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**Recovery, Empowerment and Rehabilitation: Do inpatient
psychiatric rehabilitation services empower the individual?**

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Overview

This thesis is presented in three parts. Part one reviews the literature concerning recovery from serious mental illness and empowerment, considers to what extent empowerment is an important component of recovery, and whether these ideas are relevant to current mental health services. Part two presents the qualitative empirical study which explores the extent to which individuals diagnosed with a serious mental illness experience inpatient rehabilitation units as empowering, and considers what factors may facilitate or hinder this. The main findings are presented and the clinical and service implications considered. Part three is a critical appraisal of the empirical study presented in part two, and reflects on issues that were raised throughout the research process.

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PART ONE: LITERATURE REVIEW

**Recovery from Serious Mental Illness: To what extent
is empowerment an important component?**

Abstract

Perceptions of the course and outcome from serious mental illness have changed over the last century and, more recently, the concept of recovery has gained prominence in this field. This paper reviews recent literature on recovery from serious mental illness and discusses both the meaning of the concept and the key contributing factors. Research suggests that empowerment is one of the most salient factors contributing to recovery and the relationship between recovery and empowerment is examined. Most research in the area of empowerment has, to date, focused on community settings and this paper considers the relevance of these ideas in other mental health settings. The relationship between empowerment, recovery and mental health services is discussed. Finally, conclusions are drawn and recommendations for further research are outlined.

1. Introduction

The term serious and enduring mental illness is a descriptive, not a specific nosological classification. In clinical practice it most commonly refers to individuals with a diagnosis of schizophrenia or bipolar disorder (Repper & Brooker, 2003), and of these, the majority of people who require on-going health care have a diagnosis of schizophrenia. Understanding and care of people with serious mental illness¹, in particular schizophrenia, has changed dramatically over the course of the last century. Emile Kraepelin (1887, cited in Burns, 2004) first formulated schizophrenia as a discrete mental illness at the end of the nineteenth century. During the course of his work in the mental asylums of the 19th century, Kraepelin identified an illness characterised by early onset and a deteriorating course that was increasingly debilitating and unresponsive to treatment. At this time, individuals with serious mental illness were committed to mental institutions with little expectation of amelioration or recovery.

However, evidence began to emerge that questioned this pessimistic position. The work of Adolph Meyer and of Freudenberg and colleagues suggested that the course of mental illness could be influenced by environmental factors. Based on his clinical observations, Meyer, in the 1940s, highlighted the importance of considering external and environmental influences alongside 'diagnosis'. He advocated the importance of developing a detailed understanding of the whole individual and conceptualised mental

¹ Serious mental illness, severe mental illness, psychiatric disability and severe and enduring mental health problems are used throughout the literature. Serious mental illness and severe and enduring mental illness will be used interchangeably throughout this paper.

illness and its treatment as the interaction of the individual and the environment with many opportunities for change (Burns, 2004).

The highly influential 'Three Hospitals Study' (Freudenberg , Bennett & May, 1957, cited in Burns, 2004) added empirical weight to Meyer's position. This study, conducted in three hospitals whose working practices differed significantly, demonstrated that the clinical and social functioning of patients were closely associated with the different practices. Thus the notion that the course of serious mental illness could be profoundly affected by social environment, and the level of social stimulus provided, began to be taken seriously.

Longitudinal research, starting in the 1960s, also effectively challenged the historically pessimistic view of the long-term outcome of serious mental illness. A review of 10 longitudinal studies of serious mental illness conducted in developed countries, reported the range of significant improvement or recovery of people diagnosed with schizophrenia to be 36% to 77% (Calabrese & Corrigan, 2005), while four studies reported rates of continuing hospitalisation to be 13.3% to 64% (Ciompi, 1980; Huber, Gross & Schuttler, 1975, cited in Calabrese & Corrigan, 2005; McGlashan, 1984a, 1984b; Ogawa, Miya, Watarai, Nakazawa, Yuasa & Utena, 1987).

Further evidence for heterogeneity in the course of schizophrenia comes from data from developing countries (e.g the International Study of Schizophrenia (Harrison et al., 2001; Sartorius, Gulbinat, Harrison, Laska, & Siegel, 1996)). These researchers consistently found that course and outcome of schizophrenia were better in developing

than developed countries and supported the position that different sociocultural contexts may impact on the course of schizophrenia.

All of these studies may be criticised and have limitations. Any international study has to confront the differences in diagnostic criteria used for schizophrenia in different countries, for example Swiss and German criteria are more inclusive than Scandinavian or American classifications (Calabrese & Corrigan, 2005). Different studies use different criteria for recovery, with some using multiple measurements and others a single clinical interview. However, despite these criticisms, the consistent finding of significant variability in the outcome of schizophrenia is important, and must be taken seriously. It appears that, although a proportion of sufferers do remain chronically unwell, the course and outcome of schizophrenia is not homogeneous, on-going institutional care is not always needed and improvement and recovery from schizophrenia are possible.

2. Recovery from serious mental illness

The term 'recovery' is now widely used within services and in the literature in relation to serious mental illness. However, it is increasingly used to denote a phenomenon that is somewhat different to the 'traditional' understanding of the term. In contrast to clinical outcome research which relies on objectively measurable criteria, generally with a strong emphasis on reduction in symptomatology, there is an increasing focus on subjective experience and optimising functioning. This shift is illustrated in the large number of personal accounts, and in a smaller number of qualitative studies.

2.1 The Concept of Recovery

'Recovery' is a concept commonly used in the field of physical illness and disability. In this context, recovery is not understood as meaning that all symptoms disappear or that prior functioning is completely restored. Rather, it means that the individual may improve although the disability has not been 'cured' (Harrison, 1984, cited in Anthony, 1993). In some ways the term 'recovery' is a misnomer. It is more accurate to talk of optimising function, or helping a person to manage the illness. For example, a person who has had a stroke may recover but often is left with a degree of disability that means making adjustments to life style, and the individual may need ongoing support in the community.

Since the 1990s, the concept of recovery has gained momentum in the field of serious mental illness (Anthony, 1993). Current literature, from personal accounts, empirical research and theoretical studies, proposes a similar understanding of the concept of recovery in mental health to that identified in the field of physical disability: elimination of symptoms is not a prerequisite and recovery involves optimisation of functioning by accepting and living within the limitations of the illness and finding new meaning and purpose in life (e.g. Anthony, 1993; Deegan, 1996).

Main approaches to the concept of recovery (personal accounts, empirical papers and theoretical studies) will now be discussed in turn and areas of agreement and difference identified.

2.2 Personal accounts of Recovery

Personal accounts of recovery from mental illness were first published in the 1980s (e.g. Deegan, 1988) and provide qualitative insights into the experience. The personal account literature is extensive and, by its nature, emphasises the idiosyncratic nature of recovery. However it is possible to extrapolate common themes and classify them broadly as internal and external. Internal themes relate to an individual's feelings, attitudes and beliefs, and how these impact on recovery. External themes relate to the influence of others and the environment on facilitating or hindering recovery. A number of factors within the two themes are inter-related.

Internal Factors in the Personal account literature

A number of internal factors are consistently identified in the personal account literature. These include control and personal responsibility, hope and commitment, and accepting illness and redefining the self.

Control and Personal Responsibility

Some personal accounts conceptualise recovery as a matter of personal choice and responsibility (e.g. Deegan, 1996; Frese, 2000; Mead & Copeland, 2000). These accounts postulate that the role of mental health practitioners and services should be to recognise individual needs (Anthony, 2000) and to actively support the individual in reaching their goals and making changes. They argue that it is important that people with serious mental illness are able to develop expectations of life that incorporate goals, skills and roles, even if limited by their illness (e.g. Kelly & Gamble, 2005), and that

resuming control and personal responsibility contribute to increasing feelings of self-efficacy (e.g. Lovejoy, 1982; Walsh, 1996).

Hope and Commitment

Personal accounts emphasise the belief that recovery is untenable without the individual feeling hopeful that there is a possibility of recovery, and having the commitment to pursue it. In turn, this hope and commitment are thought to lead to a sense of possibility and purpose, and a wish and determination to recover (e.g. Deegan, 1996; Mead & Copeland, 2000).

Accepting illness and Redefining Expectations

Some people who write about their own recovery have emphasised acceptance of illness as a crucial factor (e.g. Munetz & Freze, 2001; Sullivan, 1994), but they make it clear this does not imply acceptance of illness as an identity, but rather the accommodation of it within their lives without its defining the individual (Davidson, Sells, Sangster & O'Connell, 2005). Accepting illness includes finding ways to manage symptoms that allow the person to participate in his or her recovery (Fisher, 1994), and although managing symptoms in this context may involve medication or other coping strategies it importantly involves the individual being an active participant (e.g. Deegan, 1996). Many do not aspire to a return to their 'pre-morbid' selves, arguing that this would be to negate an integral part of who they are, namely their experience of the illness (e.g. Corrigan & Penn, 1998).

External Factors in the Personal Account Literature

A number of external factors are consistently identified as important in the personal account literature. These include the support of others, engagement in meaningful activities and overcoming stigma/participation in society.

Support of Others

The support of others is seen as a critical factor in the personal accounts of recovery. This refers to both the encouragement of friends, family and professionals, and also to the value of peer support (e.g. Baxter & Diehl, 1998; Mead & Copeland, 2000). Feeling that one has the support of others seems likely to impact on many other components of recovery, for example, feeling that another believes in the possibility of recovery may facilitate development of personal hope.

Meaningful activities

Personal accounts stress the need to be involved in activities that are meaningful to the individual (e.g. Bassman, 2000), which may then facilitate feelings of self-efficacy and self-esteem (e.g. Ridgeway, 2001).

Overcoming stigma/participating in society

Societal stigma is often a barrier to recovery from mental illness, and people who experience long periods of mental illness are generally aware of the social disapproval that their conditions excite (e.g. Chadwick, 1997). This may have a profound impact on an individual's sense of self worth. Overcoming the internalisation of this sense of being

stigmatised has been identified as a necessary component of recovery (e.g. Frese, 2000). Related to this is the importance of developing or expanding on social roles (e.g. Coodin Schiff, 2004), and of participating in society in a positive way (e.g. Deegan, 2003), which may be achieved through different avenues, some examples being finding paid employment or acting as a volunteer.

While the individual internal and external factors contributing to recovery can be extrapolated, individual factors seem unlikely to occur in isolation and many will have an effect on the development of others. For example, the development of hope and commitment may be facilitated both by accepting illness and redefining expectations, and by having the support of others. At the same time, the support of others may also encourage engagement in meaningful activities.

Strengths and Limitations of Personal Accounts

Personal accounts comprise the larger part of the literature in relation to recovery, and might be considered to be of lesser scientific value than more systematic empirical research. However, there is an important place for such individual and qualitative information. It captures the individual experience, and may identify issues that can then be pursued more systematically in order to produce evidence that could eventually inform service developments.

While personal accounts provide an invaluable insight into the experience of individuals, there are inherent limitations. An aspect of the experience that is of crucial importance to one individual may be of little significance to another. In addition, these accounts

are, by their very nature, written by individuals who are 'well' enough to be able to write for professional journals and, not infrequently, are practising mental health professionals (e.g. Coodin Schiff, 2004; Frese, 2000; May, 2000; Mead & Copeland, 2000). These writers are a very distinct group and represent only a proportion of those who suffer or have suffered from serious mental illness. Those who continue to be more significantly disabled by illness may have rather different experiences (Frese, 2000). There is a dearth of personal accounts of 'recovery' by people in this latter category and this area warrants future research. However, to an extent it may be argued that this has been addressed by the, admittedly small number, of empirical studies on recovery, which will be discussed in the following section. These reduce the impact of individual bias in reporting and offer more systematic data on the process of recovery as understood by a less homogeneous group of individuals.

2.3 Empirical Studies on Recovery

There is an extensive qualitative literature exploring individual themes highlighted in the personal account literature relating to recovery, for example, the impact of stigma (Barham and Hayward, 1998) or of social support (Davidson et al., 2001). A smaller number of studies have looked more broadly at the concept of recovery and these will be focused on in this paper (Mancini, Hardinman & Lawson, 2005; Meddings & Perkins, 2001; Smith, 2000; Tooth, Kalyanasundaram, Glover & Momenzadah, 2003). These authors have approached the concept in two ways: firstly they have explored the meaning of recovery for individuals with a diagnosis of serious mental illness/schizophrenia (Meddings & Perkins, 2001; Tooth et al., 2003) and secondly, they

have extrapolated the factors that clients consider important to recovery (Mancini et al., 2005; Smith, 2000; Tooth et al., 2003).

The meaning of recovery

The concept of recovery has been dogged by the difficulty of reaching an agreed definition of what the concept means. Of the two studies that sought to find such an agreement, one was fairly successful and the other failed to reach any reasonable consensus. The first of these looked at both clients and staff involved in their care. Client participants were across several stages of rehabilitation: living independently in the community, living in staffed community accommodation, or living in 24 hour nursed NHS accommodation (Meddings & Perkins, 2001). Clients and staff were interviewed using a semi-structured interview focusing on what 'getting better' meant to each person. Contrary to their expectations and much of the existing literature, Meddings and Perkins (2001) found a high level of agreement between staff and clients. Content analysis identified ten common themes related to 'getting better', of which the four most common, reported by more than 80% of participants, were improved mental state, especially reduction in symptoms, improved general well-being, especially decreased anxiety, improved relationships, especially having more friends, and empowerment, seen as related to increased confidence and self-worth. All these themes, except reduction in symptoms, are congruent with the personal account literature, and include both internal and external factors. The emphasis on reduction in symptoms contrasts with much of that literature, which generally focuses more on symptom management rather than necessarily reducing symptoms, although symptom management may, in essence, produce the same result. This finding may reflect the view of those resident in

institutions that there is an expectation that they will not be 'recovered' until they are symptom-free. This is the only study to date that has included participants currently resident in services. It may be that those who are discharged from daily supervised care and often functioning at a high level will place less emphasis on being symptom-free.

One subsequent research group conducted semi-structured interviews with people who identified themselves as in recovery and who were living in the community (Tooth et al., 2003). Unlike Meddings and Perkins' study, thematic analysis of the results showed little consensus about the meaning of recovery. The most common response, 'taking responsibility', was recorded in only 37% of participants, and the authors concluded that it was not possible to establish a single definition from the findings. It is of interest that Tooth and colleagues chose to make this conclusion, as qualitative research does not characteristically seek to reach a level of consensus. However, this finding highlights the diverse and individual nature of the meaning of recovery and reflects findings in other areas of the recovery literature.

Factors contributing to recovery

Three studies (Mancini et al., 2005; Smith, 2000; Tooth et al., 2003) sought to identify factors that contribute to recovery from serious mental illness, thus exploring the views of a larger numbers of individuals than personal accounts. 'Recovery' was subjective and defined by the participants. Participants were recruited either by placing advertisements asking for volunteers who considered themselves on the way to recovery (Smith, 2000; Tooth et al., 2003) or by approaching individuals who both identified themselves as 'in recovery' and were also currently providing mental health services to

others with mental health problems (Mancini et al., 2005). The findings are congruent with those in the personal account literature, and include internal and external factors.

Internal factors in the empirical literature

Important attitudes, beliefs and feelings that consistently emerged from qualitative studies include acceptance of illness, a sense of personal responsibility and determination to get to a stage of being relatively well, and hope that it may be possible to get better.

Acceptance of illness

As in the personal account literature, accepting illness emerged as crucial in recovery. It is often at this point, when the illness is recognised and its seriousness accepted, that individuals are able to collaborate fully with treatment (Smith, 2000). Acceptance of the true situation, leading on to a desire for change, was identified as a turning point in recovery (Smith, 2000; Tooth et al., 2003).

Personal responsibility and determination to get better

Seeing oneself as taking personal responsibility, that is taking control and making choices, emerged as a key facilitating component (Mancini et al., 2005; Smith, 2000; Tooth et al., 2003) and more specifically as a strategy for recovery (Tooth et al., 2003). This reiterates the central role of the individual, and the importance of his own decision to seek recovery or to collaborate with healthcare professionals, already highlighted in the personal account literature.

Hope

Related to taking personal responsibility is the importance of hope and belief that recovery is possible (Mancini et al., 2005; Smith, 2000). Those who felt they had achieved recovery reported that feeling hopeful that they could get better, and being able to envisage the possibility of living a productive and satisfying life (Mancini et al., 2005), along with a determination to improve (Tooth et al., 2003), were central to facilitating recovery.

External factors in the empirical literature

Most factors in this part of the empirical recovery literature are the same or similar to those emerging from personal accounts, that is having supportive relationships, engaging in meaningful activities and having to confront the stigma of the illness. The exception is the finding in empirical studies that recovered individuals see symptom reduction and taking medication as important.

Supportive relationships

Having supportive relationships with others, whether friends and family, professionals, or peers was identified as critical (Mancini et al., 2005; Smith, 2000; Tooth et al., 2003). In particular, others' belief in the individual's ability to recover was experienced as crucial, facilitating hope and self-belief in the individual (Mancini et al., 2005). Again we see that different factors impact on one another, with external support being associated with a change in internal attitude. The opposite is also true: friends and family, and especially professionals, who are experienced as coercive, indifferent or

judgemental were reported to have a negative impact on the individual's confidence and sense of hope (Mancini et al., 2005; Tooth et al., 2003).

Meaningful activities

Participation in meaningful activities was found to be important in recovery (Mancini et al., 2005; Smith, 2000). This may include developing new skills, or activities such as attending work or school (Mancini et al., 2005; Smith, 2000). Often the individual's ability to participate in these activities also depended on the sense of hope and of determination to get better. Participation was often reported to result in positive feelings of confidence and self-esteem that countered negative messages that many individuals had encountered from the social stigma attached to their experience of mental illness, or of being resident in a mental hospital (Mancini et al., 2005).

Stigma

Qualitative studies highlight a relationship between the sense of self worth and their experience of stigma or negative or hostile labelling of people with mental illness (Smith, 2000). Such stigmatising may come from individuals, but is heavily reinforced by the media to which most people with mental illness are exposed. These feelings of low self esteem can be tenacious and may represent a significant barrier to the individual recognising and believing in the possibility of recovery (Smith, 2000).

Symptoms and Medication

In contrast to the personal account literature, symptoms and the impact of medication were identified as significant factors in qualitative studies, with disabling symptoms and

adverse effects of medication highlighted as potential barriers to recovery (Mancini et al., 2005; Smith, 2000; Tooth et al., 2003). However, participants recognised the difficult balance between the distress caused by symptoms, the potential help to be gained from drug treatments, and distress caused by adverse side effects of medication. The right medication was identified as crucial both to initiating and maintaining recovery. Because adverse drug effects may affect treatment adherence, one study went so far as to advise facilitating access to both alternative and formal treatments to improve collaboration between the professionals and their patients (Mancini et al., 2005).

Strengths and Limitations of existing empirical research

As with personal accounts, these findings come from groups of individuals who are 'well enough' to work. It is possible the findings therefore reflect the experience of participants, but may not be generalisable to all people with serious mental illness. Further, the focus on 'recovery' in all these studies may have led participants to focus on those ideas relevant to the concept and to omit other potentially relevant experiences. Although Meddings and Perkins' (2001) 'getting better' encapsulated the same meaning, their study looked at a wider range of people, and was distinctive in providing the perspectives of individuals who were not volunteers or providers of services, and who may therefore have represented the more 'usual' clients of mental health services. This is an area that has been neglected and warrants further research.

Although various definitions of recovery have been proposed, both personal account and empirical literature indicate more consensus than discord about both the definition of

recovery and key contributing factors. From review of the literature, one definition that may be generally accepted is that recovery involves redefining expectations and living a meaningful and fulfilling life within the limitations imposed by the illness. Key contributing factors can be summarised as both internal and external, with internal factors including control and personal responsibility, hope and commitment, and accepting illness. External factors include the support of others, engagement in meaningful activities, overcoming stigma and, for some people, reduction in symptoms of the illness and adverse effects of medication.

Personal account and empirical literature both give a valuable insight into the experience of recovery from the perspective of the individual. In addition, a parallel literature has approached the issue more theoretically, and has advanced definitions and models of recovery. These will be discussed in the next section.

2.4 Models of Recovery

As in personal account and empirical literature, the theoretical literature does not offer a single model. For clarity, the individual models have been clustered into four paradigms for the purposes of this review. The first proposes stages of improvement, spanning severe mental illness to health. The second is a key components model, encompassing both internal and external factors. The third is criterion based and is fairly congruent with clinical outcome research. The fourth is an empirically based conceptualisation of recovery derived from quantitative findings.

Stage Models

Stage models propose a conceptualisation of recovery as a process from 'illness' to 'recovery' and although there are semantic differences in labels, they are conceptually similar. Three stage models have been proposed (Andresen, Oades & Caputi, 2003; The Recovery Advisory Group Recovery Model (RAGRM), Ralph & Recovery Advisory Group, 1999, cited in Ralph, 2005; Young & Ensing, 1999). Although all follow the general principle of movement from illness to health, each uses different terms to describe the process, and the resulting literature can therefore appear confusing and hard to reconcile coherently. Two models were developed using focus groups of individuals who had experienced serious mental illness, and derived their stages from themes that emerged from discussion (RAGRM, Ralph & Recovery Advisory Group, 1999; Young & Ensing, 1999). The RAGRM defines six stages: 'anguish', 'awakening', 'insight', 'action plan', 'determination to be well' and 'well-being, empowerment and recovery'. Within the model these are not necessarily linear; an individual may move from one to any other in either direction. The second study to use a focus group also conducted interviews with participants living in the community (Young and Ensing, 1999). In the model derived from this study, the model's stages were 'overcoming stuckness', 'discovering and fostering self-empowerment', 'learning and self-redefinition', 'returning to basic functioning' and 'improving quality of life'.

The authors of the third stage model used a literature review to identify salient themes: finding hope, re-establishment of identity, finding meaning in life and responsibility for recovery (Andresen et al., 2003) and proposed these as key processes in recovery. They then identified five qualitative studies that had illustrated phases or stages in the

recovery process (Baxter & Diehl, 1998; Davidson & Strauss, 1992; Pettie & Triolo, 1999; Spaniol, Wewiorski, Gagne & Anthony, 2002; Young & Ensing, 1999) and proposed a five-stage conceptual model of recovery based on these. These stages were 'moratorium', 'awareness' of the possibility of recovery, 'preparation' to begin recovery, 'rebuilding', and 'growth'.

In contrast to the RAGRM model (1999), which emphasises the non-linear nature of the stages and presents this as an integral feature, Young and Ensing (1999) and Andresen and colleagues (2003) do not specify whether they consider the stages of their models of recovery to be linear. However within all models, stages appear to be established by deduction, either by consensus (RAGRM, 1999) or the authors' judgement (Young & Ensing, 1999; Andresen et al., 2003). This may be an inevitable feature of models of a complex concept in the preliminary stages of development, but may also reflect a feature of the recovery literature, where the concept is repeatedly discussed and defined by individuals with little consensus. For example, Andresen and colleagues chose to propose a new model that incorporated that of Young and Ensing, rather than building upon an existing model.

What differentiates stage models, in particular the RAGRM, from key components models is their focus on the individual. Although acknowledging the influence of external factors, stage models emphasise the experience of the individual whereas key components models give equal weight to both internal and external factors.

Key Components Models

Key components models are, in essence, a summation of the findings of the personal account and empirical literature. Two models, with much in common, have been proposed (Jacobson & Greenley, 2001; Ralph, 2000). Ralph proposed four dimensions of recovery: internal factors, self-managed care, external factors and empowerment. The four dimensions are inter-related and 'empowerment' is seen as an overarching factor encompassing other dimensions. In this model, empowerment is defined as internal resources and connections with others combining to produce self-help, support and concern about oneself and others. As in the previously discussed models, Ralph (2000) does not explain how these dimensions were arrived at, but empirical studies are referenced as providing support for each dimension, for example the notion that early insight decreases likelihood of hospitalisation (Heinrichs, Cohen & Carpenter, 1986, cited in Ralph, 2000). Notably, Ralph has elected to identify self-managed care as a separate dimension. She differentiates this from the internal dimension by its focus on practical strategies for illness management, e.g. methods to decrease hallucinations. Essentially, this dimension appears to incorporate factors that involve both internal and external influences.

Jacobson & Greenley (2001) developed a conceptual model of recovery centred on identifying key contributing components. Through analysis of personal account literature, and congruent with other areas of the recovery literature, a range of internal and external components were identified as facilitating recovery. Internal conditions include experiences, attitudes and processes of change of the individual, with key internal conditions being hope, healing, empowerment and connection. External

conditions were events, circumstances, policies and practice impacting on recovery, with key conditions being implementation of human rights (e.g. eliminating stigma), a positive culture of healing (e.g. collaborative relationships) and recovery-orientated services (e.g. rehabilitation). Within this model, as with Ralph's (2000), it is assumed that internal and external conditions will have a reciprocal effect, for example collaborative relationships and empowerment will impact on each other. It is also postulated that the process of recovery, once realised, can in turn have an effect on these conditions. However, in contrast to the model proposed by Ralph (2000) no empirical evidence is presented for the model, rather it appears that the authors extracted common themes from personal accounts and categorised them, without giving any clear rationale for their choice of categories, or their decisions as to which conditions were key.

Criterion based model of recovery

Only one model has attempted to introduce measurable operationalised criteria for recovery (Lieberman & Kopelowicz, 2005). These researchers suggested that a 'criterion based' definition of recovery would facilitate research and enhance understanding of factors that inhibit or promote recovery. They proposed four criteria upon which recovery could be operationalised, including symptomatic and functional factors: 'psychotic symptoms', 'independence', 'work or school' and 'social and recreational factors'. They recognised that symptomatic recovery does not necessarily equate to functional recovery (Tohen et al., 2000, cited in Lieberman & Kopelowicz, 2005), which is seen as at least as important as a reduction in symptoms. Thus, they included criteria relating to work/school and social functioning and a dimension of independence to reflect a move towards increasing autonomy (Lieberman & Kopelowicz, 2005).

Lieberman and Kopelowicz (2005) proposed setting threshold levels for each criterion (e.g. at least half time attendance at work or school) to define recovery and suggested two consecutive years as the duration for establishing recovery, suggesting this would allow time for clinical improvement to be translated into significant change in quality of life. Some may criticise this model for its emphasis on objectively measurable criteria with less focus on the subjective experience that is so salient in the consumer literature. However, Lieberman and Kopelowicz argued that change in subjective experiences such as hope and empowerment would be reflected in their dimensions. For example, as the individual experienced improvements in symptoms and functioning, more subjective experiences such as hope would also become more evident. In addition, their choice of some criteria appears quite arbitrary, for example, half time attendance at work or school. So, although this conceptualisation avoids the confusion of the other, more individualistic models, it also negates the possibility of 'recovery' without a significant level of functional improvement, for example half time attendance at work for two years, and may therefore preclude the possibility of recognising a more limited 'recovery' for a proportion of those with serious mental illness.

Empirically Based Model of Recovery derived from quantitative findings

The final approach has attempted to bridge the gap between the more individually focused and criterion based models of recovery. Resnick, Fotana, Lehman and Rosenheck (2005) proposed an empirically based model of recovery derived from quantitative findings. They used an existing database of outcome of schizophrenia in the United States, and identified a sample of 1076 participants of whom 5.48 percent were living in an 'institution or other', 19.42 percent were supervised in the community, 21.65

percent were living with family or friends and 53.44 percent were living independently. Therefore, in contrast to the other models, derived from literature largely based on those successfully living in the community, this model included both people who might be considered to have recovered substantially or to an extent, and those who remained relatively disabled by their illness.

Resnick and colleagues reviewed the outcome measures in the existing database and identified those that reflected a theme in the recovery literature such as “quality of life, hope and empowerment” (Resnick et al., 2005, p.121). These items were grouped under headings of quality of life, mastery of mental health treatment, perceptions of mental health, knowledge of the illness, and demographic and mental health variables. The researchers randomly divided their data into two groups of 538, and conducted principal components analysis on the identified subjective items. The analysis yielded four factors that were conceptually meaningful and the researchers called them empowerment, knowledge, hope and optimism and life satisfaction. Thus, these findings were congruent with much of the existing recovery literature.

The empowerment dimension encompassed feelings of self agency (e.g. how much the individual felt their opinions and ideas counted, how much input they had into their rehabilitation plan) and feelings about mental health services (e.g. feelings that their overall service plan fits with what the individual wants). The dimension of knowledge integrated understanding of mental health (e.g. knowledge about emergency and crisis services) and procedural assistance (e.g. how to find help with housing). Hope and optimism referred to both beliefs about current mental health and optimism for the future

(e.g. expectations of mental health in 12 months or 5 years). The life satisfaction dimension incorporated family, social network, living situation, community and safety (Resnick et al., 2005). Empowerment accounted for the greatest variance in the model by a statistically significant amount (the empowerment path co-efficient was 0.85, the path co-efficients for the other three dimensions were less than 0.5) indicating that this is an important component of recovery.

2.5 Summary of recovery literature

Several factors crucial for recovery are repeatedly identified across all parts of the literature, whether personal accounts, systematic studies or theoretical conceptualisations. Personal accounts and qualitative literature give a lively sense of the personal experience of the individual, but do not evaluate the relative influence of factors, nor offer general principles to inform clinical care or research. This contribution comes more from theoretical models of recovery. However, the value of these is variable, with some offering important developments, and others appearing rather repetitive of previous work, and adding little new observation or thought.

There are considerable similarities between models of recovery. Although each is proposed to be a preliminary conceptualisation which would benefit from development, on the whole, authors do not cite previously published work or attempt to build on previously proposed models. The exception is Andresen and colleagues who incorporated Young & Ensing's findings into their model but did not then indicate why they elected to develop a new model rather than build upon the previously posited one. Key components models and the stage models, especially the RAGRM (Ralph &

Recovery Advisory Group, 1999), all emphasise the importance of internal and external processes to recovery and their reciprocal nature. Conceptually these models appear to be very similar and disparities between models appear to be largely semantic, for example concepts such as 'awakening' (Ralph & Recovery Advisory Group, 1999) and 'awareness' (Andresen et al., 2003).

Although some parts of the theoretical literature are semantically confusing, there are also developments that have allowed a more systematic evaluation of important factors and identified the most valuable of these. The criterion based model (Lieberman & Kopelowicz, 2005) introduces the notion of measurement and quantifying aspects of recovery, and whilst it may lose some of the more individual aspects of assessment it allows research findings to be compared, and operationalises the evaluation in a way that may help structure observations, not only in the research but also the clinical setting. The empirically based model (Resnick et al., 2005), based on a large database, offers a very useful analysis of a substantial amount of data and is an impressive study. No new concepts were introduced by these authors, but for the first time there was an attempt to evaluate the relative contribution of different factors to the process of recovery.

In all models there is a good level of agreement about which factors contribute to recovery. Notably, empowerment is identified as a significant factor in four models: as an outcome (RAGRM, 1999), an overarching factor incorporating all others (Ralph, 2000), a key internal condition (Jacobson & Greenley, 2001), and for Young & Ensing (1999) self-empowerment is identified as one of the stages of recovery. The empirically based model also identified empowerment as the component accounting for greatest

variance in the model (Resnick et al., 2005). Although not conclusive, the literature suggests that empowerment is a salient factor in recovery, and this will now be explored in more depth in this review.

3. Empowerment

Empowerment is a complex concept and theoretical ideas have developed in diverse fields of academia including sociology, social policy, politics and psychology. The concept stems from the social action ideology of the 1960s and the self-help ideas of the 1970s and 1980s (Eng, Salmon & Mullen, 1992; Kieffer, 1984, cited in Rissel, 1994) In the 1980s the concept of empowerment began to be discussed in the community psychology literature (e.g Rappaport, 1981; Rappaport, 1987) and in 1995, a theory of empowerment was posited by Zimmerman (1995).

Empowerment has been widely discussed in the literature and utilised in service development but, to date, as with the recovery literature, no single agreed definition has emerged. Empowerment theory is complex, incorporating many factors at multiple levels of analysis and has been criticised for a continuing lack of clarity. It is suggested that the term has been used to describe a number of different processes and outcomes in different contexts, with individuals often developing personal definitions of empowerment and 'empowering practices' (Barnes & Bowl, 2001). However, despite these arguments, empowerment theory provides a useful framework for thinking about the application of the concept of empowerment in various contexts and will be briefly

outlined in the following section. The theoretical background to empowerment theory will be discussed, followed by a possible definition of empowerment.

3.1 Empowerment theory

Empowerment theory is founded on the critical assumptions that empowerment is individualistic, contextual and dynamic (Rappaport, 1984; Zimmerman, 1990, 1995). It is assumed to be individualistic because it is influenced by an individual's idiosyncratic characteristics, experiences and history; individuals living in the same setting may therefore have very different empowerment experiences. Its contextual nature is assumed, as the setting of a person's life will influence their experience of empowerment. Finally empowerment is considered to be a dynamic concept as it varies across contexts and time. These assumptions of empowerment may in part explain the diverse use of the term and the difficulty in definition. However, empowerment's ecological embeddedness is also what differentiates it from concepts that are more individually focused such as self-efficacy. Although initially these assumptions were hypothetical, more recently, empirical support has shown that these three characteristics are evident in empowering organisations (Foster-Fishman, Salem, Chibnall, Legler & Yapchai, 1998).

The theory of empowerment proposes that empowerment occurs at multiple levels of analysis: individual, organisational and community (Zimmerman, 2000). Each level is inherently related to the others, so empowerment at one level will impact on empowerment at another. However, empowerment at an individual level is considered most pertinent to the area of recovery in mental illness. Although organisational and

community factors are inter-related, the focus in recovery remains the individual and their idiosyncratic context.

3.2 A Definition of Empowerment

It has been suggested that if empowerment varies across people, contexts and time, then a definition that will delineate the construct in all circumstances may be inherently unattainable (Perkins & Zimmerman, 1995; Rappaport, 1984). However, more recently, using a review of the empowerment literature, the concept has been helpfully operationalised as comprising eleven components (Fitzsimmons and Fuller, 2002) which may, like the concept of recovery, be considered to be either internal or external.

The internal factors include:

- “a sense of control and self-determination over things that are important to the individual”
- “a sense of self- efficacy or self-confidence in one’s ability to achieve desired outcomes”
- “a more positive self-concept or increased levels of self-acceptance and self-esteem”
- “a sense of being valued and respected by others, of being able to make an impact, a sense of connectedness to others”
- “a sense of purposiveness, a sense of causal importance, an active orientation towards advancing one’s interests, a hopeful and motivated stance”

The external factors include:

- “Having the social support necessary to facilitate the achievement of goals; the absence of alienation”
- “Increased understanding and awareness of one’s own interests, one’s position in relation to others, and one’s social and political position relative to the distribution of power”
- “The acquisition of the skills and competencies needed to achieve desired outcomes”
- “Evidence of positive outcomes for the individual such as the acquisition of competencies, changes in circumstances or the achievement of goals”
- “Participatory behaviour and involvement in relevant organisational structures”
- “Engagement in behaviours to support the empowerment of others, concern for the common good”

(Fitzsimmons & Fuller, 2002, p. 486)

It is evident that concepts of empowerment and recovery share many common features. Both can be considered to comprise key components which are both external and internal and which have a reciprocal relationship. Further, they share many of these components, for example, hope, self-determination, supportive relationships. Therefore it is perhaps not surprising that empowerment has been identified as a significant factor in recovery from serious mental illness.

Empowerment has been widely discussed in the literature across a diverse range of settings, including for example, the workplace (Foster-Fishman & Keys, 1997), and schools (Gruber & Trickett, 1987). It is beyond the scope of this paper to consider empowerment in multiple populations or settings, and the focus will be on literature relating to empowerment in the context of mental health services and individuals with serious mental illness.

3.3 Empowerment and Mental Health

The literature suggests that empowerment is a significant factor in recovery from serious mental illness, and mental health advocates and clinicians have argued that empowered clients benefit more from mental health services (e.g. Corrigan, Faber, Rashid & Leary, 1999). At the same time, it has been suggested that serious mental illness can lead to experiences which are stigmatising and disempowering (Chadwick, 1997), while individuals who are disempowered in society are at increased risk of developing mental health problems (Prilleltensky, Nelson & Peirson, 2001). There is therefore, a cogent argument for incorporating ideas about empowerment into planning of mental health services and indeed, this has been advocated in the literature (e.g. Nelson, Lord & Ochocka, 2001; Stromwall & Hurdle, 2003).

Several models of empowerment specific to those with serious mental health problems have been proposed (e.g. National Empowerment Centre (NEC), Ahern & Fisher, 1999) but, to date, these tend to be specific to a single service. For example, the NEC model is based on the programme run by that centre. This may reflect both the contextual nature of empowerment and continuing difficulties in reaching an agreed definition. However,

this is an area that could benefit from further research and development if empowerment is to be systematically advanced in mental health services.

Empirical Studies on empowerment and mental health

Much that has been written about empowerment and mental health is conceptual in nature, and empirical literature in this field is limited. However, some research has demonstrated the value of empowerment in mental health. For example, in the area of child and adolescent mental health, a small number of studies have found that approaches that emphasised empowerment significantly improved outcome (e.g. Cunningham, Henggeler, Brondino & Pickrel, 1999; MacLeod & Nelson, 2000; Prilleltensky et al., 2001). In adult mental health empowerment has also been shown to be important, although again, empirical literature is limited.

Two studies, both conducted in community settings, have explicitly examined the relationship between empowerment and mental health in adults (Kilian et al., 2003; Nelson et al., 2001). Nelson and colleagues (2001) conducted a qualitative study in three 'innovative' community mental health programmes that practised 'an empowerment philosophy'. Approaches varied between programmes but included, for example, providing individualised support, self-help groups and a supported employment programme. Specifically, all three programmes advocated consumer participation in all aspects of care. Focus group interviews were conducted with 59 stakeholders, including consumers, managers, staff, family members and volunteers, and additionally, individual in-depth interviews were carried out with six consumers. The research explored what changes in mental health consumers experienced through their

involvement in these programmes and what factors facilitated or inhibited these changes. They found that empowering processes (e.g. clients taking more initiative, supportive relationships) facilitated the recovery of mental health, and disempowering processes (e.g. fear and lack of confidence, lack of control over medical treatment) impeded mental health. However, following review of the literature, Nelson and colleagues (2001) defined both empowerment and good mental health as incorporating perceived and actual control, community integration and access to valued resources (e.g. education). They differentiated the two constructs by causality, empowerment being the “*opportunities for and conditions that promote*” these dimensions and mental health as the “*development and acquisition*” of them (Nelson et al., 2001, p.127). Therefore, in some respects, these findings seem unremarkable. It may be expected that, if empowerment and mental health are only differentiated by causality, then empowering processes will inevitably lead to improved mental health. However, perhaps more significantly, the findings of this study seem to vividly illustrate the confusion and lack of differentiation, evident throughout the literature, between empowerment and recovery of mental health.

In a later study, Killian and colleagues (2003) explored the concepts of empowerment and disempowerment in relation to the way people with serious mental illness evaluated their psychiatric outpatient treatment. Using semi-structured interviews with 100 participants, they explored the extent to which empowerment or disempowerment were reflected both in consumers’ accounts of the content and outcome of their treatment, and also in how involved they felt in the treatment process. They found that many participants described feeling helpless or indifferent, with care often described as

reduced to drug treatment, with a smaller number perceiving that they had control over decisions and actions that would affect their mental health. Killian and colleagues (2003) identified a feeling of hopefulness as an important distinction between those who felt empowered and those who felt disempowered; those who felt empowered expressed feeling reasonably hopeful that they would improve or recover, whereas those who felt disempowered expressed a complete lack of hope for recovery. These findings again suggest that empowerment is an important factor in the recovery of mental health. However, it seems probable that this research will also have been influenced by the inherent difficulties in differentiating these two concepts, evident both in Nelson et al.'s (2001) study and throughout the literature.

Although the evidence shows that there is significant overlap in definitions of the concepts of recovery and empowerment, it is possible to identify some differences. While both include internal and external components, within the concept of recovery there is more emphasis on the individual and their experience, for example within the stage models (e.g. RARGM, 1999) and the personal account and qualitative literature. Nelson and colleagues' (2001) differentiation by causality may also be a useful one. If it is accepted that empowering conditions facilitate recovery of mental health, there is a strong argument for the promotion of these conditions within current mental health services.

4. Empowerment, Recovery and Mental Health Services

Despite the lack of explicit consensus about the nature of empowerment and recovery, the literature shows that there is reasonable accord about the importance of both concepts and their place in mental health services. Government policy in the UK (Department of Health, 2001) has recommended that recovery is the way forward for mental health services and it is apparent that it has been incorporated into many settings. There has been an increasing focus on community care, where possible, for those with serious mental health problems (Department of Health, 1989; 1990) and community mental health teams (CMHTs), one of the principal features of community care, provide multidisciplinary, comprehensive care to those with serious long-term mental illness (Gournay & Sandford, 2003). Department of Health legislation (1990) advocated the Care Planning Approach (CPA), a model that has become well-established and seems to incorporate many of the principles of recovery and empowerment, for example, facilitating individual choices. This system allows individual management of care for those with ongoing and complex needs. Individuals are allocated a key worker or care manager who is expected to undertake responsibility for a wide range of issues (Burns, 2004), and care of clients is not seen as entirely illness orientated. So, explicitly or implicitly, it would seem that many current community mental health services are incorporating ideas relevant to the concepts of recovery and empowerment.

So, in contrast to much mental health care over the last century, most services in the UK now strive to facilitate people with mental health problems living fulfilling and independent lives in the community. Indeed, the importance of community settings has

been highlighted for providing services for people with serious mental health problems that facilitate empowerment and therefore recovery both in the empirical empowerment literature (Killian et al., 2003; Nelson et al., 2001) and throughout much of the theoretical empowerment literature (e.g. Fitzsimmons & Fuller, 2002). However, there remain people with serious mental health problems who continue to need some inpatient care and this is an area that has been neglected in the areas of both recovery and empowerment research. To date, there is only one study that has looked at the concept of recovery within inpatient settings (Meddings and Perkins, 2001). As previously discussed, this research found that improved mental state, improved general well-being, improved relationships and empowerment were identified as important in recovery. However, while it has been suggested that empowerment and self-esteem are essential to the concepts of coping and competence and integral to the rehabilitation and recovery of individuals with schizophrenia (Anthony, 1993), there has been no empirical research looking at empowerment in inpatient settings. This is surprising as a focus on recovery at all stages of illness would seem necessary to facilitate the move towards community living. In particular, services such as inpatient rehabilitation services, designed to provide a link between acute inpatient care and community services, would seem to be a crucial aspect of provision in facilitating the path to recovery.

It has been argued that psychiatric rehabilitation and continuing care services “should be recovery orientated” (Andresen et al., 2003, p.586) and a recent nationwide survey of managers and consultants of psychiatric rehabilitation and continuing care services supports this position (Killaspy, Harden, Holloway & King, 2005). The authors proposed a current definition of the term ‘rehabilitation’ to be “a whole system approach

to recovery from mental ill health which maximizes an individual's quality of life and social inclusion by encouraging their skills, promoting independence and autonomy in order to give them hope for the future and which leads to successful community living through appropriate support" (Killaspy et al., 2005, p.164). It is important to note that this definition is not based on responses to a question about what is currently provided, and may therefore represent an 'ideal' rather than a description of rehabilitation services currently provided. Nevertheless, the definition has considerable face validity, and suggests that there is a more recoveryoriented focus among rehabilitation services currently than has previously been the case. However, with the exception of the study by Meddings and Perkins (2001), there is a dearth of research exploring the concept of recovery in the context of inpatient services. More specifically, no research has considered whether the 'ideal' of providing recovery orientated rehabilitation services is translated into reality.

5. Directions for Further Research

This paper has considered the concept of recovery from serious mental illness and the factors that facilitate or hinder this process. Both internal and external factors that impact on recovery have been identified, with one of the most significant emerging as empowerment. Considering the concepts of recovery and empowerment in more detail, it becomes apparent that there are considerable similarities between them and therefore this finding is perhaps not too remarkable. However, this does not negate the importance of either concept. Recovery has been widely advocated as the focus for current mental health services and is evident in many services, particularly in the

community. In addition, community based mental health services with a focus on empowerment have been shown to be important in the recovery of mental health. However, it is notable that there remains a lack of consensus about definitions and models of both concepts and further research in this area may facilitate advances in service development and provision.

The majority of the empirical research looking at both recovery and empowerment has focused on outpatient or community settings. The neglect of inpatient settings represents a significant gap in the literature in this area. It may be considered that inpatient rehabilitation services are a critical stage of 'recovery' in providing care that facilitates the move from acute inpatient care to successful community living. Although recovery has been identified as an ideal service orientation in rehabilitation and continuing care services, there is a need to investigate whether this is operationalised or remains an aspiration. It seems that prior to embarking on developing theoretical or service models, there is a need to establish whether these services are experienced as facilitating recovery by those who are receiving care from them.

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PART TWO: EMPIRICAL PAPER

**Recovery, Empowerment and Rehabilitation: Do
Inpatient Psychiatric Rehabilitation Units Empower
the Individual?**

Abstract

The concept of recovery from serious mental illness has been widely discussed in the literature. Research suggests that empowerment is a significant contributing factor to recovery but, to date, all empirical research exploring empowerment and recovery of mental health has been conducted in community settings. This qualitative study aimed to explore the extent to which inpatients on psychiatric rehabilitation units felt a sense of empowerment and what factors facilitated and hindered this. Semi-structured interviews were conducted with twelve participants on two inpatient psychiatric rehabilitation units. Interpretative Phenomenological Analysis (IPA) was used to analyse the data and yielded eight themes which were clustered into three higher-order themes, 'confusion and uncertainty', 'connection vs alienation' and 'collaboration vs compliance'. These findings are discussed in relation to the current literature on recovery and empowerment and clinical and service implications are considered.

Introduction

Since the 1990s the concept of recovery has gained momentum in the field of serious mental illness (Anthony, 1993). Historically there was a much more pessimistic view of the course and outcome from serious mental illness but this position became untenable as changes in healthcare brought evidence of potentially more positive outcomes. Longitudinal research has demonstrated that a significant proportion of those with serious mental illness recover or significantly improve (e.g. Ciopmi, 1980, Harding et al, 1987a, 1987b) and there is an extensive literature of personal accounts of recovery from serious mental illness (e.g. Deegan, 1996; May, 2000).

In considering 'recovery' from serious mental illness, it is helpful to think about parallels in the field of physical illness and disability (Anthony, 1993). In this context, recovery does not necessarily mean that all symptoms disappear or there is a return to pre-illness functioning. Rather it refers to optimising functioning within the limitations imposed by the illness or disability. Recent literature, both personal accounts (e.g. Deegan, 1996; Mead & Copeland, 2000) and empirical studies (e.g. Mancini, Hardinman & Lawson, 2005) proposes a similar understanding of the concept of recovery in mental health, that is, that the individual can be helped to accept and live within the limitations of the illness, and may thus find new meaning and purpose in life.

However, although the notion of recovery is now well established, in order to promote its implementation, it is necessary to identify and understand contributing factors, especially those that can be in some way encouraged or modified. Both the personal

account literature and the empirical literature offer useful insights. While they emphasise the idiosyncratic nature of the experience, it is possible to extrapolate common themes. These can be categorised as internal and external components: internal incorporating individual feelings or behaviours that impact on recovery, for example, hope (e.g. Deegan, 1996; Mancini et al., 2005), sense of control and personal responsibility (e.g. Deegan, 1996; Mead & Copeland, 2000; Tooth, Kalyanasundaram, Glover & Momenzadah, 2003), and external referring to the influence of others and the environment on recovery, for example, supportive relationships (e.g. Baxter & Diehl, 1998; Tooth et al., 2000) and meaningful activities (e.g. Smith, 2000; Mancini et al., 2005). These factors are inter-related and many factors will have a reciprocal relationship with the others.

Another strand of the literature has drawn on both personal account and empirical literature and sought to integrate the findings into a theoretical framework and produce models that account for recovery in a less individualistic way. No single model has gained prominence, and although they differ in various respects, common factors across models can again be identified. Factors that models agree upon as being important to recovery include self-determination (e.g. Recovery Advisory Group Recovery Model (RAGRM), Ralph & Recovery Advisory Group, 1999, cited in Ralph, 2005; Young & Ensing, 1999), relationships with others (RAGRM, 1999; Ralph, 2000), and empowerment (RAGRM, 1999; Ralph, 2000; Resnick et al., 2005; Young & Ensing, 1999). Of these, empowerment is a relatively new concept, and it is used rather differently by different researchers. It has been described as an outcome (RAGRM,

1999), an overarching factor incorporating all the other factors within the model (Ralph, 2000), and one of the stages of recovery (Young & Ensing, 1999).

Although 'empowerment' has been specifically identified in the theoretical literature (e.g. RAGRM, 1999), it may be argued that there are only semantic differences between that concept and the 'sense of control and personal responsibility' of the personal account and empirical recovery literature. Indeed the concept of empowerment has been operationalised by different researchers as comprising many components that are concurrent with those identified as important in recovery, for example a sense of self-determination, self-efficacy and hope (e.g. Fitzsimmons & Fuller, 2002).

On the whole most authors do not indicate the relative influence of different factors in recovery. However, recent work suggests that empowerment may be the component accounting for the greatest variance (Resnick, Fotana, Lehman and Rosenheck, 2005). Resnick and colleagues (2005) reviewed all the measures in an existing database of outcome in patients with schizophrenia and identified those that reflected a theme in the current recovery literature such as "quality of life, hope and empowerment" (Resnick et al., 2005, p121). Principal components analyses on the identified items revealed the four dimensions of the recovery model to be 'empowerment', 'knowledge', 'hope and optimism', and 'life satisfaction', with empowerment accounting for the greatest variance in the model by a statistically significant amount. The findings of this study vividly illustrate the potential similarities in the use of the terms 'recovery' and 'empowerment'. Knowledge, hope and optimism, and life satisfaction, identified as three of the dimensions of recovery by Resnick and colleagues, have also been identified

as components of empowerment (e.g. Fitzsimmons & Fuller, 2002). It is therefore perhaps not surprising that empowerment has been repeatedly identified as a significant factor in recovery.

Although the concept of empowerment has been widely discussed in the literature, research on the relationship between empowerment and mental health is limited, with only two studies explicitly exploring this (Killian et al., 2003; Nelson, Lord & Ochocka, 2001). Findings from these studies are that empowering processes (e.g. taking more initiative, supportive relationships) facilitate recovery of mental health, and disempowering processes (e.g. fear and lack of confidence) impede mental health. Those who felt empowered expressed feeling reasonably hopeful that they would improve or recover, whereas those who felt disempowered expressed a complete lack of hope for recovery. Both of these studies were conducted in community settings and Nelson and colleagues (2001) highlighted the importance of the community setting for providing services that facilitate empowerment for people with mental health problems. This is a position evident through much of the literature (e.g. Fitzsimmons & Fuller, 2002).

In sum, there is (albeit limited) evidence that empowerment is a useful concept to inform the care of patients with serious mental health problems living in the community. UK government policy (Department of Health, 2001) recommends that a philosophy of recovery is the way forward for mental health services and many services, (e.g. some Community Mental Health Teams), broadly incorporate the recovery concept into their services (Gourney & Sandford, 2003). In contrast to previous generations of mental

health care, most services in the UK now strive to help individuals with serious mental health problems move into the community and live fulfilling and independent lives (Burns, 2004). However, this is not achieved for all patients with severe and enduring mental illness. A proportion of people continue, at times, to need inpatient care. Services such as rehabilitation units, designed to provide a link between acute psychiatric wards and community settings, are therefore a crucial aspect of provision in facilitating the path to recovery. It has been argued that psychiatric rehabilitation and continuing care services “should be recovery orientated” (Andresen et al., 2003, p.586) and a recent nationwide survey of psychiatric rehabilitation services supports this position (Killaspy, Harden, Holloway & King, 2005). These researchers interviewed consultant psychiatrists and managers in rehabilitation services and, from their responses, developed a definition of rehabilitation as: “A whole system approach to recovery from mental ill health which maximizes an individual’s quality of life and social inclusion by encouraging their skills, promoting independence and autonomy in order to give them hope for the future and which leads to successful community living through appropriate support” (Killaspy et al., 2005, p.164). From this study it is therefore apparent that concepts associated with recovery are alive in the minds of staff members in current UK rehabilitation services.

It may be assumed that people resident in rehabilitation units are more disabled or ill than those in the community, and there is little research to indicate whether the empowerment concept is of the same relevance to them. Although people with serious mental health problems and clinicians seem to be in agreement about the ‘ideal’ orientation of rehabilitation services, personal accounts of recovery often describe

inpatient care as a disempowering and frightening experience (e.g. May, 2000). There is some evidence that rehabilitation staff and residents' views on what 'getting better' means are broadly comparable with other research in the area. For example, improved mental state, improved general well-being, improved relationships and empowerment have been identified as important in 'getting better' by both staff and patients in rehabilitation settings (Meddings & Perkins, 2001). However, to date, no work has explored inpatients' views or experiences of empowerment in the same way as has been done in community studies. There is no research exploring the views of patients residing in rehabilitation units in relation to whether they experience the service as empowering, and what factors within the service help or hinder that development, and there is a need for more detailed knowledge of their experiences and perceptions of mental health service provision in this regard. Service delivery may be improved by our being aware of the degree to which contact with mental health services facilitates feelings of empowerment and, more specifically, whether patients of these services experience them as empowering.

The aim of the present study was to explore the extent to which people who are inpatients on psychiatric rehabilitation units feel a sense of empowerment, and what factors facilitate or hinder this. Empowerment was conceptualised as having various components. These included a sense of agency and self-efficacy, feelings of value and hope, engagement in meaningful activities and relationships with others. The aim was to elicit participants' own experiences and perceptions of these aspects of empowerment. A qualitative phenomenological approach (Smith & Osborn, 2003) was used in order to capture the diverse and complex nature of the empowerment concept and to allow

exploration of the participants' own experiences, perceptions and understanding of this within the inpatient rehabilitation services.

Method

Setting

Participants were recruited from two Rehabilitation and Continuing Care Units in an inner London borough. These units provide short to medium term intensive rehabilitation support to people, aged 18 – 65, with severe and enduring mental health problems. The units are designed to form a link between hospital acute psychiatric wards and community rehabilitation and accommodation for people who are reaching the end of an acute phase of illness.

Participants

The inclusion criteria were that participants were currently inpatients on the unit, were well enough to give informed consent to take part in the interview (as judged by a member of the clinical team) and had been on the unit for at least three months. As the research involved exploring the individual's experience of being on the unit it was decided, with input from the clinical team, that three months would be sufficient time to allow the individual to settle on the unit and be able to discuss their experience. People were excluded if they left the unit before being approached about the research or could not be interviewed in English without an interpreter.

Within the time period of the research nineteen people were identified by the clinical teams as eligible to take part in the research. Of those, six people declined to take part; three declined without giving a reason, two said they did not wish to speak to the researcher and one did not want to be tape-recorded. One participant was excluded from the research as they left the unit before the interview was complete.

The twelve participants comprised six men and six women ranging in age from 21 to 62 years (mean age of 41). Diagnoses included schizophrenia, paranoid schizophrenia, schizoaffective disorder, bipolar affective disorder and depression. Length of time on the unit ranged from 114 to 512 days (mean 211 days). Four participants identified themselves as White British (33%), three as Black British-African (25%), two as Black British-Caribbean (17%), and three (25%) as White Irish, Black British or mixed race. At the time of the interviews, one participant was being held under a section of the mental health act and eleven were informal patients. More detailed descriptive information about each participant is not included in order to protect confidentiality.

The researcher

Prior to commencing this study I had clinical and research experience of working with people with serious mental health problems, both in the community and in inpatient units. This work gave me some insights into individuals' experiences of mental health services and their lives more generally. These experiences contributed to my feeling that individuals with serious mental health problems often felt stigmatised by society and, as inpatients, particularly after long periods of hospitalisation, sometimes struggled to return to living in the community. I had not, prior to commencing this research, had

any experience of inpatient psychiatric rehabilitation units. I expected that experiences of these units may be somewhat different as I understood these services to be designed to facilitate reintegration into the community. As I was independent of the units, I anticipated that engaging with people for the purposes of the research may be difficult as, while working clinically, it had sometimes taken time before individuals felt sufficiently secure in our relationship to successfully engage in therapy.

Interview

Based on review of the literature of recovery and empowerment (e.g. Fitzsimmons & Fuller, 2002; Mancini et al., 2005), a semi-structured interview schedule was designed for the study in order to elicit participants' understanding and perceptions of their experience of the units (see Appendix 1). The interview covered a number of areas including autonomy and responsibility, relationships with staff and other patients, feelings about current circumstances and illness, treatment, feelings of vulnerability and support, and thoughts and feelings about the future. The interview was designed to be used flexibly in order to facilitate exploration and elaboration of any issues that might be raised by the participants. Further prompts were used, as necessary, to enable those participants who found it difficult to talk at length without structure to discuss their experiences. The style of the interview was one of "directed conversation" (Pidgeon & Henwood, 1996).

The participants were interviewed in a private room on the unit by the researcher who was independent of clinical services on the unit. The interviews lasted between 40 and

105 minutes, were conducted over 1-3 meetings and were audiotaped with the participant's consent.

Qualitative Data Analysis

The transcripts of the interviews were analysed using interpretative phenomenological analysis (IPA; Smith & Osborn, 2003). IPA is a qualitative method of analysis, which aims to systematically explore and understand in detail the individual's perception and experience of the subject under investigation. The aim of IPA is not to provide an objective account and in this sense it is phenomenological. However, it is also interpretative in that it recognises the role of the researcher as an active participant whose own conceptions and beliefs will influence the interpretation of the data. IPA was considered to be the most appropriate method of analysis in this research as it facilitates exploration of the individual's perception, beliefs and understanding of their experience within a systematic framework.

The interviews were transcribed verbatim. Due to technical difficulties with the tape recorder, it was not possible to fully transcribe one interview. Following the interview, detailed notes were made from sections of the tape it was possible to hear and from memory. This information was incorporated into the analysis where it concurred with themes emerging from other interviews, but no extracts from this interview are included in the results. In one additional interview the participant had great difficulty articulating ideas and so, although this interview was included in the analysis, it was not possible to include verbatim extracts.

Data analysis followed several steps as outlined by Smith and Osborn (2003). The first stage involved reading each transcript several times in order to identify the sort of ideas and meanings that were being expressed. The transcripts were annotated throughout this process to capture the ideas being expressed (see Appendix 2). The second stage involved clustering similar ideas into themes and constructing a preliminary list of themes for each transcript (see Appendix 3). Common themes were then identified across transcripts, resulting in a final set of themes (see Appendix 4). The third stage involved making connections between themes, resulting in a smaller number of higher-order themes which provided an organising structure (see Appendix 5). At each stage of the analysis, extracts from the transcripts illustrating the themes were recorded.

As is recommended in qualitative analysis (Elliott, Fischer & Rennie, 1999) credibility checks were carried out at a number of points to ensure that the themes generated accurately represented the data. Two supervisors reviewed the transcripts of the data and the evolving ideas and themes throughout the analysis. The themes and higher-order themes were discussed and modifications made until a consensus was reached on the final set of themes that best captured the data.

Ethical Approval

This study was approved by the local Research Ethics Committee (see Appendix 6). All participants were given information sheets (see Appendix 7) detailing the aims and procedures of the study and the extent of confidentiality prior to their being asked to participate. They all provided written consent (see Appendix 8) to participate in the study.

Results

The participants' accounts of their experiences of the units were diverse. There were varied accounts of experiences, relationships and events across individuals and this is reflected in the themes that emerged. Individual accounts were also sometimes marked by contradictions reflecting the complex experiences of each individual. Interestingly, when asked directly at the end of the interview for their thoughts about empowerment, one participant thought it had something to do with control and the others had not heard of the idea before. However all the participants were able, to varying degrees, to talk about their experiences and perceptions of the units.

Qualitative analysis of the data yielded 8 themes which could be clustered into three higher-order themes: 'Confusion and uncertainty', 'connection vs alienation' and 'collaboration vs compliance' (see Table 1). Each of the themes is presented with illustrative quotations from participants. Some extracts from the transcripts have been edited for brevity and relevance and this is indicated by three dots (...). The source of each quotation is indicated by the participant's research number. 'Patient' has been used throughout this text as it is the term used within these units.

Table 1: Higher-order themes and themes

Higher Order Themes	Themes
Confusion and uncertainty	1. Why am I here? 2. "Wondering what it's all about" 3. What happens next?
Connection vs alienation	4. Feeling heard by staff 5. Being with similar others
Collaboration vs compliance	6. Who decides? 7. Apathy and resignation 8. Does being on the unit make a difference?

Confusion and Uncertainty

Feelings of confusion and uncertainty were evident throughout most of the narratives and seemed to pertain to a lack of a sense of purpose. This was evident in a general sense of uncertainty about being on the unit and more specifically about why things were occurring on the unit. These ideas were also apparent in participants' thoughts about what the future might entail after leaving the unit although in this area there were mixed accounts; while some participants were uncertain and fearful about the future, others expressed some hope and sense of purpose concurrently with feelings of uncertainty.

Theme 1: Why am I here?

Several participants expressed a sense of confusion about the reason for being on the unit. Although most recognised that they were or had been unwell, they expressed uncertainty about their need to be on the unit, not perceiving any reason for their stay or any purpose that it would serve. For some this was evident in a lack of understanding of any reason for being on the unit at all and for others a lack of clarity about 'still' being there.

"I was there 5 months, thought my time was up instead of which they put me here, instead of release me so I'm wondering why they put me here." (P3)

"That's what I'm on about, I can't understand it, because I done this as well, people are coming and going and I'm still here and they'll come back and say oh you're here and I'll go yeah I'm still here." (P7)

A minority of participants felt that they were not unwell and that they were on the unit for unjustifiable reasons, such as there being no other place for them to go or that medical judgements were being made based on historical events.

"There's nothing wrong with me that's what I'm saying, I don't see anything, like any funny behaviours or that, I mean, they only go by, they only by what they, what they've read about the history, it's your history they use to make medical judgements..." (P8)

For some, not only was the purpose of being on the unit unclear but they also felt they were not achieving anything and expressed a sense of futility about being on the unit. They alluded to feeling stuck and wasting time when they could be moving on with their life.

“I feel as though um, it’s a big waste of time and space, I want to be out of here...no matter where I go I just want to get out of here, it’s too much, too much hassle...I’ve been here so long and they’re still hassling me to do things....I don’t want to waste my time here every day, question me and stuff like that, just want to get out of here, get back to my life.” (P10)

For the minority of participants who recognised there were reasons for being on the unit, some appeared resigned to the decision rather than conveying understanding of the reasons behind it.

“Well, I think they were right to get me to come into this place and uh bring me here, I was suffering from depression at the time, severe bouts of depression, so I can understand why they uh, they, they put me here, apparently they’re justified in their actions.” (P12)

Others felt that it was time to move on and expressed frustration and confusion about the reasons that they were still there and the uncertainty about moving on.

“My stay, my stay here has reached the end of its purpose, the end of its, the whole purpose of, of coming to a place like this is to be rehabilitated into, into the community and, if you keep someone away from the community then you’re not rehabilitating them, you’re keeping them away and why keep me away from my flat, what’s wrong in me going to my flat” (P1)

Theme 2: “Wondering what it’s all about”

In addition to feeling uncertain about why they were on the unit some participants also seemed to be unclear about why things happened on a day to day level and expressed confusion and uncertainty about the purpose of what was happening on the unit. For some this was a general sense of ambiguity and ‘wondering what it’s all about’.

“Seems to be a lot about, very much, you see them in the office writing out their report and you’re wondering what it’s all about” (P2)

Other participants expressed confusion and uncertainty about the motivation or intent behind others’ actions.

“I don’t know why I keep getting offered to see the student psychologist, they want to assess me for what reason, to ask me questions, same questions, I just tell them whatever, when I go to her I’m going to ask why psychologist doing psychology coming to see me, I don’t appreciate that you know what I mean, this distressing me you know what I mean” (P10)

“I feel frustrated because they don’t want to, they don’t want to make me better, they don’t want to give me a treatment that is going to, is going to end” (P8)

Theme 3: What happens next?

All of the participants reported feeling uncertain about their future. For some this seemed to be concomitant with a lack of hope and purpose; the future felt outside of their control and therefore too frightening and difficult to think about. This was reflected in the interviews where several participants found it difficult to think or talk about the future. Some were able to articulate this in their accounts but for others, because of their difficulty in thinking about the future, it was not possible to discuss it in any depth.

“Well, I’m not, I’m trying not to think about the future at the moment.” (P11)

“I don’t know, I can’t really talk, can’t think about it, just got to take every day, take it from day to day.” (P7)

However, some participants, although feeling uncertain about what the future held for them, expressed more of a sense of hope and purpose about their future. They were realistic about the challenges that the future would present but had aspirations of having a ‘normal’ life.

“Hopefully I’ll be, hopefully the depression would have gone away and I’d be self-sufficient in a flat, independent and uh, I’d be just getting on with my life hopefully, with

a job, I mean you know some sort of job, some sort of income, some sort of work that provides income for me to be self-sufficient and independent...yeah that would be a goal, yeah that may be normal to other people but that's a real target for me, that's a real challenge, for me to be in a situation like that." (P12)

"It will be good, I will find it more challenging...the things I'm going to have to do for myself when I live on my own to make feel challenged. I would like to overcome those challenges, try to live a normal life. It will be interesting to see how I do." (P8)

In addition, some participants reported that experiences they had had whilst on the unit had been positive in enabling them to consider and develop their goals and aspirations for the future.

"It's helped me be more realistic about my goals to be successful. I used to daydream. I used to dream about daft things. I went on to the internet, wrote letters, I got bank information, so many things I wanted to do, I want to, opportunities, stuff like that." (P8)

Connection vs Alienation

Feelings of connection with, or alienation from, others were evident throughout all the accounts. These feelings reflected the quality of participants' relationships and communication with both staff and other patients. Some participants articulated predominantly feeling either alienated and isolated or connected and supported but,

notably, the majority of participants expressed feelings at both ends of the spectrum with different people or at different times.

Theme 4: Feeling heard by staff

The relationships that participants developed with staff and the interactions with staff on the unit appeared to elicit mixed feelings. For some participants, communication and interaction with staff seemed to provide reassurance that things would be okay and left them feeling supported.

“Um just talking to the nurses, reassure that nothing’s wrong and you’ll be alright till you leave here and they just reassure you about things you know, how you feel and things like, makes me feel kind of relaxed in myself you know, it’s good.” (P4)

One participant reported interactions with members of staff as therapeutic in themselves.

“[name] was very good, he’s excellent OT man, I give him full marks, I really do, he’s got amazing energy, amazing energy and he’s very cheerful and very quick, very intelligent, he’s, he’s good therapy as a personality, I think he picks you up.” (P1)

Commonly participants expressed mixed feelings about their relationships with staff members, reflecting differing relationships with different individuals.

“I’ve doubted my sanity at times but the staff, some of the staff are very kind, some of the staff are going out of their way to help me and some of them aren’t.” (P1)

However, other participants had a different experience of relationships with staff on the units. They described a sense of alienation from staff and alluded to an atmosphere on the unit of 'them and us'.

"I never bond with the staff, they're always in the office, can't really get close to them you know. Yeah we are the patients, we're not well you know so don't want us to get too close to them you know." (P3)

"...talking about nurses or doctor or stuff like that, the nurses and that are not really into like talking to patients, the only thing they do is their notes and that, that's all I can see from them, don't know how they figure what you do or how you cope, how you think, how your thoughts are and how you're acting, that's most of the things they can recognise, they check up, they're not really the ideal people to talk to" (P10)

Communication was central in these accounts, with a lack of communication or 'poor' communication leading to feeling alienated, ignored or belittled.

"I'm alright, I'm alright, I can look after myself you know and they sort of patronise me and condescend me when I'm talking and that...when they're talking it's just like, if I'm talking they'll stand there talking." (P7)

"...that feels like, like um, like I talk a lot of rubbish and not coherent." (P8)

Theme 5: Being with similar others

Being with other patients on the units also elicited mixed feelings. For some being with other people who had mental health problems and being able to share experiences enhanced feelings of support and connectedness, enabling them to develop a more positive self-perception and feel less isolated or stigmatised.

“Just being there, just listening, people’s little problems that we’re talking about sort of thing, some of them have sickness worse than me and I feel oh I’m not the only one, they’ve got the same problems as me, just makes me feel, you know, feel a lot better in myself that I’m not the only one, nothing to be embarrassed about, anything like that you know.” (P 4)

“...just normal people, we’re all the same, we’ve all got the same kind of illness like we’ve all got mental health problems and we can talk to one another.” (P7)

However, for other participants the presence of other patients was experienced quite differently. They felt isolated and alienated from other patients on the unit, and sometimes the recognition that others were gaining support from each other increased feelings of isolation.

“Very lonely even though I have company.” (P11)

“No, it’s supposed to be supportive. Meeting other patients and talking about leaving is supposed to be supportive but it doesn’t work. It seems to work for the rest of the

patients, they go on about problems with the hospital, when they're leaving or what they're going to do, it seems to work for them but it doesn't work for me, I can't seem to get in touch with it, in touch with their, with their, I just can't get in touch with what they say... I feel iso, I feel isolated, I just feel kind of really down.” (P 8)

Other accounts, as is evident throughout many of the themes, reflected participants' varied experience of being with others on the unit.

“I can feel like I'm not alone with a lot of things which is brilliant but sometimes I feel very alone about what I am, what goes on.” (P2)

Nearly all the participants reported threatening behaviour around money and cigarettes, either having experienced it themselves or being aware of it going on around them. Some participants were able to 'ignore' this but others experienced it as an ongoing problem and quite threatening.

“...someone once tried to mug me for £2.50 for a packet of fags, said no I haven't got that, don't have to subsidise their habit....I was worried his mates were going to be outside, were going to mug me...” (P2)

For others there was a more general sense of threat from some of the other patients that led to feeling the need to isolate themselves from others.

“...they have an aura of being threatening, prone to violence I suppose, prone to some sort of violence, so I can tell, those people are I make absolutely no attempt to make social interaction with, I make no contact at all with...” (P12)

Collaboration vs compliance

Participants expressed mixed feelings about the extent to which they felt a sense of active participation, responsibility and control in their lives. This related both to participation in decisions in their day to day lives and a more general sense of control and purpose in their overall lives and the ‘bigger’ decisions.

Theme 6: Who decides?

The majority of participants felt that they took responsibility for their day to day living and participated in decisions about daily activities and events. Many commented on how this contrasted with their experiences of other units.

“...there’s more freedom really to choose yourself rather than be given timetable, given things to do, got own choice really so choose things that interest you, that interest me.”
(P6)

“Well I think you decide what you do really in terms of what you want to do during the week anyway.” (P7)

It was clear from the participants' narratives that they valued this opportunity. Several participants talked about the importance of being able to make these decisions and talked about the positive impact of this.

"Oh you have a lot of say, yes, I mean they are up to suggest things, I'd say it's very much geared around what you want to do....well it makes you feel in control of your own life, yes." (P11)

"It is important to have, um, some choice in what you want to do, what do is very important so if you're given the opportunity to choose it's good because it means you can afford to change our minds when we want...I suppose it makes me feel proud of myself, like I make decisions for myself." (P8)

However, one participant expressed feeling no autonomy over even daily decisions.

"Can I decide? I don't think we can. Just sort of do it all for you. Their orders, we have to do everything." (P3)

For some, participation in daily activities was viewed differently. Participation in suggested activities was described as a means to an end; complying with staff members' wishes and keeping them happy was necessary in order to acquire something else.

"...the doctors they told me you have to, they offer you to go, it's good for the doctor to know that you're actually doing something to please them you know what I mean, that's

the best thing about being in here, once they know you're going to day centre, out in the community and stuff, being in here, they'll feel good about you and then they'll probably, that's why I was taken off the section..." (P10)

Participants also described more formal settings in which they could raise issues and voice opinions about services, for example a community meeting for the patients on the units and a borough wide users' forum. These provided opportunities for raising issues specifically related to the unit and more broadly to mental health services. Participants reported valuing the opportunity to share concerns and opinions.

"We have like a users' forum...every month, well I went there yesterday, that's alright, it's interesting...well it's about like, every people from like the hospitals, like rehabs and all that, go to [place], like 12 of us with 3 chair people and just talk about what goes on on like other units and that and take people's opinions and views on what's going on in mental health...it's alright." (P7)

"Well it's, we discuss how the ward's getting on socially and what things are planned, that kind of thing. It's usually just the females who turn up, not the men...well I think it does [make a difference] yes, I don't think everybody would, cos it takes place in a designedly democratic way, nobody's running it." (P11)

However, experiences of perceived control and participation were specific to daily activities or daily life. Most participants reported that 'overall' decisions were made by others, either the doctor, the staff or someone unspecified.

"...they put down the rules and the rules the way they is, nothing's going to change."

(P8)

"I think it's the boss, the bosses that run this place yeah, doctors yeah, nurses yeah."

(P3)

Some participants described feeling that although they were able to voice their opinions about 'bigger' decisions that were being made, such as sectioning or leaving the unit, ultimately it made no difference to the outcome.

"I was able to discuss but it didn't have any effect on them at all. They came away saying I was a nice person, nice person, but my opinion didn't weigh anything at all..."

(P1)

One participant's account captured the experience of freedom to make choices about routine issues, but at the same time an overall sense of powerlessness.

"...freedom as in doing my own thing, I mean they let me do my own thing getting on with my own routine, they don't interfere, they don't interfere with, they don't interfere with my own routine in that sense so, so uh related to if I feel like I do, like I feel that I have freedom the answer would be yes, would be a decisive yes, decisive yes. Obviously things that I'm not allowed to do are for a reason relating to, relating to my situation

being sectioned so I'm powerless to try to, to try to change things which are beyond my power, which are beyond my power but freedom as I say I do have freedom.” (P12)

Theme 7: Apathy and Resignation

The general feeling of powerlessness over more important decisions such as treatment or discharge and participants' lives more generally was accompanied by a sense of apathy and resignation. This permeated several of the narratives. The participants expressed a sense of resignation about the way that things were, a sense that nothing they said or did would make any difference and a feeling that therefore there was little point in attempting to assert themselves.

“I'm used to it you know by now, you know I'm put away.” (P3)

“Can't say nothing, I just have to listen to them till I get out.” (P7)

“I don't really know what to explain about it, it's been a long time now so, nothing really to explain about it, the only cause is that I'm ill and I've got mental illness so nothing you can do about it so, happens all the time, rehab so, happens all the time, can't do nothing about it.” (P10)

These extracts reflect themes that repeatedly emerged, related both to time on the unit and for some participants, more generally about their lives and the future. It is possible that the sense of apathy may, for some participants, be related to their illness, side effects of medication or life experiences more generally.

Theme 8: Does being on the unit make a difference?

Participants reported a range of experiences about whether being on the unit had made a difference to them. This seemed to link, in part, to whether they felt they had been actively collaborating in choices about their treatment.

Some participants described how having the opportunity to actively engage in relationships on the unit, particularly when they might normally have felt quite isolated in life, enhanced their sense of confidence in themselves and their well-being.

“Well, I don’t know really, I, maybe I’ve got more confidence in myself cos I meet people here, I don’t usually meet other people, I meet other people make me more confident you know, maybe that, and the nurses make me more confident with talking you know, telling me things you know, helping me, so yeah I think so yeah.” (P4)

“I started talking really which makes me feel better about myself really, I can express myself more.” (P6)

Others described engagement in activities, sometimes new to them, that they actively chose to participate in as therapeutic and facilitating self-expression.

“Yeah it has, [going to theatre productions] has been a positive thing, it has been quite a positive, positive thing. As I said before I was apprehensive before I went to the shows, I don’t think there was a reason behind it, reason behind it but I think it’s really

helped me, it's like a treatment, it's like, it's remission, remission, it's sent me towards to be in remission." (P12)

"Well, yeah [art therapy] made me feel more relaxed and more, you know get a feeling in myself you know, express how I feel on paper, I think I'm more relaxed in myself, express how I feel, more open to myself you know." (P4)

As is common in many of the themes, some participants expressed mixed views about their time on the unit. Participant 1 initially reported that the only difference that being on the unit had made was increased disability and age.

"I've got older, I've got more ill, I've got more disabled." (P1)

However, at a later point in the interview, she described how relationships formed with staff and the environment as a whole had been experienced as supportive and helpful.

"...there's been someone professional to talk to, the 24 hour care, there's been someone professional to talk to, someone that will listen in a closed environment...well sometimes you don't feel like communicating, it's good to have a group, a group, it's like home, it's like my family, it's like a family, I have to move on, all good things come to an end."
(P1)

These inconsistencies seemed to relate to a change in mood as the interview progressed. Participant 1 was initially expressing frustration at not being able to leave the unit which

seemed to dissipate as the interview progressed and she reflected on her experiences. It is likely that such inconsistencies in the narratives reflect participants' conflicting feelings about the unit and perhaps also reflect their own experiences of inconsistency in their mental state both during the interview and over time.

Medication was also identified by most participants as being an important component in making a difference.

"I take medication twice a day, once in the morning and once in the evening and I take tablets for my blood pressure so obviously they're necessary and I also take sodium valporate, that's um for depression so that's helpful really, I don't mind taking them, I also have injection, depot injection yes." (P6)

However, some participants felt strongly opposed to taking medication, believing that they did not need it.

"I want to stop, I want to stop. They won't take me off, they say I have to keep taking medication." (P8)

Most participants felt that some aspect of being on the unit had made a difference to them and how they were feeling. However, a minority had a different experience. Although they did not explicitly express this, when asked directly during the interview, they articulated that they did not feel that anything had made a difference during their time on the unit. This seemed to co-exist with the feelings of apathy and resignation

described above that permeated some accounts where the patients felt they were passing the time rather than actively engaging in events.

Discussion

This study explored the experience of being on an inpatient psychiatric rehabilitation unit, specifically looking at the extent to which individuals felt a sense of empowerment and what facilitated or hindered this. The findings of this study give a valuable insight into the participants' experiences and perceptions of the units. Participants gave diverse and complex accounts of their experiences and the eight themes that emerged from the analysis reflect this. The results suggest that while some aspects of being on the units are experienced as positive and therapeutic, others result in individuals feeling undermined and powerless. Two of the most striking aspects of the narratives were the overwhelming feelings of confusion and uncertainty and sense of apathy and resignation that permeated most of the accounts. Some accounts were marked by conflict and contradiction which seemed to mirror the participants' confusion and uncertainty both about their experiences of the unit and their lives more generally.

Several participants talked about feeling unclear about why they were on the unit. For some this was in reference to being on the unit at all and for others, more specifically, the reason for still being there. All the participants expressed a desire to leave the unit and, for most, this was accompanied by feelings of frustration and bewilderment about being unable to do this. These findings suggest that the participants felt that a critical aspect of their lives was outside of their control. In addition to this sense of

powerlessness over these significant issues, some participants also described feeling that expressing their opinions in relation to these issues was futile as they felt they were perceived as invalid or meaningless. Many seemed resigned to this situation and did not seek any explanation, either from others or in their own minds. It may be that this resignation and resulting sense of apathy lessened the likelihood of clinicians being alerted to these feelings, and therefore any discussion being forthcoming.

In one way, being on the units precluded some choices being available. Within inpatient rehabilitation units, there are inexorable constraints set by necessary sections and limitations on leave and, while an empowering approach seeks to optimise the individual's abilities and opportunities, it is important to remember that it can only be done within the contextual limitations of the units (Fitzsimmons & Fuller, 2002). Participants' uncertainty might, in part, reflect uncertainty on the part of clinicians about, for example, when someone may be well enough to be discharged or when a hostel space will be available. However, it may be that enhanced communication could facilitate feelings of empowerment within these limitations. Research has shown that settings which endorse a collaborative approach and emphasise participation in decisions and mutual respect enhance feelings of empowerment (e.g. Nelson et al, 2001). Repeated, clear communication may, at least for some, diminish these feelings of confusion about what is happening and enhance feelings of collaboration, participation and self-esteem. Another factor that may have a bearing on these issues is the effect of illness, both directly and through side-effects of medication. For example, at times these may result in feelings of confusion or apathy, or have an impact on memory, and the results should be considered with this in mind. This does not detract from the

significance of the individual's experience and perceptions but it is an issue to consider in relation to the findings. For these reasons, with this population, repeated and unambiguous communication with care staff would seem even more significant.

It is also interesting to consider these findings in light of the fact that, although only one participant in this study was being held under a section of the mental health act, all of the participants expressed frustration about being unable to leave the units freely. This suggests that these findings were not influenced by the 'real' restrictions imposed by being on a section. It is possible that several other factors may have impacted on these findings. Many of the participants had entered the units under a section of the mental health act and, although these had since been rescinded, it may be that participants had not adjusted to their change in status, despite being made aware of it by the clinical team. The nature of these units may also have influenced these findings. As these are locked units and it is therefore necessary to inform a member of staff if you wish to leave the unit, it is possible that participants may have experienced this as a restriction, despite being able to request this at any time. It is also worth considering the possibility that these findings may reflect, for some of the participants, a deeper ambivalence about leaving the units. While these 'restrictions' conflicted with their desire for independence, it may be that they also provided a sense of containment and structure that the participants, at some level, experienced as helpful and necessary. While it is not possible to determine the influence, if any, of these factors, it is interesting to note that currently being held under a section of the mental health act does not seem to influence these findings.

Despite these feelings of powerlessness around 'bigger' decisions, at another level most of the participants recognised and valued the opportunity for active participation in decisions about daily activities. They felt that these activities were designedly geared towards their interests, decisions were collaborative and they could choose to 'opt out' or change their minds. Participants described the positive impact of this in various ways; through facilitating a feeling of being in control of their own lives, feelings of increased self-esteem and coping skills, and gaining skills in novel areas. These findings are congruent with much of the literature which has shown that offering opportunities that are meaningful for the individual and encouraging individual participation in the setting of goals and selection of activities is valued (Brown, Bayer & Brown, 1992, cited in Fitzsimmons & Fuller, 2002). The importance of choice and involvement in meaningful activities are central notions in the concept of empowerment (e.g. Zimmerman, 1990b) and are facilitated by providing flexible individualised approaches to accommodate a diverse range of needs and choices (Rappaport et al, 1984). In addition, research findings suggest that opportunities for choice and for changing one's mind communicate a sense of respect for the individual and their needs or wishes (Brown et al., 1992, cited in Fitzsimmons & Fuller, 2002). These findings illustrate that, although there was a more overarching sense of powerlessness in respect of wider decisions, at another level opportunities for choice, participation and collaboration were evident, and these were experienced as significant and valued.

Relationships with other patients also emerged as an important component of the experience of being on the unit. Participants expressed mixed feelings about the nature of this contact. Some participants perceived relationships with other patients to be a

source of support. Being with others who they felt had similar problems was experienced as reassuring and increased feelings of self-confidence. These findings are consistent with research findings about the importance of peer support (Nelson, Ockocka, Griffin & Lord, 1998), and also the theoretical empowerment literature which suggests that mutual support is an important component of an empowering service (Rappaport et al., 1985; Zimmerman, 1990b). However, concomitantly, a minority of participants described feeling alienated from other patients and, for some, the realisation that others were gaining support from each other, increased those feelings of alienation. In addition, some participants reported feeling threatened by others' behaviour or presence. Although this may, in part, reflect symptoms of illness, for example feelings of paranoia, it was a significant concern. Previous research has shown that it is not an uncommon experience on inpatient units for patients to feel threatened or intimidated by other patients, either directly or as a result of their behaviour and that this can result in feelings of vulnerability and helplessness (Wood & Pistrang, 2004). Thus, in contrast to those who positively gained from relationships with others on the units, for a minority these relationships resulted in feelings of alienation and vulnerability, which seem likely to have negatively impacted on any sense of empowerment.

Relationships with staff on the unit were also complex and varied. For some, these relationships provided support and feelings of reassurance. Indeed, some participants described them as therapeutic in themselves. However, others described interactions that resulted in them feeling ignored or belittled, and ultimately feeling alienated from the staff. Staff were sometimes experienced as indifferent or lacking in any genuine concern, and some participants alluded to an atmosphere of 'them and us' on the units.

It seems likely that this would accentuate feelings of difference and stigmatisation and ultimately hinder any feelings of empowerment.

Another salient feature of the narratives was the fragility of the participants' hope and optimism for the future. For some the future was too difficult to think about and this seemed to result from their experiences of things happening to them, sometimes against their wishes, and being out of their control. In some ways this returns to the earlier point about communication and encouraging participation in important decisions. Hope and optimism are considered key features of both empowerment (e.g. Fitzsimmons & Fuller, 2002) and recovery (e.g. Mancini et al., 2005), both of which seem unlikely in the absence of hopefulness. Again accounts were varied and, more positively, a smaller number of participants described realistic hopes and aspirations for the future, although their hope also often appeared to be fragile. However, while recognising the challenges presented, they expressed hopefulness about having a 'normal' life and, significantly, a few described how experiences on the unit had enabled them to develop these positive and realistic goals for the future.

Encouragingly most participants felt that being on the units had made a difference to them in some way. This is an interesting finding in light of the confusion about being on the unit more generally. In particular, they highlighted new skills that they had acquired, such as knowledge of the internet, and other activities that were available, such as cooking and outings to the theatre. The participants described how participation in these, sometimes novel, activities enhanced feelings of competence and self-confidence and for some, revealed new opportunities that had thus far not been considered. It seems

significant that these findings relate to those aspects of the unit where the participants described opportunities tailored to accommodate individual needs and interests, choice and collaborative decision making, all identified as facilitating a sense of empowerment (Fitzsimmons & Fuller, 2002).

Conclusions

The findings in this study suggest that patients in inpatient rehabilitation units have complex and diverse experiences and that many factors contribute to these. Opportunities for choice, collaborative decision making and supportive relationships were valued and were reported to increase feelings of autonomy, self-esteem and hope. However, perceived lack of control over, and exclusion from, significant decisions along with more negative experiences of relationships, often resulted in feeling confused, alienated and hopeless. Thus, while some aspects of the service appear to facilitate feelings of well-being and empowerment, others seem to induce feelings of uncertainty, vulnerability and resignation, hindering any sense of empowerment.

These findings highlight the challenge that services face in providing empowering experiences for individuals, when these people may already feel disempowered by the nature of their illness (Chadwick, 1997), and are placed within circumstances which are inherently, to some degree, disempowering. People with serious mental health problems are often regarded very negatively by society at large, and more directly by their local community (Nelson et al., 2001), and therefore have sometimes had an extensive history of negative experiences. Many of the feelings evoked by experiences on the unit, such as confusion, uncertainty, apathy and resignation, may be entrenched in these

individuals from extended use of mental health services and life experiences. In addition, the nature of serious mental illness and mental health services sometimes necessitates actions that remove autonomy and decision making powers from the individual. Clinicians and service providers are dealt the difficult task of finding the balance between working within the imposed limitations and facilitating a sense of empowerment for individuals who are, arguably, inherently disempowered. It may be unrealistic to envisage that rehabilitation units can undo years of stigmatisation and long-term service use, but perhaps with careful communication and enhanced discussion, individuals may feel increasingly respected and valued, and that their opinions are heard and validated even if, ultimately, their options are limited by circumstantial constraints.

Methodological Limitations

The findings of this study must be considered in the context of a number of methodological limitations. Firstly, the participants included those who were judged by the clinical team to be well enough to give informed consent. Although the sample reflected the diversity of the units in terms of diagnoses and duration of stay, it is possible that the inclusion criteria resulted in the exclusion of patients with very different experiences. For example, it may be that the wish to leave the unit reflected the fact that these participants were less 'unwell' and therefore feeling more frustration at continuing hospitalisation. Secondly, experiences and perceptions may have been influenced by the nature of the participants' illness or side effects of medication. This is an issue for any qualitative study with individuals with serious mental illness who are currently unwell (e.g. Humberstone, 2002), but the nature of their illness should not

exclude these individuals from contributing to research findings. To some extent the impact of these factors can be reduced during analysis. A careful balance needs to be struck between not over interpreting the meaning of, for example markedly psychotic material, whilst at the same time remaining consistent with inductive methods. However, it seems likely that, despite this, issues such as memory difficulties may have influenced the data to some extent.

Finally, significant issues arose about the difficulty of discussing issues of empowerment with individuals who are, arguably, inherently disempowered. During the interviews, it was noticeable that a few participants had difficulty in expressing their opinions, either consistently responding that they 'didn't mind' or 'didn't know', or communicating concern about 'knowing the right answer' or 'wanting to say the right thing'. This raises questions about whether people who potentially have extensive experience of feeling disempowered are able to feel empowered enough to express this.

Directions for further research

The concept of 'recovery' is increasingly becoming a focus of mental health services in the UK (Department of Health, 2001), and empowerment has been shown to be an important component of the process of recovery (e.g. Resnick et al., 2005). Previous research has shown that community based services which practice an 'empowering' approach facilitate recovery of mental health (e.g. Nelson et al., 2001) and the findings from this study suggest that empowering conditions such as opportunities to make choices, participate in decisions and engage in supportive relationships are valued and facilitate well-being. However, to date, there has been no other research exploring the

experience of empowerment in inpatient settings. Inpatient rehabilitation units are only one aspect of mental health care. Experiences of other services, for example acute or community rehabilitation, are likely to be very different. Some individuals will experience all of these service types, and it seems likely that these experiences may impact on each other. It would be interesting to compare the extent to which individuals feel empowered at different stages of service delivery. Further, relationships have the potential to play a crucial role in the facilitation of empowerment as they can influence many other areas such as choices, hope, and control (Mancini et al, 2005). Extending the current research to include the perspectives of clinicians, their experiences of the units, and what factors they consider significant would allow for a fuller understanding of the complexities of the environment on the units.

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PART THREE: CRITICAL APPRAISAL

Introduction

This paper is a critical appraisal and reflection on the process of carrying out the research discussed in paper two. A number of issues and dilemmas arose in the process of conducting this work, both methodological and conceptual, and this appraisal will consider three broad areas. First, issues about conducting qualitative interviews with individuals with serious mental illness are considered. Secondly issues arising from exploring the complex concept of empowerment with people with serious mental illness are discussed. Finally, this paper will consider the clinical context in which this research took place, specifically the dynamics of the rehabilitation units, and reflect on how psychoanalytic ideas may offer a useful way to think about them.

Conducting qualitative research with people with serious mental illness

All participants in this study had been diagnosed as suffering from a serious mental illness. The nature of this illness means that such participants are often characterised as having poverty of speech and thought, negative symptoms and cognitive difficulties. As discussed in part two of this thesis, these difficulties may have impacted on the findings of the study. Further, it seems likely that they would impact on an interview process that aims to elicit rich information that reflects the depth and complexities of individual experience and perceptions. As such, this population may be considered difficult to interview, and questions are raised about the viability of conducting qualitative research in this context (Humberstone, 2002). However, while acknowledging these potential difficulties, I decided that to allow them to preclude conducting this research would be to neglect an area where individual experiences and perceptions seem pertinent. Based on my prior clinical and research experience, and following discussion with others with

experience in the area, I made a decision that, with flexibility and perseverance, these problems should not be insurmountable.

Therefore, prior to commencing the research it was clear that the interviewing process would need to be flexible to accommodate individual needs and fluctuations in mental state, and a number of measures were put in place to facilitate this. Every effort was made to accommodate participants by scheduling interviews at times which most suited them. So, if a participant indicated that they were at 'their best' in the evening or that was their most preferred time, the interview would be scheduled for that time. Being flexible about rescheduling was also crucial as, on several occasions, at the agreed time, an individual felt too unwell to be interviewed, or had forgotten. I ensured that participants were aware that re-scheduling at any stage was always possible and reiterated this throughout the process, and a number of interviews were conducted over several meetings for various reasons. I had anticipated that for reasons of continuity it would have been preferable to complete each interview in a single meeting, but, contrary to this expectation, the majority of participants who required several meetings remembered with great precision what we had discussed previously.

A further issue that was more difficult to anticipate was fluctuations in mental state that occurred within some interviews, and necessitated my having to manage these as they arose. For some participants with significant mental state fluctuation during an interview it was sometimes difficult to make an immediate judgement about whether to continue or re-schedule. Overall, it seemed important to strike a balance between allowing the participants time and space to discuss issues that were important to them,

while remaining sensitive to the need to stop the interview if the person became increasingly distressed. Inevitably, clinical skills will come into play in a situation such as this. However, it was important to be clear about the boundaries of my role as a researcher, both in my own mind and with the participant, so that the interview did not inadvertently develop into a more clinical meeting. Thus, it was necessary to make judgements throughout about the material that emerged, allowing exploration of pertinent issues while being clear that I was unable to offer advice or engage in discussion about specific clinical issues.

Although the participants were aware that I not working as a clinician on the unit, it was clear that they perceived me as having an association with the clinical team. This was an accurate perception as my external supervisor was a clinician on one of the units and the participants were made aware of this. However, I felt this raised many issues about the nature of our relationship, particularly in relation to confidentiality and how open they felt they could be with me. A related issue that I had anticipated impacting on recruitment for the study was the necessary tape recording of the interviews. Prior to commencing the interviews, I had some concerns that this may preclude some individuals feeling able to participate, perhaps due to feelings of paranoia. Contrary to my expectations, only one person who was approached declined to participate for this reason, and none of the participants expressed any concerns about this. However, for both of these reasons, it seemed important to stress the confidentiality of the interviews, while being transparent about the limitations of this. Naturally, participants were made aware of this prior to commencing the research both verbally and through reading the information and consent sheets. However, I was aware that some participants might

forget this information as time passed and, in order for them to feel free to talk about their experiences, both negative and positive, it was important to reiterate this frequently.

Concerns about the viability of eliciting the depth of information that is necessary for qualitative research and that accurately reflected the complexities of the individual's experience and perceptions of the unit emerged fairly early on. Some participants had difficulty engaging in the interview process and I felt that, at times, there was a risk of the interview turning into a question and answer session, with little opportunity for exploration. Some expressed anxiety about knowing the right answer while others seemed reluctant to discuss some areas in any detail. Sometimes this seemed due to considerable difficulty in thinking about certain areas, for example fears and anxieties about the future. At the same time I felt that this could be interpreted in part as communicating their feelings of resignation, apathy and disempowerment. However, although in one way these were important communications, clearly it was also important to facilitate open discussion. I endeavored to overcome these difficulties in two ways. Firstly, by relaxing the interview process and allowing more 'general' discussion about day to day events, for example what they had done over the weekend, participants seemed to feel more relaxed and able to engage with me. This seemed to then facilitate more extensive discussion of other areas. This was particularly important with participants who I had been unable to spend any prolonged time with prior to the scheduled interview time. Secondly, I began to spend more 'informal' time on the units, sitting in the lounge, watching television and chatting with the staff and patients. Although this inevitably made the process more time consuming, it allowed me to form

a more relaxed relationship with individuals and learn about their interests which could be a useful starting point for the interviews. Further, I believe this allowed them to feel more at ease in their interactions with me and therefore facilitated engagement in the interview process.

When setting up any research project ensuring that the process is clear and transparent is both ethically sound and is likely to enable the participants to feel able to engage in free discussion with the researcher (Smith & Osborn, 2003). My experience of conducting this study suggests that this is particularly significant when the participants are currently unwell and at times suffering symptoms and side-effects that impact on their thinking and well-being. Adopting a more 'informal' and flexible approach, and reiterating the confidential nature of the research interviews, resulted in rich responses from the participants that reflect the depth and complexities of their experiences. This lends support to the feasibility and value of conducting qualitative research with this population, an area that, to date, has been much neglected.

Finally, although every effort was made to include as diverse a sample as possible in the research, the participants necessarily included those who were judged by the clinical team to be well enough to give informed consent to participate in the research. It is possible that those who were not considered well enough have very different experiences of the units. Although the aim of qualitative research is not to produce findings that are generalisable in the way of quantitative work, when considering clinical implications and service development it seems important to be aware of these limitations.

Managing the complexities of empowerment

When setting up this research project, inevitably it was necessary to consider how the subject under investigation may influence the design of the research. There were issues to be considered around designing an interview schedule that could fully capture the nature of experiences of a concept as complex and diverse as empowerment. In addition, during the interviews, questions were raised about whether it is possible to discuss empowerment and the related issues with individuals who, it can be argued, are inherently disempowered.

It became clear to me when perusing the literature around the concept of empowerment that translating this into an interview schedule would not be straightforward, and these difficulties seemed likely to be compounded by the nature of the participants who may have little experience or understanding of the concept. As discussed in part one and two of this thesis, empowerment is a complex concept and the difficulty in definition is well documented (e.g. Barnes & Bowl, 2001). Much of the research on empowerment has begun with direct questions about the concept and then explored areas that seemed significant as they emerged (e.g. Foster-Fishman, 1998). However, I felt that this population may find the word 'empowerment' and therefore the concept meaningless and this was born out by discussion of this with each participant at the end of the interview. Therefore, in designing the interview schedule, I endeavored to accommodate as many components as possible and relate them to the areas that would be meaningful to the participants. For example, it seemed that feelings of hope and optimism would be most apparent in thinking about the future and what it holds, rather than asking more general questions. Similarly, a focus on more specific choices about

activities or treatments, seemed most likely to generate information about feelings of autonomy and self-determination.

There were also more specific issues about conducting research into this area with this population that became apparent during the interview process. Although most participants described both positive and negative experiences about being on the units, some seemed initially to have concerns about saying the right thing or simply expressed that they didn't know or didn't mind. This raised questions in my own mind about whether potentially being used to life being outside of their control and becoming resigned to that situation leaves people ultimately unable to express that they don't like something or would like something to be different. It seemed possible that their life experiences of feeling disempowered may have resulted in difficulty expressing opinions or identifying feelings.

So, although the interview did produce information pertaining to these ideas, and interpretative phenomenological analysis allowed interpretation of more implicit communication, by choosing to adopt this approach, it is possible that issues pertinent to empowerment in relation to individual experiences of the unit may have been missed. There are several qualitative methodologies available to us and other methods of analysis might have yielded different information. In particular, an alternative way to approach this research that seemed particularly pertinent to both the subject matter and the participants, may have been to incorporate some of the ideas involved in participatory action research. Participatory action research advocates the involvement of the 'participants' in the whole process of the research, from developing research

questions to reflecting on the data (Nelson et al., 1998). Further, a “major goal of participatory action research is to help empower those with little or no power to control their lives, or to amplify their ‘voices’ and expand their ‘choices’” (Nelson et al., 1998, p.885). These two central ideas made me consider my own research process and how this may have been improved. Prior to the research it may have been prudent to have discussed the interview schedule with some of the potential participants to ensure that nothing significant had been excluded. However, as discussed above, the nature of the concept of empowerment may have made this difficult with this group. More realistic would have been to discuss the findings from the study with the participants to gain an insight into whether they felt that their experiences and perceptions were accurately represented. Although this would inevitably have required more time, I believe this may have added to the research for two reasons. Firstly, I think it may have added to the accurateness and richness of the data and, secondly, it seems that when carrying out research on the importance of the concept of empowerment, it would have been consistent to ensure that the research process itself was as empowering for the individuals as possible.

A related issue is the use of the term ‘patient’. It may be thought than in reporting a study looking at experiences of empowerment, it is incongruent to use the term ‘patient’ to describe participants. Although it can be argued that the term ‘patient’ is disempowering to the individual, introducing a power imbalance between the person being treated and the person treating, I decided this was the most appropriate term to use. I put much thought into this before starting the research and during writing up and decided to use the term ‘patient’ throughout the write up of this research for a number of

reasons. Firstly, I do not personally recognise that the term patient is inherently disempowering. We all have different 'labels' in different relationships and, as long as they are appropriate to the setting, we accept them. For example, a person may be a patient in one setting and a therapist in another. These terms do not define the individual but their role in one context. Other terms have been posited as more appropriate, such as client, service user, and consumer (e.g. Deegan, 1997). However in my view these terms all suggest an element of choice and, for the participants in this study, this seems less applicable. Indeed, in my experience, in many contexts 'patient' is the preferred term for the person concerned. Interestingly, clinicians on the units have attempted to introduce the term 'resident' but this has not been adopted by the patients. It is only possible to speculate on the reasons behind this; one possibility is that this term suggests a permanence that is incompatible with their perception of the situation; they do not consider the units to be their residence in the sense that many understand the word, that is, their home. Finally, and most importantly, participants identified themselves as patients and repeatedly used this term in referring to themselves and others. This apparently reflected their perception that they were currently unwell and in need of treatment in a hospital and therefore, as is the case in physical illness, in this context they are patients. This is an interesting and widely discussed issue (e.g. Sharma et al., 2000) and it is an area that I believe would be interesting to explore more fully with individuals with serious mental health problems.

The Dynamics of the Rehabilitation Units

Pertinent to the findings of this study were relationships that patients formed on the units, both with other patients and with the clinical team. While some experiences were

positive and helpful to the individual, others were less so, and this led me to reflect on my own observations during my time on the unit. Both patients' narratives and my own observations suggested there was often a feeling of difference and separateness between patients and staff. It seemed likely that these relationships would contribute to the atmosphere on the units and the experience of being there, for both patients and staff. I was interested to understand more about what might make committed professionals relate in a rather distant way with patients and wondered whether psychoanalytic ideas about the dynamics of institutions might usefully help in understanding some of the observed relationships.

There is extensive discussion in the psychoanalytic literature about dynamic processes in institutions. These are suggested to occur at both conscious and unconscious levels and are thought to underlie functioning in institutional environments. In particular, collective defences may emerge that protect individuals from severe anxiety sometimes generated by working in difficult environments. However, ultimately these defences, because their function is not to further the tasks of the institution, but to deflect anxiety, may themselves undermine the functioning of the units (Menzies-Lyth; 1989). For example, Donati (2000, cited in Hinshelwood & Skogstad, 2002) observed an inpatient ward of an old mental hospital. She found that staff seemed to actively discourage any lively interaction, and postulated that this was due to anxiety that liveliness might lead to loss of control and madness. These anxieties, fuelled by unconscious phantasies about the dangerousness of engaging in relationships or facilitating any form of liveliness, defensively resulted in suppression of any lively interaction. What she then observed was an environment that discouraged interactions and that she experienced as 'dead'.

Thus, while such defensive techniques may work effectively to protect staff from severe anxiety, ultimately they may be unhelpful, as they undermine interpersonal functioning in the unit.

Some of these ideas may be applied to thinking about the relationships formed on the units in this research. It is possible that the perceived apathy and distance of some clinicians may reflect underlying anxieties about working with people with serious mental illnesses, who may be perceived to be, and occasionally actually are, frightening. Thus, the observed emotional distance may act as a defence against anxieties relating to difficulties of working in this environment. This proposal is necessarily, speculative, and only more detailed and systematic observations of the dynamics of the units would allow more firm conclusions to be drawn. However, thinking about these issues in this way allows us to consider the impact of the environment from a different perspective, and to think about the impact not only on patients but also on clinicians. It has been suggested that more structured containment and support may enable clinicians in difficult environments to avoid being caught up in these institutional dynamics (Hinshelwood & Skogstad, 2002). In addition, engaging clinicians in the observational techniques used in much of this work may facilitate awareness of unconscious dynamics. This approach may not be needed or feasible in the units involved in this study but, I suggest, remains an area worthy of consideration in many inpatient settings.

Conclusions

This research explored the extent to which individuals with serious mental illness experienced inpatient psychiatric rehabilitation units as empowering. As has been

discussed, issues arose throughout the process about how to conceptualise empowerment most effectively and how to facilitate discussion of these ideas with the participants. Decisions made at every stage of the research are likely to have impacted on the findings of the study and different choices may have improved the research. In particular, I suggest that it would have been congruent with the subject matter to have included the participants more fully in the research process, for example by discussing the findings with them before writing up. Another area of potential incongruence was my choice in use of the term 'patient'. While this was an active and personal decision, I recognise that this is an issue that is often highly controversial. The issue of terminology is fraught with difficulties and is one that, I believe, would benefit from further systematic study.

Psychoanalytic theory about the dynamics of institutions offers a helpful and interesting way of thinking about the dynamics created on units such as these, and how they may contribute to the atmosphere and therefore experience of spending time there. Although my ideas in relation to these units are necessarily speculative, I think it would be valuable to explore these issues more explicitly as they may have significant clinical implications.

Finally, one of the most significant and positive findings that has emerged from this research process, has been how it has illustrated the depth of information that it is possible to elicit from people who are suffering from a serious mental illness and are currently unwell. Hopefully, this finding may actively encourage others to engage in further work with a group who are relatively neglected in the qualitative research literature.

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APPENDIX 1: INTERVIEW SCHEDULE

APPENDIX 1

Interview Schedule

Version 1

Date 06.07.05

Project ID: 05/Q0511/81

Getting to know the participant

- Demographics
- How long have you been on this unit?
- How are you finding it being here?
- Is it what you expected?
- Have you been on other units like this before? Do you find this one different or the same?
(In what way?)

Choices

I'm interested in what sort of things you do on the unit and how much you get to decide what you do?

Activities/day to day life

- What do you do on the unit?
- What things do you enjoy doing on the unit?
- What things do you not enjoy doing?
- Are there things you would like to do that you don't do?
- Can you decide what you do on the unit? What sort of things do you decide about? How did you decide? Is that what usually happens? Do you feel that you are free to do things that you want to do/when you want to do them?

Treatment

I'm interested in different things that happen here like people taking medication, seeing a psychologist, OT, groups, activities etc. Do you do any of those things?

Who decides about which things you do? Are there things you would like to change?

Do you feel you have enough of a say in what you do?

Are there things you can't decide about?
(How do you feel about that?)

When other people decide things for you what's that like?

Relationships with others
(Service users/staff)

I'm interested in how you find being on the unit with other people, both other people who are inpatients and also the staff.

- How do you get on with other people here?
- Do you have people you get on well with?
- What sort of things do you do with them? What do you talk about? Do you enjoy doing things with them/talking with them?
- Does talking to them/doing things with them make a difference to what it's like for you here?
- Do you find other people make you feel better or worse?
(In what way?)

Staff

Do you feel your relationships with staff make a difference to how you feel about being here?

Others

Do people come and visit you on the unit? (family, friends)

What's that like? What do you do when they come to visit you?

Are you able to see them as much as you like?

Feelings of Vulnerability/ Feeling valued/Identity

Has anything happened that has made you feel bad while you've been here?
Can you tell me a bit about that?

Has anything that happened make you feel better/worse?
(Can you give me examples, did anyone help you, what did they do?)

Has being on the unit changed you in any way?
(In what way?)

Can you tell me about anything on the unit that has made you feel differently about yourself? (Positive/negative?) (In what way?)

Maximising Skills

I'm interested in what you feel has been useful since you've been here and if you're getting what you hoped for. Is there anything you have learnt on the unit that you feel might be helpful after you leave here? (can you tell me about that?)

Are there things that have been not so helpful?

Are there things you would like to have been different? (things you would have liked to do that you weren't able to)

Aspirations and hope for the future

I'm interested in what thoughts you have about how things will be when you leave here.

What do you think is going to happen when you leave here? What do you think about that/feel about that?

Have you talked about it with anyone here? How was that?

What are your thoughts and feelings about the future?
(hopelessness, excitement, fear, optimism)

Do you feel happy when you think about the future?

Empowerment

I'm interested in any thoughts or ideas you might have about something people sometimes talk about and that's empowerment?
(Does the word mean anything to you? Have you heard it before?)

Finishing the interview

Is there anything else you would like to talk about?

How has it been talking about these things?

Thank you very much for talking to me.

APPENDIX 2: ANALYSIS STAGE ONE

APPENDIX 2
Interpretative Phenomenological Analysis Stage One
Identifying initial ideas

Extract from interview with participant 12

<p><i>Hopefully I'll be, hopefully the depression would have gone away and I'd be self-sufficient in a flat, independent and uh, I'd be just getting on with my life hopefully, with a job, I mean you know some sort of job, some sort of income, some sort of work that provides income for me to be self-sufficient and independent...yeah that would be a goal, yeah that may be normal to other people but that's a real target for me, that's a real challenge, for me to be in a situation like that.</i></p>	<ul style="list-style-type: none"> • <i>Hopefully depression would have gone away</i> • <i>Self sufficient in a flat, independent</i> • <i>Getting on with my life</i> • <i>Some sort of job, some sort of income</i> • <i>May be normal for other people</i> • <i>A real target for me, that's a real challenge</i>
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Extract from interview with participant 4

<p><i>Just being there, just listening, people's little problems that we're talking about sort of thing, some of them have sickness worse than me and I feel oh I'm not the only one, they've got the same problems as me, just makes me feel, you know, feel a lot better in myself that I'm not the only one, nothing to be embarrassed about, anything like that you know.</i></p>	<ul style="list-style-type: none"> • <i>Just being there, just listening</i> • <i>Some of them have sickness worse than me</i> • <i>I'm not the only one</i> • <i>They've got problems same as me</i> • <i>Feel a lot better in myself that I'm not the only one</i> • <i>Nothing to be embarrassed about</i>
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Extract from interview with participant 8

<p><i>No, it's supposed to be supportive. Meeting other patients and talking about leaving is supposed to be supportive but it doesn't work. It seems to work for the rest of the patients, they go on about problems with the hospital, when they're leaving or what they're going to do, it seems to work for them but it doesn't work for me, I can't seem to get in touch with it, in touch with their, with their, I just can't get in touch with what they say... I feel iso, I feel isolated, I just feel kind of really down.</i></p>	<ul style="list-style-type: none"> • <i>Supposed to be supportive but doesn't work</i> • <i>Seems to work for the rest of the patients</i> • <i>Doesn't work for me</i> • <i>Can't seem to get in touch with what they say</i> • <i>Feel isolated</i> • <i>Feel kind of really down</i>
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APPENDIX 3: ANALYSIS STAGE TWO

APPENDIX 3
Interpretative Phenomenological Analysis Stage Two
Identifying preliminary themes

Extract from interview with participant 12

Hopefully I'll be, hopefully the depression would have gone away and I'd be self-sufficient in a flat, independent and uh, I'd be just getting on with my life hopefully, with a job, I mean you know some sort of job, some sort of income, some sort of work that provides income for me to be self-sufficient and independent...yeah that would be a goal, yeah that may be normal to other people but that's a real target for me, that's a real challenge, for me to be in a situation like that.

- *Hope/optimism*
- *Aspirations/goals*
- *Normal for others*
- *Recognise it's a challenge*

Extract from interview with participant 4

Just being there, just listening, people's little problems that we're talking about sort of thing, some of them have sickness worse than me and I feel oh I'm not the only one, they've got the same problems as me, just makes me feel, you know, feel a lot better in myself that I'm not the only one, nothing to be embarrassed about, anything like that you know.

- *Sharing problems with others*
- *Not feeling alone*
- *Others have similar problems*
- *Feeling better about self*

Extract from interview with participant 8

No, it's supposed to be supportive. Meeting other patients and talking about leaving is supposed to be supportive but it doesn't work. It seems to work for the rest of the patients, they go on about problems with the hospital, when they're leaving or what they're going to do, it seems to work for them but it doesn't work for me, I can't seem to get in touch with it, in touch with their, with their, I just can't get in touch with what they say... I feel iso, I feel isolated, I just feel kind of really down.

- *Aware others gaining support*
- *Feeling disconnected/different*
- *Feeling isolated*
- *Feeling upset*

APPENDIX 4: ANALYSIS STAGE TWO CONT.

APPENDIX 4
Interpretative Phenomenological Analysis Stage Two continued
Identifying Common Themes

Extract from interview with participant 12

<p><i>Hopefully I'll be, hopefully the depression would have gone away and I'd be self-sufficient in a flat, independent and uh, I'd be just getting on with my life hopefully, with a job, I mean you know some sort of job, some sort of income, some sort of work that provides income for me to be self-sufficient and independent...yeah that would be a goal, yeah that may be normal to other people but that's a real target for me, that's a real challenge, for me to be in a situation like that.</i></p>	<p>Theme 3: What happens next?</p>
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Extract from interview with participant 4

<p><i>Just being there, just listening, people's little problems that we're talking about sort of thing, some of them have sickness worse than me and I feel oh I'm not the only one, they've got the same problems as me, just makes me feel, you know, feel a lot better in myself that I'm not the only one, nothing to be embarrassed about, anything like that you know.</i></p>	<p>Theme 5: Being with similar others</p>
---	--

Extract from interview with participant 8

<p><i>No, it's supposed to be supportive. Meeting other patients and talking about leaving is supposed to be supportive but it doesn't work. It seems to work for the rest of the patients, they go on about problems with the hospital, when they're leaving or what they're going to do, it seems to work for them but it doesn't work for me, I can't seem to get in touch with it, in touch with their, with their, I just can't get in touch with what they say... I feel iso, I feel isolated, I just feel kind of really down.</i></p>	<p>Theme 5: Being with similar others</p>
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APPENDIX 5: ANALYSIS STAGE THREE

APPENDIX 5
Interpretative Phenomenological Analysis Stage 3
Identifying higher-order themes

Connection vs Alienation

Extract from interview with participant 4

<p><i>Just being there, just listening, people's little problems that we're talking about sort of thing, some of them have sickness worse than me and I feel oh I'm not the only one, they've got the same problems as me, just makes me feel, you know, feel a lot better in myself that I'm not the only one, nothing to be embarrassed about, anything like that you know.</i></p>	<p>Theme 5: Being with similar others</p> <p>- connection</p>
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Extract from interview with participant 8

<p><i>No, it's supposed to be supportive. Meeting other patients and talking about leaving is supposed to be supportive but it doesn't work. It seems to work for the rest of the patients, they go on about problems with the hospital, when they're leaving or what they're going to do, it seems to work for them but it doesn't work for me, I can't seem to get in touch with it, in touch with their, with their, I just can't get in touch with what they say... I feel iso, I feel isolated, I just feel kind of really down.</i></p>	<p>Theme 5: Being with similar others</p> <p>- alienation</p>
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APPENDIX 6: ETHICAL APPROVAL

Camden & Islington Community Local Research Ethics Committee

 Room 3/14
 Third Floor, West Wing
 St Pancras Hospital
 4 St Pancras Way
 London
 NW1 0PE

 Telephone: 020 7530 3799
 Facsimile: 020 7530 3931

31 August 2005

 Ms Emily Hughes
 Trainee Clinical Psychologist
 Sub-Dept of Clinical Health Psychology
 University College London
 Gower Street
 London
 WC1E 6BT

Dear Ms Hughes

Full title of study: An exploratory study into the experiences of being an inpatient on a psychiatric rehabilitation unit focusing on issues of empowerment and self-determination.

REC reference number: 05/Q0511/81

Thank you for your letter of 16 August 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternate vice Chair, Mr Matthew Lewin.

Confirmation of ethical opinion

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

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to complete Part C of the application form or to inform Local Research Ethics Committees (LRECs) about the research. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		08 July 2005

Investigator CV		(None Specified)
Protocol	1	06 July 2005
Covering Letter		06 July 2005
Peer Review	Dr Oliver Mason	08 December 2004
Interview Schedules/Topic Guides	1 - Draft	06 July 2005
Letters of Invitation to Participants	1	06 July 2005
GP/Consultant Information Sheets	1 - Letter	06 July 2005
Participant Information Sheet	2	16 August 2005
Participant Consent Form	2	16 August 2005
Response to Request for Further Information		16 August 2005
Supervisor CV	Dr Graham Pickup	(None Specified)

Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor and the R&D Department for NHS care organisation(s) that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0511/81

Please quote this number on all correspondence

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

Enclosures:

Standard approval conditions
Site approval form (SF1)

APPENDIX 7: PARTICIPANT INFORMATION SHEET



Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

General Enquiries: 020-7679 1897
Clinical Tutor Team: 020-7679 1258
Teaching Programme Administrator:
020-7679 5699

UCL Switchboard: 020-7679 2000

Code from overseas: +44 20

Fax: 020-7916 1989

www.ucl.ac.uk/clinical-health-psycholog

The experience of being an inpatient in a rehabilitation unit Information for Participants

We are inviting you to take part in a research study about the experience of being an inpatient on a rehabilitation unit. Before you decide whether you wish to take part, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

What is the purpose of the study

We would like to find out what it is like to be an inpatient on this unit. In previous research both staff and inpatients have identified that an important aim of these services is improving how you feel. This may be achieved in many different ways. We are interested in hearing about your experience on this unit. The study will give you the chance to talk about being on the unit and the effect that this has on how you view yourself and your recovery. This information will be useful to us in thinking about how we might make things better on units like this.

What does taking part involve?

If you decide to take part in the study you will be interviewed about your experience of being on the unit. The interview will take one to one and a half hours in total and may take place over two or three separate meetings. I will tape record the interview so that I have a record of what we talked about. No one else will listen to the tape. A written record will be made of the interview and the tapes will then be destroyed. When we have finished all of our meetings you will be paid £10 for your time and effort.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to participate in the study you will be given a copy of this information sheet and asked to sign a consent form. If you decide to take part you will be free to stop the interview at any time. Deciding not to participate or withdrawing from the study will not affect your care in any way.

Will the information be confidential?

All information collected during the study will be kept in a safe place off the unit. Anything we discuss in the interview will be confidential but if we feel you are at risk of harm in any way we will discuss this with you and may need to discuss this with a member of staff on the unit. The information that we collect will not have your name or any details that might identify you on it. Tape recordings will be destroyed at the end of the study.

What will happen to the results of this study?

The results of the study will be used to help us think about making things better on units like this. When the project is finished we will send you a written summary of the results. We may also write up the results for publication in a scientific journal. It will not be possible to identify you or anyone else in any report/publication.

What are the possible risks and benefits?

We hope this project will be of benefit in informing us how we might make things better on units like this. It is possible that talking about your experiences could be upsetting. We will ensure that you are given extra support should it be needed.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of the study, the normal National Health Service complaints mechanisms should be available to you.

Who has reviewed the study?

All research projects in the NHS are reviewed by an ethics committee before they can proceed. The Camden and Islington Community Local Research Ethics Committee have reviewed this project.

Contact for further information

Please do not hesitate to contact one of the project team if you have any questions about the study.

Thank you for thinking about taking part in this study.

Emily Hughes
Trainee Clinical Psychologist
University College London

APPENDIX 8: CONSENT FORM



Sub-Department of Clinical Health Psychology
UNIVERSITY COLLEGE LONDON
 GOWER STREET LONDON WC1E 6BT

General Enquiries: 020-7679 1897
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 Fax: 020-7916 1989
www.ucl.ac.uk/clinical-health-psycholog

Centre Number:
 Study Number:
 Patient Identification Number for this trial:

CONSENT FORM

The experience of being in a rehabilitation unit

Researcher: Emily Hughes

Please initial box

I confirm that I have read and understood the information sheet dated.....for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that sections of my medical notes may be looked at by responsible individuals from the project team or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

I agree to take part in the above study

 Name of Participant

 Date

 Signature

 Name of person taking consent
 (if different from researcher)

 Date

 Signature

 Researcher

 Date

 Signature

1 for participant; 1 for researcher; 1 to be kept with hospital notes