did not mean they were ‘better’: “it’s like you’re not well (laughs) you’re really not well! You’re just possibly well enough not to have to be in there!” (Marie, 5, 34-35). It seems from Marie’s comment here, that the thought that you are ‘well’ when leaving hospital is a comical notion, perhaps because for some, it is just not that simple.

4.2 Role of medication.

Three participants felt that medication had a role to play in their journey to recovery, albeit not always a good one. For others, medication enabled them to live their lives with fewer symptoms:

> The medication is one area that is another safety net, for many years I was on several different types of depo injection, which erm didn’t help at all. Again I was anti-psychotics like amisulpride, Olazapine, but the one I’ve been on currently for about 4-5 years now is Clozaril and it’s a miracle what it’s done in my life……(Gary, 9, 17-21).

Although it appears that it can take several attempts to get it right.

4.3 Recovery as fragile.

The recovery to well-being could be a struggle and one where their health was seen as something that could easily deteriorate again: “it made me think that erm, it made me think that erm (pause) that it er, it just felt as though all the work that everyone had done including myself to stay well would just go away" (Mina, 8, 28-30).

4.4 There is no magic wand!

Literature about physical illnesses often talks about people's battle to overcome it, for example cancer. It seemed that some people with mental illness view their journey to recovery in a similar way. Participants acknowledged that there was no quick route to recovery, that there was no quick solution. Sally discussed her hopes that there was: "I thought this (DBT) was going to solve all my problems. *This* was going to be the magic wand (laughs)" (Sally, 4, 16017). However, it seemed that they then realised that they had to take responsibility for their own recovery: "I've got to help myself, it's gotta come from me you know, they can't make me better I don't think, it's gotta come from me" (Gwen, 20, 37-38).

4.5 Recovery as a journey.

Recovery emerged as not only something to battle to obtain, but something that was hard work and took time: "it is hard trying to get them to understand that it's not like erm, flicking a switch and you're better you know, it's an on-going process that takes an awfully long time" (Marie, 15, 5-7). It emerged as a journey to go through in order to get to the other side: "if they (other patients) had been in hospital and gone through what I've gone through and had come out the other end" (Sally, 17-, 31-32).

Participants questioned their journey: "Oh I've come through a journey, why I've been through this journey I don't know. Where it's leading me, I don't know, one thing I do know was where I've come from" (Gary, 3, 6-7). This seems to suggest that Gary feels he does not have control over his future, that his path in life is uncertain.

4.6 Readiness to change.

It seemed that participants made the decision to begin to do something different: “I had to make a conscious decision that I have three children that I obviously love very much and I, I couldn’t do it for me but I did it for them” (Marie, 5, 36-38). Participants at some point realised that they were the ones that had to take responsibility for their recovery: “you’re the only one, that can really say when you’re ready to be managed by yourself as it were (laughs)” (Gill, 12, 31-32) and spoke of a desire to want to get better. For others, it seemed to happen more naturally: “yeah it’s just something that naturally happens, yeah, over a period of time” (Mark, 12, 23-24), rather than making a conscious decision to do something.

4.7 Change as a challenge.

However, change was difficult: “you know you’ve gone forty something years of thinking in a certain way and handling things in a certain way and suddenly being asked to do things differently. Very, very difficult” (Sally, 4, 9-11). Marie’s repetition of words and exclamations highlight just how difficult it was: “Oh jeez, oh many, many times I’ve wanted to give up and go the other way but, I’m so glad I didn’t” (Marie, 14, 32-33). The notion of ‘going the other way’ perhaps signifies a path, where there are other options and roads to take. It seems that each new experience along their journey, brought with it new challenges that were difficult: “I learnt from it, but with that came, when I moved on, came along a load of other new issues along with that” (Gary, 2, 29-30).

One interpretation of change being such a challenge and having to take responsibility for this yourself might be that for some, it is too difficult or they are not at the right time, therefore choose not to take up the fight:

> every person I know who has got a lot better has made a conscious decision I am gonna fight this I am gonna do everything I can to get over this, but, I don't know I, I, I don't know what goes on with other people but I'm guessing some…..people either just don't have the strength or, they've been through too much I don't know. (Marie, 11, 1-2….14, 6-9).

4.8 Feelings about the future.

In addition to worrying about their future when they were discharged from hospital, participants spoke about their views of the future. Many had hopes for their future, mixed with feelings of apprehension and uncertainty: "but that doesn't happen yet (waking up feeling good) but hopefully it will. So I've just got to take each day as it comes as I say really" (Gwen, 17, 34-35). The importance of looking forward was highlighted: "you have to (pause) not dwell on what you might have done in the past but try to look to the future and think, no, I'm not going to be that person anymore" (Marie, 14, 7-9). It seems here that the road to recovery involves becoming a different person, one that is well, rather than the person they used to be who was unwell and needed support.

5) Self-Beliefs /Identity.

5.1 Understanding/attitudes to mental illness.

Over half of the participants spoke about how mental illness is viewed and understood by others. The notion of normality was something that emerged frequently in the transcripts. Family often expected them to return from hospital and be 'better,' failing to understand the nature of mental illness:

> You can see if someone breaks their leg can't you, but if there's something wrong with your mind then erm, you, you know you've, nobody can see it really, every things that you were nobody thinks until they start talking to me and they realise I'm not the way I used to be. (Gwen, 10, 31-35).

On the other hand, Gary reported that some symptoms of mental illness are more obvious and can lead to individual's being vulnerable to harm:

> If someone in the community sees someone in the street laughing on their own that's just one example, another example might be, erm, shuffling along and erm all these tell-tale signs, physical signs erm, makes people want to take advantage of people like that or to take a stand against them cos they think you know erm, erm probably not worth living you know. (19, 17-23).

Many felt that mental illness could not be fully appreciated by others unless they had experienced what it was like themselves: "I don't think no one can really understand mental illness unless they've felt it themselves… it is hard trying to get them to understand that it's not like erm, flicking a switch and you're better" (Marie, 15, 1-3, 5-6). Marie seems to stress that mental illness is not simple and instant like 'flicking a switch,' indicating that it takes longer and is more complex. She discusses having to 'feel' mental illness before fully empathising with it.

Other people's lack of understanding has often been cited as one of the reasons for stigma around mental illness. Participants spoke about being judged, labelled and being on the receiving end of stigma due to having a mental illness. The media also has a role to play in the portrayal of mental illness:

> well occasionally you get in the news, you get schizophrenic stabs someone, schizophrenic you know erm, they erm don't do themselves any favours, erm I guess society sees it as you know, oh here we are another case, so we should lock these people up forever. I guess I was on the receiving end of that when I was in all the hospitals. (Gary, 18, 26-31).

Stigma about mental illness can also occur within families and within certain cultures: "and it's a stigma in the Indian community. And that if your, if you've got a mental illness you should be locked up in a strait jacket and the key thrown away in a padded room" (Mina, 18, 28-31).

5.2 Sense of self with mental illness.

One theme that seemed to occur frequently was a sense that participants felt a loss of self during their admission and discharge experience. Some were treated as someone with a mental illness: "but my parents will always bring it up, in an argument like 'Oh you don't know what you're talking about'" (Mina, 19, 39-40).

British people are typically viewed as people who get on with life and who do not really talk about feelings. Therefore it might be interpreted that anyone who does not fit this, is not 'normal'. Gill seems to imply this in her view of how she sees herself:

> Always felt I've had to cope, had to be seen to be coping I don't think, because that's what you do, so to actually admit that you weren't coping, it's not, cos you know asking for help changing a light bulb, asking for help to have the hedge cut or things like that is different because they are concrete things that they're not difficult in admitting that you can't do. (20, 22-27).

Participants at times were made to feel that ‘others can cope’ and therefore if they were struggling, then there was something wrong with them: “but at no other time was I ever made to feel like a hysterical female, a neurotic female, a waste of space” (Gill, 22, 14-15). This perhaps confirmed to Gill that there was something inherently wrong with her if she couldn’t cope: if others could cope with her situation, by default she must be a neurotic, hysterical female.

Sally explained that her doctor assumed all her symptoms were due to depression rather than how she was as a person:

> I get up at 5 o’clock, I’m a morning person, that’s the way I’ve been since I’ve been a small child. He (Doctor) tells me it’s a sign of depression, early morning waking. I say No! If I sleep late, I would say it’s far more likely I’m depressed. (18, 18-21).

5.3 Feeling valued.

From participants’ accounts, there were times where it seemed they were not valued as people. Several participants had an experience where they struggled to get support: “she (1st care coordinator) never, answered I did try to ring her, she never, she wouldn’t be there, she’d never get back with my calls” (Sally, 5, 14-15). They felt as though people did not care about them, that they were not important: “you were just basically left to get on with it yourself” (Dan, 12, 5-6). The response from staff was often unhelpful and devaluing:

> The X (CMHT) and my GP and psychiatrist and the police, they were all to listen to my mum and dads listen to what they had to say, because I was supposed to be the

> mental person in it all. And whatever I said didn't make any sense or probably wasn't, didn't carry its weight in what it was worth. (Mina, 10, 26-30).

Insensitive phrases could be misinterpreted, but left participant's feeling as though they were not worthy of support:

> on one occasion in hospital I was made to feel that my problems were quite trivial and for goodness sake snap out of it and that was a psychiatrist. He said to me "everybody gets made redundant, everybody has, gets divorced, everybody has to sell their home, everybody loses their job" and I don't think for one moment he meant it in the way I took it. (Gill, 21-22, 40-5).

In addition, Marie felt that due to lack of resources people did not get the care they needed: "so many women who would, who are living half their life in hospital and they, they're like the, the forgotten ones to me erm, and it, yeah it does it makes me angry" (Marie, 3, 28-30).

These excerpts give a sense that people with mental illness should 'pull themselves together' because their care is expensive, everyone has problems and so they should be able to cope. For them, it felt as though they were not important, their problems were trivial and they were a drain on resources.

5.4 Being different.

Participants discussed feeling as though they did not belong in society. At times they felt as though they did not belong in hospital, but equally, going home felt strange: "so it was like, walking into a strange house and having to ask permission if we could make a cup of tea" (Gill, 17, 28-29).

There was a sense of camaraderie among patients and sense of hope gained from others who were progressing: "it's a sense of belonging you know? You get a sense of, if they can do it I can do it (laughs)" (Gary, 9, 1-2). However, the community was a different story: "but mainstream society is er, still got a long way to go before they make people feel safe and you know that they're not in any harm" (18, 6-13). Gary remained wary of the community and disclosing his mental health history for fear of the consequences of this: "I don't think I can hide it but you know I'm not going to blow a trumpet you know and say I've done this and I've done that, they don't accept me" (Gary, 22, 22-25).

5.5 Asking for/accepting help as difficult.

Although participants acknowledged that they needed support from staff, it seemed the support had to come to them first. Over half of the participants spoke about a difficulty in both asking for and accepting help: "that's the difference, is you know seeing the help there and taking it and sort of er, erm, accepting it you know" (Gary, 16, 25-27).

Admitting that she needed help was difficult for Gill as she believed that she should be able to cope. Trying to verbalise her difficulties was a struggle:

> To actually admit that I wasn't coping emotionally, was quite hard, was very hard for me and to actually say to anybody, that I, it was too difficult to put into words. I think that was half the trouble because it just seemed so silly to phone up out of the blue and say "I'm not feeling very well today", it I think because emotions are so (pause)

> vague and er, they're tangible things really but to actually phone up and be able to articulate how you're feeling is quite difficult. And I used to think that, they would think I was, or they would dismiss it as a load of rubbish type thing. (21, 16-21).

Even when provided with service telephone numbers, participants found it difficult: "I could ring her anytime, with, you know, if I needed support, up until 9 o'clock at night, but I wouldn't ring you see……. but er, I saw that as a sign of weakness, not coping" (Sally, 5, 7-9 & 12-13). Participants felt they were being a "burden" by calling for help or that they were not "ill enough" to warrant help.

One interpretation might be that participants felt they did not deserve help and therefore waited until they needed admission to hospital. Another view might be that they did not want to be seen as unable to cope; perhaps this is seen as a sign of weakness. Additionally, it seems as though participants might have felt embarrassed at needing help.

5.6 Staff genuineness.

As well as having staff to support them through their discharge, it seemed that the qualities of the staff were significant. Often it emerged that there was one significant staff member who made a huge impact on their lives and recovery.

These staff provided hope when the participant had none. For example, Marie spoke of a time she was suicidal and felt there was no light at the end of the tunnel:

> She (psychologist), she grabbed hold of my hand and she said look, she said I'll hold the light, just follow me and, it, was, she, she basically said to me that if I worked hard, in the therapy that I would get out the other side. (11, 12-15).

They were treated with respect and as though they mattered:

> I was always talked to as if they were genuine concerns that I had and I, that also was a very big help because if you can, it's easier to ask for help if you're not being made to feel as if you're wasting someone's time if you ask for it. (Gill, 16-19).

It was important for participants' experiences to be normalised and that professionals also have to practice skills and cope with life:

> They tell you actually life is difficult. We, you know it's not one big party and how they handle their emotions, you find actually, you know I'm not totally mad, there is hope that I can change and erm, you know it convinced me to start practising these skills. (Sally, 7, 8-11).

5.7 Building relationships as important.

In addition to the skills and qualities of the staff, it emerged that building a relationship with someone was important. Having someone familiar to talk to, someone they could trust was important, it made it "easier" (Mark, 3, 10) when he was discharged to work with the same people. Gill described changing staff as having to say "goodbye", likening it almost like a bereavement of sorts:

> Being introduced to (discharge coordinator) and then I had to say goodbye to (DC) and be introduced to somebody else. And each time it was, it got, each time it got more difficult really I was losing my circle of support. (10, 31-34).

Sally spoke of her trust for her therapist who she had been seeing weekly for a long time, which allowed her to discuss her fears in a safe environment. In a different vein, Dan had not spoken to his parents for over three years and seemed a bit ambivalent about starting up a relationship with them: “it’s nice to know they love you and that, so, that they care about me… er, it, it wasn’t that nice, no, it wasn’t that bad but it wasn’t that nice either” (16, 4-8 & 10-11).

5.8 Support as a privilege.

Participants spoke of being “fortunate” and “lucky” when they received services or therapy, or staff that they got along with. It seemed this was not always the norm and they felt blessed that they had received treatment. The length of time people had input for was not consistent: “I was extremely fortunate in that, my support seemed to go on for a lot, until I was ready. I don’t know whether that was the norm or whether I just happened to strike lucky” (Gill, 12, 15-17). Participants felt that it was often an arbitrary process as to whether they received support or not: “from my experience when you are discharged, it was a complete lottery whether you got home treatment or not, it’s not like a definite you will get it” (Marie, 2, 34-36). Sally felt it was due to luck whether you had a good experience with your coordinator: “in some ways I think it all depends on who you meet” (26, 5-6).

5.9 Importance of support.

The very thought that there was someone there if they needed help, or knowing that someone was coming to visit them often acted like a “safety net” for participants. They felt a sense of relief knowing they were not alone:

> You know that if things aren’t right, you know that you do feel vulnerable, or you feel as though you are going to wobble a bit you know that what you can do is you can just get in touch with the team you can access the services, (pause) so you know that there’s somebody there. (Mark, 15, 2-6).

Mark’s uses of the words “stumble” and “wobble”, give a sense of the vulnerability of their mental health. It gives the impression of a fine balance where people could easily fall of the tight rope. The extra support appears vital in keeping people going: “that extra bit of help, to keep us going in life you know” (Gary, 20, 6).

Knowing someone is there seems just as important as actually seeing someone:

> I have some sleep overs so that’s nice, erm cos she (daughter) doesn’t live that far away you know so she’s always there; I know she’s always round the corner. If I want to go and see her she’s always there. (Gwen, 7, 15-18).

5.10 Support needed.

Participants spoke about the support they felt they needed or would have been beneficial for them. Whilst acknowledging restraints on resources, the general consensus was for discharge support to be more consistent and for there to be a number that people can call anytime they need support rather than having an expiry date.

Linking staff in the community with the hospitals was something that was deemed beneficial. Many participants had never met their care coordinator in the community before they were discharged:

> I'd that, possibly having somebody who you got to know *in* hospital, obviously not once of the staff, the ward staff because that wouldn't be practical but if you could get to know somebody while you were in hospital who could carry that support on after you were discharged you've got a bridge. (Gill, 14-15, 38-2).

In addition, having the opportunity to discuss their difficulties and experiences with people who had been through similar and come out the other side was needed:

> Some sort of peer support or something, that would have been very, very useful. Cos I would listen to them and I would have believed them. Because if they had been in hospital and been through what I had gone through and had come out the other end, it would prove to me it did work. (Sally, 17, 29-33).

5.11 Self and others.

Participants expressed a sense of responsibility towards others and concern regarding the impact their mental health difficulties were having on them. Having finally been convinced to call her therapist when she needed support, Sally spoke of the worry she felt about the impact on the therapist's life: "and I phoned her and when I look back I, god what her family must have thought! I phoned her on *Easter Saturday* and she spent about an hour on the telephone to me" (16, 29-31).

The impact to family members was a source of guilt and concern:

> No I just, poor husbands self-employed he couldn't work for two weeks, he's you know with me constantly which then of course makes me feel even worse cos I've got

> the guilt of him not being able to work and having to look after me, (big sigh) Oh. (Marie, 17-18, 36-3).

Marie seems to describe a vicious circle where she needs support but then feels guilt about it, which further lowers her mood. The big sigh and 'oh' at the end of her comments signify the enormity of this feeling for her, it seems a heavy weight.

However at times, considering the impact on their family was what kept them alive and spurred them to get well:

> What the grandchildren would say, what would my daughters say, I can't do that to them I know it's not fair for me to be thinking that way cos they're all trying to help me and I'm the only one who's not helping me really. (Gwen, 20, 32-35).