

The role of empowerment in recovery from the experience of severe psychological distress: A grounded theory exploration

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Abstract

Empowerment has been identified as important in recovery from severe psychological distress by policy makers, mental health services and by service users. However, while there has been a huge amount of research into the role of empowerment in recovery for people with severe psychological distress, constructions of mental health and illness differ regarding the factors involved in recovery and what encourages empowerment. In addition, much of the research in this area has been conducted by professionals; the process of empowerment has yet to be explored and delineated from the perspective of the service user. This research aims to explore the role of empowerment, and conversely disempowerment, in recovery from severe psychological distress involving the experience of hearing voices or having unusual beliefs. A social constructionist grounded theory methodology was adopted using two methods of data collection: semi structured interviews with 8 service users and 12 narrative accounts written by authors in recovery. Findings indicated that participants were disempowered by invalidating events and relationships. This led participants to attempt to cope with distress and voice hearing by disconnecting from themselves, from other people and from their feelings. Compensatory fantasies regarding power were often developed as a way of coping with disempowerment. These strategies tended to be unsuccessful and participants became increasingly overwhelmed, losing a coherent sense of self and eventually became socialised into becoming a 'mental patient' and surrendering control to professionals. Conversely, participants became empowered through feeling validated in their relationships with others, with their voices and with themselves. Participants made connections socially through forming more understanding relationships, reintegrating parts of themselves and understanding voices through relating them to past experiences. Through this people gained an increased sense of autonomy and purpose, finding it easier to accept themselves and their voices. Recommendations for practice are made and areas for further research suggested.

1.0 Introduction

Empowerment, defined by the World Health Organisation (2010) as the level of choice, influence and control that people can exercise over their lives, is identified as an important factor in recovery from severe psychological distress by policy makers, mental health services and by service users. The World Health Organisation launched a partnership project with the European Commission in 2009 to focus on ways to empower people with mental health problems and their carers. Empowerment has been identified as a central priority in the Mental Health Declaration for Europe (2005), the European Mental Health Action Plan (2013) and the European Pact for Mental Health (2008), which defines mental health as a human right; one which enables people to enjoy well-being, quality of life and health and that promotes learning, working and participation in society. Rethink Mental Illness, a charity supporting people who experience severe psychological distress, argues that the ultimate goal for people using mental health services is to regain control and independence and that professionals need to support people to increase their levels of empowerment (Rethink, 2012).

However, while there has been a huge amount of research into the role of empowerment in recovery for people with severe psychological distress, the process of empowerment has yet to be delineated. Furthermore, in the mental health field constructions of mental health and illness differ widely; as do conceptualisations about how the self develops, what causes psychopathology, what the factors involved in recovery are and what factors facilitate empowerment. This research study will attempt to synthesise these divergent theoretical constructions, as well as consider gaps in understanding by exploring the experiences that participants found to be empowering or disempowering during times of severe psychological distress and how these impacted on them. A grounded theory of this process will be produced to increase understanding of how empowerment and recovery can be supported from the perspective of service users.

1.1 Terminology

Labels and identities constructed through language impact on quality of life and understandings of experience (McLaughlin, 2009). The National Involvement

Partnership (2014) surveyed users of mental health services and found that although service users had different preferences about the language and terminology used, it was generally considered important that language reflected a position of equality and challenged stigma. For some respondents, the use of the term 'patient' was felt to pathologise experience. After considering language, the term used in this research is 'people with experience of severe psychological distress.' This identifies that the degree of distress is meaningful (as everyone experiences some level of psychological distress). Rather than the voice hearing per se being the cause of the distress, this recognises that it is the nature of the voice and the response to voices by the self and others that become distressing. Distress may affect emotional, social, relational or physical functioning. The term severe psychological distress is preferred to 'mental illness' which arguably pathologises emotional experiences through focusing primarily on biological, rather than psychosocial factors.

1.2 The social construction of 'mental illness'

Social constructions of 'mental illness' vary within and between cultures and over time. What is regarded as an illness in one culture may be constructed as advanced spiritual insight in another (Bhargav, Jagannathan, Raghuram, Srinivasan, and Ganadhar, 2015) or as part of normal human experience (Romme, Escher, Dillon, Corstens, and Morris, 2009). Sociologists, critical psychiatrists and psychologists question whether voice hearing should be regarded as a psychiatric symptom. Between 4-8% of the population hear voices without experiencing distress or reduced functioning (Johns and van Os, 2001; Romme and Morris, 2013). However, research suggests that more negative stereotypes are held about psychiatric diagnoses involving voice hearing than other diagnoses, such as depression and anxiety. Voice hearing is also more likely to be constructed as 'madness' in the western world, contributing to stigma (Schulze and Angermeyer, 2003). There is a public misconception of an increased likelihood of violent behaviour by voice hearers, out of proportion with the reality of risk (Penn, Kommana, Mansfield, and Link, 1999; Crisp, Gelder, Rix, Meltzer and Rowlands, 2000) and these beliefs are thought to be perpetuated by media constructions of 'mental illness' (Corrigan and Watson, 2004; Williams and Taylor, 1995). Disempowering attitudes have been found to be held by both the general public and professionals regarding

authoritarianism and benevolence; with a misguided and stigmatising belief that individuals with mental health problems lack capacity, responsibility and need paternalistic care (Corrigan, 2000; Corrigan and Watson, 2004; Angermeyer and Matschinger 1997).

Within the developed world different frameworks for understanding severe psychological distress include the medical model, the psychotherapeutic model and the social model; the way that the causes of severe psychological distress are constructed within these frameworks impact on the treatment offered. The medical model, while acknowledging the impact of social and psychological issues constructs symptoms as biological 'disorders'; treatment therefore focuses on diagnosis and medication. The Diagnostic and Statistical Manual of Mental Disorders, currently in the fifth edition (DSM-5) (American Psychiatric Association, 2013) is used to classify and diagnose and to make recommendations for treatment.

Psychotherapeutic theorists, sociologists and psychiatric survivors challenge the validity of diagnostic categories (Sullivan, 1956, 1962; Romme, et al, 2009; Dillon, Johnstone and Longden, 2012). Instead, severe psychological distress is conceptualised as an understandable response to overwhelm and trauma (Dillon, Johnstone and Longden, 2012). The social model of disability has also been adopted as a framework to understand psychological distress (Mulvany, 2000; Hughes and Paterson, 1997). This model reframes disability by focusing on the role played by a disabling social environment (Oliver, 1990; Barnes, 1998; Shakespeare and Watson, 1997), thereby enabling people experiencing severe psychological distress to communicate and understand the damage caused by the disabling response in society. This emphasises the significance of social barriers rather than personal impairment (National Involvement Partnership, 2014).

1.3 The recovery movement

Civil rights, protest and women's liberation movements of the 60's and 70's advocated change to social policy, such as in housing and employment while service user groups challenged stigma (Warner, 2009). In this period of challenging previously accepted social positions, service users voiced

dissatisfaction with the effectiveness of mental health services. Alongside this, individuals described their own personal stories of recovering from severe psychological distress. This led service users to campaign for improved services and for a more positive approach to psychological distress recognising the possibility or probability of recovery. This social context influenced the development of the recovery model during the late 1980's (Deegan, 1988; Anthony, 1991, 1993; Barton, 1999; Adler, Pajer, Ellison, Dorwart, Siris, Goldman, Lehman, and Berlant, 1995). From the 1970's – 90's international quantitative studies from the World Health Organisation found greater levels of recovery than previously anticipated in the developed world (Wood, 1980; Harrow and Jobe, 2007), improving the expectations of professionals, academics, service users and their families. It is now recognised that a substantial group of people experiencing severe mental distress can go on to cope with unusual experiences and live meaningful, productive lives (Lysaker and Roe, 2016; Silverstein and Bellack, 2008). Although, a 26 year longitudinal study has found that outcomes are still significantly lower for those given a diagnosis of 'schizophrenia' than other psychiatric diagnosis except for dementias (Jobe and Harrow, 2010).

1.4 Models of recovery

The construct of recovery has been debated. Sociologist Pilgrim (2008) outlines three different recovery approaches: recovery from illness through successful treatment, recovery from impairment through successful rehabilitation and recovery from invalidation through survival; these frameworks affect the construction and response to psychological distress. These models are explored in the literature review; recovery from illness relates to the medical model, recovery from impairment to the recovery model and recovery from invalidation to the survival model.

Davidson and Roe (2007) writing from a social psychiatry and rehabilitation approach distinguish between 'recovery from' and 'recovery in' severe psychological distress. The medical model is a 'recovery from' perspective; within this framework recovery is thought to be evidenced through reduced distress, significant reduction in symptoms and a return to a previous level of functioning, whereas the social-psychiatry approach, (Anthony, 1991,

1993), reflects a 'recovery in' approach; a remission of 'symptoms', productive activity, the independent management of everyday needs, leisure activities, satisfying relationships and working collaboratively with professionals (Lieberman, 2008). A further distinction has been made between clinical recovery and personal recovery (Slade, Amering and Oades (2008); clinical recovery being a reduction in voices and unusual ideas and personal recovery a subjective definition of recovery.

The psychiatric survivor model emphasises social justice and political change. Survivors critique social psychiatry for retaining an invalidating professional authority (Coleman, 1999). Coleman, a former service user and founder member of the Hearing Voices Network argues this model of recovery still emphasises 'impairments' which are to be treated by 'experts'. It has been suggested that the term 'recovery' implies something to be recovered from, rather than learned about and integrated into the self (Adame and Knudson, 2008).

1.5 The role of empowerment in recovery

Empowerment has been recognised as significant in the recovery process and identified as reducing the negative effects that psychological distress has on quality of life (Chou, Shih, Chang, Chou, Hu, Cheng, Yang and Hsieh, 2012). Research from a perspective of social rehabilitation found that empowerment is enhanced through encouraging independent action (Rogers, Chamberlin, Ellison and Crean, 1997), confidence in one's decisions (Corrigan, Faber, Rashid, and Leary, 1999) and self-efficacy over health care and social circumstances (Chamberlin, 1997; Fisher, 1994). It has been suggested that a sense of powerlessness can be reduced through decreasing barriers to decision making (Seligman, 1975; Bandura, 1977). A relationship has also been found between empowerment and having larger support networks and resources (Corrigan et al, 1999). Increasing empowerment has been related to a reduction in distress caused by symptoms, improved quality of life, better social support and an increase in self-esteem from a perspective of health promotion (Sakellari, 2008). Service users have stressed the importance of an increased ability to cope, improved control over life (Chamberlin, 1997; Schofield, 1998; Young and Ensing, 1999) and being treated as an individual (Chamberlin, 1997; Fisher, 1994). Rehabilitation and being taught 'how to

recover' has been identified as empowering (Petersen, Frills, Haxholm, Nielsen, and Wind, 2015). There is a relationship between service user's ratings of their own sense of empowerment and outcomes, quality of life (Kosciulek and Merz, 2001), social support (Beale and Lambric, 1995), self-esteem, (Segal, Silverman, and Temkin, 1995) and level of symptomatology, (Roth and Crane-Ross, 2002).

Conversely disempowerment has been implicated in relapse through inducing helplessness (Seligman, 1975), uncontrollability (Rotter, 1966), powerlessness (Seeman, 1959,) and low self-efficacy (Bandura, 1977). Research concerned with public health highlights that disempowerment can be related to depression (Link and Phelan, 2002). Disempowerment is associated with lower quality of life (Rogers et al, 1997), feeling like an object of medical treatment (Chamberlain 1997, Fisher, 1994), reduced self-efficacy (Vauth, kleim, Wirtz, and Corrigan, 2007), increased stigma, poorer social networks, internalised stigma and discrimination (Sibitz, Amering, Unger, Seyringer, Bachmann, Schrank, Benesch, Schulze and Woppmann, 2011).

1.6 Research gap / rationale for study

While social psychologists, psychotherapists, social psychiatrists, sociologists, people experiencing psychological distress and policy makers identify empowerment as having a significant role in recovery, there remains a lack of research on the factors that encourage empowerment and how these are experienced by individuals experiencing severe psychological distress. It has been suggested that there is still a need for a conceptual theory to facilitate the process of recovery (Wisdom, Bruce, Saedi, Weis and Green, 2008).

Despite service users increased involvement in research, empowerment remains a term often defined, assessed and evaluated by professionals; it has been suggested that the research literature in this field is dominated by professionals and academics, marginalising the voices of service users (Geekie, 2004). Invisible populations can lack the opportunity to express experiences (Stone, 2003; Fisher and Ragsdale, 2005). This research focuses on the experience of the service user, both those who have 'recovered' and those who continue to experience severe psychological distress.

1.7 Aims and objectives of study

The aims of the study are:

- 1) To explore what is experienced as empowering and disempowering and the role this has on the experience of severe psychological distress; specifically recovery and relapse
- 2) To develop a grounded theory of this process

A further objective of the research is to 'give voice' to service users, a marginalised group, as this can be a first step towards empowerment (Cosgrove and McHuge, 2000).

It is hoped that delineating these processes will be helpful for service users and survivors, clinicians and policy makers to provide support, enable independence and plan services. The potential benefits of understanding the role of empowerment seem especially significant given that studies indicate that those with a diagnosis of 'schizophrenia' have a lower quality of life than the general population and those with another mental or physical health diagnosis (Sibitz et al., 2011).

2.0 LITERATURE REVIEW

2.1 The prevalence of severe psychological distress

A recent review commissioned by the Department of Health into the prevalence of 'schizophrenia' and 'psychosis' in England (rather than the UK) found an overall annual incidence of 32 incidents per 100,000 people and a greater incidence in men until the age of 45 years when the gender difference decreased (Kirkbride, Errazuriz, Croudace, Morgan and Jackson, 2012). 'Schizophrenia', affective psychosis (including psychotic depression and bipolar disorder) and broader psychotic disorders were categorised separately in terms of analysing data. 'Schizophrenia' had an annual incidence rate of 15 per 100,000 people with a much higher incidence in young men and black and ethnic minority groups and amongst those in more socially disadvantaged communities. 'Affective psychoses' had an incidence of 12 per 100,000 people. Men and women had a similar incidence and for both genders this decreased with age. The incidence was significantly higher amongst black and ethnic minority groups for both 'schizophrenia' and psychosis. The average age of onset was mid to late twenties with earlier onset for non-affective disorders and for women. Approximately 1% of the population will develop psychosis over their lifetime (NICE guidelines, 2014). 'Schizophrenia', 'bi-polar disorder' and 'psychotic disorders are diagnoses that are constructed and offered, rather than reflecting specific syndromes that have developed.

Voice hearing is not always perceived negatively by the voice hearer and for some people this does not cause distress or affect functioning (Barker, Lavender and Morant, 2001; Mawson et al, 2011). Particular factors increase the likelihood of a transition from voice hearing to experiencing severe psychological distress. An experience of trauma increases the likelihood of severe psychological distress. Research findings suggest that 70% of voice hearers experience voices related to trauma (Romme et al, 2009; Read, Mosher and Bentall, 2004). Adults who were abused in childhood are 9.3 times more likely to develop psychosis and for those who have suffered severe abuse the risk of psychosis increases to 48 times (Janssen, Krabbendam, Bak, Bijl, De Graaf, Vollebergh and van Os, 2003). Other factors contribute to an experience of severe psychological distress following voice hearing including

the response of others to voice hearing, a loss of former social relationships and an increase in isolation; the number of social contacts and relationships is significantly lower than amongst the general population (Davidson, Hoge, Godleski and Griffith, 1996; Lester and Tritter, 2005; Onken, Craig, Ridgeway, Ralph, and Cook, 2007). An internalisation of stigma also affects the sense of self and increases the likelihood of distress (Goffman, 1963; Sibitz et al., 2011; Corrigan, 1998).

2.2 The psychosocial impact of living with severe psychological distress

Personal accounts of severe psychological distress describe a loss of or 'nothingness of the self' which occurs separately from other symptoms of psychosis (Kean, 2009). Others describe a duality of the self, separating a real or 'well' self and an 'ill' self which unsettles the sense of self and feels unrecognisable (Wisdom, Bruce, Saedi, Weis and Green, 2008). The self is not shattered as participants are aware of changes in identity, but is disrupted (Lysaker, Buck and Lysaker, 2012). Service users describe it as a frightening experience affecting self-image. Maintaining a sense of meaning and identity is a struggle when everything feels fragmented (Onken et al, 2007).

The experience of being perceived as having a 'mental health problem' can lead to both self-stigma and stigma from wider society. Self-stigma profoundly effects the sense of self, preventing the formation of a positive identity, self-acceptance, low self-esteem (Corrigan, 1998) and a lack of self-efficacy (Vauth et al, 2007; Corrigan, Watson and Barr, 2006; Link, Cullen, Frank and Wozniak, 1987; Ritscher and Phelan, 2004). Stigmatisation has a negative effect on recovery, making it hard to participate in work and education (Petersen et al, 2015). A qualitative analysis by Judge, Estroff, Perkins, and Penn (2008) confirmed findings by Nelson, Lord, and Ochocka (2001) that a lack of motivation, sometimes due to fearing failure and low expectations, affected recovery as did a lack of control over treatment, stigma, limited resources and poverty. A negative evaluation of the self has been linked to increased risk of relapse (Holding, TARRIER, Greg and Barrowclough, 2013). This has a detrimental effect on identity and contributes to a sense of helplessness and hopelessness (Chamberlin, 1997; Fisher, 1994; Young and Ensing, 1999;

Koehn and Cutcliffe, 2007; Schrank, Bird, Rudnick and Slade, 2012). It can also reduce perceptions of having personal responsibility (Slade, 2009). Challenges to recovery include isolation and people struggle with a lack of social relationships and opportunities (Lester and Tritter, 2005; Onken et al, 2007). Involvement in the community is difficult to undertake, through lack of resources, lack of housing and services and stigmatization (Browne, Hemsley and St John, 2008). Although service users have highlighted that involvement in community activities and relationships assist recovery and there is recognition that social integration supports empowerment and reduces risk of isolation, few service users are actually involved in such activities (Petersen et al, 2015). For many experiencing psychological distress, social contact can feel disempowering and problematic. Social contact tends to be limited, occurring within family networks or with other acquaintances experiencing psychological distress (Breier, Schreiber, Dyer and Pickar, 1991).

Experiences such as social inequality, racism, poverty, discrimination, domestic violence and neglect have been found to have a detrimental impact on psychological wellbeing (Bentall, 2006; Harper, 2011; Pilgrim and Bentall, 1999). This can result in reduced opportunities, social power and poverty (Lord and Dufont, 1996). A recent health audit found that 80% of homeless people reported a mental health issue; 45% had been formally diagnosed with a 'mental health problem', highlighting the link between homelessness and psychological distress (Homeless Link, 2014). A vicious circle can be formed as poverty, social issues and psychological distress reinforce difficulties and make recovery more challenging.

2.3 Recovery from severe psychological distress

The International Study of Schizophrenia (Hopper, Harrison, Janca and Satorius, 2007) found rates of recovery from 'schizophrenia' to be significantly higher in the developing world, while mortality rates are lower (Harrison, Hopper and Craig, 2001; Warner, 2009). Furthermore, psychiatric patients are significantly more likely to be in full-time employment, and there are higher rates of social inclusion and increased engagement of families in treatment. Nearly three-quarters of Indian participants with a diagnosis of schizophrenia

were married, compared with a third of people in the developed world (Warner, 1994). Warner suggests that pessimism about the possibility of recovery may not be internalised in the same way in developing countries (Warner, 2009). The International Study of Schizophrenia (Hopper et al, 2007) concluded that family involvement in developing countries may be more significant with less expression of criticism. It is suggested that recovery rates in the west are negatively affected by the impact of stigma (Sartorius, 2002) and the detrimental effects of major tranquilizers (Lilienfeld, 2007; Breggin, 1983; Sartorius, 2002).

Research from social psychology and social work identifies that recovery and empowerment are linked and that empowerment supports the recovery process through increasing decision-making capacity, confidence, and advocacy (Rogers, Chamberlin, Ellison and Creen, 1997) reducing psychological distress and improving coping resources (Sakellari, 2008, Corrigan, 2004; Linhorst, Hamilton, Young and Eckert, 2002; Rogers et al., 1997), findings which are supported by Rethink, (2010) and World Health Organisation, (2010). Constructions of empowerment vary between disciplines and the meaning has changed over time. Bartunek and Spreitzer (2006) argue that during the 1960's civil rights movement, the focus was on strengthening the power and pride of under-represented groups. In the 1970's there was an increased focus on human welfare, whereas in the 1980's and 1990's empowerment became associated with improving productivity and taking responsibility. The constructions of severe psychological distress, empowerment, recovery and treatment will now be considered from the perspective of the service user, the medical model, the psychotherapeutic model and the sociological model.

2.4 Constructions of severe psychological distress, treatment and recovery

2.4.1 The service user/survivor approach

It is suggested that those experiencing severe psychological distress construct themselves and their distress in three different ways; as 'patient', 'consumer' or 'survivor' (Speed, 2005). Those who identify with being a patient accept the medical model and regard aetiology as biological. A consumer discourse

involves an integration of predominantly medical explanations with a recognition of the influence of life events and history, whereas survivor discourse rejects and challenges the medical model and personal history biography is used to develop understanding of experiences (Speed, 2005).

Unlike the social model of disability which was developed by people experiencing disability (Oliver and Barnes, 2012), mental health service users have struggled to shape policy (Thomas, 2007 and Beresford, 2016). There have been some positive developments in service user involvement; service users and public funding bodies have increasingly recognised the importance and value of service user involvement in the development of services and research and applications for research in the UK must now evidence service user involvement or justify a lack of involvement. The inclusion of service user perspectives has been demonstrated to improve the quality and relevance of research (Staley, 2009; Staniszewska, Herron-Marx, and Carole, 2008), through producing more credible research findings (Boote, Baird and Beecroft, 2010). Talking to researcher/service users enables participants to be more candid about experiences (Faulkner and Williamson et al, 2010) and a stronger focus is maintained on using research to benefit service users (Staley, 2009). The impact is found to be greater if service users are involved throughout projects (Barber, Beresford, Boote, Cooper and Faulkner, 2011) and some organisations such as Involve (National Institute for Health Research, 2004; 2005: 2009) encourage projects that are user controlled, with service users being actively involved in the design, planning, analysis and write up of research studies.

However, it has been suggested that the level of service user involvement remains consultative, and that despite claims to involve service users in mental health research, this continues to be 'on' and not 'with' service users (Beresford and Russo, 2014; Milton and Bracher, 2013). Service user researchers argue that their expertise continues to be viewed as less authoritative by academics and policy makers and that the basic assumptions of scientific academic research, which values objectivity and neutrality, results in experiential knowledge being devalued in the arenas of policy and academia (Beresford, 2003, 2016). Fears have been expressed that service user knowledge is 'co-opted' (Penney and Prescott, 2016) with service users

struggling to maintain control over the knowledge produced. Instead, more powerful groups are in a position to interpret priorities in a way which makes these less threatening to the status quo (Penney and Prescott, 2016). Priorities established by service users, such as hope and recovery are suggested to be co-opted by policy makers and the potential power of these concepts diluted. It has been argued that through this process, research may not genuinely empower service users (McWade, Milton and Beresford, 2015). The difficulties in ensuring that service user knowledge informs policy strengthens the need for research that significantly involves service users and which is grounded in their experience.

'Mad studies' is the bringing together of knowledge by psychiatric survivors and critical researchers and academics to form a radical discourse challenging the medical model (LeFrancois, Menzies and Reaume, 2013). This new discipline provides a framework for an alternative to psychiatry developed from survivor movements; instead of following the agenda of academics and policy makers, service users themselves set the priorities and develop the arena of discourse to prioritise the voices of those with lived experience (Beresford, 2016). This may provide a more positive and radical framework for service users to construct discourses and pursue an alternative agenda.

2.4.2 Views on Treatment

An essential component of empowerment for service users is involvement in the planning and delivery of treatment (Crane-Ross, Lutz, and Roth, 2006; Dickerson, 2006; Kosciulek and Merz, 2001). Research indicates that increased involvement in services is a number one priority for service users who believe they lack sufficient opportunity and information to make informed choices about care (Thornicroft and Tansella, 2002).

Importance has been placed on professionals being good communicators, providing helpful information and encouraging and supporting service user involvement in care planning; these qualities are influential in terms of empowerment and recovery (Walsh and Boyle, 2009). A relationship has been found between the extent to which people participate in service decisions and the level of reciprocity and respect between service users and professionals (Crane-Ross et al, 2006; Torpor, 2001). Service users argue that

they receive inadequate information about side-effects (Rose, Ford, Lindley, Gawith, and the KCW Mental Health Monitoring Users' Group (1998) and would like increased control and choice over medication (Samele, Wallcraft, Naylor, Keating and Greatley, 2007). In addition many identify an over-reliance on medication, and feel that access to psychological therapies is limited (Service User Research Enterprise, 2007).

Critical psychologists and social researchers describe the distress caused by the iatrogenic effect of treatment (Spandler and Stickley, 2011); medication may reduce psychotic symptoms but the side effects of medication have a negative effect on quality of life (Staring, Van der Gaag, Van den Berge, Duivenvoorden, Mulder, 2009). Research by Killian, Lindenbch, Lobig, Matthias, Petscheleit, and Angermeyer, (2003) suggested that most participants passively accepted treatment, although nearly a quarter indicated that treatment brought no benefit. It has been found that difficulties about medication were not taken seriously by professionals (Lester and Tritter, 2005). However, relating psychological difficulties to life experiences and developing self-awareness can increase the likelihood for recovery (Longden, Corsten, Escher and Romme, 2012; Stainsby, Sapochink, Bledin and Mason, 2010).

Service user narratives describe gaining a sense of empowerment through relating voices to personal experience, rather than being a victim of voices and that it is validating to meet with professionals who accept voices as real (Romme et al., 2009). This contrasts with cognitive behavioural approaches which challenge the 'realness' of voices, rather than engaging with them. Interestingly, recovery narratives describing what is empowering therapeutically, focus on professional's personal approach, rather than on what has been 'done' or 'treatment' (Romme et al, 2009). Service users have recognised the importance of having an ally providing external authority to assist them within the system, when they themselves lack power (Lester and Tritter, 2005). For some service users it is important to 'own' their experiences which forms part of their identity and can be empowering (Lester and Tritter, 2005).

Feeling socially connected, talking and being listened to are identified as very significant (Perry and Gilbody, 2009; Hyde, Bowles and Pawar, 2015) as well as sharing with other service users (Hyde et al, 2015; Waite, Knight and Lee, 2015). This interaction was experienced as validating and provided a sense of belonging. For those with supportive families, this is identified as significant in recovery through providing them a sense of still being present (Hyde, Bowles and Pawar, 2015). Conversely, a lack of social relationships and opportunities are experienced as difficult (Lester and Tritter, 2005). However, the prospect of involvement in the community often feels frightening and lonely (Lester and Tritter, 2005). Acceptance was assisted by positive social relationships and increased resilience (Waite et al, 2015). The way that one relates intrapersonally is regarded as having a significant impact on recovery, which is made more difficult if distress leads to internal and external feelings of shame and criticism (Turner, Birchwood, Jackson and Jones, 2013). Experiencing meaning in life and being able to define one's own experiences (Romme et al, 2009; Onken et al, 2007) is important. Services users recognise the importance of having motivation and free will to make changes (Nelson et al, 2001; Petersen et al, 2015) and believing that change is possible, (Perry and Gilbody, 2009).

2.4.3 How recovery is constructed

Service users construct recovery as an individual process, significantly influenced by personal relationships and the wider community. It is important to the service user/survival movement that individuals have ownership over their personal recovery and that recovery is not defined by professionals or academics.

Rediscovering one's self, regaining or developing a new positive sense of self and regarding oneself with dignity, self-respect (Kogstad, Ekeland, and Hummelvoll, 2011; Wisdom et al, 2008, Waite, Knight and Lee, 2015) and acceptance is valued as part of recovery (Waite et al, 2015). Service users have associated recovery with understanding oneself with compassion which can reduce perceptions of threat, minimise risks of depression and improve self-esteem (Laithwaite, O'Hanlon, Collins, Doyle, Abraham, Porter, and

Gumley, 2009). Some service users have related the experience of psychosis to personal growth through gaining individual strength, making changes and beginning opportunities (Waite et al 2015).

2.5 Constructions of severe psychological distress, treatment and recovery

2.5.1 The medical model

The medical model remains the dominant discourse within Western psychiatry, for psychiatrists, many psychologists, therapists and nursing staff, defining severe psychological distress as a brain disorder with an organic cause. Consideration is taken of social and psychological factors, but the priority is to clinically diagnose and provide medical treatments, including involuntary treatment (Barker, Lavender and Morant, 2000). The assumption of the medical model is that 'something is wrong,' rather than finding out 'what has happened' to the person (Pilgrim, 2014) and the aim of treatment is to 'cure' or manage symptoms more effectively. Qualitative and quantitative analysis suggests the significance given by psychiatrists to the social and psychological context of a 'disorder' is highly individual (Kilian, Lindenbach, Lobig, Uhle, Petscheleit and Angermeyer, 2003).

Research into the neurobiology of severe psychological distress is ongoing. Areas of interest include genetic contributions, abnormal brain structures and function, dysfunctional neuro-circuits, dysregulated synapses and abnormal neurotransmitters (Sekar, Bialas, de Rivera, Davis and Hammond et al, 2016). It has been suggested by Konstantinos and Shanker (2016) that 'psychotic symptoms' are associated with aberrations in the dopaminergic system; other neurotransmitters cited as potentially significant include cortisol (Pruessner, Bechara-Evans, Boekestyn, Iyer, Pruessner, Malla, 2013) glutamate, glycine and noradrenaline. However, the role of these neurotransmitters in severe psychological distress is as yet unclear (Konstantinos and Rohit, 2016). Over activity of dopamine has been linked to an increased risk of severe psychological distress (Kapur and Remington, 2001) but the dopamine hypothesis has been criticised by critical psychiatrists who argue that this is unsupported by any evidence (Moncrieff, 2009). Pies, an eminent psychiatrist

and professor of psychiatry (2011) has also described the chemical imbalance theory as an 'urban legend' that was never taken seriously by 'thoughtful psychiatrists'.

Gold, a professor in philosophy and psychiatry (2009) suggests that neurobiology alone cannot explain a psychological experience. No evidence has been found of biological causes of any mental disorder, despite advances in neuroscience (Gold, 2009). Furthermore, no biological differences have been identified that enable diagnosis of mental 'disorders' or can distinguish one 'disorder' from another (Deacon, 2013). Attempts to explain these inconsistencies focus on the suggestion that 'schizophrenia is a heterogeneous group of disorders representing different aetiologies, courses and outcomes' (Tandon, Nasrallah and Keshavan, 2009). However, there are no definitive biological underpinnings of severe psychological distress; diagnosis relies solely on clinical presentation (Konstantinos and Rohit, 2016).

2.5.2 Treatment

The NICE guidelines on 'psychosis' and 'schizophrenia' in adults recommend that service users receive a multi-disciplinary comprehensive assessment and care planning approach, and that professionals work in partnership with service users around medication ensuring service users are provided with the necessary information to make informed decisions. While psychotherapeutic approaches, such as cognitive behaviour therapy for psychosis have become more established and are described as an 'indispensable part of treatment' (NICE guidelines, 2014) medication remains primary. In first episode psychosis, a combination of oral antipsychotic medication is recommended alongside cognitive behavioural therapy and family intervention to develop coping strategies, reduce stress and improve functioning. NICE guidelines state there is little evidence that cognitive behaviour therapy or family interventions are effective without medication.

While proponents of the medical model perceive medication as promoting recovery and empowerment, critics argue that high levels of medication increase compliance and/or sedation (Johnstone, 2000; Breggin, 1983). Common side effects of major tranquillisers or neuroleptics include feeling emotionally deadened and restless (akathisia), tardive dyskinesia

(uncontrollable physical movements which can remain even after medication has stopped), weight gain and sexual dysfunction, cognitive side effects such as poor concentration and apathy (Johnstone, 2000; Lilienfeld, 2007; Breggin, 1983; Sartorius, 2002). These all increase feelings of alienation from self and others, alter functioning and physical appearance and can be stigmatising and distressing (Johnstone, 2000). The benefits of medication are hotly debated by critical psychiatrists (Rapley, Moncrieff and Dillon, 2011; Speed, Moncrieff and Rapley, 2014) and medication is not the treatment of choice, for many service users (Rappaport, Hopkins and Hall, 1994), especially if people have a good prognosis. In addition, medication may actually increase the risk of psychosis (Warner, 1994).

Deacon (2013) suggests that current medications have few advantages over those used in the 1950's with service users continuing to experience a range of side effects. Clozapine, with a range of unpleasant and potentially dangerous side-effects, is used to treat service users described as 'treatment resistant' when all other treatments have 'failed,' However Clozapine does not have the same effects in everyone and those who do not respond to Clozapine are described as 'ultra resistant' (Mouaffak, Tranulis, Gourevitch, Poirier, Douki, Olie, Loo, Gourion, 2006). Amongst those who take medication as prescribed, 50% still relapse (Caseiro, Perez-Iglesias, Mata, Martinez-Garcia, Pelayo-Teran et al, 2012). Deacon (2013) argues that it is the marketing of medication which has changed with major tranquilisers now being sold as 'anti-psychotics,' although these medications reduce symptoms rather than alter brain functioning. The lack of progress in finding more effective medical treatments has led to pharmaceutical companies significantly reducing the funding put into developing new medications to 'treat' voice hearing (Fibiger, 2012).

It has been argued that the assumptions of the medical model – that psychological distress has an organic explanation - induces hopelessness, belief that medication must be remained on for life (Boyle, 2002; Johnstone, 2000; Breggin, 1983), while acceptance of a diagnosis has been associated with a lower perceived control over the 'illness' (Romme et al., 2009; Johnstone, 2000). The notion of psychological distress as an 'illness' encourages the perception that individuals lack control over their wellbeing by psychiatric services, services users and wider society (Bentall, 2004). This can

encourage dismissive attitudes and the infantilising of people in psychological distress (Mehta and Farina, 1997; Johnstone, 2000).

Critical psychologists and sociologists have argued that the psychiatric system reflects class, gender and cultural biases with boundaries of dysfunctional behaviour being agreed according to dominant assumptions of normality. Foucault (1991) argued that power is pervasive and transmitted through accepted forms of knowledge and scientific understanding which becomes adopted as truth. The power granted to psychiatry results in the 'cultural authority of clinical discourse' (Houghton, 1995) with these assumptions becoming accepted, trusted and internalised by the general population (Crowe, 1998; Bentall, 2004; Read, 2004). It has been suggested that those whose behaviour does not conform, have a higher probability of being treated for mental illness (Reissman, 1992).

The bio-medical model and social medical model as well as some psychological perspectives have been criticised for being individualistic, shifting the locus of blame onto the individual rather than understanding the context, content and experience of the person and appreciating the significance of trauma (Boyle, 2011; Harper 2011). Recent research suggests practitioners may prescribe higher levels of medication and in combination, in a pre-emptive way, to avoid acute psychotic episodes (Robinson, Schooler, John, Correll, Marcy, et al, 2015).

A meta-analysis found that 75% of the response to a drug is due to the placebo effect (Kirsch and Sapirstein, 1998) and links have been found between the expectations that drugs will work and the outcome. In a trial of Reboxetine, 90% of patients who reported very positive expectations responded to treatment compared to 33.3% of those with low expectations (Krell, Leuchter, Morga, Cook and Abrams, 2004). There is neuroscientific evidence to suggest that a placebo effect can be caused by the symbolic significance attached to any object or event (Brody, 2000). The objects associated with medicine and healing are powerful and can contribute to 'symptom reduction' through a conditioned response, such as the taste and colour of pills and even white coats and stethoscopes (Benedetti, 2013). The placebo effect can also be influential in therapeutic and psychiatric settings;

Benedetti (2013) suggests that treatment, both medical and therapeutic, occurs in a complex, psychological context which can be as significant as the treatment or therapy itself. The social interaction and connection between doctor and patient is significant with positive outcomes being influenced by the expectations, trust and hope held by the patient towards the doctor and the empathy and compassion shown by the doctor to the patient. The level of trust felt towards the doctor can influence the patient's positive expectations that healing will occur, which in turn can increase personal motivation (Price, Finniss, and Benedetti, 2008) while reducing negative and self-defeating thoughts (Stewart-Williams and Podd, 2004). This is a powerful process.

2.5.3 How recovery is constructed

The biomedical model constructs severe psychological distress, such as 'depression' and 'schizophrenia' as 'mental illness'; as less emphasis is placed on the significance of social and psychological influences, biological treatment is thought to be most appropriate (Andreasen, 1985; Lilienfeld, 2007). Within this framework recovery is constructed as a cessation or significant reduction of symptoms and a resumption of usual levels of functioning.

The aim of the medical model is not empowerment in terms of increased autonomy or self-awareness, although patients are encouraged to take responsibility for medication. Proponents of the medical model, such as Tallis (2004), a clinical psychologist, suggest that this offers a framework to understand psychological distress which reduces stigma. Empowerment arguably comes through having an explanation of confusing experiences and some service users describe relief from learning about their 'disorder' (Sartorius, 2002).

2.6 Constructions of severe psychological distress, treatment and recovery

2.6.1 Psychological models

Psychological perspectives are broadly divided between psychodynamic, humanist/existential and cognitive behavioural approaches. Although cognitive behaviour therapy is a psychological approach, it shares a positivist epistemology with the medical model.

Cognitive model

Cognitive behavioural therapies are psychological but also positivist, regarding voices and unusual experiences as symptoms. Cognitive models suggest that some people are more vulnerable to psychological distress, a vulnerability that is constructed as partly hereditary and biological and which can be triggered after experiencing stress levels beyond the coping capabilities of the person (Zubin, 1987); the stress vulnerability model. Cognitive theorists argue that stressful events can trigger core beliefs or schemas which cause psychological distress, such as persecutory thoughts. Although, some people are regarded as more vulnerable to severe psychological distress, it is the appraisal of experiences that are key and which can result in distress (Birchwood, 2000; Haddock and Slade, 1996).

There is a broad belief across amongst other psychological approaches that high levels of stress and trauma alone can lead to severe psychological distress; distress is constructed as a response to problematic relationships and events rather than biology.

Psychodynamic model

Freud (1949) originally constructed severe psychological distress as a response to early trauma, specifically sexual trauma. However, he later abandoned his 'seduction hypothesis' arguing instead that the sexual drive, rather than trauma, was the source of all conflict. However, contemporaries of Freud, most notably Ferenczi, continued to argue that psychopathology was primarily caused by emotional and sexual trauma in childhood (Ferenczi,

1933/1980). The notion of trauma was expanded by object relations theorists, such as Fairbairn (1974), Guntrip (1971) and Winnicott (1960, 1965) to include a failure by parents to meet psychological needs of the child.

Harry Stack Sullivan, (1956, 1962) founder of the American school of interpersonal psychoanalysis, provided a radical and humanist understanding of “problems in living”. Sullivan emphasised the role of interpersonal and intrapersonal experience in psychological distress as well as the importance of cultural and environmental experiences, a radical challenge to classical constructions of psychological distress. Sullivan recognised that positive human interaction and secure attachment in the child-mother (or child-father) relationship are vital for emotional security and mental wellbeing. Rather than being regarded as a ‘mental illness’ Sullivan suggested that delusions and paranoia were maladaptive coping mechanisms to manage threat and anxiety in an attempt to cope and disassociate from feelings induced by traumatic early relationships. These internal dynamics provided respite from reality but made it harder for the traumatised individual to distinguish between reality and fantasy and led to ongoing difficulties in relationship with the self and others (Sullivan, 1956, 1944).

Kohut, founder of the school of self psychology argued that a cohesive sense of self develops in individuals who are loved and cherished in childhood by an empathetic self-object (Kohut, 1977, 1980). A lack of positive attachments leads to vulnerability to psychological distress. The self can feel empty and defences develop against the fears that come with trauma resulting in “arrested development” (Karon and VandonBos, 1981). Without structuralisation the self can become fragmented leading to aggression or social withdrawal; other people or substances may be sought to soothe.

Similarly, Bowlby (1969) stated that attachment led to internalised mental representations of the self in relationship to other people, developing patterns of relating which continue into adulthood. Recent research indicates that patterns of attachment significantly influence later social relationships, severe psychological distress (Berry, Wearden and Barrowclough, 2007; Read and Gumley, 2008; Ponizovsky, Nechamkin and Rosca, 2007) and the experience

of internal voices (Mawson, Berry, Murray and Hayward, 2011). Quantitative studies have related insecure attachment styles to severe psychological distress, leading to low self-esteem, expectations of being rejected, to increased levels of distress and poorer outcomes (Gumley, Schwannauer, MacBeth, Fisher, Clark, et al, 2014; Korver-Nieberg, Berry, Meijer, de Haan and Ponizovsky, 2015). Dismissing-avoidant attachment is associated with positive symptoms and less strongly to negative symptoms (Korver-Nieberg, Berry, Meijer and de Haan, 2014), preoccupied-anxious attachment with positive, but not negative symptoms and avoidant and anxious attachment styles have been correlated with voice hearing and delusional ideas. Avoidant attachment styles have also been associated with withdrawal and lack of emotion (Ponizovsky, Nechamkin and Rosca, 2007). These attachment styles have been related to increased difficulties coping with trauma, while secure attachment encourages a positive sense of self, and more resilience in coping with difficult emotions (Mikulincer and Shaver, 2012). There are higher levels of attachment anxiety after experiencing interpersonal trauma (Berry, Wearden and Barrowclough, 2007) and attachment theory has made links between relational trauma and voice hearing (Longden, Corstens, Escher and Romme, 2012; Korver-Nieberg et al, 2015). Research by Varese, Smeets, Drukker, Lieveise, Lataster, Viechtbauer (2012) found that an average of 55% of males and 65 % of females on an inpatient ward had been sexually or physically abused in childhood. Research suggests that following childhood sexual abuse people are 9.3 times more likely to experience psychosis and for those experiencing severe abuse the risk increases to 48 times (Janssen, Krabbendam, Bak, Hanssen, Vollebergh, de Graaf and van Os, 2004). Paranoia has been related to attachment difficulties (Pickering, Simpson, and Bentall, 2008) and to a history of severe victimization and powerlessness (Janssen et al, 2004; Mirowsky and Ross, 1983).

The humanistic/existential model

The humanistic approach (Rogers, 1951, 1980) suggests that self develops through the positive regard provided within empathic relationships and that psychological distress arises when love is conditional. Parts of the self are

therefore denied and defended against, leading to a state of incongruence (Rogers, 1951, 1980) which causes psychological distress (Speierer, 1996). For both Kohut and Rogers, severe psychological distress was significantly affected by poor interpersonal, early relationships.

Laing drew on both psychoanalytic and existential ideas and like Sullivan and Rogers, argued that psychosis was located not only in the individual but in the family and wider culture. For Laing, the pressure to conform made the self less coherent and could result in psychosis (Laing and Esterson, 1964; Laing, 1978) as a strategy to survive in an intolerable situation (Laing, 1967). However, Laing suggests that psychosis can have positive effects of enabling the self to transform and become healthier and more fully functioning (Laing, 1990).

2.6.2 Treatment

Cognitive behavioural therapy considers thoughts, emotions, physicality and actions to be connected. 'Negative' thoughts can potentially establish a vicious cycle of increasing self-defeating thoughts. The aim of cognitive behavioural therapy is to understand and break this cycle and develop alternative, less destructive patterns (Chadwick and Trower, 1996; Birchwood and Tarrier, 1992; Birchwood, 2000). An aim of cognitive behavioural therapy is to reduce the degree of distress caused by difficult thoughts and to improve quality of life, rather than to eliminate voices, through changing the construction of these events (Morrison, 2004). The therapist challenges beliefs that are constructed as 'dysfunctional', and attempts to create alternative explanations and reduce the strength of beliefs. However, Sommerbeck (2005) argues that correcting beliefs can potentially be experienced as confrontational and might encourage the person to defend and reinforce them.

Psychoanalytic approaches explore complex and deep-rooted difficulties in self-perception, relationships and the impact of past experiences. This involves working with the unconscious and the therapist takes an interpretative approach in analysing meaning (Kohut, 1977, 1980) and establishing patterns in relationships. In working with severe psychological distress, Dewan (2016) describes that deficit object relations can be worked with to increase complex representations of the self and others and develop the range of understandings

of relationships. It is recognised that unusual ideas, such as those in severe psychological distress, form a protective defence that cannot be shattered in therapy, as the underlying reality may be more painful and frightening. The relationship with the therapist is used as part of therapy, reflecting the inner world of the client; these relational patterns can be worked with in transference. The aim of therapy is for a profound change in development, understanding and personality and to develop a more coherent sense of self.

Person-centred approaches, based on Rogers, suggest that working with people experiencing severe psychological distress requires engaging at a relational level (Mearns, 2004). Therapy involves addressing issues of incongruence (Speierer, 1996; Rogers, 1951). The therapist accompanies the person in their experience to share their reality with understanding and empathy (Sommerbeck, 2005). This removes reasons to defend, enabling the space to explore different realities and inconsistencies. A value of person-centred therapy is to accept the client's self without judgement or criticism (Rogers, 1951). This approach does not necessarily encourage deep levels of exploring which may be considered over-whelming. Instead the process is directed by the client who can choose to explore at a deeper or less deep level. An aim of therapy is for the therapist to support the person to develop their own personal understanding and self-awareness, rather than the therapist advising and directing either the therapy content or the individuals understanding and development of meaning. Rather than trying to change the person the therapeutic process is about showing genuine interest, being non-demanding and accepting. A trusting relationship with the therapist is essential.

2.6.3 How is recovery constructed

Within the cognitive model recovery is regarded as the development of alternative interpretations of perceptions and experiences, so that these are no longer experienced as so distressing. The process of therapy aims to normalise some of these unusual experiences to decrease emotional distress, facilitate the development of coping strategies and increase individual control. The focus in cognitive behavioural therapy is on reducing symptoms experienced, whether these are anxiety, low mood, hearing voices or other unusual experiences.

In psychotherapeutic approaches, more generally, recovery is not necessarily regarded as a reduction in 'symptoms,' but an improved ability to

understand oneself and unusual experiences, integrating these into one's sense of self and coping more effectively with experiences. A higher level of insight leads to increased self-compassion, self-esteem and ego strength. Humanistic therapies understand recovery as reflecting personal growth and understanding; developing sense of worth, accepting feelings as valid, recognising ways that approval is sought and being congruent about feelings and needs. Person-centred therapy suggests that it is empowering for the person to make connections with past experiences to understand painful feelings. Humanist models value developing self-awareness, identity and changing power relations, through appreciating and exploring subjective experience (Rogers, 1986). The focus on developing the therapeutic relationship in psychodynamic and humanistic therapy and revising damaging relational templates, can encourage empowering relationships through promoting mutuality in the therapy process, rather than adopting a hierarchal approach (Rogers, 1951; Sullivan, 1956, 1962).

2.7 Constructions of severe psychological distress, treatment and recovery

2.7.1 The sociological model

The social model puts psychological distress into a broader social, political context and emphasises the ways in which social issues such as poverty, inequality, nutrition, stress in pregnancy, witnessing domestic violence, childhood sexual, emotional and physical abuse and neglect, bullying, racism, rape or physical assaults as an adult (Read van Os, Morrison, and Ross, 2004, Moskowitz, Schafer, and Dorahy, 2009; Larkin and Morrison, 2006; Read and Bentall, 2012) impact on psychological distress (Warner, 1994; Wilkinson and Pickett, 2009; Faris and Dunham, 1939; Eaton, 1980; Sharpley, 2001; Mohler and Earls, 2002; Gilman, 2001). Research findings suggest that poverty is more closely related to psychosis than to other forms of psychological distress. It has been suggested that children who experience poverty are eight times more likely to develop psychotic disorders (Read, 2004).

There is evidence that ethnic minorities, women and the less well-off are more likely to be diagnosed with a 'mental health' problem (Neugebauer, Dohrenwend, Dohrenwend, 1980; Torrey, Bowler, Clark, 1997; O'Callaghan,

Cotter, Colgan, Larkin, Walsh, 1995; Mangalore, Knapp and Jenkins, 2007), while psychiatric admissions to hospital increase during a recession (Brenner 1973), linking financial difficulties with psychological distress. Research indicates that working class and ethnic minority patients are more likely to be given a more severe diagnosis than middle class patients with similar symptoms (Johnstone, 2000; Werner, Malaspina, and Rabinowitz, 2007; Crowe, 1998; Bentall, 2004; Read, 2004), are less likely to be given psychotherapeutic options and are more likely to receive physical treatments and longer hospital admissions (Warner, 1994; Johnstone, 2000). It seems that the disempowered are then further disempowered by the treatment offered, creating a circle of oppression (Crowe, 1998; Bentall, 2004; Read, 2004).

2.7.2 Treatment

The traditional, paternalistic system of healthcare is regarded by socially orientated perspectives as disempowering, dehumanizing, reductive and prone to encourage helplessness and passivity (Chamberlin, 1997; Young and Ensing, 1999; Fisher, 1994; Todres, Galvin and Holloway, 2009). Empowerment is argued to be enhanced through reducing reliance on mental health services and advocating for oneself. Professionals are urged to work in collaboration (Dickson-Swift, James, Kippen, Liamputtong, 2006; Kosciulek and Merz, 2001) and to hold positive views about recovery (Warner, 2004). The psychosocial difficulties that can arise from psychological distress, institutionalisation or from side-effects of medication, such as withdrawal, reduced performance and ability in functioning and sometimes cognitive deficits, can be regarded as the very opposite of the attributes needed to encourage empowerment (Dickerson, 1998). There is a problematic contrast between a view of empowerment which focuses on strengths and independence and medical training which focuses on deficits and 'compliance' with medication.

2.7.3 How recovery is constructed

Social models are concerned with how society and social values impact on recovery from severe psychological distress. Recovery within the social model is understood as being a social rather than a biological or psychological process. Recovery involves having an improved quality of life and being

comfortable and accepted within communities with decreased levels of stigma. It understands that reduced quality of life comes from a lack of opportunities and from unmet social and functional need as much as from the struggle with 'symptoms' (Chan and Mak, 2014) and that recovery can be limited by environmental factors (Angermeyer and Kilian, 1997). Recovery includes practical concerns such as having a stable environment in which to recover, secure accommodation (Ashcroft, Anthony and Martin, 2008), financial independence and finances to support opportunities (Davidson and Strauss, 1992). Social psychology approaches understand relationships and social roles as significant in assisting recovery and empowerment (Topor, Borg, Di Girolamo, and Davidson, 2011).

There is an understanding that society's values influence what is regarded as recovery; this involves social change affecting how those experiencing psychological distress are perceived and supported in communities. It involves a decrease in the prejudice and stigmatisation that is experienced, which in turn decreases levels of internalised stigma (Sibitz et al., 2011). Recovery also involves increasing levels of empowerment and decreasing levels of inequality; Lord and Dufont (1996) argue that individuals suffering from severe psychological distress are disempowered through being an oppressed group, often lacking power and experiencing stigma and poverty. Recovery involves collective action for changes, rather than simply individualised action (Speer, 2008). Power has been defined as not being owned by the individual but as emerging between people (VanderPlaat, 1999).

2.8 The rationale for further research on what is empowering and disempowering in severe psychological distress.

Research in this area has been dominated by academic researchers, mental health professionals, psychologists and critical psychiatrists; consequently research findings are dominated by the perspectives of professionals with generally a limited involvement from service users. Furthermore, the majority of the research in this area is positivist and quantitative, often using instruments such as questionnaires to gather data; tools which can become disempowering as participants are unable to use their own voice to describe and make sense of

experiences. Although quantitative research can enable some generalisation from results, the dominance of this method limits a wider understanding of the factors involved in empowerment and mental health, particularly from the perspective of the service user.

Much research on empowerment and psychological distress has been conducted within the arena of social work or other social sciences, rather than within therapeutic areas of research. Issues of empowerment are central to counselling and psychology; the professional practice guidelines of the British Psychological Society Division of Counselling Psychology professional practice guidelines stress that counselling psychologists need to 'recognise social contexts and discrimination and to work always in ways that empower rather than control'. Examining these issues within a counselling psychology framework will enable the identification of what empowers and disempowers individuals suffering from severe psychological distress from service users' reflection of their own experience. This understanding will develop awareness of factors indicated in recovery and relapse as well as increasing reflection on how factors enhancing empowerment can be encouraged.

A qualitative, social constructionist approach has been adopted for the current study to enable the validation of other realities; qualitative research encourages an expression of participant's subjective experiences using their own words. Both personal narratives and interviews are used in this research; the personal accounts form reflective, thoughtful narratives of subjective experience which provide an initial perspective on empowerment and disempowerment. Personal accounts can have a liberating feel to them (Wisdom et al, 2008; Ridgeway, 2001) and provide alternative constructions of experiences (Adame and Knudson, 2008). Participant interviews have also been used to enable a dialogue to occur which is co-constructed and negotiated between the interviewee and interviewer. These bring a powerful perspective of coping with severe psychological distress day to day.

2.9 Summary and conclusion

While a range of empowering factors in recovery for people with severe psychological distress have been explored, the process of empowerment in

recovery, and conversely, of disempowerment have yet to be delineated. Furthermore, in the fields of psychology, psychiatry and sociology constructions of mental health and illness differ widely, as do conceptualisations about how the self develops, what causes psychopathology, and what factors facilitate recovery and empowerment. This research study attempts to synthesise the findings and consider gaps in understanding by exploring survivors and sufferer's narratives of severe psychological distress to develop understanding of what is experienced as empowering and disempowering. It is hoped that the grounded theory constructed from the data will increase awareness of how empowerment can be supported from the perspective of service users.

Methodology

3.0 The research paradigm

My epistemological position is social constructionist (Charmaz, 1990), an approach which takes a critical stance towards the development of knowledge and contests that meaning is subjective and constructed through social interaction; that people and events can be defined and understood in different ways, rather than meaning being 'natural' and fixed (Burr, 2003). Ontologically, as a critical realist, I understand that while some aspects about the world may be measurable, other beliefs about reality are socially constructed and understandings of experience are dependent on shared meanings influenced by social interaction. People can imagine the consequences of alternative actions and this ability to imagine helps to develop a sense of personal agency as described by Mead (Aboulafia, 1991). As feminist, disabled and socially orientated writers argue (Traustadottir, 2001; Oliver, 1992; Smith, 1999) constructions of reality and representations of groups are constructed by the powerful voices in society, rather than by marginalised groups. I am interested in the power relations underpinning the dominant discourses and representations of groups of people in society and this framework seems appropriate for the current research.

A constructionist approach also recognises the significance of the interaction between researcher and the researched, both of whom may understand the research process differently. Meaning is co-constructed within the interview if the interaction is collaborative and as different meanings come together. This can be a powerful process possibly leading both the researcher and the participant to think about issues in new way, and hopefully being empowered by the process.

3.2 Rationale for a qualitative methodology

Positivist methods have traditionally been used in psychological research to follow the methods of natural sciences and produce measurement, experimentation and statistics. Quantitative research attempts to describe that which is believed to exist to produce objective knowledge, but attempting

'quantification of the unquantifiable' (Devereux, 1967, p.6) is problematic when researching social processes and how participants construct their experiences. Qualitative research methods were thought to be more appropriate for developing understanding of complex social and psychological experiences (Strawbridge and Woolfe, 2003). Furthermore I wanted to ensure that the research methods I adopted were not experienced as disempowering by participants; it has been argued that qualitative methods are more responsive to the interviewee (Liamputtong and Ezzy, 2005) and suited to researching sensitive areas and marginalised or stigmatised groups (Warren, 2002; Daly, 1992) allowing rich, detailed and contextualised descriptions to be gained. In addition, qualitative research can provide a first person perspective on the experience of psychological distress; this can potentially impact on clinical practice through focusing on the needs and ideas of service users from their perspective (Todres, Galvin and Holloway, 2009).

3.3 Rationale for grounded theory

Given my epistemology and research question I felt that a constructivist grounded theory methodology would be the most appropriate. In accordance with the methodology, I approached the research question with an open mind and examined my initial biases and assumptions, which felt like the basis for a more collaborative approach of research. I wanted to consider how participants constructed their experiences; to focus on what was constructed as empowering or disempowering. Becoming empowered involves an interaction of psychological and social processes making grounded theory an effective method; ideal for exploring what participants were doing, not doing or were thinking about doing. This encouraged an understanding of how, why and when participants might find it harder or easier to have a sense of agency. Grounded theory enables subjective experience to be placed in a social context (Willig, 2012).

Constructionist grounded theory encourages a reflexive approach, recognising that the researcher is an integral part of the research and needs to be critical of the research process (Schwandt, 2001) through questioning the methods of collecting data, examining the influence of the researcher, the transparency of the interpretation by the researcher and recognising power

relationships within the research situation (Alvesson and Skolberg, 2009). To ensure reflexivity in grounded theory it is important to ensure that procedure is documented, that there is depth in the descriptions and an awareness of how much the theory is dependent on researcher's assumptions; this helps to ensure that the theory is 'well-informed' (Guba and Lincoln, 1994; Hall and Callery, 2011). Classical grounded theory is underpinned by a positivist epistemology whereas Charmaz's version, while utilising the same methods, focuses on construction, rather than 'discovery' or 'emergence'; theory is recognised as being constructed by the researcher in interaction with the data (Charmaz, 1990). Social constructionist grounded theory recognises there are multiple realities and that people construct identity and reality through social interaction in a social and cultural context (Charmaz, 2006, Grbich, 2004). Therefore, the 'theory' constructed is acknowledged to be one interpretation rather than reflecting a 'truth'.

3.4 Reflexivity

Reflexivity requires the researcher to acknowledge that they are part of the social context and that their assumptions and biases affect what they will notice and how they interpret the world (Finlay, 2002; Powers and Knapp, 1995). I acknowledge that my ideas, personality, political and social agenda will impact both on how I conduct my research as well as how I interpret my findings, consciously and unconsciously (McLeod, 2011; Grbich, 2004; Charmaz, 2006). Engward and Davis (2015) argue that assumptions can 'silently influence the research work'. For research to have significance, my values need to be transparent so the reader is aware of my theoretical framework and can interpret research with this knowledge (Silverman, 1998).

To facilitate this, I kept a post comment interview sheet to record my feelings and responses during the interviews. A personal journal was also kept to record my perceptions and monitor how my ideas changed as the research progressed. This was beneficial to keep account of expectations and biases (Miles and Huberman, 1984; Pidgeon and Henwood, 1997). Most importantly, I considered the power relationships between myself and the participants and the ways in which our perceptions of each other affected the research. As a

researcher interviewing marginalized groups who experience stigma, discrimination, unemployment and other social difficulties there is an inherently unequal power imbalance between us. I was aware that I had to remind myself of this; I was also aware that when I am in the position of being the more socially powerful I find this hard to recognise and acknowledge. However, given that the information sheet given to participants stated that I was at University and completing a professional doctorate in counselling psychology this was something I had to consider. One participant was very keen to tell me that he too had studied when in prison and had qualifications, possibly to narrow this gap.

In addition, as social workers, Krumer-Nevo and Sidi, (2012) point out 'representing the other' is always a process of dominance and control, in which the person represented is reduced to an 'object'. There is some debate about whether 'outsiders' can or should write about experiences of which they are not a part (Krumer-Nevo and Sidi, 2012; Traustadottir, 2001). I was aware of the responsibility to accurately represent participants' experience but wanted to reduce the social distance between voice hearers as an 'other' group (Traustadottir, 2001). I was aware of my responsibility to give an accurate account of participants' experiences, feelings, and context to reduce the quality of 'otherness'. Furthermore, more status is accorded to some voices than others (Hall and Callery, 2001). It felt very important to interview participants whose voices would not usually be heard; who were not on service user forums or mental health groups but were just trying to get by as best as they could.

During my research journey I became increasingly aware of my own assumptions and biases and how my work experience has affected my viewpoint. I worked as a social worker in mental health teams from 1996-2013, which had a profound influence on my constructions of psychological distress. Although I became a social worker partly because of my political orientation and my wish to have a useful role where I could help address issues of inequality, once in a mental health team I was initially drawn to the positivist medical model. This seemed to provide an explanation and to reflect a more sophisticated level of knowledge and theory than that of social work. However, I became increasingly dissatisfied with, and critical of, a medicalised approach to

problems with living. Despite working in a multi-disciplinary team with psychologists and a mixture of professionals trained in cognitive behavioural and family work with psychosis, I observed that people who heard voices were offered limited therapeutic input.

All the service users that I worked with were prescribed medication and had been given a diagnosis (or several diagnoses) but most continued to hear voices, although the quality of these was dampened down by the medication. The nature and content of the voices was very rarely worked with, although this may be different in other teams. My experience with psychiatrists themselves was not necessarily negative and they usually listened to other professionals. However, the dominance of the medical model and the lack of any therapeutic alternatives frustrated me; I felt that other alternative ways of working must be possible.

In 2010 I began training as a counselling psychologist. I wanted to explore different ways of working with people experiencing severe psychological distress and develop my therapeutic skills. During this time I worked within a community resource centre facilitating a hearing voices group. I noticed group members valued sharing feelings and experiences with others who understood. Members expressed concerns about developing relationships, a lack of control over experiences and often a deep sense of self-doubt, which contributed to my concerns about, and interest in, this area.

Although research needs to be for the benefit of the participants, we learn something about ourselves as researchers and this research led me to question my own experiences of empowerment and disempowerment. I have become aware of times when I fail to speak out (although I am a very good listener!). This perhaps stems from my early experiences and ideas of what being a girl/woman meant, which needs challenging internally. Difference and social inequality is an area I have always felt passionately about, probably bringing me to the study of empowerment. This gave me something of insider perspective and potentially encouraged participants to express themselves. I have brought this knowledge into my therapeutic practice, empathising with service users' difficulties speaking out.

As a trainee counselling psychologist, I noticed I tended to focus on the relationship between myself and the participant during interviews. Although interviews are not the beginning of a therapeutic relationship, it was hard not to relate to participants as a therapist, but as an empathic researcher. I was aware of ensuring I did not communicate as a therapist which would have affected the quality of the research and the nature of the interaction, but wondered whether it was helpful for participants to experience an empathic relationship. A level of trust is necessary for interviews to accurately represent participant's genuine concerns (Hall and Callery, 2001). However, as my professional role was known I was perhaps identified as a therapist as well as a researcher which may have affected the way that participants communicated. I didn't want to be perceived as an expert, but being identified as a professional may have meant participants were less likely to criticise other professions, services or their medication.

An awareness of the impact of my social identity was important. It has been interesting to consider the shifting power relations between myself and the participants, and the amount of social and structural power that is brought to the interview by each party (Daley, James, Ulrey, Joseph, Talawyma, et al, 2010). I considered where I positioned myself and where people would position me and how this might affect the narrative that people chose to tell. It was valuable to be aware that certain factors can narrow or widen the social distance between researcher and participant (or therapist and client). These connections or differences could be in terms of gender, age, education, race and ethnicity (Ale'x and Hammarstro"m, 2008). Two female participants wanted to talk about their role as parents/mothers. I shared that I was also a parent and wondered whether this impacted on the narrative they shared. Female participants seemed keen to discuss embodiment, concerns about weight and exercise. This could have been based on their assumptions that I would understand or maybe on my own assumptions which encouraged them to discuss these issues. In these discussions, I became more of an insider again and we could talk with a shared understanding. As an insider, I felt able to disclose more about myself and my experience which assisted a sense of collaboration.

The taking of an insider or outsider perspective was fluid. Three of the men interviewed were black, making me reflect on how the critical voices they experienced were affected by experiences of racism and their perception of themselves as black men. The sense of difference between us was more apparent; I am a white, middle class woman and non-voice hearer so potentially have a privileged position, but as a woman my social status in some cultures may be considered inferior. I wondered how I was viewed by them but did not ask. With hindsight this may have been interesting to discuss, but I felt unsure whether this was within the remit of the research and perhaps lacked the confidence to ask that question. This has made me realise how uncomfortable discussing empowerment is, yet ignoring it reduces the depth of understanding.

I was concerned that some material may be upsetting and was aware of the importance of looking after myself emotionally. It was important to build breaks into transcribing to ensure that I did not become overwhelmed. However, the emotion I felt when listening to transcripts was a quiet sadness in hearing stories where people were still struggling and trying to make sense of experiences that were hard to understand. I am not religious but religion was important to many interviewees. Again, I had to be aware of my own perspective; it was important to acknowledge this difference to myself and accept that people had beliefs that I did not necessarily understand. These were important issues to hold in mind when conducting this sensitive research.

Method

4.0 Research design

This was a qualitative study using a constructionist grounded theory methodology. Two sources of data were used; semi structured, face to face interviews with individuals who had or who were still experiencing difficulties with voices and published recovery narratives from people who considered themselves to be on a journey of recovery from hearing voices.

4.2 Participants

Published narrative accounts by 12 authors who had experienced hearing voices, and who defined themselves as being in a process of recovery were coded. It was unclear from the narratives if all of the authors had been given a formal psychiatric diagnosis, but all defined themselves as voice hearers and had experienced psychiatric treatment. Ethnicity and age were unspecified. See Table 2, in appendices for available narrative participant demographics.

Eight participants were then interviewed who were currently involved with mental health services. Seven had been diagnosed by psychiatrists and had experienced more than one episode of hearing voices. See Table 1 in appendices for participant demographics and diagnosis. Six interviewees were still hearing voices but were emotionally stable during the time of the interview (see inclusion criteria). Using theoretical sampling an eighth participant was recruited who had experienced a brain injury and depression following bereavement, but did not hear voices. This was a useful interview to help refine my thinking about the processes involved. All interviewees attended the same secondary care resource centre and lived in supported accommodation, and had been prescribed psychiatric medication.

This research focuses on individuals who have experienced severe psychological distress while hearing voices and/or who have received a psychiatric diagnosis of 'schizophrenia,' 'schizo-affective disorder' 'or 'psychosis.' These diagnoses have been found to be particularly stigmatising (Schulze and Angermeyer, 2003; Romme and Escher, 1996) leading to increased involvement with mental health services (Schulze and Angermeyer,

2003) and increased risk of suicide amongst those experiencing psychosis (NICE guidelines, 2014).

4.3 Inclusion criteria

Interviewees were over 18 years old and able to give informed consent. Authors of the narratives were not contacted for consent as the recovery stories selected were in the public domain. The decision about whether interviewees could give informed consent and were stable enough to be involved in the research was made by the manager of the resource centre, a qualified art therapist who worked closely with all interviewees, and by myself when I met with participants to discuss the interview. Interviewees were given written information about the research and we talked about the aims and background of the study. This was a collaborative discussion to ensure they understood the purpose of the research and could ask questions. I discussed with interviewees whether they felt emotionally able to be involved in research and the potential risks and benefits of participating. I considered broaching allocated psychiatric nurses but contact with the mental health team was infrequent while staff at the resource centre met with participants almost daily and were better placed to make an informed decision about emotional well-being. This assessment was based on the staff's knowledge and understanding of participants' psychological well-being and how they presented to me during the interview process; were they able to explain the purpose of the interview and how information would be used, did they understand the role of confidentiality and was their level of coping with voices currently worse than usual, the same or better than usual? As a social worker I had attended regular training on mental health capacity assessments and felt capable to make this decision working collaboratively with interviewees and staff at the resource centre.

An additional inclusion criteria was that participants had a support network in place, such as a supportive professional, a support group or a supportive family network.

4.4 Exclusion criteria

Participants were not interviewed who were experiencing florid symptoms, affecting their level of functioning and psychological vulnerability. This was to ensure that interviewees were able to make an informed decision about the potential risks and benefits of participation.

4.5 Procedure

4.6 Sampling

I wanted to use two groups of participants to provide a different experiential perspective. My initial sample were authors of recovery narratives which enabled me to gather material from people who had been able to reflect on what was empowering from a position of recovery. Recovery narratives were selected from two sources. Some narratives were used from the National Empowerment Centre, an organisation placing helpful resources and recovery stories online to support those affected by the experience of psychological distress. Other narratives are taken from '*Living with Voices: 50 Stories of Recovery*' (Romme et al, 2009).

Initially I considered choosing a random sample of narratives from these resources, for example choosing every fifth story. On reading the recovery stories however, I felt that some provided greater depth and were more suited to my research topic. The criteria for selecting stories was to use first person accounts written by the survivor (rather than an interviewer). Narratives were chosen which were rich and descriptive and which provided detail both of the early development of psychological distress, the process of recovery, and on the process of empowerment and disempowerment, and the factors which had been helpful and unhelpful in recovery. These accounts challenged social constructions of psychological distress and the authors described wanting to define themselves and their psychological distress in a way that was personally meaningful.

Theoretical sampling enabled me to reflect upon and choose the sample of participants to interview, which answered questions and deepened insights highlighted in the analysis of narratives. Through theoretical sampling, the

sample can be adapted as the research process continues to further develop ideas. The research process guides the theoretical sample which in turn provides new material. To develop my ideas on empowerment and disempowerment after analysing the narratives, I reflected that to understand more about disempowerment I needed to interview participants who were finding the process of recovery difficult. My theoretical sample were a second group of participants, currently using mental health services and who were potentially struggling with empowerment. This group of service users perhaps had fewer opportunities to express their opinions and experiences than the narrative authors. Using theoretical sampling I reflected that it would be useful to interview a participant experiencing severe psychological distress who was not a voice hearer to increase my understanding of the voice hearing experience.

4.7 Analysing narratives

I began by analysing published narratives written by authors who considered themselves to be in a process of recovery. These were written with hindsight and demonstrated the authors' ability to reflect on this process as well as their constructions of their experiences.

4.8 Recruitment

I approached a resource centre where I also worked as a therapist to discuss the possibility of recruiting participants for the research. Resource centre staff were informed about the aims of the research and the inclusion and exclusion criteria. Staff discussed the research with potential interviewees, but were clear there was no obligation for people to participate and no monetary incentive. Staff personally introduced me to participants, which was helpful in facilitating the interview. I wondered whether there was increased trust as although I did not interview anyone with whom I had previously worked, I am known by some service users. A relationship between the interviewer and the interviewee that has reciprocity and trust may lead to the interviewee giving a more accurate portrayal of significant issues (Hall and Callery, 2001). Participants

were invited to meet with me before the interview, to ask questions about the research and the interview process.

4.9 The research setting

Participants were interviewed at a resource centre which they were familiar with and where they said they felt comfortable. This is a small centre where activities and therapeutic groups are facilitated. It is a community project and everyone who attends is living in supported housing.

4.10 The research interview

Semi-structured interviews were conducted with these participants which provided a different perspective. Some described beginning to get over difficult experiences, while others were still struggling. They were given the choice of being interviewed face to face, via Skype, online or in two short interviews if this felt less challenging. However, everyone chose a face to face interview which lasted between 60 and 90 minutes. Interviewees were informed that they could withdraw from the study at any time up until submission should they no longer want their data to be included.

I wanted the interviews to be an empowering experience and for participants to have as much practical and emotional control over these as possible. I aimed to reduce the power imbalance inherent in qualitative interviews through asking participants about their personal experiences of severe psychological distress about which they were the expert and about which I wanted to learn and understand more. I asked questions that demonstrated my interest, curiosity and open-mindedness about their experience. Interviewees were not initially asked about voice hearing in terms of feeling disempowered. It was important not to prompt that hearing voices specifically were causing the distress or influencing a lack of control. However, prompt questions were asked about the experience of hearing voices. The participant information sheet (see appendices, page 212) stated that I was interested in voice hearing and unusual experiences.

Participants were asked 4 broad questions during the interview;

Could you say something about what you may have found helpful or unhelpful when managing your psychological distress?

Can you say something about what has helped you feel more empowered or in control?

Can you say something about what may have made you feel less empowered or in control?

Is there anything else you would like to add about your experience?

Participants began by talking about their psychological distress as they defined it and how this developed. Research is facilitated by an understanding that the researcher is sincere and genuinely interested in the participants (Berk and Adams, 2001). By taking a non-expert role, I hoped to encourage interviewees to explain their understanding and what was important to them. Power relationships needed to be acknowledged to ensure that all possible efforts were made to reduce its affects - an imbalance of power could result in participants discussing sensitive issues that they may not feel comfortable talking about (Daly, 1992). Barnard (2005) believes it is unethical to delve too deeply into distressing issues, even though from a research perspective useful information may be obtained. I wanted to ensure that participants did not disclose more information than felt comfortable. Participants were informed that they could chose not to talk about areas that felt too upsetting or personal. It was explained that the interview could be ended at any time at either the wish of the researcher or the participant. If a participant had appeared distressed, they would be asked whether they wanted to stop the interview, take a break, or discuss a different aspect. An informal atmosphere was encouraged through making participants a drink before and after the interview, ensuring that they were comfortable and choosing a peaceful room. Participants were given time to think and talk; further discussion was based on the responses to questions and to encourage elaboration. Communication reflected the level of language ability of individual participants and questions were rephrased if participants did not understand (Booth, 1999). Interviews were recorded on a digital recorder and later transcribed with all potentially identifying data being removed at the point of transcription.

Interviewees were asked if they would be willing to meet again to discuss my interpretation of their data. Credibility checks have been specified as important in qualitative research and a suitable method for this is through checking understandings with participants (Elliott, Fischer and Rennie, 1999). The process of being involved in research and contributing to understanding can be empowering in itself (Rickard, 2003). In addition I didn't want participants' voices to be clear in the findings but get lost in my interpretation (Willig, 2012). Although the constructions made of the data was my own, it was important that interviewees were offered the opportunity to comment and reflect on this; research would seem invalid if the model did not fit participant's experience. I asked at the interview whether participants would be happy to meet with me again. I discussed this with the resource centre manager in case there were any concerns and then telephoned four participants to arrange a second meeting. I met with four participants who had given in depth interviews and who made some suggestions and comments which I thought it would be helpful to follow up. We talked through the findings guided by a diagram illustrating my construction of the findings (see appendices, Table 3). This involved potential ethical issues and I was initially slightly tentative about the findings in case any of the analysis may be distressing or over whelming. I was aware of being sensitive in how I described findings as I did not want this be re-traumatising. Participants responded well to this and remarked that the diagram encapsulated the process that they had gone through. This deepened material within the interviews and provided a collaborative aspect of attempting to ensure understandings were shared. No disconfirming information was added. However, new insights were contributed about the potential difficult relationships with staff and difficulties finding the words to communicate feelings. I wondered whether interviewees would be reluctant to contradict my findings, but it was important to enable this process as far as possible (Bloor, 1997; Seale, 1999).

4.11 Ethical considerations

The Department of Health guidelines (2005) state that research needs to protect the 'dignity, rights, safety and well-being' of participants. Participants are contributing their time and experiences and it is imperative that researchers act to ensure that research makes a positive difference (Warr, 2004) and that

participation does not have a damaging impact on the participant's physical, emotional and social well-being (Melrose, 2002; Hoong Sin, 2005). This is even more significant with participants who have already experienced discrimination and disempowerment. Research with potentially vulnerable groups necessitates an ethical consideration of whether the research is morally justified and whether it could contribute to further stigmatisation, marginalisation or discrimination (Dickson-Swift, James, Kippen, Liamputtong, 2006). However, it has been suggested that not involving vulnerable people in research is paternalistic and denies people the chance to communicate their experience. Furthermore, having the opportunity to talk about experiences, be listened to and be taken seriously can be therapeutic and empowering (Cutcliffe and Ramcharan 2002; Rickard, 2003; Hess, 2006). It was agreed by an NHS ethics committee that I could undertake this research.

4.12 Consent

Morally valid consent has been described as containing disclosure (providing enough information for an informed decision to be made), understanding, voluntariness and competence (Bosk, 2002). Potential participants were given written information about the research at least a week before the interview so they had time to consider the risks of participating, understood the rationale for the study and had the opportunity to ask questions. Interviewees were asked if they wished to have the information read to them, or wanted to read this themselves. I asked them questions to assess whether they had understood the information and the process of consent.

4.13 Confidentiality

Interviews were downloaded onto a computer and transcribed. Participants were given a pseudonym and the identity of the participant who generated each interview was known only to myself. No identifying material was included in the research. The content of interviews was confidential and not discussed with the staff team working with participants.

Participants were informed of the limits of confidentiality; that confidentiality may be breached should a participant disclose examples of unprofessional

practice, or if information was disclosed that the person themselves or other people had been or were being threatened with abuse, or if participants were threatening someone else. No incidents were disclosed that caused such concerns.

4.14 Care at the end of the interview

At the end of the end of the interview I checked that participants felt safe and comfortable and informed them that support was available if needed from support staff. Participants could spend some quiet time in the therapy room or go to the resource centre where other service users and staff were present. Debrief sheets (see appendices, page 220) were given that included contact numbers for support agencies in case issues had arisen over which participants would like further support or advice. Professionals involved with the participants were aware that the interview was occurring in case follow up support was needed.

4.15 Issues of risk

Resource centre staff had a thorough knowledge of participant's well-being, current situation and risk history. Participants were not interviewed if staff advised against their involvement due to potential risk to either the researcher or participant or other relevant concerns. I was not given specific information about participants risk history to protect participants' confidentiality and no information was shared which was not necessary. Interviews were held in a community resource centre during office hours, with other professionals in the building and not at the end of the day when staff were leaving.

I was aware of the need to look after myself psychologically. The impact of researchers themselves being sensitive and vulnerable is increasingly identified (Melrose, 2002; Liamputtong, 2007) recognising that painful and distressing emotions can be evoked, which Melrose terms 'labour pains'. This includes feeling powerlessness over having to leave participants in difficult situations and a feeling of having shared suffering (Morse, 2000). It was important to be aware of my emotional responses and well-being and use supervision to discuss these issues.

4.16 Method of analysis

4.17 Constant comparison

Key to grounded theory are the two related processes of constant comparison and theoretical sampling. The method of constant comparison is a process of simultaneous data collection and analysis. In this research, this meant that each narrative or interview was transcribed and analysed before the next one was conducted. This method enables new information to be compared with that previously collected to identify repeated patterns and differences which encourages rigorous comparison of the data (Elliott and Lazenbatt, 2004). For example, Stephen described that he sometimes changes the quality of voices to turn it back to a noise. By analysing his interview before conducting the next, I was able to ask subsequent interviewees whether they experienced a similar phenomenon (and some did describe a heightened sensitivity to noise).

Comparisons were made firstly by exploring similarities and inconsistencies within individual narratives. The narratives were then compared with each other, which enabled patterns to be identified within the narratives as a whole data set. The interviews were then analysed using the same process of constant comparison and finally the narratives and interviews were compared with each other. The process becomes increasingly analytical as data, codes and categories are compared. Through this process I became aware of further questions which guided my sampling strategy using theoretical sampling.

4.18 Coding

Coding is an active, dynamic process with the researcher interacting with the data (Charmaz, 2006). There are three levels of coding in grounded theory which steers the movement between the data and development of theory. Narratives and interviews were coded line by line and given a code to describe the actions in the data. Focused coding then looked at larger segments of material to determine which of the initial codes had the most analytic significance and passages were labelled with a descriptive code. Theoretical coding then considered how the codes related to one another, enabling me to

move from analysis to theory formation; this involves a higher level of abstraction. Finally, selective coding was used to elaborate and refine the categories; through selective coding the relationship between codes can be specified and integrated into theory.

Through the process of coding standard questions are asked of the data such as; what is happening in the data, what does the action in the data represent, is the conceptual code part of the participant's vocabulary, in what context is the action used, are codes related, is the code encompassed by another code or is a new code needed and are there codes that have similar patterns? Themes constructed through the process of coding were compared to those constructed in subsequent interviews to generate new ideas and understandings. As each interview was coded before the subsequent interview I developed codes from each interview to use in the next. Grounded theory specifies that the amount of data gathered needs to be suitable and sufficient to gain detailed descriptions of a range of views and perspectives, to make comparisons between data and develop categories.

4.19 Memos and field notes

Field notes were written after each interview to record my observations, overall impression of the participant's experience, my sense of being with the person and the impact of hearing their experience. It was useful to note points where I had a strong response to my participants. Memos were effective in identifying patterns that were shared by participants as well as unique experiences.

4.20 Constructing categories

My initial tentative categories were constructed through coding the narratives which focused on the process of recovery. Using constant comparison with the data from my interviews enabled me to refine categories concerning loss of opportunities and loss of self and the losing or gaining power. The role of relationships in participants' lives was very strong, not just with other people but with the voices and with themselves. Following this process a pathway of becoming disempowered and a pathway of becoming empowered was constructed.

4.21 Developing a category

Categories were continually refined throughout the research process as I continuously compared the codes of the narratives and interviews with each other. A record was kept of significant codes which came from memo writing, constant comparison and line by line analysis. These were then ordered under a category heading which encompassed codes that shared particular aspects. I assessed whether the category included all the relevant information. Writing the codes and category headings onto cards was useful in this sorting process and different ideas continued to be fed into the research. Using memos and codes I created a diagram (see appendices, Table 3) to help me theorise about the relationships between categories and the processes involved in empowerment and disempowerment. Classical grounded theory (Glaser and Strauss, 1967; Glaser, 1978) suggests delaying the literature review so that research is not influenced by 'received theory'. As suggested by Charmaz (2006), I began a limited literature review before beginning my research to understand and engage with ongoing debates and returned to literature throughout the process to develop my categories and to consider how my construction of the findings fitted with previous research.

5.0 RESULTS AND ANALYSIS

Narrative accounts of recovery allow the authors to reflect on the process of recovery with hindsight, giving these accounts a polished quality understandably lacking in the interviews. There may be a more complete sense of self to reflect upon because these authors had developed a coherent narrative and sense of themselves (Lysaker and Lysaker, 2002). The narratives focus on a journey of developing self-awareness, understanding and reintegration leading to the development of a more coherent sense of self. These accounts are written from a position of understanding and empathy towards the self, rather than of confusion and criticism, and connect the person they were in the past with the person they are now.

The interviews are more chaotic and unstructured with participants struggling to verbally describe and make sense of their current experiences and of changes in their personality which they recognise but find harder to link to their former selves. This is also partly due to the nature of interviews, which are a more unstructured process, with less time to gather and clarify one's thoughts. Interviewees were able to clearly express the experience of having an incoherent and disorganised sense of self. Much of the interview narrative is about coping from day to day rather than on reflection.

The recovery narratives are written with more anger than the interviews; though both accounts make powerful reading. It is unclear what to attribute this to; whether realisation of the disempowering and violating nature of some experiences grows through the process of recovery or whether having that anger gives a strength and purpose that supports people to move out of the psychiatric system or whether their experiences were simply different. It may be that part of the recovery process is to acknowledge feelings of anger and reintegrate these which can become empowering, rather than to split off and defend against feelings of anger. This in itself may stimulate some movement and a sense that personal action can result in change. Interviewees may have been more affected by the sedating effects of medication, which may partly explain some instances of confusion and the absence of anger. Narratives can provide the opportunity to challenge the dominant narrative by changing

constructions and not accepting dominant cultural stories (Young, 2009). This creates a powerful medium. There were many similar views and experiences expressed in interviews and narratives, as well as some interesting differences.

The grounded theory constructed from the data begins with invalidating experiences, including both events and relationships. Participants described their subsequent struggles to understand these experiences, and the solutions they adopted to cope, which often involved disconnecting socially, before eventually becoming overwhelmed and losing a coherent sense of self. The empowering pathway begins with a feeling of validation, before making connections socially, with themselves and with voices, eventually gaining a sense of autonomy.

The following pathway of becoming disempowered explores *being invalidated: experiencing a traumatic threat to self, struggling to understand, attempting solutions: disconnecting the self, and then overwhelm: shattering into pieces and finally 'becoming a mental patient.'*

5.1 BECOMING DISEMPOWERED

5.2 BEING INVALIDATED: EXPERIENCING A TRAUMATIC THREAT TO

SELF 5.2.1 From traumatising others

The majority of authors and interviewees described invalidating and destabilising experiences of loss, violence, neglect and physical injury. For some this was due to changes in relationships, living or work arrangements or a significant traumatic event which led to periods of internal disorganisation and instability. A history of trauma was not specifically asked about in the interviews, so some interviewees may have experienced traumas which were not disclosed. Amongst the narratives six authors had experienced sexual abuse, five of these in childhood. Another experienced unspecified abuse while living in a children's home. The psychological impact of trauma was clearly described. Mary Lou (American, voice hearer, narrative, National Empowerment Centre) wrote,

"I am a survivor of childhood trauma and abuse...I can trace now how systematically I was taught to believe I was defective and sick."

*"Us children never knew if we would wake up the next morning. We were told by the staff of the orphanage that in the event of an invasion that they, our house parents, would do the compassionate thing and kill us in our sleep..."*Charlie Hughes, (American, 'schizophrenia', narrative, National Empowerment Centre).

"I was destroyed by the rapist who was older than us, he was about 10 years older than us (we were the same age) and I really couldn't fight back...I switched immediately to out of control mentally." Owen (Black/British 'schizophrenia', interviewee).

"Everything I had been so certain about had been destroyed... I was to discover I had been sent back to the adoption agency by one couple as it was believed I was defective in some way and possibly brain damaged." Debra Lampshire, (voice hearer, narrative, 'Living with voices').

Many participants had experienced strong feelings of powerlessness in relationships through being victimised, assaulted, sexually and/or physically abused, or faced with the threat of abandonment. Control was perceived as precarious and felt reliant on factors or people beyond the participant's individual control; unpredictable events therefore increased the overall sense of powerlessness and vulnerability experienced. There was a sense of participants trying to cope emotionally by defending themselves against traumatic events.

5.2.1 From invalidating voices

Trauma further threatened the sense of self through an internalisation of blame and self-criticism; some participants located the blame for difficulties within themselves, and later on, as voice hearers, continued to internalise feelings of blame. Voices expressed criticism which further undermined the self. Many participants described an intense but disconnected relationship with their voices, which were regarded as separate and other. Although voices may initially have been identified as supportive, these began to be perceived negatively and became another invalidating force. Many participants described

how the quality of voices changed following a trauma or as participants were encouraged to perceive voices as disruptive; they then became confused about whether or not the voices were trustworthy or malevolent. As voices became more threatening, so participants became increasingly disconnected and fearful of them. Often participants began to experience being bluntly instructed what to do by the voices giving the relationship a bullying quality. It was difficult for participants not to believe the voices which made them more frightening. Caroline (White/British, 'schizophrenia', interviewee) described how her voice, initially protective, became increasingly threatening:

"It was trying to stop me doing things that was causing things so it was very difficult to switch off from the voices."

Stephen (White/British, 'schizophrenia', interviewee) explained that voices acted by,

"...making you think things...different memories join with the voices and gang upon you."

Jan Holloway (voice hearer, narrative, 'Living with voices') wrote,

"They are very moralistic which makes me feel really judged."

The sense of self became increasingly confused and disorientated as preoccupation shifted from the external to the internal world. As the self was undermined further it perhaps became harder to challenge critical voices and these formed an increasingly central role in many participants' lives. Most participants described descending in to a spiral of questioning, judging and criticising oneself from which it was hard to escape, creating a confusing world with no secure sense of self.

5.2.3 From the psychiatric system

Relationships with professionals and the psychiatric system was similarly complex as control was increasingly taken by professionals. Interviewees described a lack of control over a range of areas, including accommodation, meal times and work. Interviewees described being moved to accommodation without involvement in the decision making process, but, rather than complaining, expressed gratitude for the support received. Again it is possible that psychiatric medication, which all interviewees were prescribed, could have

had a sedating effect making them less likely to become explicitly angry or frustrated. There was an uneasy balance between these two positions of wanting and valuing support, but being frustrated by how this limited freedom,

“Yeh, they intervened like and said we’re here to help you and you need to comply or we’ll force medication on you. So I complied cos they don’t like it when you won’t connect with civilisation.”

(Stephen, White/British, ‘schizophrenia’, interviewee).

Authors of the narratives were more explicit about the invalidating nature of these interactions and the balance of power in favour of professionals. Jacqui Dillon (White/British, ‘schizophrenia’, narrative, ‘Living with voices’) wrote,

“I was expected to be the passive recipient of treatment for this disorder and medication was the only option open to me. I was being told what to do.”

“I begged them not to lock me up, because I didn’t want to lose my two jobs. I kept saying ‘please let me go so I can go to work, please, I can make a no harm contract, but I don’t want to miss work’, but I ended up losing these jobs.” Will Hall, (American, ‘schizo-affective disorder’, narrative, National Empowerment Centre).

The response that participants received when they first mentioned their voices was invariably negative and invalidating; many were told that hearing voices was dangerous and that help was needed. Eleanor Longden (White/British, ‘schizophrenia’, narrative, ‘Living with voices’) describes a friend’s response:

“...She was absolutely horrified saying that hearing voices is not a good thing and that I should get some help.”

In her case help entailed an assessment with a psychiatrist:

“The psychiatrist equated voice hearing with insanity and I got a diagnosis of schizophrenia.”

Once voice hearing was disclosed, which often felt like revealing of a shameful secret, the focus of other people’s attention shifted from the participant to the voices. These took precedence, dwarfing the individual’s personal distress or

trauma. What participants remembered, rather than being listened to, was the reframing of their experience as an illness. Some participants questioned this whereas others accepted the diagnosis. The impression given was that participants were 'ill'; the focus was biological rather than psychological.

"Through taking them (psychiatric medication) and being prescribed them, I was under the impression that I was mentally sick and that this sickness lay solely within me."
Mary Lou (American, voice hearer, narrative, National Empowerment Centre).

"So I still went through this episode of being diagnosed schizophrenic and mentally ill and that also went into my mind as well, "you're mentally ill instead of healthy" so that caused a lot of confusion for me as well." Owen (Black/British, 'schizophrenia', interviewee).

These invalidating encounters with the psychiatric system often led to feelings of hopelessness,

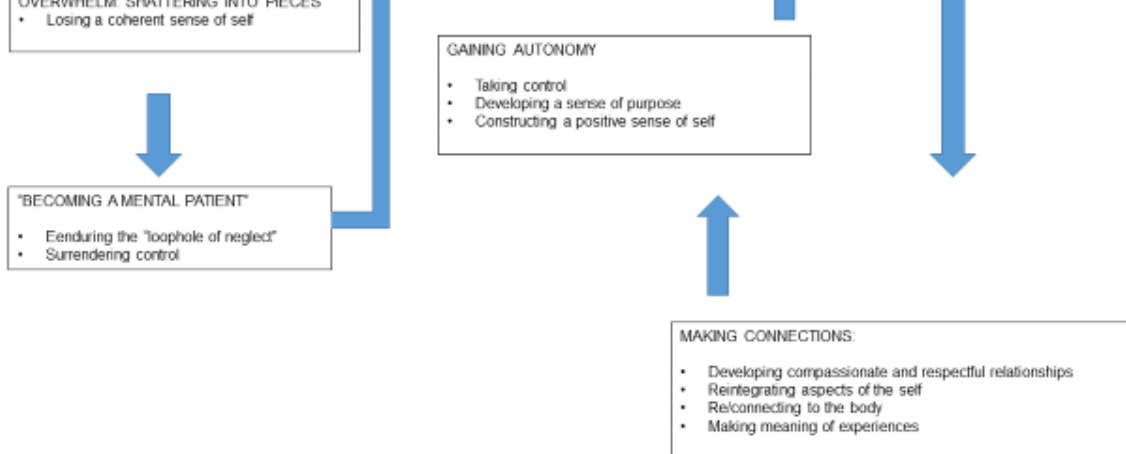
"I was told that I was very mentally ill and that medications were the only relief from my torment that could be hoped for."
Charlie Hughes, (American, 'schizophrenia', narrative, National Empowerment Centre).

"...I was told I was a severe and enduring case and that no more could be done for me." Amanda (voice hearer, narrative, National Empowerment Centre).

The necessity of keeping quiet and of the unacceptable nature of voices was learnt early and the voice hearer themselves became less active and vocal and weren't asked about experiences,

"They didn't ask what the content was and weren't interested in the meaning, just "is it commanding you to do things"...They said, 'it's your illness and we've got to get rid of it.'" Jan Holloway (voice hearer, narrative, 'Living with voices').

"Despite the threats my abusers had made...psychiatrists I tried to talk to either denied my experience or told me I would never recover."
Jacqui Dillon (White/British, 'schizophrenia', narrative, 'Living with voices').



“At times this system contributed to my unwellness by negatively influencing my ability to move forward with my life... It led to my feeling I had no choices and no control over my life.”

Amanda, (voice hearer, narrative, National Empowerment Centre).

Sue Clarkson (voice hearer, narrative, ‘Living with voices’) wrote,

“It (hospital) didn’t feel like an environment where I could talk about my voices: voices were looked upon as delusional ...hearing voices and mental health environments do not mix...mental health environments are much more distressing and destructive than any voice hearing experience.”

Meaning making of voices was foreclosed and subjective experience and interpretations ignored by professionals who constructed voices as evidence of illness. There was no space to reflect upon or consider alternative understandings which participants experienced as invalidating and disempowering; attempts to think about voices and experiences in a different way were often regarded as a lack of insight. Meaning was determined by professionals and it seemed impossible to question the dominant medical framework. These invalidating responses led to a number of defensive strategies.

5.2.4 Losing social and interpersonal security

Just as security was threatened by interpersonal and intrapsychic experiences of invalidation, security was lost in practical and social ways as some participant's experienced enforced exclusion from activities such as work, education and from roles which connected participants with their communities. This exclusion further invalidated the fragile self as participants experienced rejection in different guises, from more subtle inferences to outright hostility.

"...different professionals all gave the same sort of message, time and time again: my prospects for the future were not great; I shouldn't have expectations about school, or work, or having any relationships." Stewart Hendry ('schizophrenia', British, narrative, 'Living with voices').

Will Hall (American, 'schizo-affective disorder', narrative, National Empowerment Centre) described,

"As a result of this manic side effect and the shame of how I had acted, I ended up leaving work...I lost all my colleagues, friends and professional contacts and started spiralling down into poverty...Once you've revealed your history to someone and then they treat you as less than a full human being for it, fearing you or acting differently towards you, you learn to keep your history hidden. This means a life in the shadows, a second class citizenship, a sense of not being part of the human community. Try living with that and see if you start to feel paranoid."

As a result of these social and relational losses participants became more involved with mental health services, rather than with friends and acquaintances, shifting the nature of their social relations. There is a sense that some basic needs have to be met. Stephen, (White/British, 'schizophrenia', interviewee) described,

"...you have to be able to rely on some accommodation and a stable place to live. It's a basis to a good start to your mental health getting better."

Some fundamental needs are necessary to ensure physical wellbeing, without which emotional well-being appeared to be even harder.

5.3 STRUGGLING TO UNDERSTAND

5.3.1 Emotions and experiences

All participants struggled to make sense of these experiences; the more so as meaning making was discouraged - many participants did not have many relationships where they could explore and understand their experiences and exploration was discouraged by professionals.

“Since I was a child I've struggled with extreme emotions, voices, and powerful out of body experiences. I saw cartoons projected on the ceiling, and my fear was sometimes so strong I became mute. I often hid away, alone, overwhelmed and unable to describe what was going on.” Will Hall, (American, ‘schizo-affective’ disorder, narrative, National Empowerment Centre).

Caroline (White/British, ‘schizophrenia’, interviewee) attempted to distinguish between a shared sense of reality and her internal world, making both her external and internal worlds a source of confusion. She explained,

“It was very difficult to see between reality and normal life.”

5.3.2 Voices and symptoms

While the authors of the narrative accounts were able make sense of their experiences in retrospect, interviewees remained confused and found some experiences incomprehensible; the metaphor of untangling knots in the mind came through very strongly. Lacking an explanation that felt valid or reasonable, as well as having meaning making foreclosed, contributed to the sense of lacking control, making the world feel unpleasantly unpredictable. Owen (Black/British, ‘schizophrenia’, interviewee) described understanding why trauma had disturbed him but struggled to comprehend his symptoms:

“I didn’t understand Schizophrenia as a word...I knew what had done it, I knew the rape had caused it but what it had caused I didn’t understand. So I couldn’t control it.”

Stephen (White/British, schizophrenia, interviewee) describes puzzling where the voices arose from,

“But is it really there or is it in my own head or is it really there, I don’t know...it’s as if voices come from everywhere. They can’t be there and they can’t be in my own head either...”

Other participants mistrusted voices due to other people’s responses towards them:

“Because everyone responded so negatively to the first voice I heard, I learned not to trust my voices.”
(Eleanor Longden, White/British, ‘schizophrenia,’ narrative, ‘Living with voices’).

5.3.3 Others responses

Without confiding these experiences, all participants lost a sense of a consensual reality that could be shared with others. It became hard to know whether to trust their own explanations, those of other people or the voices, which led to further confusion. Paul (White/British, ‘schizophrenia,’ interviewee) tried to talk about it to his dad who told him that voices were,

“...a figment of your imagination.”

Such comments seemed to shut down both communication and meaning making; for

Paul it was difficult to use this explanation helpfully as his voices felt very real. This created a disconnection between themselves, other people and voices, making it harder to understand experiences.

5.4 ATTEMPTING SOLUTIONS: DISCONNECTING THE SELF

5.4.1 Disconnecting from others: retreating into a solitary world

All participants described a process of withdrawal from the external world, their emotional landscape changed as they turned inwards to a more unusual internal world which was experienced as time consuming, preoccupying and pervasive. Relationships with others were often experienced as shaming and confusing.

“I had friends but I lost all of my friends. I became so different from everyone else. I feel ashamed when I think about it now. I never really saw anyone from school much after that.”
Katherine, (White/British, ‘schizophrenia’, interviewee).

Participants described a sense of the world becoming smaller as they became less involved in wider activities and avoided relationships. Participants described being sensitive to the intentions of other people and some interviewees explained that they picked up ‘vibes’;

“...there’s vibes in the air you know, like when you think of people and think about what they think of you and then you start listening to the voices and that you know that they’re coming from the illusion of whoever you’re thinking about....I became very self-conscious about what other people think of me and I think I know what they think.” Stephen, (White/British, ‘schizophrenia’, interviewee).

Owen (Black/British, ‘schizophrenia’, interviewee) described determining whether people were genuine to protect himself from victimisation; relationships were assessed as positive or negative depending on whether they contributed to either his illness or health,

“I’m more stand backish than forward and involved with the person. Instead of being involved and blindfolded and then being victimised....I meet and meet againhow they treat me or react to me and then decide good or bad, healthy or illness.”

Participants described becoming increasingly mistrustful which perpetuated social disconnection and a wish to maintain social distance. The combination of shame, mistrust, rejection and difficulty talking about experiences made social relationships at the very least confusing and led to loneliness and social isolation. Stephen (White/British, ‘schizophrenia’, interviewee) commented that,

“You can get a bit isolated and become withdrawn and then it’s easy to stay isolated. Everyone needs a friend in life but I always seem to end up the odd one out.”

Becoming withdrawn and isolated is often constructed as part of the ‘illness’ and sometimes as ‘paranoia’ but provided all participants with a way of protecting themselves from threatening and invalidating experiences and therefore seemed a safer option than relating to others.

5.4.2 Disconnecting from feelings: becoming numb

Participants described becoming disconnected from themselves both emotionally and physically as they attempted to protect themselves from intolerable feelings.

“...I went into shut down. I withdraw completely and stayed in my room and sort of curled into a ball basically realising everything I’d done.” Caroline (White/British, ‘schizophrenia’, interviewee).

This loss of connection was exacerbated by medication which had a tranquilising effect and deadened feelings. A lack of empathic relationships also made it hard to express and connect with feelings. Furthermore, many participants learned that powerful emotions were often regarded as a sign of ‘illness’ resulting in a decision to suppress and fear emotion. Will Hall (American, ‘schizo-affective disorder’, narrative, National Empowerment Centre) wrote,

“Everything became a symptom...they told me my feelings were part of my disorder.”

“What started off as experience became symptoms.” Eleanor Longden (White/British, ‘schizophrenia’, narrative, ‘Living with voices’).

“I had to become totally emotionless and was not allowed to display any grief or sadness because that was dangerous.” Jeanette Woolthuis (‘psychosis’, Netherlands, narrative, ‘Living with voices’).

The connection between feelings and experiences withered, leaving participants feeling numb, disconnected and alienated.

“I had no emotion linked with any of the experiences I described. I was numb.” Abbey (‘schizophrenia’, narrative, National Empowerment Centre).

Participants described a process whereby feelings were externalised onto other objects, including voices and higher powers. This prevented feelings from being recognised, understood, challenged and perhaps resolved. The voices often seemed to express feelings that participants struggled to

experience and articulate, such as anger, as well as aspects of the self which participants seemed to have disowned, such as authority.

5.4.3 Disconnecting from the embodied self

Disconnection was increased by the side effects of medication which decreased the control and familiarity that people had with their bodies. Several participants struggled with weight gain after taking medication which had a detrimental effect on self-image and furthered weakened the sense of self. Participants described struggling to establish control over basic bodily functions of eating, sleeping and for some participants, bodily movements. Problematically, some of the side effects of medication also affected the ability to speak properly further hampering self-expression.

“When I first had that medication I slept for a day and when I woke up I realised something was different. I experienced what I later learned were side effects; my tongue got swollen, and I couldn’t stand and my eyes started rolling.”

Stewart Hendry, (British, ‘schizophrenia’, narrative, ‘Living with voices’).

“I was overwhelmed by the numerous drugs, these often filled an entire card index and the reactions I experienced ranged from hallucinations to paralysis, weight gain and lethargy to name only a few.”

Abbey, (‘schizophrenia’, narrative, ‘National Empowerment Centre’).

Physical pain was sometimes experienced alongside distress and perhaps reflected emotional pain. Several participants perceived their bodies as being diseased or unhealthy, increasing a sense of disembodiment. The body as well as the mind was perceived as a battleground or a source of conflict that couldn’t trusted or contained.

Furthermore, the body was sometimes perceived as toxic. Jacqui Dillon (White/British, ‘schizophrenia’, narrative, ‘Living with voices’) described worries about her unborn baby,

“I feared contaminating her with all the poison that swirled around inside me.”

Several participants experienced dissociation following trauma, as though they no longer owned their body. This was particularly strong after childhood sexual abuse.

Jeanette Woolthuis (Netherlands, 'psychosis,' narrative, 'Living with voices') wrote that when she was raped,

"I was in so much shock I didn't realise what was happening to me. I was actually watching myself from a distance. The memories of what actually happened are the memories of a bystander."

Participants used substances such as food, drugs, cigarettes and alcohol to alter their embodied self and mood. While this strategy helped to regulate emotions and induce a state of coping, it often led to an increased sense of disconnection exacerbating participants' sense of feeling 'not themselves'.

5.4.4 Disconnecting from consensual reality: developing compensatory fantasies

Many participants developed self protective compensatory fantasies, such as feeling powerful, being chosen by God, being special or having increased influence and authority and exerting influence on local or international events. These fantasies, or alternative realities, appeared to enable coping with the increasing lack of autonomy in the external world.

"A complex and mystical explanation developed in which I believed I had been chosen to receive a message from God....I was being tested by demons and the devil." Debra Lampshire, (voice hearer, narrative, 'Living with voices').

"I started to feel that things that were happening in the news were something that I contributed to or caused". Caroline, (White/British, 'schizophrenia', interviewee).

"I believed it to be true and found out later that it was as the voices said. It made me nervous and made me feel responsible for the health and lives of other people...The voices threatened others, something I was not allowed to do because I was responsible for the demise of others." Jeanette Woolthuis, (Netherlands, 'psychosis', narrative, 'Living with voices').

The response to this perceived power varied. For the majority of participants this was a disturbing and distressing burden, contributing to feelings of overwhelm and a frightening sense that events were spiralling out of control. Despite having an exaggerated sense of influence, participants felt unable to reverse or alter bad events occurring in the world. The experience was of a debilitating, crushing sense of responsibility. The process described seemed to mirror what was happening for many participants in their daily life. For other participants, this belief in increased power was welcomed. Wayne developed feelings of authority and entitlement after believing he had nothing in his life. This enabled a validating reframing of his experiences. Wayne (Black/British, 'schizophrenia,' interviewee) described conviction in his authority, even while detained at a high security prison,

"I brought change to the hospital by my conviction...I was locked in a side room and I said I would bring about change and a week later the police came and investigated the brutality and it was on the news."

Power was regularly deferred to a higher agency; for some participants this was a religious or spiritual force or the voices. For three interviewees, God gave power when they were in a desperate situation. This spiritual experience increased participant's sense of worthiness and perhaps provided compensation for loss of day to day respect, power and advocacy. The relationship with power was often complex; although some participants believed they held some power, paradoxically power was externalised to a higher authority which effectively removed their autonomy.

"I felt like I was going to give up the ghost ...when I could hear this voice, it says "I have come to save you"...and I knew it was God who spoke to me. There was only one person who could speak to me like that and that was the Almighty. I couldn't believe that God chose me as an individual for some big cause in this life." Wayne (Black/British, 'schizophrenia', interviewee).

Debra Lampshire (voice hearer, narrative, 'Living with voices') described,

"A complex and mystical explanation developed in which I believed I had been chosen to receive a message from God. This message would relieve mankind of war and conflict and

peace would prevail... In the meantime I was being tested by demons and the devil to prove I was a worthy recipient of the message."

5.5 OVERWHELM: SHATTERING INTO PIECES

5.5.1 Losing a coherent sense of self

Jacqui Dillon (British, 'schizophrenia', narrative, 'Living with voices') describes being 'shattered into pieces' in her narrative; a powerful reflection of the breakdown of her sense of integration. This disintegration was apparent in both narratives and interviews with participants using metaphors such as 'break down', 'fragmented', 'cracking up' and being 'scattered'.

"I felt that I didn't really know who I was anymore...I am totally nothing...that's what's happened to me. Who I am now is my own voices...it's not me anymore."

Eleanor Longden, (White/British, 'schizophrenia', narrative, 'Living with voices').

"I spent several months taking a very powerful 'anti-psychotic' tranquiliser drug called Navane...It completely changed my personality and denied me the most basic sense of who I was...I have photos of that time and the look in my eyes is totally different, not me, a different person."

Will Hall, (American, 'schizo-affective disorder', narrative, National Empowerment Centre).

Participants described doubting themselves on a cognitive, emotional, perceptual and relational level, not knowing who or what to believe or trust.

Stephen (White/British, 'schizophrenia', interviewee) expresses this confusion and questions,

"...whether you are what they say you are and then you start thinking who are they, who is there, is there anybody there really you know, or is it all just my imagination."

Many feared a descent into 'madness'.

"I became intensely paranoid and terrified to leave the house. I felt like I was going mad." Jacqui Dillon (White/British, 'schizophrenia', narrative, 'Living with voices').

"I had a lot of weird and violent thoughts running through my head most of the time... The voices seemed real but they

would most often occur when there was no one around.... At that point I know I was going absolutely mad.”

Charlie Hughes, (American, 'schizophrenia', narrative, National Empowerment Centre).

All participants described confusion over barriers or borders of the self. It became less clear where voices or other people ended and the participant began or what belonged to them or to someone else. As the self becomes less distinguishable and fragmented, the confusion between self and the 'other' contributed to further withdrawal and loss of personal identity.

“I felt quite overwhelmed by these people. So the therapy, the work, the friendships all contributed to me starting to feel as though people could get inside my head. They could take my thoughts away and put theirs in...”

Jan Holloway, (British, voice hearer, narrative, 'Living with voices').

Jacqui Dillon (White/British, 'schizophrenia', narrative, 'Living with voices' experienced her voices as dissociated selves as she became not one self but multiple selves,

“I began to realise that I was inhabited by different people.”

Voices contributed to a sense of being invaded and lacking boundaries. At times the connection with the voices felt so strong it seemed hard for some participants to identify themselves as having an independent self. For all participants there was a breaking point of being overwhelmed, withdrawing and disconnecting from the world and from themselves. The attempted solutions to protect the self, contributed to an already vulnerable and traumatised self being further undermined and invalidated. This led participants to feel increasingly terrified and overwhelmed.

5.6 'BECOMING A MENTAL PATIENT'

5.6.1 'Enduring the loophole of neglect'

As a result of the processes described above; the assaults on the sense of self, the breakdown of relationships, and an increasing sense of overwhelm and terror, many participants became socialised into the role of 'mental patient'.

That this term was frequently used by patients indicated the ways in which they had internalised the social constructions around abnormal experiences. Psychiatric care was often experienced as dehumanising, paternalistic and punishing which further invalidated participants and kept them stuck in what one interviewee described as 'the loophole of neglect'. Will Hall (American, 'schizo-affective disorder', narrative, 'Living with voices') described feeling simultaneously like a prisoner, a child and a criminal, losing sense of himself within this process,

"...I was treated like a disobedient child with a broken brain, punished and controlled...I went from being a human being to being a mental patient."

"I went into hospital a troubled, confused 18 year old and I came out a schizophrenic-and I was a good one...I came to embody what psychosis should look and feel like...I was being socialised into a mental patient. I was encouraged to see myself as a broken invalid, to forget my strengths and instead focus on my weaknesses and vulnerabilities as evidence of being a defective human being."

Eleanor Longden (White/British, 'schizophrenia', narrative, 'Living with voices').

Having undergone a process of withdrawing, losing a secure sense of self, struggling to maintain power in relationships and disengaging from making decisions and activity, it was difficult not to surrender control to professionals by adopting the sick role.

5.6.2 Surrendering Control

All participants described finding it increasingly hard to manage daily situations as well as their feelings, which intensified a sense of lack of control and eventually control was surrendered, at least for a time.

Strategies giving the appearance of increasing control were often actually deferential. Individual autonomy seemed to be split off and located within an external other.

"I listen to the life force all the time, but I hear what the skinnys are saying. They say, "that's what's wrong with you,

that's what's wrong with you..." At the moment I'm beating them. My life tells me how to do things and how I feel about them'." Ash (Black/British, 'schizophrenia', interviewee).

"I'm not very good at making decisions. I let other people make decisions. Only if I'm forced to make decisions do I make them."

Wayne (Black/British, 'schizophrenia', interviewee).

Participant's loss of autonomy was further exacerbated by medication, about which participants expressed mixed feelings. All the interviewees were prescribed medication at the time of interview about which the majority were unquestioning. This was noticeably different from the written narratives which were much more challenging of the medical model. Some interviewees were strongly in favour of medication while others expressed uncertainty. Some perceived medication as deadening distress and helping maintain some sense of normality.

"Medication has been helpful. The reliability and routine of it. Stabilisation, it has helped me with my stability. Medication helped with my mood swings and how I felt about myself, but not on the voices." Owen (Black/British, 'schizophrenia', interviewee).

Katherine (White/British, 'schizophrenia', interviewee) had experienced distressing side effects with previous medication, but spoke positively of her more recent medication,

"The medication has made a huge difference to me. I am like a different person since I changed medication."

Stephen (White/British, 'schizophrenia', interviewee) described being pulled between two different states, neither of which are fully within his control. He describes that medication does,

"Take it away, take it away. Deaden your mind to it. They sort of changed you mind like, as if they sort of change what you're thinking...when that medication wears off you get some of the schizophrenia back and it just gets worse until you take more medication. You don't get to choose medication. They talk about it but I don't understand how to speak my mind about medication... after cracking up, medication gave me some stability."

Paul (White/ British, 'schizophrenia', interviewee), a very accepting and passive man in many ways, described his experience of ECT which had had a permanent effect on his memory,

"I could feel it going through my head. The first few I didn't feel nothing at all, but the last 6, from about the 3rd treatment I started to forget."

Authors were less ambiguous about medication. Eleanor Longden White/British, 'schizophrenia', narrative, 'Living with voices') wrote,

"I wasn't encouraged to do anything actively to help myself. Therapy meant drug therapy. It was hugely disempowering."

Stewart Hendry (British, 'schizophrenia', narrative, 'Living with voices') movingly summed up his experience,

"...as it turned out the treatment never really stopped them (the voices), just me."

Different forces could be attributed power, which might create an illusion of gaining control, but which had the effect of removing power and individual advocacy. Compensatory fantasies had a function in maintaining an illusion of control. Unfortunately, rather than this power leading to increased respect and control, these new ways of owning power led to participants being disregarded further. The narrative of mental illness increased as these perceptions of power were interpreted as evidence of lacking responsibility and sanity. Actual power became increasingly limited with restrictions on agency and choices, especially if hospitalisation occurred, causing further potential disruptions in power relations.

6.0 BECOMING EMPOWERED

If participants were supported in understanding invalidating and traumatising threats to the self by validating others, or by the self, this appeared to lead to a more empowering pathway of intra and interpersonal relationships. This pathway enabled participants to reconnect lost aspects of themselves, reconnect with others, and make sense of their experiences. This process also led to a greater degree of autonomy and sense of purpose. It is important to recognise that recovery and empowerment are not 'all or nothing' states; no-one is completely disempowered or empowered and some participants moved between the two pathways. Authors tended to have moved further down the pathway of empowerment, which reflected their stage of recovery. *Feeling validated* will be explored, followed by *reconnecting socially, reconnecting with oneself, with one's body, making sense of experiences, reconnecting with the voices themselves, taking personal ownership and redefining the self*.

6.1 FEELING VALIDATED

This began by participants both seeking help and receiving positive validation either from others, the voices or the self. This experience made a powerful impact and was identified clearly in the narratives as being central to the process of empowerment and recovery.

6.1.1 Feeling validated by self

Some participants described using willpower and self-belief to make changes. The ability to draw on one's own strength could be powerful and appeared to involve recognition of free will; that a choice can be made to do something different. Amanda (voice hearer, narrative, National Empowerment Centre) explained,

"I left that meeting accepting that this was to be my future and that I had no say in it. However, in the ten minutes it took me to reach a park near where I live I decided "NO". No-one had the right to decide my future except me."

Jeanette Woolthuis (Netherlands, 'psychosis', narrative, 'Living with voices') reflected that,

“Looking back, I realise I made a number of choices. The first choice was to stay alive. That was an important decision because I stopped thinking about not wanting to live anymore.”

6.1.2 Feeling validated by externalised others (voices)

At times, some participants sought support from their voices and found that their power provided guidance and reassurance. Jeanette Woolthuis (Netherlands, ‘psychosis’, narrative, ‘Living with voices’) described that before her voices became threatening,

“The voices took me seriously when I was anxious and all alone... They were the only ones who understood me and gave me support and therefore became more influential...”

Several participants experienced positive voices as well as critical and as some participants became more empowered, voices became increasingly used in a validating way. This was experienced to a greater extent by narrative authors. The communication and then relationship with voices began to change, as slowly these participants began to respond to voices in a different way. Stewart Hendry (British, ‘schizophrenia’, narrative) described,

“My mum and Nan’s voice were more helpful, saying things like I was a good person and shouldn’t kill myself. Sometimes my mum and Nan’s voice would talk together. The way I explain and always think of it, it was Nan saying goodbye.”

Jacqui Dillon (White/British, ‘schizophrenia’, narrative, ‘Living with voices’) described one of her voices as a,

“loving mother with a soothing, calm voice.”

For Ash, (Black/British, ‘schizophrenia’, interviewee) one of his voices voice which he calls his ‘life voice’ talks reassuringly to him and seems to reflect a positive part of himself. Ash describes this voice,

“...tells me how to get healthy, how to do things. How to get over these voices, these skinny ones. It tells me everything really, everything about life, about how I should be...”

There were times when the relational benefits of voices were apparent; they could be loving, providing advice and companionship.

6.1.3 Feeling validated by external others

Most participants, both interviewees and narrative authors, identified the value of a non-judgemental environment where they could talk freely about their voices and experiences. Having a validating relationship, whether with a friend, family member or professional, who was trusted and who listened was extremely significant.

“My friend always allowed me to drive the process and come up with strategies to confront the voices. This demonstrated their belief that I was resourceful, competent and able to drive the recovery process, that I did in fact have the courage, resilience and capacity to heal myself. I had not been able to get this validation from physicians. My friend’s support was hugely affirming and established a sense of control within me.” Eleanor Longden (White/ British, ‘schizophrenia’, narrative, ‘Living with voices’).

Participants, described internalising validating professionals or others who remained open, hopeful, empathic and supportive. Validation was also received from other service users; for many participants bonding with service users was crucial in their journey of recovery. When talking with professionals or family members was too difficult, talking with other service users seemed easier.

“I had an opportunity to speak freely about my voices. My experience was accepted as real and not only negative.”
Sue Clarkson (British, voice hearer, narrative, ‘Living with voices’).

Gaining positive feedback from professionals was experienced as validating. Abbey (‘schizophrenia’, narrative, National Empowerment Centre) wrote of one of her psychiatrists,

“He provided me with literature and research and most of all a feeling of control and a voice in relation to my own care which was meaningful and sincere. This was truly refreshing.”

Caroline (White/British, ‘schizophrenia’, interviewee) said of a resource centre group,

“...in this group here people expressed quite deep feelings of sadness sometimes, not feeling able to cope and just knowing you could come and relay those feelings made me feel more comforted not just about not being on my own, but having a safety place to come.”

Of her relationship with her psychiatrist,

“That was really nice that somebody was there to help me through the journey of understanding. That really made a difference. It started the road for me to be able to forgive myself. Yeh, so that helped me be able to forgive myself for things that had happened and start making progress on getting better and focusing on coming back to normal.”

“In the last year (the) staff have helped me by just being there really and other residents help me really by just being there. People just being themselves...It helps talking to people, solitude is the worst enemy I’ve got, being on my own. I tend to go into a sort of schizophrenic world like, when I’m by myself and develop schizophrenia.... I find that company brings you back to reality, instead of going away from reality when you go into a world of your own”. Stephen (White/British, ‘schizophrenia’, interviewee).

Stewart Hendry (British, ‘schizophrenia’, narrative, ‘Living with voices’), reflected on his relationship with his social worker,

“She was much more informal and friend like, treating me more like a person. We talked about the future, about doing things and relationships and she really started me on the road to doing something about what I wanted. I think she was one of the reasons I’m at this point now... It was important to have some hope at a time when I thought my life was over and I couldn’t be expected to recover.”

Participants generally felt that if people accepted their voices without being shocked, overwhelmed or dismissive, then perhaps they had also accepted them.

“It seems to me people who have a tolerance for the unusual and who are able to challenge some of the ideas that are not helpful to me—that’s the theme that runs through the people that I want to talk to when I’m going through a bad time with voices and paranoia.”

Jan Holloway, (British, voice hearer, narrative, ‘Living with voices’).

An important aspect of validation was that participants could express themselves without feeling judged and had felt their experiences were accepted and heard. There was a sense that others had a genuine interest in them as individuals, rather than concern with eliminating the voices. Through this connection, validated participants were able to share their reality with others who would listen and try to understand. Expressing themselves perhaps also helped participants to make sense of their own experiences rather than defending against them.

6.2 MAKING CONNECTIONS

Making connections included connecting socially with other people, connecting with oneself and with the voices in a different way. However, it seemed that the experience of validation was necessary for connections to be made; feeling validated led to participants becoming more able to take the risk of reaching out to others and through relationships, internalise a more positive relational experience.

6.2.1 Developing compassionate and respectful relationships

Connecting socially seemed fundamental to becoming more empowered. This was a very individual process with participants, both interviewees and narrative authors, being inspired or reassured by different people or motivations, but a re-engagement in the community seemed necessary.

Debra Lampshire (voice hearer, narrative) described that,

“...I decided I needed to take the risk of inviting real people into my world...this became my new quest...It proved to be pivotal to my recovery.”

Participants described being highly attuned to who was genuine and attended closely to these impressions when choosing relationships. Meeting with people on a social level involved making decisions about who was helpful and positive for them personally. Stephen (White/British, 'schizophrenia', interviewee) described of people he connected with,

“Just knowing that their there and their kindness to be there really, like cos they care, cos they're welcoming people, sort of friendly people, whereas oppressive people I avoid them.”

For Owen (Black/British, 'schizophrenia', interviewee) religion and smoking helped him connect. He described how, having to go out to buy cigarettes or cannabis,

“...makes me communicate again instead of sitting there going into my own world. Makes me come out and have to relate to others and share, but apart from that religion helped as well, going to church. That also helped me share myself instead of being in my shell alone with nothing apart from me.”

6.2.2 Reintegrating aspects of the self

As the quality of relationships with others changed, many participants, mainly but not exclusively narrative authors, described coming increasingly connected with themselves, feeling more integrated and able to develop compassionate and respectful relationships with themselves. Connecting with oneself involved developing an emotional understanding and acceptance of one's person and experiences. This can be regarded as part of the process of re-building the self which had been shattered by psychological distress. Rather than externalising and splitting off from fears as something other, these participants, especially narrative authors, described an increased ability to contextualise their fears and perceive them as meaningful. An awareness of the external world was rebuilt alongside the sense of self, allowing some participants to form a more coherent narrative. Reflecting upon the causes of distress and the psychological impact of events was not an easy process, but could be cathartic and powerful.

Some participants, again mainly narrative authors, found that making connections was facilitated by reducing or coming off medication. Stephen Hendry (British, 'schizophrenia', narrative, 'Living with voices') described,

"He started reducing the medication I was on and that was a really big thing because I started to feel things again, you know feeling emotions and that sort of stuff. I came to realise that, before then, I hadn't really felt things. It was from then on I began to feel more like a normal person again."

There was a process of beginning to recognise, name and identify emotions which had been lost in the suppression of feelings. This supported some participants to understand feelings and brought them into focus. Jan Holloway, (British, voice hearer, narrative, 'Living with voices') explained,

"I am more in touch with what I am feeling now. There were times not that long ago when I would have feelings and I wouldn't even know what they were called, whether it was anger or sadness."

This enabled some participants to monitor and cope with emotions, as Sue Clarkson (voice hearer, narrative, 'Living with voices') described

"My coping strategies are to review my emotions daily; deal with my emotions through a series of explanations; to be mindful of what I'm feeling and why."

Emotions contribute to a sense of humanness; having presence, as opposed to being numb, shut down and dissociating. Reconnecting with emotions supported participants to acknowledge and accept feelings; reflecting on how they felt about voices, themselves and their experience of the world. Through noticing emotion many participants gradually distinguished between their voices and their emotions, enabling them to form a clearer sense of identity.

"I've got a deeper understanding of myself now than I did before. I've got more inner knowledge of myself." Amanda (voice hearer, narrative, National Empowerment Centre).

Several interviewees described writing as a way to express emotions.

Owen (Black/British, 'schizophrenia', interviewee) explained,

"...as an adult I found ways of communicating with myself. I put pen to paper about it, like notes that I'd go over sometimes and it does help, that I agree with or ask questions about the notes that I jotted down. About my relationships and experiences with others."

6.2.3 Re/connecting to the body

Reconnecting also involved reconnecting with the body, allowing participants to feel present in the world, rather than being withdrawn and closed off. Sometimes this change came through reducing medication; participants began to feel present in the world, rather than being withdrawn and closed off. The body appeared to provide a concrete arena for control to be developed and recognised in a helpful way. Several participants, including interviewees and narrative authors, began to choose food and some became more aware of health needs and began to exercise. Others described taking more care of their appearance,

"I think giving up smoking and losing weight were very important. I never thought I would be able to do that. How I feel physically has been very important for me. Looking after myself, watching what I eat. I used to drink as well and I don't drink anymore. I feel much better.... I feel totally different now. I have got my spirit back."

Katherine (White/British, 'schizophrenia', interviewee).

Caroline (White/British, 'schizophrenia', interviewee) described going to the gym in hospital and deciding to exercise again now she was in a stage of recovery.

"I think there's something really simple in the natural endorphins in your brain that you get from exercise that helps so I think that's another thing that's quite key with getting better."

"I used to just race around and I used to find it hard to relax...but these days I tend to be able to relax a bit more, as if my body just grew old. It stopped just wanting to run away from everything and felt more comfortable and easily able to deal with other people and not just have to keep on fleeing"

situations. I found it hard to find some sort of ground control.”
Stephen (white/British, ‘schizophrenia’, interviewee).

“I also found taking care of myself physically really helped complimentary therapies that work holistically, taking account of the whole person, mind body and spirit, really appealed to me.” Jacqui Dillon (White/British, ‘schizophrenia’, narrative, ‘Living with voices’).

An increased sense of embodiment implies increased awareness of the connection between physical and emotional needs. Being more comfortable with one’s body seemed to symbolise a feeling of being more integrated.

6.2.4 Making meaning of experiences

An important part of recovery was the development of a personal understanding of voice hearing. It seemed that some, although not all, interviewees were struggling with this process and some had as yet not formed a connection between their voices and experiences in order to make sense of them. Ash remembered about being in Somalia as a child,

“The beginning really as a two year old was like living in paradise, but then when the war started it was hell, really bad... You always remember what bad things happened.”

However, he made no connection between what he had witnessed as a young child and the traumatic voices he experienced as an adult.

This process was sometimes supported through expressing oneself creatively. Writing down feelings was one way of making sense of these by interviewees and narrative authors, as well as externalising experiences;

“The writing it down definitely helped. I could reflect back then on what had been going on in my head... I read back over some of it and then I’d rip it up and get rid of it and I think that helped.”

Caroline (White/British, ‘schizophrenia’, interviewee)

“I began writing a daily journal which gave me a sense of order and structure in what often felt like a chaotic environment. Writing became my way of putting the different voices and feelings that were troubling me outside of me.”
Jacqui Dillon (White/British, ‘schizophrenia’, narrative, ‘Living with voices’).

Through this process of exploration, reconnection and contextualisation, some participants, although predominantly narrative authors related the content of the voices to their experiences and construct their voices as responses to traumas rather than as arbitrary, ridiculous and irrational. This established a non-blaming, non-medicalised way of understanding their experiences, rather than evidence that something was 'wrong' with them;

"I wanted a framework which would enable me to safely listen to my voices and make sense of my experience.... I began to comprehend the impact of my early experiences." Jacqui Dillion (White/British, 'schizophrenia', narrative, 'Living with voices').

"I personally believe that my illness developed as a consequence of a prolonged stress, anxiety and deep depression." Abbey ('schizophrenia', narrative), National Empowerment Centre.

Sue Clarkson (voice hearer, narrative, 'Living with voices') writes,

"I believe my voices are suppressed emotions that are denied within myself... it starts to make sense, the more we explore our voices the more we discover and start to understand."

Debra Lampshire (voice hearer, narrative, 'Living with voices') writes,

"I believe it was not one specific traumatic event that made me susceptible to voice hearing but a succession of significant, distressing events which established a vulnerability and of being worthless, defective and unlovable."

Owen (Black/British, 'schizophrenia', interviewee) explained,

"My distress was about relationships. I went through a rape of my girlfriend (she was raped by someone else) and that's what triggered my psychological illness."

Caroline (White/British, 'schizophrenia', interviewee) described,

"I was raped ...and that made an impact on how I was and why I was so paranoid my daughter was going to be raped, so it was something that made it more realistic, you know, made me see where the thoughts had come from and where the voices had come from".

For many participants, establishing meaning changed their understanding of, and their relationship with, their voices. These participants moved from feeling dominated by the voices and constructing them as irrational or untrustworthy, to greeting the voices with compassion. Voices were then constructed as a reflection of their emotions rather than as an irrational and therefore frightening force. Authors wrote of treating voices with understanding and of accepting voices as personal rather than as something disconnected from themselves.

“...My sense of my own identity shifted. I moved from being ‘me’ to ‘we’. My relationship with my different selves changed over time.

I wanted to encourage communication between the different selves and eventually worked towards a mutual collaboration with them.”

Jacqui Dillon (White/British, ‘schizophrenia,’ narrative, ‘Living with voices’).

Eleanor Longden (White/British, ‘schizophrenia,’ narrative, ‘Living with voices’) wrote,

“I began to slowly realise that yes, he’s a demon, but he was a very personal demon. Everyone has their private demons and his demonic aspects were unaccepted aspects of my self-image. He is like an externalising form of my own insecurities and that part is relevant and does need attending to, does need taking seriously because it is meaningful.”

Debra Lampshire (voice hearer, narrative, ‘Living with voices’) described,

“One of the first things I did was to change my attitude towards them, instead of being fearful of them and bowing to their every whim, I embraced them as friends and welcomed their intrusions, I thought about the role the voices played in my life and discovered they fulfilled a need in me – a need to be connected to someone, a need for a friend, a need to belong....As unkind as they were, they were only telling me the truth about myself.”

Sue Clarkson (British, voice hearer, narrative, ‘Living with voices’) detailed that,

“The voices sometimes seemed to be another entity, but when I later explored my voices I realised that this entity was in fact my human spirit within; so now I perceive it to be within me, part of me and also part of the universal life force which is in us all...”

She considered voices to be related but not part of her writing,

“I have perceived them as being other people: the abuser when I was a child; a woman who I perceive as being weak; and one inner voice who communicates through feelings as the Almighty universal force or God.”

However, this was a difficult process and generally authors of narratives had progressed further in this than had interviewees, who were either still struggling to make sense of their voices, or avoiding reflecting upon them altogether. For some participant's distraction appeared to be preferable to developing an understanding of their experiences.

6.3 GAINING AUTONOMY

As a result of feeling more validated and making connections, some participants described becoming more confident and able to engage with services, with the social world and with decision-making. Again, authors of the narratives, who defined themselves as on a journey of recovery, had taken more steps to support their autonomy. These participants described a change in power relations, many described moving from a subservient position to assuming a significant level of control and personal agency. This often involved challenging themselves and others.

6.3.1 Taking control

To regain a sense of increased individual power often required questioning, challenging and testing out the power of the voices and setting boundaries. Stephen (White/British, 'schizophrenia', interviewee) described having developed a technique that increased his control over voices. He explained that,

“I've learnt to cope with voices over the years even down to turning them around and making them into better voices, good voices... you can readjust your mind to listen to it and make it, so you can hear it say something else.”

“...now I doubted him and I began to question him further. I began to put boundaries in place, saying things like, 'don't talk to me until 8 in the evening because I will not talk to you. Over time I began to have more control of the times and again I began to question, if he is willing to wait until after

Eastenders, how powerful is he?" Eleanor Longden, (White/British, 'schizophrenia', narrative, 'Living with voices').

Stewart Hendry (British, 'schizophrenia', narrative, 'Living with voices') explained,

"I was already able to talk back to my voices with my thoughts, but I learnt to make a specific time of day, the evening, when I could focus, and would simply tell the voices 'later' if they came at another time. And it worked!"

Sue Clarkson (voice hearer, narrative, 'Living with voices') related her ability to challenge voices to her increased understanding of them,

"I understand what makes them negative so they don't have the power they once possessed."

Authors in particular described a significant shift in the balance of power between themselves and their voices once they connected with their experiences and reconstructed their voices as being related to their trauma history. This construction normalised their voices so that they no longer questioned their sanity, but considered their response as an acceptable reaction.

A significant challenge was for participants to ensure that professionals responded to their voices in a way which corresponded with participants own revised understanding. Several met with different professionals until they found someone who shared their constructions of their experience. Charlie Hughes (American, 'schizophrenia', narrative, National Empowerment Centre) described,

"I finally found a therapist that was dedicated enough to accept a challenging case like me. She was very patient and listened to what I had to say about my condition."

Sometimes participants had to be defiant. Mary Lou (American, voice hearer, narrative, National Empowerment Centre) stated,

"Know that you are a human being first, and that a diagnosis is someone's subjective opinion. FIRE anyone who refuses to see you as one."

Caroline (White/British, 'schizophrenia', interviewee) described getting an advocate,

"It was my own idea. I found the number on a bulletin board...so I phoned and got an advocate...I wanted to go down the route of having counselling and psychology but I felt they (the hospital) just wanted to dope me up and I was worried I wouldn't get the other support but I did get the other support eventually. It took a while but then I eventually got the support from psychology."

It required strength and confidence to challenge the system in this way and for some participants, particularly the interviewees, this was perhaps harder to do. However, some participant, again particularly the authors of narratives, described becoming empowered and increasingly taking back control; this also involved owning their own role in their 'problems in living':

"Through my work with her (a psychologist) I came to realise my own part in many of the negative events which I believed had "been done to me!" As painful as it was at the time to realise that I had in fact played a part in some of my own misery, it was exciting to learn that I did in fact have some control and through this realisation, had a choice as to whether it would happen again." Mary-Lou (American, voice hearer, narrative, National Empowerment Centre).

Amanda (voice hearer, narrative, National Empowerment Centre) had a realisation of being ultimately responsible for herself,

"I painfully realised that it was actually my own reactions and learned behaviour that was keeping me stuck within services which were not working for me. Along with this self-awareness came the realisation that only I could change my life, no-one else could do it for me.... I had to take personal responsibility for all areas of my life and for my future. I was the expert on myself, no-one else was an expert on me".

"I realised the psychiatric system had made me a victim."
Eleanor Longden (White/British, 'schizophrenia', narrative, 'Living with voices').

Having an awareness that control was possible and doing what was within one's control, however limited that might be, was very significant. Abbey ('schizophrenia', narrative, National Empowerment Centre) described the importance of trying to,

“...focus on all that is in your control at that time. It could be something as simple as getting out of bed in the morning – it is your choice.”

“It makes you feel much better when you’ve looked after yourself and had a shower. It makes you feel much better about yourself rather than just festering away and making excuses not to do this and not do that...I try to do little things there and it all adds up.”

Stephen (White/British, ‘schizophrenia’, interviewee).

Some participants used voices to help with this process, usually once they had reconnected with them:

“When my voices change for the worse I am now much more aware that I need to change how I am running my life, maybe slow down a bit or change certain relationships with people...But over the years I have learned to use my voices as a bit of a barometer; either internally or externally.” Jan Holloway (British, voice hearer, narrative, Living with voices’)

6.3.2 Developing a sense of purpose

Gaining autonomy involved developing a life beyond hearing voices, having interests,

roles and a sense of purpose.

“I think because my self-esteem started to rise a bit more, it gave me a purpose rather than just sitting around drinking cups of tea.”

Stewart Hendry (British, ‘schizophrenia’, narrative, ‘Living with voices’).

For some authors passionate feelings were aroused about the position and treatment of psychological distress in society which instilled a different level of action.

“Suddenly, my own experiences were put into a wider context. I was not alone in feeling outraged by the damage done by society, in pathologising survivors of abuse. The personal became political.”

Jacqui Dillon (White/British, ‘schizophrenia’, narrative, ‘Living with voices’).

“I used the information by going along to the meetings and conferences and actually becoming an active member of the

network.” Sue Clarkson (voice hearer, narrative, ‘Living with voices’).

For Caroline (White/British, ‘schizophrenia’, interviewee) her role as a mother was vital. She clung to this even through very troubled times and prioritising her role as a parent was a protecting factor keeping part of herself intact. She explained,

“Focusing on what my daughter needs and the future for her. That’s the biggest part for me really... I need to be that strong person for her again that I know I can be.”

It seemed important for participants to achieve something that for them represented establishing a sense of ‘normality’. Some participants, both interviewees and narrative authors, pursued the socially recognised markers of ‘normality’ which confirmed a more positive status and self-image, whether this be working, driving, wearing fashionable clothes, going for lunch or studying. Owen (Black/British, ‘schizophrenia’, interviewee) had studied for 3 NVQ’s while in prison which increased his self-esteem and confidence and found,

“I’d 3 NVQ’s from course work in prison and I haven’t been back to prison for 15 years with the NVQ’s as support and guidance...these things made me have more control over myself and putting things into words, to explain.”

Two interviewees gained autonomy through having the freedom of their own transport, choosing where and when they wished to go and both enjoyed this independence.

6.3.3 Constructing a positive sense of self

Becoming empowered involved beginning to understand oneself in a different way. Rather than constructing themselves as ‘sick’ or ‘unhealthy’ or ‘damaged’, some participants were able to accept themselves and their experiences, reconstruct themselves as survivors and to feel proud. Wayne (Black/British, ‘schizophrenia’, interviewee) described,

“I feel different because I’m more mature now, I’m more settled and I have my direction better. I know where I’m going in life.”

Authors of the narratives appeared to have developed a more integrated sense of self and demonstrated, greater self-acceptance, however the authors were writing to promote recovery based on their own experiences, whereas many of the of the interviewees had not reached this point in the journey of recovery.

“Gradually I felt less ashamed and began to marvel at how creative I had been in surviving such monstrous abuse.I live life to the full and each day find myself becoming closer to who I want to be.”

Jacqui Dillon (White/British, ‘schizophrenia’, narrative, ‘Living with voices’).

“Most of all, to strive towards self-respect, self-worth and more importantly, self- acceptance; to learn to acknowledge the good and bad inside myself and to bring change to the things which are negative-and learn to accept who I am.” Sue Clarkson (voice hearer, narrative, ‘Living with voices’).

Stewart Hendry (British, ‘schizophrenia’, narrative, ‘Living with voices’) described a reconstructing of his philosophy and himself;

“I don’t really see it as an illness, in fact I don’t see it as an illness at all. I know why I started hearing voices, because of what was happening to me at the time, although I still don’t know why those things came out as voices. I just accept that this is me and, all in all, things have turned out okay.”

Will Hall (American, ‘schizophrenia’, narrative, National Empowerment Centre) perceived that,

“I might be different than most people around me, but being different also means being creative and sensitive. I stopped seeing myself as a broken person with no chance for recovery.”

For recovery, the self needs to be rebuilt or rediscovered in some way. This can be a difficult and painful struggle requiring reflection and honesty about why the shattering occurred. An acceptance was developed of voices through the processes of making personal meaning of the voices and understanding them as being an externalisation of difficult feelings that no longer needed to be rejected.

The processes discussed are interconnected and feed into each other. The experience of receiving validation and connecting socially had an impact in helping participants reconnect with themselves and construct a positive self-

concept. As relationships improved and became more accepting, so participants found it easier to reflect on personal experiences and the psychological impact of these. Being open emotionally in turn made it easy to converse and relate to other people. These positions were not fixed; participants moved back and forth between them at times, but the relational aspect with the self, with other people or with the voices was a constant factor throughout.

7 Discussion

7.1 Summary of results

This study aimed to explore what is experienced as empowering and disempowering and the role this has on the experience of severe psychological distress, developing a grounded theory of this process. The grounded theory outlined above describes the social psychological processes involved in the process of recovery and the relational factors which were constructed as empowering and disempowering. The construction of this theory was influenced by my epistemological belief in the existence of multiple realities, as well as by my relational framework. This study aimed to explore the role of empowerment in recovery and the experience of severe psychological distress from the perspective of service users and in doing so address identified gaps in the research and theoretical literature in this substantive area.

All of the participants in the current study described invalidating experiences with traumatising others, including their voices and the psychiatric system; which contributed to social withdrawal as well as disconnection from the self. Participants described overwhelming fear and mistrust of interpersonal and intrapersonal relationships, climaxing with a sensation of the self 'shattering' as boundaries were lost between the self and the external world. This loss of a defined, autonomous self, contributed to passive disengagement and adoption of the role of 'mental patient', which increased the sense of invalidation. Social, relational and psychological losses built up throughout the process and were experienced as re-traumatising and re-invalidating.

Conversely validating relationships encouraged connections socially and intrapsychically, and supported the development of a meaning making process about experiences. These were experienced as empowering and enabled participants to actively engage, redefine and accept themselves and claim increased control. Relationships were highly significant in this process of empowerment and recovery. There was movement between these pathways, but a deep level of validation was needed to affect a strong, more lasting sense of empowerment.

7.2 Key findings from previous research

7.2.1 Empowerment and disempowerment through relationships with others

Invalidating experiences in early relationships have been found to contribute to problematic patterns of relating to the self and in interpersonal relationships (Bowlby, 1969; Mikulincer and Shaver, 2012; Read and Gumley, 2008). Research findings consistently indicate that a high proportion of people affected by severe psychological distress have experienced trauma or victimisation (Janssen et al., 2003; Mirowsky and Ross, 1983; Shevlin, Houston, Dorahy and Adamson, 2008; Read, van Os, Morrison and Ross, 2005; Johnstone, 2007; Read, van Os and Bentall, 2012; Read and Bentall, 2012; Read and Gumley, 2010). Insecure, preoccupied and fearful attachment patterns have been hypothesised to increase the risk of voice hearing alongside severe psychological distress (Korver-Nieberg et al, 2014; Korver-Nieberg et al, 2015; Gumley, Taylor, Schwannauer and MacBeth, 2014; Harder, 2014; Huguelet, Mohr, Rieben, Hasler, Perroud and Brandt, 2015; MacBeth, Gumley, Schwannauer and Fisher, 2011; Shevlin et al, 2008; Dillon et al, 2012). It has been found that social contact is often difficult for individuals suffering from severe psychological distress; research findings indicate that increased loneliness, isolation and a significantly reduced number of social contacts are experienced by this group compared with the general population (Davidson, Hoge, Godleski and Griffith, 1996; Lester and Tritter, 2005; Onken et al, 2007), and contacts tend to be restricted to family networks and other service users (Breier, Schreiber, Dyer and Pickar, 1991). Research has identified that a poor social network contributes to disempowerment and increased stigma, while social withdrawal can lead to the internalisation of stigma, when people accept a stigmatised view of themselves (Goffman, 1963; Sibitz et al., 2011; Corrigan, 1998).

The role of relationships is discussed in social and psychological approaches but much less so within medical and cognitive models. Findings from these fields have identified relationships as critical in recovery from distress (Torpor et al., 2011), through enabling hopefulness and realistic goals, (Cutcliffe and Koehn, 2007; Houghton 2007; Spandler and Stickley, 2011; McCann, 2002), developing supportive social networks (Sibitz et al., 2011;

Stromwell and Hurdle, 2003), and encouraging openness about emotional experiences (Corrigan, 1998; Corrigan, Larson, Michaels, Buchholz, Rossi, Fontecchio, Castro, Gause, Kryzanowski and Rusch, 2015). User led research (Walsh and Boyle, 2009) described respectful, empathic and trusting relationships with staff as valuable, while qualitative research by Rethink with service users and led by service users, 'Getting back into the world' (2009) found that stigma increases isolation and can lead to low mood. Service users described feeling something deeper than lonely and isolated; feeling disconnected from human contact. For recovery it was crucial to have empathetic and understanding relationships, to choose and retain nurturing friendships but reject harmful relationships. Sociology and social psychology highlight that the opportunity for inclusion and integration in the community and the availability of community resources can improve quality of life (McCann, 2002; Mattsson, Forsell and Torpor 2008; Torpor, et al, 2011). Research indicates that developing a group identification is empowering (Jetten, Branscombe, Schmitt and Spears, 2001). Sharing with others with similar experiences can provide support, advocate for change and encourage a positive identity (Dickerson, 1998; Whitley, Harris, Fallot and Berley, 2008; Mayhew and Gilbert, 2008; Zimmerman, 1995; Kirkpatrick, Landeen, Woodside and Byrne, 2001; Romme et al., 2009; Torpor et al, 2011) and can decrease the negative effect on self-stigma (Corrigan, 2010), while supportive family relationships maintain hope and a stable sense of identity (Deegan, 1998; Smith and Velleman, 2002; Torpor et al; 2011). It is suggested that openness about psychological distress can decrease the negative effect on self-stigma (Corrigan, 2010).

The processes outlined in this study indicate that the struggle for everyone concerned to manage feelings towards voices and difficult experiences can contribute to the social withdrawal of the voice hearer. In this arena of uncertain relationships, some security is achieved through withdrawal, which this study suggests is often a reasonable response to a painful situation where relationships are no longer fulfilling or attuned. This supports Sullivan's assertion (1956, 1962) that withdrawal can be a protective coping mechanism. . Rather than perceiving relationships negatively or with suspicion, which the medical model would regard as a symptom of 'schizophrenia', participants were

aware of being stigmatised, but also recognised when relationships were well-intentioned and supportive. Findings from the current study suggest that an expectation of social rejection can lead to caution which reflects a need to protect the self from rejection and prejudice. However, for some participants this this diminished their support networks further in the long term.

Conversely, relationships have the potential to prevent withdrawal from the social world through providing understanding and compassion. Findings from this study confirmed the importance of validating relationships (Sullivan, 1956; 1962; Rogers 1951, 1980). Receiving a validating response from others, either in social relationships or by professionals, was often a turning point for participants. This was Feeling listened to and understood, established a sense of hopefulness, supporting findings from social psychology, (Perry and Gilbody, 2009; Hyde, et al, 2015; Houghton, 2007; Spandler and Stickley, 2011; Erikson and Erikson, 1998; Kirkpatrick, Landeen, Bryne, Woodside, Pawlick, and Bernado, 1995). This research confirmed findings that service users want to be open about experiences (Corrigan, 1998; Corrigan et al, 2015), but also indicates the importance of being able to talk without fear of prejudice or alarm about emotions and voice hearing experiences. For some participants the lack of opportunity to vocalise their experiences made these more preoccupying and overwhelming.

This research indicates that with positive relationships, movement is possible between the pathways of being disempowered to more empowered and valued, even if temporarily. As one interviewee put it, 'everyone wants to feel wanted'.

This research supports previous findings concerning the difficulties finding compassionate, respectful and accepting relationships for many service users. Goffman (1963) and Petersen et al, (2015) have suggested that acceptance is often limited to other service users, a finding confirmed by this study. However, for many participants these relationships were often found to be supportive, inspirational and promoted a positive identity (Romme et al., 2009; Torpor, Borg, Girolamo and Davidson, 2011; Kirkpatrick et al., 2001; Zimmerman, 1995; Dickerson, 1998; Whitley, Harris, Fallot and Berley, 2008; Mayhew and Gilbert, 2008; Zimmerman, 1995). Furthermore, despite the lack

of purposeful roles amongst interviewees, a meaningful role was that of being a friend to other service users.

However, this research indicates that people experiencing severe psychological distress can struggle to develop wider relationships, despite living within the community, and even while in recovery. This may reflect continued stigmatisation and how communities take a position of 'othering', keeping a social distance from those regarded as 'different' (Krumer-Nevo and Sidi, 2012). Many participants reflected upon difficulties finding support when they experienced extreme distress and noted that it was easier to obtain support for a physical health emergency than an emotional one. The difficulty finding effective support contributed to a feeling of their distress being devalued.

This study acknowledges the challenges many participants experienced in establishing therapeutic relationships with professionals, which were often not perceived as collaborative. There appeared to be a shared lack of hope of recovery between professionals and service users. However, when a positive, hopeful, collaborative relationship with a professional was formed this reflected a significant change. This supports research findings regarding the importance of professionals holding hope for service users and developing a shared understanding (Turner and Frak, 2001; McCann, 2002).

The value of being able to talk in a supportive and understanding environment seems to have been under researched. As outlined above, research into therapies and severe psychological distress has tended to focus on cognitive behavioural therapy, arguably a less relational approach. Severe psychological distress is still be categorised in some fields as less responsive to talking therapies, due to the dominance of biological explanations, implying that talking, listening and processing experiences are less a part of the recovery process.

This research challenges ideas of mentalization which describe severe psychological distress as causing a disruption in the ability to recognise and understand emotion (Dimaggio and Lysaker, 2010). In this study many participants seemed acutely aware of social relations and were very sensitive to the emotions and behaviour of others. It is possible that medication impacted on some participants' ability to be reflective; some had also received electro

convulsive treatment (ECT), and had perhaps been affected by the iatrogenic effects of long term psychiatric treatment.

7.2.3 Empowerment/disempowerment and the relationship with psychiatry

The dominant treatment received by participants was medication. Many (but not all) described psychiatric treatment as disempowering, supporting findings that the psychiatric system is experienced as dehumanizing by many patients (Todres, Galvin, and Holloway, 2009). Goffman (1961) observed the “degradation rituals” which occurred in psychiatric hospitals and which were experienced as humiliating by patients as these reduced their individual identity to that of ‘patient’ or ‘inmate’.

Although research stresses the importance of service user involvement in decision-making (Crane-Ross et al., 2006; Dickerson, 2006; Kosciulek and Merz, 2001) this was rarely reported in participants accounts. The current research suggests that a response of ‘learned helplessness’ (Seligman, 1972) develops following invalidating treatment (Johnstone, 2000) and that these invalidations lead to the construction of the identity of a ‘mental patient’ developed through a reduction in control over decision-making, acceptance of the diagnosis and lower perceived levels of control, which supports the findings of Romme et al, (2009) and Johnstone, (2000).

7.2.4 Empowerment/disempowerment and the relationship with voices

The empowering and disempowering role of voices was complex. While social and medical models do not focus on relationship with voices, psychological research has found links between voice hearing and patterns of attachment in existing relationships; if people have a sense of inferiority or struggle in interpersonal relationships, they are more likely to feel dominated and intimidated by voices (Benjamin, 1989; Chadwick, 2003 and 2006; Hayward, 2003). However, research has also shown that voices are more likely to provide friendship when there is a lack of other available interpersonal relationships (Chin, Hayward and Drinnan, 2009). Research indicates that some people have a friendly relationship with their voices; in some cases replacing relationships with people as voices can provide advice, reassurance and companionship with less risk of rejection (Mawson et al, 2011; Barker et al, 2001). Narratives from

the survivor movement describe the benefit of developing a positive relationship with voices and understanding them as being part of oneself, rather than existing as an inexplicable 'other'. This enables personal meaning and authority to be developed about the voice hearing experience which can develop empowering insights about the self (Romme and Escher, 1989, 1996, 2000; Romme et al, 2009; Romme and Morris, 2013; Coleman, 1999; Mawson et al, 2011; Birchwood, 2000; Harrow, Jobe and Faull, 2012; Chadwick, 2006a and 2006b) as well as diminishing fear of voices (Jackson, Hayward and Cooke, 2010). However, research suggests that some voice hearers reject the development of a relationship with voices, fearing that this reinforces the stigma, and the construction of 'madness'.

Findings from the current study suggest that working relationally with voices readdressed the experience of the power relationship with voices and reflected a positive shift in power relations in other interpersonal relationships. This had a significant impact for the authors of narratives; an acceptance of voices appeared to encourage an empowering acceptance of the self and the ability to understand oneself and one's voices with compassion. Voices could be normalised and accepted as part of one's experience. This helped some of the authors to gain status and control in the voice hearing relationship, while also increasing the confidence held in their social relationships more generally. There was a cyclical nature of how relationships with oneself, with other people and with voices impact on one another, either in a helpful or unhelpful way.

However, this research highlights the challenges for service users in developing a relationship with their voices when both internalised and external stigma encouraged a rejection of voices and unusual thoughts as something frightening to be eliminated. For some participants, particularly interviewees, voices were constructed as external and difficult to accept as being part of the self. Through this process, voices were experienced as disempowering. Forming constructive relationships with voices was supported through social interaction and an understanding social network. Without this support network compassionate relationships with voices were difficult to develop.

7.2.5 Empowerment/disempowerment and the relationship with self

Psychological models indicate that the sense of self is affected in severe psychological distress through internalised stigma (Corrigan, 2000; Corrigan and Watson, 2002; Angermeyer and Matschinger 1997). Research suggests internalised stigma prevents the formation of a positive identity, self-acceptance, low self-esteem (Corrigan, 1998) and a lack of self-efficacy (Vauth et al 2007; Corrigan, Watson and Barr, 2006; Link, Cullen, Frank, and Wozniak, 1987; Ritscher and Phelan, 2004). This can be reinforced by public stigma which is experienced as invalidating. Social models and critical psychiatry suggest the former identity can be submerged into the disempowering, stigmatised identity of 'mental health service user' lacking power and status (Topor et al, 2011). In response, a 'sick role' may be adopted which reduces personal responsibility. This immersion in an illness identity can further contribute to the loss of the former identity (Johnstone, 2000). Previous research highlights the importance in recovery of creating an identity independent from that of 'service user' (McCay and Seeman, 1998).

Fuchs, writing from a critical psychiatry approach, suggests that severe psychological distress affects the sense of self through disturbance in the embodied self, causing disruption in bodily functioning and a feeling of being disconnected socially (Fuchs and Schlimme, 2009). Alienation can occur as the body feels unfamiliar (Fuchs, 2001; Fuchs, 2010; Borda and Sass, 2015). Narrative approaches suggest it is difficult to develop a coherent narrative of the self when experiencing severe psychological distress as ideas about the self become fragmented (Lysaker, Lancaster and Lysaker, 2003; Lysaker, Wickett and Davis, 2005), resulting in the loss of identity (Lysaker, and Lysaker, 2008; Lysaker, Buck and Hammoud, 2007). Lysaker describes the self in severe psychological distress as becoming barren, monological or cacophonous (Lysaker and Lysaker, 2002; Lysaker Buck, and Lysaker, 2012; Lysaker and Lysaker, 2006; Davidson and Roe, 2005; Beck and Hammoud, 2007; Stanghellini, 2004). However, this was not supported in this study as most participants, both authors and interviewees, even when struggling to make sense of complex experiences, were thoughtful and reflective. It is possible that some of interviewees who were less reflective may have been affected by psychotropic medication or from received electroconvulsive therapy (ECT).

This research supports findings that traumatic and invalidating relationships impact negatively on the sense of self and can affect severe psychological distress. It suggests that development of the self cannot be dislocated from the social context and is a relational rather than an individualised process; relationships can construct or destruct the sense of self. This contrasts with the medical model which constructs severe distress and voice hearing as a symptom of an underlying illness. Participant's identity was deconstructed by relationships if these were disempowering, invalidating, and prevented exploration, open communication and self-awareness. Compassionate relationships encouraged the formation of an empowered identity and prevented the internalisation of stigma. There was a strong sense of the importance of power relations throughout this research. It is suggested that power can be given or taken in relationships, having a profound impact on identity. For participants, there was something important about feeling able to accept power and take personal control and responsibility.

These findings indicate the process by which the individual sense of self can become overwhelmed and diminished by dominant cultural narratives about psychological health and 'illness'. This confirmed the importance of the internalisation of stigma; if culturally accepted concepts of sanity and 'madness' were internalised this potentially led to a disempowering identification with being 'mad', helpless and worthless. Participants struggled to withstand social and cultural pressures and this research outlines the relational processes which lead to the acceptance of the identity of 'mental patient' with a loss of an individual sense of self. This research is important in identifying the strength and hopefulness required to recognise and challenge existing power relations, be that with family, voices or the psychiatric system; a strength which can be supported through relationships. Previous research describes the importance in the recovery process of having valued roles and the resources to participate in the community (Topor et al., 2011; McCann, 2002; Mattsson, Forsell, and Torpor, 2008; Perry, Taylor and Shaw, 2007). However, this study identifies the difficulties in finding another 'role', for the individual who has been constructed as a 'mental patient'. Rebuilding the self and a sense of identity involves reconnecting physically, emotionally and socially. These findings suggest that establishing personal meaning is very significant, both in maintaining a strong

sense of self, and in the recovery process (Romme and Escher, 1989, 1996, 2000, Romme et al, 2009; Romme and Morris, 2013).

7.3 Limitations to this study

The researcher is integral to the research process (Charmaz, 2006) and it is important to consider how I may have influenced the research process. There are ways in which I may have influenced participants to feel more or less empowered during the interview, potentially affecting the material. I am known as a therapist at the resource centre where interviews were held which may have affected the response of participants. It is possible that they did not perceive me as objective or independent, leading them to moderate their descriptions of services. Alternatively, participants may have found it empowering to share their experiences.

My questions, although open, still influenced the direction of the interviews, potentially implying an assumption that participants were experiencing empowerment or disempowerment, again influencing the data.

The sample of participants who chose to be interviewed may not have been representative of people experiencing severe psychological distress. There may have been particular reasons influencing the decision to take part, such as having specific experiences of feeling empowered or disempowered which they wanted to impart. All interviewees attended the same resource centre which was attached to an organisation providing supported housing. It is possible that participants experienced a range of shared circumstances through this organisation, such as working with the same staff. This may have affected their shared experience of mental health services and perspectives of what was empowering or disempowering. The resource centre itself has a therapeutic focus and it is possible that participants may have been socialised into a more therapeutic way of thinking, even if they did not attend therapeutic groups. The manager of the resource centre was an art therapist with a positive and hopeful perspective on recovery, which may have become embedded into the centre. It is possible that participants were more thoughtful and reflective about their experiences through receiving this support. If this had occurred, this in itself would provide helpful feedback relevant to the development and approach of

services. All except one participant had been involved with the organisation for several years. It is possible that these participants may have developed deep or complex relationships with other service users and staff which would have influenced their views on the significance of relationships.

There were limitations to the use of recovery narratives. These came from only two sources; a published book and an online support site. Decisions would have been made by the editors to select particular stories and narratives were possibly chosen which reflected a certain perspective. Many of the published narratives were supportive of the Hearing Voices Network and some authors were involved with the network. These views may not be representative of what is constructed as helpful in recovery, or may at least represent a certain perspective. In choosing which narratives to sample, I may also have been unconsciously drawn to narratives which favoured a particular perspective or which had a particular quality. I was interested in narratives which challenged the medical model and which supported alternative understandings of psychological distress and recovery. Authors themselves may have had particular experiences or agendas motivating them to publish their narrative, which again may not be shared by wider service users. Recovery narratives required some skill to complete, which meant this material was drawn from individuals with a certain level of ability. It is possible that authors had some shared characteristics, such as the confidence and motivation to tell their story, which may be more unusual amongst service users and which influenced their perspective. However, it was hoped that the use of interviews alongside narrative interviews allowed the experience of people with a range of abilities to be represented, as well as enabling the process of constant comparison to generate new ideas.

There were external limitations imposed in terms of reaching a wide sample. Two NHS community mental health teams were approached, who described that staff were too busy to be involved in research. However, different experiences and perspectives were gathered through contrasting people at different stages of recovery. Through the constant comparison process I was able to compare divergent experiences; those who felt empowered with those who were more marginalised and disempowered. The process of constant

comparison enabled me to consider alternative explanations and to theorise as well as reducing the impact of my assumptions on the research analysis.

It would have been beneficial to increase service user involvement in the research process and in any future research I would collaborate more with participants, perhaps doing joint research. It would be important to consider how to ensure this was an empowering process. To be the most empowering and informed process, it would be beneficial if service users were involved in this process from the outset which would affect every part of the research, including the very question explored. I would be interested in beginning with a focus group to explore the important issues that service users perceived as requiring research. Members of the focus group could become collaborators in the research choosing levels of involvement; some may wish to be fully involved in the process while others could choose to be involved in the planning stage or discussing the analysis of material. Involvement could vary depending on the level of commitment they wished to make. This process would need to be continually reflected upon during the research to assess the extent of real collaboration and empowerment for service user researchers and to be aware of issues of power and control amongst the team (including my own issues of letting go of control).

Criticisms are made of the method of grounded theory (Thomas and James, 2006), suggesting that it oversimplifies complex meanings, is over preoccupied with method and procedure and that while providing understanding, it does not develop theory. Constructivist grounded theory (Charmaz, 2006) addresses some of these concerns; the understandings developed are grounded in the data and are supported by the method of constant comparison (Munhall and Oiler, 1986).

There is debate in grounded theory over when the literature review should be conducted to avoid the research being influenced by existing theories rather than grounded in the data (Glaser and Strauss, 1967; Glaser, 1978). Charmaz (2006) suggests an awareness of literature to define the broad parameters of the research. I read literature initially to define the research area, however, I chose not to explore the literature too deeply during the early stages in an attempt to retain a relatively open mind.

7.4 Methods to ensure the quality of research

Elliott and Lazenbatt (2004) suggest that research methods should contribute to the process of the research. There are essential features in grounded theory to increase the quality and potential value of the research; concurrent data collection, constant comparative analysis, theoretical sampling and writing memos (Elliott and Lazenbatt, 2004; Guba and Lincoln, 1994). I followed a continuous procedure of concurrent data collection and constant comparative analysis (Elliott and Lazenbatt, 2005); ensuring that analysis occurred throughout the process which then affected the focus of following interviews through theoretical sampling. This process required reflexivity for an awareness of how my interpretation impacted on my analysis to ensure that the development of new categories reflected the data and to consider whether these remained constant in following interviews. Validity is increased if the reader has an accurate impression of how the findings have been influenced by the researcher's assumptions and interpretations (Silverman, 1998). It is important to keep the construction of ideas as transparent. I found recording my personal responses in interviews and when analysing the data using field notes and memos extremely helpful to acknowledge my biases. This also ensured that memos were related to the data rather than simply my own ideas. It helped me to remain open and transparent about the decisions I made throughout the research process (Engward and Davis, 2015), both to myself and to the reader. This was a dynamic process which increased the validity of the findings. There is debate over how the quality of research can be assessed and I decided to use a process of member checking. As well as being reflexive and empowering, member checking enabled my interpretation of the data to be considered by interviewees (Seale, 1999). I met with four interviewees to discuss the diagram that I had constructed from the data. Interviewees did not disagree with my interpretation, but added more data which I integrated into the analysis. This contributed another level of information and increased my confidence in my reading. Hopefully this supported interviewees' involvement in the research process.

7.5 Implications

This research has implications for policy makers, psychiatrists, therapists, service users and their families. In terms of policy, this indicates the potential loss to people with an experience of severe psychological difficulties through the closure of day and resource centres. Social inclusion has been a dominant feature of mental health policy as part of the 'modernisation agenda' (Department of Health, 2008) used to organise services. Social inclusion has been supported by policy makers, academics and activists, leading to a move to social inclusion outreach services and inclusion focused day services (Department of Health, 2008). Day centres were perceived as being out of date, segregated and as encouraging dependency, rather than promoting social inclusion and independence; social inclusion was regarded as promoting choice and human rights (Sayce, 2001).

However, research has challenged whether social inclusion is desirable for all people at all times (Secker, Hacking, Spandler, Kent and Shenton, 2007) or whether it makes assumptions about what is a desirable lifestyle, implying a need to be conform to the mainstream (Spandler, 2007). Psychological needs can be perceived as deficits compared with dominant cultural values (Bates, 2002). Instead of challenging society to question its values, individualised changes are promoted (Bates and Davis, 2004). Although day services needed modernisation in approach, to close so many has, I think, been detrimental to service users' social, psychological and relational wellbeing. Resource centres can provide therapeutic and practical support in an attitude of hopefulness and positivity. In the current environment there are fewer opportunities available for relationships to be developed with other service users, with supportive staff and with others in the wider community. Interviewees in particular, were not involved in alternative activity and still experienced stigma, discrimination and a lack of integration in the local community.

This research would support the need for service users to be more involved in research and to influence social policy (Karow, Pajonk, Reimer, Hirdes, Osterwald, Naber, and Moritz, 2008). It highlights a need for the concerns of a wide group of service users to be recognised, rather than only those who are perhaps better placed to eloquently express their needs.

There is a direct relationship between the power of psychiatry, social control and mental health legislation through the legal power and responsibility to detain those considered at risk to their own safety or that of others. Although this can help ensure the safety of vulnerable people, it creates disempowering experiences and social researchers recognise the oppression inherent in such practices (Lester and Tritter, 2005; Double, 2002). Szasz, a critical psychiatrist and constructivist (1961, 1970) argued that rather than helping people, psychiatry was used to control difficult or 'deviant' behaviour for society and often led to inhumane treatment. Szasz described 'schizophrenia' as the 'sacred symbol of psychiatry' (Szasz, 1976) and argued that psychiatry needed 'schizophrenia' to retain dominance of the understanding of mental health. Evidence challenging this was perceived as a threat to psychiatry and the drug companies relying on psychiatry. It has been argued that recent increases in the number of diagnoses added to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) may be less to do with an increased understanding of psychological distress and more to do with a medicalization of social, economic and emotional problems. Clinical psychiatrist, Breggin (1983) argues that western psychiatry contributes to iatrogenic fear and helplessness through the possession of moral and political authority. He writes that 'schizophrenia' is, 'nothing more than an expression of total helplessness, including helplessness in the control of one's own mind', and that psychiatry maintains helplessness through encouraging patients to surrender autonomy. There is criticism from critical psychiatrists of global bias towards western understandings of psychological distress and the strong economic links between pharmaceutical industry and psychiatry. As these powerful, medically based ideas expand into the non-western world, alternative concepts of wellbeing are undermined, diminishing patterns and understanding of psychological health in local communities (Thomas, Bracken and Yasmeeen, 2007).

Medical models (and some psychological models) hold an individualistic framework of empowerment, reflecting acceptance of being a 'patient' and adopting a 'sick role'. Guilt, shame and stigma stem from a lack of

understanding in society about severe psychological distress, while medical explanations remove responsibility from society to make collective changes. These assumptions are disempowering, as it remains the role of the medical expert to explain difficulties, rather than the service user developing self-awareness which is considered to promote change. There are suggestions from social psychologists and social psychiatrists that biological explanations for psychological distress decrease perceptions/attributions of blame (Corrigan, Rowan, Green, Lundin, River, Uphoff-Wasowski, White and Kubiak (2002). However, Angermeyer, Holzinger, Carta, and Schomerus (2011) reviewed 39 papers of population-based studies of public attitudes towards psychological distress, to measure the desire for social distance (a measure of prejudice and the public's willingness to have day to day contact with those in psychological distress) and found no evidence that holding biogenetic causes led to a lower perception of responsibility. Sociologists, social medical scientists and clinical psychologists found some evidence that biogenetic models actually increased perceptions of dangerousness and unpredictability (Phelan, Link, Stueve, and Pescosolido, 2000) as well as benevolence, stigma and an enhanced belief in 'difference' (Corrigan and Watson, 2004).

This study highlights the lack of psychological and relational support received from psychiatric services. For some people professional therapeutic support is necessary and an increase in the availability and range of psychological therapies is needed for those experiencing distress from voice hearing, including person-centred, humanistic and psychodynamic therapies. Although cognitive behavioural therapy has a place, this does not suit all service users and these findings indicate a need for a more relational and constructionist focus. This research emphasizes the importance of making meaning of the voices, rather than confronting them to develop a more positive relationship with voices.

The 'We Need to Talk Coalition' (2014) conducted a survey with service users who had used or tried to use psychological therapies within the NHS. Of those who had experienced severe psychological distress (in this survey this meant a diagnosis of 'schizophrenia, 'bi-polar disorder' or 'personality disorder'), one in five waited over a year to access psychological therapies,

over a half had no choice in the type of therapy received, only one third felt they had as many sessions as they needed and less than 30% referred accessed therapy within three months. This coalition indicated a limited choice other than cognitive behavioural therapy for psychosis as well as a lack of investment from Improved Access to Psychological Therapies (IAPT) for those with 'severe mental illness'. 11% of people chose to pay for therapy as the therapy they wanted was unavailable on the NHS. Furthermore, when service users had a full choice of therapies they were four times more likely to report feeling well after therapy than those who weren't offered choice. The Royal College of Psychiatrists (2014) notes that services are not providing the breadth of therapies recommended by the NICE guidelines, although these are limited to a recommendation of cognitive behavioural therapy, art therapy and family intervention for affected families (Nice guidelines, 2014). The medical model remains dominant in mental health services despite the potential disempowering consequences.

There are examples of other models of working with severe psychological distress, such as Soteria communities (Mosher, 1995). These are supportive, collectivist treatments based on a social model of care. A review of controlled findings comparing Soteria with medical model approaches suggests that results for these service users are at least equal to outcomes for patients on psychiatric wards. In some areas, Soteria achieved more successful outcomes with much lower levels of medication (Calton, Ferriter, Huband and Spandler, 2008).

7.6 Practice recommendations

Having therapeutic involvement within multidisciplinary teams is crucial so that a relational understanding, a focus on trauma and subjective experience is held by the team. These findings suggest this is more beneficial than a medicalised understanding of severe psychological distress. The Commission on Acute Adult Psychiatric Care (2015) set up by the Royal College of Psychiatrists to address concerns about the quality of inpatient care, found that service users desired permanent staff with whom they could form relationships, but that there is a lack of appropriately trained staff to provide patients with empathy and sensitivity. Rethink Mental Illness (2014) exploring how services need to be

improved described that service users want psychological interventions. This highlights a gap between what is offered and what service users describe as being supportive.

This research highlights recommendations for practice for different professionals. While professionals inevitably hold different constructions of psychological distress; these findings suggest that all professionals need to work in a genuine, collaborative way, forming empathetic relationships. An atmosphere of hope provides positive expectations and opportunities to support recovery. Training in relational skills could be extremely beneficial in enhancing the development of therapeutic relationships. Then instead of service users feeling that 'no one wants to hear my story' as one interviewee described it, people can feel listened to and validated.

The importance of the response by staff when voices are first confided is very significant. These need to be listened to and accepted as a confusing but meaningful experience, rather than staff being overwhelmed by the presence of voices. An initial negative reaction made it harder for relationships to be supportive and sometimes this feeling of overwhelm was transferred to the participant. Instead the service user needs an opportunity to reflect on events and be involved in decision making, rather than experiencing other people as acting on their behalf. This requires an increase in therapeutic resources and training to support staff to feel comfortable talking about people's voices, emotions and experiences.

7.7 Recommendations for therapeutic practice

This research has implications for therapists of all approaches in identifying the significance of the therapeutic relationship and confirms that therapeutic approaches can have positive outcomes for those experiencing severe psychological distress. It supports the use of a relational approach to assist people to develop understanding of their experiences and voices as suggested by Romme and Escher (2009). Although cognitive behavioural therapy remains dominant within mental health teams, there are criticisms from psychodynamic and humanist approaches that this individualistic approach puts the attention onto the individual and away from the social and environmental context. Critics

argue that within cognitive behavioural therapy the focus remains on individual 'dysfunctional thoughts' (Boyle, 2011) rather than looking at past experiences to make sense of current ones. This diminishes the role of trauma in psychological distress and does not enable service users to develop personal understanding. The disempowering assumption remains that 'something is wrong' with the person (Boyle, 2011; Johnstone, 2000).

This research indicates that whichever therapeutic approach is held, the importance of working relationally is paramount and individual constructions of distress need to be taken seriously. This involves holding a systemic approach supporting the person to make links between their experiences and possible traumas in effecting voice hearing as well as supporting people to develop relationships with their voices rather than fearing them. Forming positive therapeutic relationships can provide an experience of a compassionate and empathetic other to help the individual revise invalidating relational templates (Sullivan 1956, 1962; Rogers, Gendlin, Kiesler, and Traux 1967; Rogers, 1980, 1951).

Counselling psychologists have a valuable role to play through rejecting diagnosis in favour of a focus on understanding subjective experience. It is important that relational therapists develop confidence in working with those suffering from severe psychological distress. This includes developing the confidence to work in mental health teams and acute teams and to challenge the medical model when necessary (Walsh, Frankland and Cross, 2004). Counselling psychologists are in an ideal position to support people following trauma and who are experiencing a wide range of psychological issues, including voice hearing and unusual ideas. It is important to work alongside the person in a way that enables them to share their subjective experience without feeling fearful. For the counselling psychologist this can mean holding some difficult feelings when hearing unusual experiences that might induce feelings of alarm making effective supervision crucial.

Therapists working within multi-disciplinary teams can encourage trauma and relationships to be considered during assessments, formulations and interventions. Trauma is now widely recognised as impacting on voice hearing (Janssen et al., 2003; Mirowsky and Ross, 1983; Shevlin, Houston,

Dorahy and Adamson, 2008; Read, van Os, Morrison and Ross, 2005; Johnstone, 2007; Read, van Os and Bentall, 2012; Read and Bentall, 2012; Read and Gumley, 2010) and a comprehensive assessment by mental health professionals can gather information that begins to make sense of the content of voices. Rather than being 'treated' using the medical model, this approach develops a formulation or a shared understanding of the person's experience and therapeutic interventions to support the processing and integration of traumatic experiences (Johnstone and Dallos, 2006).

Therapists will face conflicts working within a medical setting; the therapeutic and medical approach have different understandings and practice, perhaps especially when working with people who are perceived as acutely unwell and who may be detained in hospital. Research describes this can lead counselling psychologists to question their abilities and competence and creates a struggle to maintain professional identity (Freeth, 2007; Gazzola, De Stefano, Audet, and Theriault, 2011). It is suggested that counselling psychologists can respond in different ways; sometimes choosing to leave teams which adopt medical models (Elkins, 2009) or conforming to medical models in public but in practice focusing on the subjective experience and therapeutic relationship (Elkins, 2009; Freeth, 2007; Frost, 2012). It is important to find ways to manage this tension (Walsh, Frankland and Cross, 2004) including having effective supervision and peer support to assist counselling psychologists to hold confidence in their ability and values.

There is fascinating research into how different therapeutic approaches can be used with severe psychological distress, including compassionate focused therapy with hearing voices (Gumley, Braehler, Laithwaite, MacBeth, and Gilbert 2010). Narrative approaches too, offer different therapeutic models encouraging the development and acceptance of alternative, more compassionate interpretations of experiences (Davidson and Roe, 2005; White, 1995; White and Epston, 1990; Lysaker, Gumley and Dimaggio, 2011).

This research highlights the need for social as well as psychological responses to severe psychological distress; the importance of challenging stigmatising attitudes in psychiatric services and in wider society is evident. This research would suggest it is important for counselling psychology to take a more socially active stance. Although as psychologists we are aware of internal

processes, the impact of social and environmental factors and conditions also need to remain paramount in developing formulations and in understanding how empowerment is possible. Alongside therapeutic interventions there is a need to increase social understanding and awareness of the causes of severe psychological distress, including the day to day impact of aspects such as inequality and discrimination.

7.8 Future research

Further research on the process of help-seeking and confiding about voice hearing would be beneficial. The question could be researched of the response voice hearers need when they when they first confide about their voice hearing experiences? A fear of the stigma attached to psychosis can prevent people from talking at an early stage about voice hearing (Judge, Estroff, Perkins, and Penn, 2008). Qualitative research exploring this would increase understanding about how people report that they are hearing voices and what makes this process easier. It would develop awareness of 'what happens' and what service users would like to happen. In this research participants were quickly drawn into psychiatric services, but did not receive the support that they wanted.

Another important question leading on from this research is what resources would service users' value to support the development of relationships? Given the value of relationships suggested by this research and the difficulties people experiencing psychological distress have finding spaces to form relationships, research into what facilitates this sociality is important. Again, qualitative research following a social constructionist approach which is not policy driven or undertaken with a particular agenda in mind, would enable the perceptions and ideas of service users to be identified. This could form a potential model of future service provision that involved the community and met therapeutic need as well as enabling service users to meet and share experience.

It would be beneficial if more research was driven by service users as experts to utilise their knowledge of what change is necessary. However, research needs to include the views of more vulnerable and struggling service

users, so that their voices are also heard and influence the development and approach of services (Karow et al, 2008).

An under-researched area is the feelings of professionals and an important research question could be, how do professionals feelings of over-whelm and anxiety affect the treatment decisions made about service users experiencing severe psychological distress? Research into the fears and concerns of professionals would be helpful in understanding how these may impact on service users. Overwhelm in professionals can lead to higher levels of medication being prescribed to avert a crisis (Robinson, Schoole, John, Correll and Marcy et al, 2015) when this is not the only or the most effective response. Qualitative, social constructionist research would enable the reactions and concerns of different professions to be captured and is potentially a sensitive area of research.

7.9 Conclusion

This research considers the different psychological and social processes in becoming empowered and disempowered. It indicates the significant relational processes involved in severe psychological distress both in terms of what empowers and disempowers; expanding knowledge of how relational difficulties can affect the personal response to voice hearing and impact on relationships. These findings challenge research to take a more systemic approach in forming understanding of severe psychological distress and to be aware of the impact of relational difficulties.

This research has developed a positive relational model of the voice hearing experience when this is accompanied by severe psychological distress. It has established the immense value of supportive relationships and the profound impact that compassionate, empathic and respectful relationships can have both on wellbeing, empowerment and how voice hearing is defined and understood. This recognises that both the voice hearer and helpful supporters can play a positive role in facilitating change through encouraging understanding rather than fear of voices, of emotions and of relationships. Staff of all professions can have a huge impact through developing relationships which are validating, confirm a positive sense of self and encourage

hopefulness for the future. For service users, the power and strength that can be found through sharing with one another is clear and there is much to be gained from friendship and sharing in experiences and successes. Relationships in themselves can be inspiring and empowering, whether with family, friends or professionals.

The role of talking therapies in severe psychological distress, often neglected in research and practice, is something that service users themselves are desperately requesting. This provides an opportunity to talk and explore emotions, experiences and relationships with someone who is not overwhelmed, threatened or who reacts to voices with panic. Counselling psychologists are well placed to work with the subjective experience, supporting connections to be made with voices and enabling voices to be integrated as an acceptable part of a more empowered self. As a profession they have a significant role to play within mental health services to encourage positive cultural changes in how severe psychological distress is understood. Through validating relationships those experiencing severe psychological distress can be supported to look forward to living, with or without voices.

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The role of empowering relationships in recovery from severe psychological distress

Abstract

Empowerment has been identified as important in recovery from severe psychological distress by policy makers, mental health services and by service users. While there has been research into the role of empowerment in recovery for people with severe psychological distress, constructions differ regarding the factors involved in recovery and empowerment. Much of the research has been conducted by professionals; the process of empowerment has yet to be explored and delineated from the perspective of the service user. This research aims to explore the role of relationships in empowerment and the influence of relationships in recovery from the severe psychological distress. A social constructionist grounded theory methodology was adopted using two methods of data collection: semi structured interviews with 8 service users and 12 narratives accounts written by authors in recovery. Findings indicated that participants became empowered through feeling validated in their relationships with others, with their voices and with themselves. Participants made connections socially through forming more understanding relationships, reintegrating parts of themselves and understanding voices through relating them to past experiences. Through this people gained an increased sense of autonomy and found it easier to construct a more positive sense of self and accept their voices. Recommendations for practice are made and areas for further research suggested.

Introduction

This research focuses on individuals who have experienced hearing voices which have caused psychological distress and/or have received a psychiatric diagnosis of 'schizophrenia', 'schizo-affective disorder' or 'psychosis'. These diagnoses have been found to be particularly disempowering and stigmatising (Schulze and Angermeyer, 2003; Romme and Escher, 1996) leading to increased dependence on mental health services (Schulze and Angermeyer, 2003). The term 'severe psychological distress' is used to refer to psychological distress caused by an individual's sense of reality being constructed as different from consensual reality, with experiences of hearing voices or unusual ideas which are causing distress through affecting emotional, social, relational or physical functioning. This term is preferred to 'mental illness'

which focuses primarily on biological, rather than psychosocial causes. From the 1970's – 90's international quantitative studies from the World Health Organisation found greater levels of recovery than previously anticipated in the developed world (Wood, 1980; Harrow and Jobe, 2007), improving expectations of professionals, academics, service users and their families.

Relationships with others

Research indicates that relationships with friends, family and professionals significantly affect quality of life and sense of identity for individuals suffering from severe psychological distress and be empowering (Jetten, Branscombe, Schmitt and Spears, 2001). Relational and social roles have been identified as critical in recovery (Torpor, Borg, Di Girolamo, and Davidson, 2011), through encouraging hopefulness, (Cutcliffe and Koehn, 2007) fostering realistic goals, (McCann, 2002), developing supportive social networks (Sibitz, Amering, Unger, Seyringer, Bachmann, Schrank, Benesch, Schulze, and Woppmann, 2011; Stromwell and Hurdle, 2003) and encouraging openness (Corrigan, 1998; Corrigan, Larson, Michaels, Buchholz, Rossi, Fontecchio, Castro, Gause, Kryzanowski and Rusch, 2015). The opportunity for inclusion and integration in the community (McCann, 2002; Mattsson, 2008; Torpor, Borg, Di Girolamo and Davidson, 2011). However, there remains little understanding of the process of empowerment and recovery from a relational perspective

Invalidating experiences in early relationships have been found to contribute to problematic patterns of relating to the self and in interpersonal relationships (Bowlby, 1969; Mikulincer and Shaver, 2012; Read and Gumley, 2008). Research findings consistently indicate that a high proportion of people affected by severe psychological distress have experienced trauma, neglect, abandonment or victimisation (Janssen, Krabbendam, Bak, Bijl, De Graaf, Vollebergh, and van Os J, 2003; Mirowsky and Ross, 1983; Shevlin, Houston, Dorahy and Adamson, 2008; Read, van Os, Morrison and Ross, 2005; Johnstone, 2007; Read, Van Os and Bentall, 2012; Read and Bentall, 2012; Read and Gumley, 2010). Insecure, preoccupied and fearful attachment patterns are hypothesised to increase the risk of voice hearing alongside severe psychological distress (Korver-Nieberg et al, 2014; Korver-Nieberg et al, 2015; Gumley, Taylor, Schwannauer and MacBeth, 2014; Harder, 2014; Huguelet, Mohr, Rieben, Hasler, Perroud and Brandt, 2015; MacBeth, Gumley, Schwannauer and Fisher, 2011; Shevlin et al, 2008; Dillon, Johnstone and

Longden, 2012). Poor early experiences of relationships may form templates influencing patterns of future relationships and the development of psychological distress (Mikulincer and Shaver, 2012, Read and Gumley, 2008).

Social contact is often difficult for individuals suffering from severe psychological distress; research findings indicate that increased loneliness, isolation and a significantly reduced number of social contacts are experienced by this group compared with the general population (Davidson, Hoge, Godleski and Griffith, 1996; Lester and Tritter, 2005; Onken, Craig, Ridgeway, Ralph and Cook, 2007). Existing contacts tend to be restricted to family networks and other service users (Breier, Schreiber, Dyer and Pickar, 1991).

Research has identified that social withdrawal can lead to the internalisation of stigma (Goffman, 1963; Sibitz et al., 2011; Corrigan, 1998) when people adopt a stigmatised view of themselves (Goffman, 1963; Corrigan, 1998). Self-stigma can profoundly affect sense of self preventing the formation of a positive identity and self-efficacy (Corrigan, 1998; Vauth, Kleim, Wirtz and Corrigan, 2007; Corrigan, Watson and Barr, 2006; Link, Cullen, Frank and Wozniak, 1987; Ritscher and Phelan, 2004). Self-stigma is associated with defensive coping strategies (Link and Phelan, 2001). A study by Judge, Estroff, Perkins, and Penn (2008) found that 60% of participants used withdrawal as a coping strategy, and 35% described how stigma prevented them from seeking help.

Relationships with professionals

Relationships with professionals can encourage hopefulness if these are trusting and respectful (Kirkpatrick, 1995). It is suggested that practitioners can 'carry hope' (Turner and Frak, 2001; McCann, 2002) and empower through imparting knowledge, skills and motivation (Petersen, Frills, Haxholm, Nielsen and Wind, 2015). Alternatively, relationships can limit opportunities and choice (Townsend, 1998) and create feelings of dependency (Petersen, Frills, Haxholm, Nielsen and Wind, 2015). Interestingly, recovery narratives focusing on what empowers emphasise the personal approach of professionals, rather than what has been 'done' in therapy or 'treatment' (Romme, Escher, Dillon, Corstens, and Morris, 2009).

Service users have identified the importance of themselves and their families being central in decision-making (Crane-Ross et al, 2006; Deegan, 1996), working

collaboratively (Dickerson, 2006; Kosciulek and Merz, 2001) being properly informed and supported to actively manage distressing experiences (Corrigan and Garman, 1997) and being positive about recovery (Warner, 2004).

Relationships with voices

Research has found links between voice hearing and patterns of attachment in existing relationships; if people have a sense of inferiority in interpersonal relationships, they are more likely to feel intimidated by voices (Benjamin, 1989; Chadwick, 2006a and 2006b; Hayward, 2003). Conversely research indicates that voices can provide friendship when there is a lack of other available interpersonal relationships (Chin, Hayward and Drinnan, 2009). In some cases, voices can replace relationships with external people through providing advice, reassurance and companionship (Mawson, Berry, Murray and Hayward, 2011; Barker, Lavender, and Morant, 2001). It has been indicated that developing a positive relationship with voices can significantly impact on the power balance in this relationship. This more understanding relationship comes through relating voices to individual experience to form a personal meaning, rather than constructing oneself as being a victim of voices (Romme and Escher, 1989, 1996, 2000; Romme and Morris, 2013; Romme, Escher, Dillon and Corstens, 2009; Morris, and Escher, 2009). Service users have expressed finding it helpful to have voices accepted as real by professionals (Romme et al, 2009).

Why this is an important area to study

It is hoped that developing understanding of the beneficial role of relationships in recovery will be helpful for service users and survivors, clinicians and policy makers to provide more effective and empathic support, encourage a positive sense of self and plan services that respond relationally. This seems especially significant given that research indicate that those with a diagnosis of 'schizophrenia' have a lower quality of life than the general population and those with another mental or physical health diagnosis (Sibitz et al., 2011).

Methodology

Design

This research is concerned with social processes and how participants make sense of their experiences and qualitative research methods are well suited to developing this understanding (McLeod, 2003; Liamputtong and Ezzy, 2005) and to researching sensitive areas and marginalised groups (Warren, 2002; Daly, 1992). Given my social constructionist epistemology, a constructivist grounded theory was the most appropriate methodology (Charmaz, 1990). I wished to reflect the construction of experience as well as developing a theoretical understanding of what was experienced as empowering in relationships for individuals suffering with severe psychological distress.

Two sources of data were used; semi structured interviews with individuals currently experiencing severe psychological distress and published recovery narratives by individuals who considered themselves to be on a journey of recovery. Interviews are ideally a collaborative process where meanings are co-constructed and rich, social contextualised descriptions can be gathered which are valuable in developing our understandings of complex social and psychological experiences (Strawbridge and Woolfe, 2003). To reduce the power imbalance, I emphasised that I wanted to gain understanding more about participant's experience, on which they were the expert. Narratives provided rich and thoughtful insights into the experience of recovery.

Participants

8 participants were interviewed who were currently involved with mental health services and who attended the same resource centre. 7 interviewees had experienced more than one episode of hearing voices and were still hearing voices but felt emotionally stable during the period of time surrounding the interview. Following the grounded theory method of theoretical sampling an 8th participant who did not hear voices, but who was suffering from depression and brain injury was interviewed to enable comparisons with interviews with voice hearers. Published narratives were coded from 12 authors who had experienced hearing voices and who defined themselves as being in a process of recovery. All participants were over the age of 18 years and considered able to give informed consent.

Procedure

Published narrative accounts were analysed which described a process of change from the time of voices beginning, to a turning point or gradual recovery. This analysis generated a number of potential categories. Semi-structured interviews were then conducted with a second group of participants which provided a different perspective and facilitated the process of constant comparison. Interviews were recorded on a digital recorder and transcribed. To increase credibility and involve participants in the research process through member checking, I met with 4 interviewees to discuss the process diagram. This deepened material and enabled collaboration through attempting shared understandings.. No disconfirming information was added but new insights were integrated into the analysis. However, I wondered whether participants would be reluctant to contradict my findings (Bloor, 1997; Seale, 1999).

Coding

Grounded theory follows a process of simultaneous data collection and analysis with each interview being transcribed and analysed before the next. Interviews were analysed line by line and themes constructed from this data were compared to those constructed in subsequent interviews. This constant comparison method encourages rigour as new information is compared with that previously gathered to identify repeated patterns and differences (Elliott and Lazenbatt, 2004). There are 3 levels of coding in grounded theory which steers the movement between the data and development of theory. Open coding involves breaking data down into chunks of material which is given a code to describe the actions in the data. The coding becomes more focused as particular codes are continuously identified. The final stage of coding is theoretical coding when codes are refined to form the grounded theory. Through this process categories are identified, then relationships between categories and finally the core category around which other categories revolve (Chiovitti and Piran, 2003).

Ethical issues

The power imbalance inherent in the research situation has the potential to result in participants reluctantly discussing sensitive issues (Daly, 1992). Participants were

informed that they could chose not to talk about areas that felt too personal and did not have to answer questions. If done sensitively, being listened to can be therapeutic and empowering (Cutcliffe and Ramcharan 2002; Rickard, 2003; Hess, 2006). More status is accorded to some voices than others (Hall and Callery, 2001) and it felt important to interview participants whose voices would not usually be heard.

The potential benefits and risks of participation were discussed prior to participants agreeing to participate and different methods for the interview were offered, including Skype, online communication or two short interviews, although everyone chose to have face to face interviews.

Reflexivity

It was important to remain aware of the impact of my assumptions and personal responses which influenced the research process and my interpretation of the data (McLeod, 2001; Grbich, 2004; Charmaz, 2006; Powers and Knapp, 1995). I kept a personal journal to record my feelings, expectations and bias (Miles and Huberman, 1984; Pidgeon and Henwood, 1997). I considered my social identity; gender, ethnicity, education and class, all of which might affect the narrative that participants chose to tell and potentially affected issues of empowerment.

Findings

Findings suggested that validating relationships were exceptionally important, sometimes transforming the process of recovery; including relationships with themselves, with voices, with people around them and with psychiatric services.

Feeling validated

Experiencing a validating response in relationships had a powerful impact on participants.

Feeling validated by external others

Participants identified the value of a non-judgemental environment where they could talk freely about their experiences. Having a validating relationship who was trusted and listened was extremely significant. Participants described internalising validating

professionals or others who remained open, hopeful and empathetic. Debra Lampshire ('voice hearer', narrative account) explained,

"My friend always allowed me to drive the process and come up with strategies to confront the voices. This demonstrated their belief that I was resourceful competent and able to drive the recovery process, that I did in fact have the courage, resilience and capacity to heal myself."

Participants identified qualities that made relationships rewarding. There was a perception that if people accepted the voices without being shocked, over-whelmed or dismissive, then perhaps they had also accepted participants. Jan Holloway (British, voice hearer, narrative) explained positive relationships were with,

"...people who have a tolerance for the unusual and who are able to challenge some of the ideas that are not helpful to me..."

Stephen (White/British, 'schizophrenia, interviewee) reflected that,

"It helps talking to people. Solitude is the worst enemy I've got, being on my own. I tend to go into a sort of schizophrenic world like, when I'm by myself and develop schizophrenia.... I find that company brings you back to reality, instead of going away from. reality when you go into a world of your own."

Validation was received from other service users and participants indicated that bonding with service users had been crucial. When talking with professionals or family members was too difficult, talking with service users seemed easier.

Sue Clarkson (voice hearer, narrative account) described that at self-help groups,

"I had an opportunity to speak freely about my voices. My experience was accepted as real and not only negative."

Other service users were often positive role models providing inspiration. Will Hall (American, 'schizo-affective disorder,' narrative account) expressed that,

"Most importantly, I reached out to other people who had also been diagnosed as mentally ill, and we began supporting each other in discovering our own pathways to healing. For too long I had been

trying to do this all on my own. Having people around me who believed in my recovery was crucial.”

Gaining positive feedback from professionals was validating. Caroline (White/British, Schizophrenia, interviewee) said that professionals had,

“...said I’d made some much progress I could have my own flat. So it just shows that in their eyes I’m getting better as well.”

Abbey (‘schizophrenia,’ narrative account) wrote of one of her psychiatrists,

“He provided me with literature and research and most of all a feeling of control and a voice in relation to my own care which was meaningful and sincere. This was truly refreshing.”

A relationship with someone genuine and understanding was supportive and holding. Amanda (voice hearer, narrative account) wrote,

“At times I can lose my hope and at these times others have to temporarily hold it for me.”

The important aspect of validation was that participants expressed themselves without feeling judged and felt their experiences were accepted. Through this connection, participants might not gain a shared consensual reality, but were able to share their reality with others who would listen and try to understand.

Feeling validated by voices

At times some participants sought support from voices and found that their power provided guidance and reassurance. Jeanette Woolthuis (Netherlands, ‘psychosis’, narrative account) described that,

“The voices took me seriously when I was anxious and all alone... They were the only ones who understood me and gave me support and therefore became more influential...”

Some participants experienced some positive voices and as participants became more empowered, voices became increasingly used in a validating way. Stewart Hendry (British, ‘schizophrenia’, narrative account) described,

“My mum and Nan’s voice were more helpful, saying things like I was a good person and shouldn’t kill myself. Sometimes my mum and Nan’s voice would talk together. The way I explain and always think of it, it was Nan saying goodbye.”

For Ash (Black/British, ‘schizophrenia’, interviewee) one of his voices talks reassuringly to him and

“...tells me how to get healthy, how to do things. How to get over these voices, these skinny ones. It tells me everything really, everything about life, about how I should be...”

For many participants, establishing meaning changed their relationship with voices. Participants moved from feeling dominated to forming positive relationships with them. Participants began to construct their voices as a personal reflection of their emotions rather than as an irrational, frightening force disconnected from themselves.

“...My sense of my own identity shifted. I moved from being ‘me’ to ‘we’. My relationship with my different selves changed over time.”

Jacqui Dillon (White/British, ‘schizophrenia,’ narrative).

Making connections

Making connections included being able to connect socially, connecting with oneself and with the voices in a different way. Feeling validated led to participants taking the risk to increase social connections. They described feeling more supported to begin exploring their sense of self and make intrapersonal connections; reintegrating aspects of themselves and internalising positive relational experiences.

Developing compassionate and respectful relationships

Some participants perceived that voices provided protection and that isolation felt safer, but connecting socially involved challenging oneself and being more open to relationships. Debra Lampshire (voice hearer, narrative account) described that,

“The voices kept me so busy I had no time for any other relationships and they also spared me from the pain and hurt I had experienced from numerous rejections from people in the past...I decided I needed to take the risk of inviting real people into my world.....It proved to be pivotal to my recovery.”

Participants described being highly attuned to who was genuine and attended closely to these impressions and assessing who was helpful for them when choosing relationships. Jacqui Dillon (White/British, 'schizophrenia', narrative account) described,

"I stopped having contact with people who undermined me and slowly developed relationships with people who supported me."

For Owen (Black/British, 'schizophrenia,' interviewee) described how just going to buy cigarettes,

"...makes me communicate again instead of sitting there going into my own world. Makes me come out and have to relate to others and share...instead of being in my shell alone with nothing apart from me."

Connecting socially was an individual process, but a re-engagement in the community seemed pivotal. Validation supported participants to develop compassionate and respectful relationships with themselves, with others and with voices.

Discussion

Forming validating relationships

Validating relationships were extremely significant in the process of recovery. This occurred through being listened to and feeling understood, and could develop in informal relationships, affirming voices or from supportive professionals. Participants described wanting the opportunity to talk without fear of being regarded as 'ill'. This enabled the development of a more positive sense of self rather than stigmatising oneself through psychiatric labels. This enabled an openness about emotional experiences rather than withdrawing socially as described by Corrigan, (1998) and Corrigan, Larson, Michaels, Buchholz, Rossi et al, (2015). In compassionate relationships, participants had the opportunity to reflect upon original traumas and create a personal meaning of voices. Validation reflected that it was not necessary to be overwhelmed by the voices and provided a foundation for understanding, coping and accepting oneself. This was especially important when voices were first disclosed, when a negative reaction often precipitated a process of social withdrawal.

Although validation was often a turning point for participants, this research indicates difficulties finding this in relationships with professionals and in the wider community.

Making connections

This research confirmed findings that social relationships were vital to establish hopefulness (Houghton 2007; Spandler and Stickley, 2011; Erikson and Erikson, 1988; Kirkpatrick, 1995) which could be held by other people (Turner and Frak, 2001; McCann, 2002). Hope is associated with setting realistic goals and increasing self-efficacy (Schrank, Bird, Rudnick, and Slade 2012; Kirkpatrick, Landeen, Byrne, Woodside and Byrne, 2002). This research indicates the importance of developing supportive social networks to reduce isolation (Stromwell and Hurdle, 2003; (Sibitz et al., 2011)) and improve quality of life through maintaining valued roles activity, relationships and influence over decision making (Topor et al., 2011). This was often through sharing with another understanding service user (Romme et al., 2009; Torpor et al, 2011) as participants described sharing strategies (Kirkpatrick et al., 2001) and that 'successful' service users were inspirational. This highlights the importance of service user involvement in psychiatric services and that being part of a group encourages the development of a positive identity (Kirkpatrick et al., 2001; Zimmerman, 1995). Several participants had attended hearing voices groups and found these helpful opportunities to share and advocate for change (Dickerson, 1998; Whitley, Harris, Fallot and Berley, 2008; Mayhew and Gilbert, 2008; Zimmerman, 1995). Connecting with voices was potentially life changing, but was an interactive process requiring support. Developing a personal meaning to explain voices was necessary to develop a more understanding relationship with them. This supports research from the hearing voices network (Romme and Escher, 1989, 1993, 2000; Romme et al, 2009; Romme and Morris, 2013). Developing a compassionate relationship with voices often mirrored compassion for oneself.

Future research

Further research would be beneficial on the process of help-seeking and confiding about voice hearing. A fear of the stigma attached to psychosis can prevent people from talking at an early stage about voice hearing (Judge, Estroff, Perkins, and Penn, 2008). Qualitative research could what people would like to happen when they report hearing voices.

Research into needed resources to facilitate the development of relationships is important. Again, qualitative research following a social constructionist approach which is not policy driven, would enable the perceptions and ideas of service users to be explored. This would help form a potential model of future service provision to meet therapeutic need.

It would be beneficial if more research was driven by service users, including vulnerable and struggling service users to reflect their needs and to ensure their knowledge is fully utilised to influence the development of services (Karow, Pajonk, Reimer, Hirdes, Osterwald, Naber, and Moritz, 2008).

Research into the feelings of overwhelm by professionals would be helpful in understanding their concerns and how these impact on service users. Overwhelm in professionals can lead to higher levels of medication being prescribed to avert a crisis (Robinson, Schoole, John, Correll and Marcy, 2015) when this is not the only or the most effective response.

7.28 Limitations

There are ways in which I may have influenced participants during the interview process potentially affecting responses. I am known as a therapist at the resource centre where interviews were held and it is possible that this moderated participant's descriptions of services.

The sample of participants has an impact on the research findings. Those who chose to take part in the interview may not have been representative of people experiencing severe psychological distress. Participants may have had particular experiences of relationships and empowerment influencing their decision to be interviewed. Authors too, may have had particular experiences motivating them to tell their story which were not necessarily typical. There were external limitations imposed on the research in terms of reaching a wide sample. Two NHS community mental health teams were approached, who informed me they were too busy to be involved in research. Some of the authors of recovery narratives had been involved with the hearing voices network and were perhaps more supportive of this approach, which again, may not have been representative of what people generally find supportive when experiencing severe psychological distress.

Criticisms are made of the method of grounded theory process (Thomas and James, 2006). It is suggested that grounded theory oversimplifies complex meanings, is over preoccupied with method and procedure and, but provides understanding but not theory. Constructivist grounded theory (Charmaz, 2006) overcomes some of these concerns and the understandings developed are grounded in the data and supported by the method of constant comparison (Munhall and Oiler, 1986).

7.29 Methods to ensure the quality of research

There are essential features in grounded theory to increase the quality research; concurrent data collection, constant comparative analysis, theoretical sampling and memoing (Elliott and Lazenbatt, 2004). I followed a continuous cycle of procedure of concurrent data collection and constant comparative analysis (Elliott and Lazenbatt, 2005); ensuring that analysis occurred throughout the process which then affected the focus of following interviews through theoretical sampling. This process required reflexivity to ensure I was aware of how my interpretation impacted on my analysis, to ensure that the development of new categories reflected the data and whether these remained constant in following interviews.

Validity is increased if the reader is informed about the researcher's assumptions and interpretations (Silverman, 1998). Keeping a record of my personal responses in interviews and when analysing the data using field notes and memos assisted me in being transparent about the decisions I made throughout the research process (Engward and Davis, 2015). Memos provided an audit trail of how I interpreted my data and constructed my categories.

7.30 Clinical implications

The findings from this study indicate the importance of relationships for individuals suffering from severe psychological distress, in ensuring the individual feels validated and develops a positive sense of self. This has implications for therapists, mental health professionals, psychiatrists, social workers and policy makers. The most significant factor for all professionals is the relationship they provide. It is important to ensure that they work in a genuine, collaborative way to ensure that the

service user feels understood and to provide hope and support by holding positive expectations.

Professionals will hold different constructions of psychological distress, however, participants found it particularly empowering to share and explore the content of voices and relate this to personal experience. This focus shifts blame away from the participant and placed emphasis onto the painful experience (Romme et al, 2009). The importance of the response when voices are first confided is very significant. This needs to be, listened to and accepted as a confusing but meaningful experience. Training for staff is crucial so that they themselves are not overwhelmed.

Participants received little psychological support from psychiatric services to process trauma. Trauma is now widely recognised as impacting on voice hearing (Janssen et al., 2003; Mirowsky and Ross, 1983; Shevlin, Houston, Dorahy and Adamson, 2008; Read et al, 2005; Johnstone, 2007; Read et al, 2012; Read and Bentall, 2012; Read and Gumley, 2010). Counselling psychologists have a valuable role to playthrough rejecting diagnosis in favour of a focus on understanding subjective experience. It is important that relational therapists develop confidence in working with those who are suffering from severe psychological distress, and to challenge the medical model when necessary (Walsh, Frankland and Cross, 2004). Counselling psychologists are in an ideal position to work with people following trauma and who are experiencing a wide range of psychological issues, including voice hearing and experiencing unusual ideas. It is important to work alongside the person in a way that enables them to share their subjective experience. This can mean having to hold some difficult feelings which makes effective supervision crucial.

Counselling psychologists can encourage trauma and relationships to be considered in assessments, formulations and interventions Participants interviewed were able to attend a resource centre attached to a supported housing service, but this is a limited resource not available to the majority of service users. Interviewees in particular, were not involved in other meaningful activity. Participants still experienced stigma and discrimination in the local community and there was not a lot of mixing beyond family, other service users and with professionals. This has implications for policy makers as opportunities need to be made available for service users to meet and give each other much needed support as well as providing

therapeutic and practical resources, but which are not segregating as traditional day centres.

This research highlights the need for a social as well as an individualistic response with psychology taking a more socially active stance. The impact of social and environmental factors and conditions need to remain paramount in developing formulations and understanding how empowerment is possible, including consideration of the impact of inequality and discrimination.

Conclusion

This research considers different psychological and social processes in becoming empowered and disempowered. It indicates the significant relational processes involved in severe psychological distress in terms of what empowers and disempowers; expanding knowledge of how relational difficulties can affect the personal response to voice hearing. These findings challenge research to take a more systemic approach in forming understanding of severe psychological distress.

This research has developed a positive relational model of the voice hearing experience. It has established the immense value of supportive relationships and the profound impact that compassionate, empathic and respectful relationships can have both on wellbeing and how voice hearing is defined and understood. This recognises that both the voice hearer and helpful supporters can play a positive role in facilitating. Professionals can have a huge impact through developing relationships which are validating, confirm a positive sense of self and encourage hopefulness. Service users can gain strength and friendship through sharing with one.

The role of talking therapies in severe psychological distress, often neglected in research and practice, is something that service users themselves are desperately asking for. This provides an opportunity to talk and explore emotions, experiences and relationships with someone who is not overwhelmed or threatened by unusual experiences. Therapists are well placed to work with the subjective experience, enabling voices to be integrated as an acceptable part of a more empowered self and encouraging positive cultural changes in how severe psychological distress is understood. Through validating relationships those experiencing severe

psychological distress can be supported to look forward to living, with or without voices.

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Appendices

Demographics of Participants

Table 1: Demographics of Interviewees

Name	Ethnicity	Age	Diagnosis	Therapeutic experiences
Stephen	White/British	50 years	Paranoid Schizophrenia	Attended Open Art Therapy group for a year, Anxiety and Confidence group for a year, swimming group 8 months, Individual drama therapy with a trainee – 12 weeks (no DNA) Pathways – 121
Owen	Black/British	48 years	Schizophrenia	Thinking skills course in prison with a psychologist, Going to church, 121 art therapy- 12 sessions, open art therapy – 12 sessions
Wayne	Jamaican	60 years	Schizophrenia	Creative writing and art therapy group – 6 months Doing exercise Open Art Therapy group – 18 months Recovery group – 12 weeks
Paul	White/British	67 years	Schizophrenia	Drop in Going out on his motorbike
Ash	Somalian	31 years	Schizophrenia	Open Art therapy – 12 sessions

Katherine	White/British	49 years	Schizophrenia	Shopping, Losing weight and stopping smoking, drop in Pathways – 121
Natalie	White/British	50 years	Brian injury	Sometimes going to church, Colouring in pictures, Music Open Art Therapy group – 18 months Woman's well being group – 12 weeks Pathways – 121
Caroline	White/British	40 years	Schizo-affective disorder	Hearing voices group in hospital and at resource centre, Relaxation group in hospital, Psychology in hospital, Writing about experiences, Exercise Attended Woman's closed Art therapy group – 13 months, Individual Art therapy – 13 months, Open Art therapy – 13 months (off and on), Music production – 12 weeks, Woman's swim – only managed a couple of sessions Woman's well being group – 12 weeks, Pathways – 121

le 2: Demographics of Authors of Recovery Narratives

Name	Diagnosis	Nationality (if known)	Therapeutic experiences
Will Hall	Schizo-affective disorder	American	Yoga and meditation, regular exercise, wellness tools, acupuncture.
Charlie Hughes	Schizophrenia	American	One therapist who used different approaches
Amanda	Unspecified; hearing voices, detained in hospital		CBT, WRAP (wellness recovery action plan).
Abbey	Schizophrenia		Supportive GP and psychiatrist. Psychologist who used CBT approach.
Debra Lampshire	Unspecified, hearing voices, hospitalised		No therapy noted. Worked therapeutically with a close friend.
Sue Clarkson	Unspecified; hearing voices, hospitalised		Hearing voices network meetings, Self help groups
Stewart Hendry	Schizophrenia	British	Social worker who supportive Worked closely with family GP
Eleanor Longden	Schizophrenia	British	Therapeutic sessions with a psychiatrist, Hearing voices network
Jacqui Dillon	Unspecified, hearing voices, hospitalised	British	Counsellor and therapist, Personal crisis plan, Writing daily journal, Painting and creativity
Jan Holloway	Unspecified, hearing voices, hospitalised		Therapist and attended some hearing voices network meetings and talks.
Jeanette Woolthuis	Psychosis	Dutch	Therapeutic sessions with a psychiatrist
Mary Lou	Unspecified, hearing voices, hospitalised	American	No therapies recorded

Table 3: Diagram of Pathway of Empowerment and Disempowerment

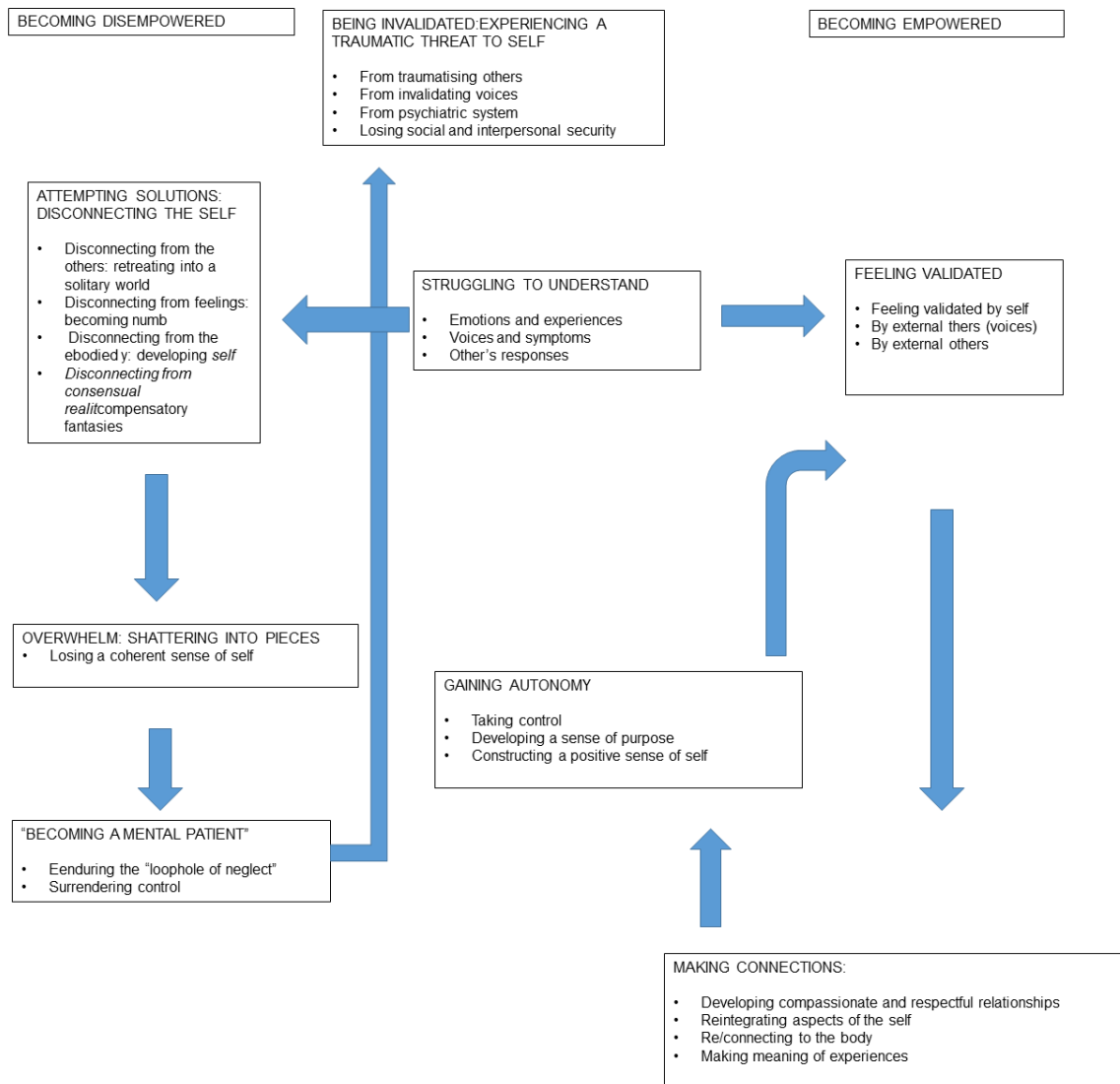


Table 4 Transcript and Coded Interview with Stephen

(researcher in italics/ Stephen in regular font).

Dialogue	Closed Coding	Focused Coding
<p><i>I wondered whether you could tell me about sort of experiences you have that make you distressed, whether it might be voices or thoughts that you have</i></p> <p>It's a bit hard really to think about what makes them happen, because they just happen like you know, there's vibes in the air you know, like when you think of people. And think about what they think of you and then you start listening to the voices and that you know as if they're coming from the illusion of whoever you're thinking about.</p> <p><i>Okay</i></p> <p>And the voices are just like always bad voices, and there's some sort of memories and you get different memories join with the voices and ganag up on you...and I see illusions at the same time, like delusions about, trying to envisage a person to go with the voice or noise. But like the thoughts just start again and again when you wake up. It just happens again like the only freedom you get from it is when you're asleep. You just end</p>	<p>Finding hard to think about what makes voices happen, because they just happen like you know, feeling vibes in the air. Thinking about people. thinking about what they think of you listening to voices knowing they're coming from the illusion of whoever your thinking about.</p> <p>Hearing bad voices remembering memories joining different memories with the voices feeling ganged up on seeing illusions at the same time envisaging a person to go with the voice or noise. having thoughts again and again and again when you wake up sleeping brings only freedom listening to them ignoring them thinking things that you don't normally think about</p>	<p><i>Struggling to understand Where voices come from. experiencing a vibe when thinking about people which turns into a voice and an illusion.</i></p> <p><i>Feeling persecuted by bad voices</i> <i>Memories join up with the voices</i> <i>And gang up on him.</i> <i>Outnumbered</i> <i>Creating a vision of a person</i> <i>To fit with a voice</i> <i>Feel not in control of own mind</i> <i>Continuous cycle of thoughts starting again and again that he can't find freedom from.</i></p> <p><i>Forcing him to think about things that doesn't</i></p>

<p>up listening to them and ignoring them like, and they can stress you out by making you think things that you don't normally think about, whether you are what they are insulting you to be and questioning it like, whether you are what they say you are and then you start thinking who are they, who is there, is there anybody there really you know or is it all just in my imagination. It's like as though there's a spirit world that like controls voices and delusions and makes voices.</p> <p>And then you get that question you know, like when did it all start. But the fact that it's going on means that you can never answer it because you never get back to square one. You've just got to over ride it, just ignore it, but it can be quite stressful to ignore it as it just seems to reoccur all the time, nonsense really, sort of insanity really. Insane thoughts really, like that I'm a bad person or like that I could be a murderer or a paedophile or like I could be a rapist or a sex maniac or anything detrimentally insulting. All these thoughts come into my head.</p> <p><i>It sounds like that makes you question yourself.</i></p> <p>Yes and then I become very self-conscious about what other people think of</p>	<p>becoming stressed being insulted questioning whether you are what they say you are</p> <p>thinking who are they wondering who is there, is anybody there wondering is it all just in my imagination describing as a spirit world that like controls voices and delusions and makes voices. questioning when did it all start.</p> <p>Never ending questioning Answering impossible overriding it, ignoring it, finding ignoring it stressful reoccurring all the time, understanding as a sort of insanity really describing as insane thoughts hearing I'm a bad person or a murderer or a paedophile or like I could be a rapist or a sex maniac having detrimentally insulting thoughts coming into my head.</p>	<p><i>want to think about. Hearing insults and questioning these, then questioning who voices are.</i></p> <p><i>Questioning himself and his identity.</i></p> <p><i>Searching for an explanation; wondering if there is a spirit world that controls voices.</i></p> <p><i>Struggling to understand why voices started.</i></p> <p><i>Thinking reoccurring horrible thoughts that are very difficult and stressful to ignore.</i></p> <p><i>Doubting his sense of himself and his humanity, because he lacks control over his thoughts.</i></p>
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<p>me and I think that I know what they think. And I start to think that other people think those things of me and that that is their opinion and maybe it is, some people might do but not everybody does.</p> <p>It makes me think that's the answer, that's what they think of me and I get paranoid to go out and things like that because I can't face reality because it makes me think that people think I am that bad character type descriptions and solitude, being on my own a lot sort of causes stuff to play on your mind. You get an issue that's upsetting you, like someone disturbed you with their actions or something or looked at you a certain way and then you dwell on what you gonna do about it like you know. If someone borrowed some money off you and you keep thinking are they going to pay it back or not like you know and it stress you out. You start to think they're going to ask for more getting more and more stressed.</p> <p>You start getting bored and drinking loads of coffee and coffee and cigarettes tend to trigger off states of mental health which aren't very good. Yeh</p>	<p>becoming very self-conscious wondering what other people think of me thinking that I know what they think. thinking that other people think those things of me believing it is their opinion and maybe it is considering some people might do but not everybody</p> <p>making me think that's the answer making me think that's what they think of me feeling paranoid stopping going out avoiding facing reality thinking that people think I am that bad character being on my own playing on my mind.</p> <p>getting an issue that's upsetting you, being disturbed by someones actions believing looking at me a certain way</p> <p>dwelling on what you gonna do about it</p> <p>thinking are they going to pay it back stressing me out starting to think they're going to ask for more money</p> <p>becoming bored drinking loads of coffee smoking cigarettes</p>	<p><i>believing that he knows people are thinking badly of him; makes it hard to trust people and to form relationships (but knowing not everyone thinks that of him so a possible alternative perspective).</i></p> <p><i>Withdrawing socially from the world and fearful of facing a reality where people think he is bad person (as though different realities).</i></p> <p><i>Becoming more introspective when he is alone. Becoming more disturbed by his thoughts which are making him question his interactions and relationships.</i></p> <p><i>Using strategies to distract him when he is bored which are unhelpful.</i></p>
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<p><i>Can you tell me something about what's been helpful in helping you manage?</i></p> <p>Having willpower really and company. being helped by staff and residents by just being there really finding people just being themselves. trying to forget about the...I spent 9 months in the hospital and became quite unwell.</p> <p>Medication was affecting me as well, like it was having an adverse effect I think... Medication helps me, like the taking medication taking away a lot of the problems I get, curing my bad mental state questioning whether I'm addicted to them or not</p> <p><i>What do you think they do that makes it feel better?</i></p> <p>Take it away, take it away. Deaden your mind to it. They sort of change your mind like, as if they sort of change what your thinking. They take your mind of the monotony of sending yourself mad and mad thoughts and help you relax a bit more you know and stop getting so stressed. They have side effects themselves where when the medication wears off you get some of the schizophrenia come back. And it just gets</p>	<p>triggering off states of mental health which aren't very good.</p> <p>Having willpower really and company. being helped by staff and residents by just being there really finding people just being themselves. trying to forget about the...I spent 9 months in the hospital and became quite unwell.</p> <p>Being affected by medication thinking medication helps me, taking medication taking away a lot of the problems I get, curing my bad mental state questioning whether I'm addicted to medication</p> <p>Taking it away, Deadening my mind to it. Changing my mind changing what your thinking. taking your mind of the monotony of sending yourself mad and mad thoughts</p>	<p><i>Having genuine relationships with staff and service users helps him forget some of the distress he has experienced.</i></p> <p><i>Questioning and feeling some uncertainty about the value of medication; is it reducing or creating problems.</i></p> <p><i>Experiencing a deadened sense of self from medication; stopping thoughts. Idea that mind can be altered, (so does it belong to him). But an awareness that this is not resolving his distress.</i></p>
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<p>worse until you take more medication.</p> <p>Okay.</p> <p>I don't know but on past experience without medication I get sent into a withdrawn schizophrenic state anyway so I need medication to maintain a sort of normal existence.</p> <p>It's something like, you have to take medication when you're unwell. I became unwell when I was about 20 cos I had some sort of strange nervous breakdown and questioned to the world whys it me that is having to deal with all these problems and</p> <p>just destitute and homeless and living on garbage and things like that and medication gave me some stability and it has done before as cracked up like, and started hearing voices and seeing delusions just cracked up like, and started hearing voices and seeing delusions and ended up in a manic state, well.</p> <p><i>Do you stay on medication all the time or are there times when you don't take it?</i></p>	<p>helping you relax a bit more you know stopping getting so stressed</p> <p>wearing off of medication returning schizophrenia</p> <p>having side effects getting worse taking more medication. Withdrawing into a schizophrenic state needing medication maintaining a sort of normal existence</p> <p>having to take medication when unwell. Becoming unwell when I was about 20</p> <p>Having some sort of strange nervous breakdown questioning to the world whys it me</p> <p>having to deal with all these problems</p> <p>cracking up like hearing voices seeing delusions ending up in a manic state, becoming destitute and homeless living on garbage and things like that gaining some stability from medication</p>	<p><i>Maintaining some sense of normality with medication but that he is being drawn into two different states; neither of which are within his control</i></p> <p><i>Questioning the world and his role in it; is he to blame or is he a victim.</i></p> <p><i>losing sense of himself and of losing everything else; becoming fragmented and only stability came from medication.</i></p>
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<p>No I have to take it every day, twice a day. Sometimes I think it's not enough, sometimes I think it's the right amount and sometimes other times I think it's too much. But I have to rely on what the dr says, I mean the doctor prescribes it and like you know without it I'd end up in a psychiatric hospital.</p> <p>The voices and delusions would get so bad that I'd end up having a psychotic episode and become quite schizophrenic, you know. And psychosis starts and I end up living in a withdrawn state, trying to live under society.</p> <p><i>So for you can medication be helpful?</i></p> <p>Yeh, but you don't get to choose medication. They talk about it but I don't understand like how to speak my mind about medication and what it does, it just makes me feel better.</p> <p><i>So when you have a review of your medication do you feel able to ask questions about it and talk with your doctor about it?</i></p> <p>Yeh, I talk with them about it. In the past they've kept it the same but this time they wanted me to go on some other medication but it involved tests so I didn't want it cos I don't like blood tests</p>	<p>taking it every day, twice a day thinking it's not enough, thinking it's the right amount thinking it's too much. relying on what the doctor says, I mean the doctor prescribes it and like you know without it I'd ending up in a psychiatric hospital.</p> <p>Hearing voices and delusions so bad Ending up having a psychotic episode becoming quite schizophrenic, you know. And psychosis starts living in a withdrawn state, trying to live under society.</p> <p>Not choosing medication. Hearing talk about it Not understanding Not speaking my mind about medication and what it making me feel better.</p> <p>talking with them about it being kept on the same</p>	<p><i>Deferring to medical advice despite his own uncertainties. Lacking confidence to question.</i></p> <p>.</p> <p><i>Fearing that hearing voices means losing everything and not having a place or a connection with society.</i></p> <p><i>Experiencing that he has no choice over taking medication but having to defer to medical opinion about what is best for him; lacking a voice.</i></p> <p><i>Experiencing a lack of options and alternatives other</i></p>
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<p>so I'm forced to stay on what I've got now.</p> <p>Okay</p> <p>Though it does make me wonder whether the other stuff would have been better and helped me get better but I can't have blood tests so I have to live with that fact that I'm not going to find out but then the last review I went to, that's what the outcome of it was. Talking about the medication and deciding to change it but I wouldn't agree to take the new medication cos I didn't want blood tests so I stayed on the old medication. The old medication helps, it takes away the voices and stops me from becoming psychotic but it's anxiety that I get problems with as well, where I get a build up of stress like and tension over a little matter and perhaps somebody is in a bad mood and I think it's my fault and you blame yourself all the time and get really stressed and worked up about it. I get a lot of tension in my heart and anxiety sort of kicks in during the day in between taking the medication in the morning and the evening</p> <p>as it wears off you know and leaves me open and vulnerable to an attack of</p>	<p>wanting him to go on some other medication involving blood tests disliking blood tests having to stay on what I've got now.</p> <p>wondering whether the other stuff would have been better wondering if help get better</p> <p>not having blood tests having to live with that fact that I'm not going to find out</p> <p>going to reviews talking about the medication deciding to change not agreeing to take the new medication staying on the old medication</p> <p>finding old medication helps taking away the voices stopping me from becoming psychotic</p> <p>getting problems with anxiety</p> <p>building up of stress like and tension over a little matter and perhaps somebody is in a bad mood</p> <p>thinking it's my fault if somebody's in a bad mood</p> <p>blaming myself all the time</p> <p>getting really stressed and worked up about it getting a lot of tension in my heart</p> <p>kicking in of anxiety</p>	<p><i>than the medication he is currently taking.</i></p> <p><i>Taking the voices away as though voices are the only cause not the result of problems.</i></p> <p><i>'Becoming psychotic or Schizophrenic'; as though his whole identity changes in this experience.</i></p> <p><i>Over identifying himself as responsible when things go wrong. Perceiving that he has a major influence on relationships.</i></p> <p><i>Embodying his feelings of stress and tension in physical sensations.</i></p>
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<p>anxiety cos medication is designed to last all day and all night so I don't know why I keep getting anxiety attacks, like sort of a panic attack like more stress related, like that type of feeling where you get a terrible stressful feeling inside you.</p> <p><i>That's really unpleasant isn't it.</i></p> <p>I've been taking some temporary tablets, they've given me some prn to take just for a short while to see if it goes away. Yeh</p> <p>But I've got problems with my nerves as well at the moment. I've been trying to take something to take for that instead of taking the anxiety tablets to try and get rid of the nerve problem, so I've got all of these things that I think about you know and sometimes I get stressed and anxious.</p> <p>Anxiety is totally different from schizophrenia, schiz is like when my mind is sort of waking up in the morning I tend to have schizophrenia. And I get an attack of schizophrenia where there's voices and delusions but the more I wake up and get stronger to ignore the more they go away like you know, as if in my subconscious there's some kind of turmoil.</p>	<p>wearing off of medication during the day</p> <p>leaving me open and vulnerable to an attack of anxiety</p> <p>knowing medication is designed to last all day and all night</p> <p>not knowing why I keep getting anxiety attacks getting a terrible stressful feeling inside me.</p> <p>taking some temporary tablets</p> <p>being given some prn to take just for a short while seeing if it goes away.</p> <p>having problems with my nerves as well</p> <p>trying to take something to take for that instead of taking the anxiety tablets trying to get rid of the nerve problem</p> <p>thinking about getting all of these things</p> <p>getting stressed and anxious</p> <p>explaining anxiety is totally different from schizophrenia, waking up of my mind is sort of waking up in the morning</p> <p>having schizophrenia getting an attack of schizophrenia where</p>	<p><i>Experiencing himself as being vulnerable and that being attacked and lacking an internal protection. 'Schizophrenia' is an enemy.</i></p> <p><i>Locating another problem as Being his nerves; separating problems out instead of seeing issues and mind body as connected.</i></p> <p><i>Trying to make sense of his experiences and understanding as a turmoil in his subconscious as though there is a battle in his mind or a distress that cannot be settled. Being attacked by schizophrenia as though a battle.</i></p>
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<p><i>You said you get stronger which helps you ignore them. What do you think helps you to do that?</i></p> <p>Just waking up with a few cigarettes and a few cups of coffee cos that's my addictions. I got a coffee and a nicotine addiction and when you've been asleep for a long time your body hasn't had any fixes so waking up and having a fix of nicotine or caffeine replenishes the levels of drugs inside you which I'm addicted to. I'd try to stop drinking coffee and smoking cigarettes but it brings me back to from a subconscious state where I'm not cos once I've had a few cups of coffee and a few cigarettes I sort of feel more awake and alert and I'm not under a sort of schizophrenic attack where voices and delusions are the first thing I hear in the day you know,</p> <p><i>So there's something about being more awake and more alert and involved in the world.</i></p> <p>Yeh that's right and sort of not being in a nightmare cos I wake up in bad state all the time. I take my medication at 6 o'clock at night and I don't take another one until 8 o'clock in the morning so</p>	<p>there's voices and delusions waking up getting stronger ignoring going away having a turmoil in my subconscious</p> <p>waking up with a few cigarettes and a few cups of coffee having a coffee and a nicotine addiction waking up needing fix of nicotine or caffeine replenishing levels of drugs inside me trying to stop drinking coffee and smoking cigarettes bringing me back to from a subconscious state having a few cups of coffee and a few cigarettes feeling more awake and alert not being under a sort of schizophrenic attack hearing voices and delusions the first thing I hear in the day</p> <p>not being in a nightmare waking up in bad state all the time</p>	<p><i>Embodying sense of his emotional state; trying to nurture and create a sense of balance with coffee and nicotine and feel strong enough to battle with voices and delusions. Subconscious; explore ideas about who or what is he really and what is reality.</i></p> <p><i>Feeling of being in a Nightmare; again sense of him inhabiting different worlds. That he is not a free person.</i></p>
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<p>when I wake up at 7 o'clock my minds been asleep and I spend the next hour sort of battling with voices and things like that until I take my medication and it gets rid of it.</p> <p><i>So do you know it changes quite quickly once you take it.</i></p> <p>Yeh it does, which is a good thing really. I think street drugs probably caused a lot of damage to my mind, years ago when I used to take cannabis and take LSD and things like that when I was about 20 and I started doing a lot of work and committed myself to a lot of work and was doing 66 hours a week night shifts and struggling to mend my car and just cracked up. I think a combination of alcoholism and smoking seemed to cause some kind of breakdown. That's probably where it all began, but ever since I've been taking medication, cos I've been taking it for 20 years, it makes me feel a lot better. I can lead a normal sort of life. It slows me up a bit.</p> <p>It helps talking to people, solitude is the worst enemy I've got, being on my own. I tend to go into a sort of schizophrenic world like, when I'm by myself and develop schizophrenia. Voices</p>	<p>taking my medication at 6 o'clock at night taking another one until 8 o'clock in the morning waking up after my minds been asleep spending the next hour battling with voices and things like that taking my medication getting rid of it.</p> <p>thinking street drugs probably caused a lot of damaging my mind, taking cannabis and LSD when I was about 20 starting doing a lot of work committing myself to a lot of work doing 66 hours a week night shifts struggling to mend my car cracking up thinking a combination of alcoholism and smoking having some kind of breakdown beginning of it all taking medication for 20 years making me feel a lot better leading a normal sort of life slowing me up a bit.</p> <p>talking to people, being on my own and solitude is the worst enemy I've got</p>	<p><i>Life is structured by medication.</i></p> <p><i>(battling with voices internally until conflict is taken away by medication).</i></p> <p><i>Looking for an explanation for his psychological experiences and experiencing a sense of his body and mind being overwhelmed and his self breaking down. Wanting to find some normality.</i></p> <p><i>Experiencing his physicality as changing over time and with medication, being embodied.</i></p> <p><i>Experiencing schizophrenia as being another world and reality. People connect him to a different world;</i></p>
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<p>and thoughts that are like a voice in your head that sound like a voice that's outside of your head, or noises that become like the sound of a voice that all sort of add up to going really schizophrenic, going sort of downhill.</p> <p><i>So when you're on your own that sounds harder to control?</i></p> <p>Yeh it's like being by myself is like drifting back into mental illness, like mental illness is like taking your hands to yourself and itching yourself and doing things other than being with somebody. I spend a lot of time like rolling around in bed, like bored, you know. I find that company brings you back to reality, instead of going away from reality when you go into a world of your own. You've got no choice but to live by yourself if you are a single sort of person but other people cope with it better, they don't get schizophrenic problems like I seem to do as if I've got an ongoing mental state where I talk to myself in my mind.</p> <p><i>So something about being with other people and having friendships and</i></p>	<p>going into a sort of schizophrenic world like being by myself developing schizophrenia having voices and thoughts that sound like a voice in your head sounding like a voice that's outside of your head</p> <p>hearing noises that become like the sound of a voice adding up going really schizophrenic going sort of downhill.</p> <p>being by myself drifting back into mental illness</p> <p>comparing mental illness with taking your hands to yourself and itching yourself</p> <p>doing things other than being with somebody spending a lot of time like rolling around in bed, being bored</p> <p>finding that company brings you back to reality not going away from reality</p> <p>going into a world of your own</p> <p>having no choose living by yourself if you are a single sort of person believing other people cope with it better</p> <p>having ongoing mental state where I talk to myself in my mind.</p>	<p><i>experiencing different realities connecting with people brings him back into their reality. Awareness of the power of relating to people.</i></p> <p><i>Noises begin to sound like voices (idea of it coming and going; overtaking him and being pushed away).</i></p> <p><i>Experiencing a lack of physical comfort.</i></p> <p><i>Sense of aloneness; as though he is a different type of person from other people, sense of 'otherness'.</i></p> <p><i>Fluctuating sense of whether he feels able to cope or questions his abilities.</i></p> <p><i>Communicating with himself in his mind (but everyone does this, don't they).</i></p>
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relationships sounds really helpful.

It is, some company makes all the difference. I used to be lucky enough to have a girlfriend and I used to be lucky enough to have friends when I grew up and went to work, but I sort of became ill really and I ended up in a world of my own and in supported housing. Where I've been in hospital before it sort of brings me back into the real world with other people to relate to.

Sort of being in the room by yourself you can get a bit isolated and become withdrawn and then it's easy to stay isolated.

Help will come to you but I tend to go out and find people if I get stuck in a situation like that. It's not always easy to find someone.

What do you think helps you to do that, to go out and find someone and find other people to connect with?

Just knowing that their there and their kindness to be there really, like cos they care, cos they're welcoming people sort of friendly people, whereas oppressive people I avoid

Having some company makes all the difference
Remembering I used to be lucky enough to have a girlfriend
Remembering I used to be lucky enough to have friends when I grew up and went to work becoming ill
ending up in a world of my own
living in supported housing
being in hospital before it sort of brings me back into the real world
relating to other people

being in the room by yourself
becoming isolated and become withdrawn staying isolated being brought back by help
tending to go out and finding people
getting get stuck in a situation like that
finding someone can be hard

knowing that they're there and their kind ness to be there really,
feeling care and kindness

Relating to other people brings him back into the world, rather than being caught in his own world.

Being drawn into a cycle of isolation. Believing that he needs to find people to help him; a reliance but also self-awareness of value of connecting and relationships. Searching and struggling to find relationships; not wanting to be alone.

Perceiving people as genuine or oppressive; choosing to

<p>them. The help that I find is within myself cos I know that it will be good for me.</p> <p>It's something that I just do, like I just decide to go and be with somebody and I can do that and make the effort to do that. You have to help yourself when you're in a solitude state and you know that there's people to be with</p> <p><i>You mentioned having willpower</i></p> <p>I've had thoughts about suicide but it doesn't take much willpower to sort of shrug it off. I don't think about those things really. The willpower that I've got is like to ignore voices that are insulting me and mimicking everything that I do and taking the piss out of him basically.</p> <p>It's the willpower to know your innocent and don't let it get you down too much. It's the willpower just to walk away and go and do something else.</p> <p>The willpower to just want to live no matter how bad. The willpower to just want to live and not to think about dying. It's so easy to think about dying and want to die. You sort of</p>	<p>feeling welcomed by sort of friendly people, avoiding oppressive people</p> <p>finding help within myself knowing that it will be good for me</p> <p>just doing it</p> <p>deciding to go and be with somebody</p> <p>making the effort to do that</p> <p>having to help yourself when you're in a solitude state</p> <p>knowing that there's people to be with</p> <p>having thoughts about suicide</p> <p>shrugging it off with willpower</p> <p>not thinking about those things really</p> <p>ignoring voices that are insulting me</p> <p>ignoring voices that mimicking everything that I do and taking the piss knowing you're innocent</p> <p>not letting it get you down too much</p> <p>walking away and go and doing something else</p> <p>wanting to live no matter how bad.</p> <p>not thinking about dying</p> <p>thinking about dying and wanting to die is easy.</p>	<p><i>connect or avoid people and making assessments of relationships.</i></p> <p><i>Knowing what is helpful for him and has times of motivation to find relationships. Having faith in people.</i></p> <p><i>Needing self-belief and some strength in sense of self to ignore critical voices.</i></p> <p><i>Showing that feels intense desperation at times. Believing that he can have control over his thoughts; intrapersonal conflict.</i></p>
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<p>wish that life would come to an end and be free of life but the willpower is to want to live and want to be part of the living world and be happy. You've got to carry on just doing what I was doing and do the work that you do and just like look after yourself and you'll succeed in overcoming the mental illness that you</p> <p><i>What do you think helps you to have that control over the way your thinking, cos it sounds like you think very positively?</i></p> <p>Practice, practice really</p> <p><i>Is it</i></p> <p>Cos I've had a lot of things along those lines so I've got used to how to respond to mental illness and bouts of schizophrenia and anxiety. If I don't know what I'm doing, like if somethings not familiar to me to know what I'm doing then I have to see a doctor or something.</p> <p><i>So when you say practice do you have particular ways of thinking</i></p> <p>Yeh it just becomes a routine and you just behave in a certain way so you can just carry on behaving the way you</p>	<p>wishing that life would come to an end being free of life</p> <p>wanting to live and want to be part of the living world and be happy is willpower carrying on just doing what I was doing doing the work that you do</p> <p>looking after yourself succeeding overcoming the mental illness that you</p> <p>Practicing, practicing</p> <p><i>Is it</i></p> <p>having a lot of things along those lines learning how to respond to metal illness and bouts of schizophrenia and anxiety.</p> <p>Knowing if I don't know what I'm doing then I have to see a doctor or something.</p> <p>becoming a routine behaving in a certain way</p>	<p><i>Appreciating the value and positives that come from connecting to the world and understanding he belongs in the world. That individual strength affects wellbeing. He moves in and out of the social world throughout the interview.</i></p> <p><i>Needs motivation and dedication.</i></p> <p><i>Valuing the importance of himself and being caring and compassionate to himself.</i></p> <p><i>Acknowledging willpower and personal strength in changing thoughts and</i></p>
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<p>know and not be influenced into like you know doing anything stupid because of the mental illness. You have to sort of forget about it and put your mind elsewhere and occupy yourself but it's very difficult when you're by yourself to find something to occupy your mind with cos everything seems like one mental health trap you know, and your mental health is never going to improve,</p> <p>but if you wait long enough someone is going to come along and help you. That's what I find, someone usually comes along and helps me. If I'm stuck eventually someone will come along and I can relate to them or ask them for help or just be with them or help them or something. Cos helping people is one way of taking your mind off your own problems.</p> <p>Sometimes people show you how to behave in respect of a problem cos by noticing what they do you can copy them you know so you end up in a similar situation. Like stress you know, and because you've watched</p>	<p>carrying on behaving the way you know not being influenced into doing anything stupid because of the mental illness</p> <p>forgetting about it putting your mind elsewhere occupying yourself being by yourself makes harder to occupy your mind feeling like everything is one mental health trap you know</p> <p>feeling like your mental health is never going to improve</p> <p>waiting long enough knowing someone is going to come along and help you finding someone usually comes along being helped being stuck knowing eventually someone will come along relating to them asking them for help being with them helping them</p> <p>helping people taking your mind off your own problems. learning how to behave in respect of a problem from other people noticing what they</p>	<p><i>actions. Forming strategies. But mind can also trap him. No freedom within himself.</i></p> <p><i>Having times of feeling desperate, Having to depend on other people to rescue him, but lacking control over finding this support, A passivity in relationships. He has more control over himself (through strategies) than over other people's actions.</i></p> <p><i>Importance of relationships with people who understand. A</i></p>
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<p>someone else respond to an epileptic fit or something then you can snap out of it yourself before you get too ill. If you have a fit you've got to wait for it to go away but I only learnt that by watching somebody else suffer, cos I helped them get by. I don't know everything about how ill you can get, I'm just as ill as I am. I'm not too bad. Thankfully I'm not physically disabled in a bad way. I've got my own physique and capabilities and I've got some bad mental problems sometimes but on the face of it all I'm not too bad. In respect of everybody else, there's always worse isn't there.</p> <p><i>You said about sharing and supporting other people, do you talk with other people who've had similar experiences very much?</i></p> <p>Sometimes, or you don't have to talk with them just be with them or look at them and see that they're doing something to pass the time. Or they've got a routine that they've developed and you can like join in and do the same with them. Like G will watch telly so I spend a lot of time with G</p>	<p>copying them ending up in a similar situation watching someone else respond to an epileptic fit or something snapping out of it yourself before you get too ill learning by watching somebody else suffer helping them get by not knowing everything about how ill you can get, being as ill as I am not being too bad being thankful for not physically disabled possessing physique and capabilities</p> <p>having bad metal problems not being too bad.</p> <p>Not having to talk with them Being with them or looking at them and seeing that they're doing something to pass the time Joining in with their routine doing the same with them</p>	<p><i>reciprocity in these relationships.</i></p> <p><i>Feeling grateful when he compares his difficulties to those of people physical health difficulties. As though there is a hierarchy of difficulties.</i></p> <p><i>Valuing and sharing each others skills and experience; gaining positive sense of self from helping others. Gaining a role in reciprocal relationships.</i></p>
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<p>watching telly whereas when I came to the Maples house I never used to watch telly but G seems to show me a few things about how to sort of cope. He's got quite a good routine and he goes out and watches telly and wash and has his breakfast. He's got a lot of problems with ocd and checking everything but he's an example of somebody that, I help him like if he wants something from the shop cos I'm more agile than him or if he wants anything I go and get it for him, but that's because I just volunteer to do that cos I like doing it you know,</p> <p>but more of the time he helps me, like people sort of help each other in certain ways. I just sort of get lucky really and someone will come along to help me you know. I haven't really fallen into a situation that I haven't been able to cope with too much. I've managed to cope reasonably well with various melodramas.</p> <p><i>You said someone usually comes along to help, would you feel able to go and ask for help if you needed it?</i></p>	<p>spending a lot of time with G watching telly coming to the Maples house I never used to watch telly but G seems to</p> <p>showing me a few things about how to sort of cope. Observing he's got quite a good routine and he goes out and watches telly and wash and has his breakfast.</p> <p>Knowing G's got a lot of problems with obsessive compulsive disorder and checking everything Recognising him as an example</p> <p>helping him if he wants something from the shop knowing I'm more agile than him or if he wants anything I go and get it for him</p> <p>volunteering to do that cos I like doing it but more of the time he helps me</p> <p>helping each other in certain ways</p> <p>getting lucky really knowing someone will come along to help me</p> <p>not falling into a situation that</p> <p>not coping with managing to cope reasonably well with various melodramas.</p>	<p><i>Coping seems to be through chance and luck and reliance and hope that he will receive support from someone. Difficult to find reliable support.</i></p> <p><i>Diminishing of his problems as 'melodrama'.</i></p>
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<p>Yeh, it's hard though. It's hard to find somebody to listen you know. It depends what sort of help you need. If you need help in respect of someone to sit and listen to you it's a lot more difficult than if you broke your leg and needed help to get an ambulance to get to hospital. There's a difference between the sort of levels of help you can get. Some situations of getting someone to just sit with you to chat to is rarer than the emergencies of a painful situation.</p>	<p>finding somebody to listen is hard depending what sort of help you need needing help in respect of someone to sitting and listening to you it's a lot more difficult than if you broke your leg and needed help to get an ambulance to get to hospital. recognising a difference between the sort of levels of help you can get. getting someone to just sit with you to chat to is rarer than the emergencies of a painful situation.</p>	<p><i>Contradicts earlier comment that physical health was harder to cope with. This implies that psychological distress is undervalued compared to physical health difficulties. Having what seems like a simple need for social support (talking) which shouldn't be so difficult to find.</i></p>
<p>It's like sitting here talking to you is like peaceful you know. It's good therapeutically wise because it helps me use my time to relate to somebody whereas being by yourself you've just got 4 walls and it leads to mental deterioration in your health and I find that if I wanted to find somebody like you to talk to it would be a lot more difficult to do that on say a Saturday night than it would be if I broke my leg. To get help then I could dial 999 and I'd get some help for my leg but you can't dial 999 and say I'm isolated and they'll send</p>	<p>sitting here talking is peaceful Talking is good therapeutically helping me using time to relate to somebody being by yourself you've just got 4 walls leading to mental deterioration in your health finding that if I wanted to find somebody like you to talk to it would be a lot more difficult to do that on say a Saturday night than it would be if I broke my leg getting medical help I could dial 999 and I'd get some help for my leg can't dial 999 saying I'm isolated and they'll send</p>	<p><i>Talking to someone who listens sound most important support and helps prevents him withdrawing into and being trapped in his own world.</i></p>

<p>somebody around to sit and talk to me for a while can you.</p> <p>It's like a loophole of neglect for people who haven't got anybody in their life.</p> <p><i>No, I understand what you mean by that.</i></p> <p>It's hard to explain what its like. It's as if you shouldn't be by yourself for too long. You start climbing the walls but nobody does anything about it. Everyone needs a friend in life but I always seem to end up the odd one out.</p> <p><i>Yeh, you're right and if its something physical it can be easier to get help,</i></p> <p>You can talk to the Samaritans on the phone, I suppose that's something I could do if I was in a bit of trouble. I find it hard to manage to do everything like. I just tend to cope in a stressful situation by just enduring the stress really I don't really talk to anybody about it.</p> <p>That's one thing I miss about not having any teeth, you can't speak the same. It changed my whole vocabulary skills</p>	<p>somebody around to sit and talk to me</p> <p>recognising it's a loophole of neglect for people who haven't got anybody in their life's.</p> <p>Struggling to explain what it's like. knowing you shouldn't be by yourself for too long. climbing the walls but nobody does anything about it needing a friend in life ending up the odd one out.</p> <p>talking to the Samaritans on the phone I suppose I managing to do everything is hard tending to cope in a stressful situation enduring the stress really not talking to anybody about it.</p> <p>missing not having any teeth, not speaking the same changing my whole vocabulary skills</p>	<p><i>Loneliness becomes a form of social neglect. Powerful image.</i></p> <p><i>Emotional content of desperation and frustration. Experiencing it as unnatural And unhealthy to be alone but a sense of him not fitting in with society (ever).</i></p> <p><i>Relying on professionals and organisations. Having to hold onto and endure his emotions because there is no way of releasing or expressing them Swinging between strength and loneliness throughout the interview.</i></p> <p><i>Struggling to speak physically and emotionally.</i></p>
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<p>and I've had to learn how to speak again.</p> <p><i>That's tough</i></p> <p>Cos your teeth help you shape your words and it's a massive change but they had to go.</p> <p><i>Are there areas of your life where you feel you'd like to have more control than you have at the moment or that it's hard to make decisions.</i></p> <p>I'd like to have more control over money I suppose. I spend money too fast cos money helps you pass the time by having a bit to spend every now and again but I tend to spend too much at once and end up skint. When you've got no money you're in a mental rut then and just basically skimping by. I spend too much time doing that like. I should probably budget better and then I could enjoy life more instead of bingeing but that's just something I've got to learn my lesson really.</p> <p><i>Yeh cos I guess once you haven't got money it's harder to pass the time.</i></p> <p>It breaks the day up you know going to the café for a coffee. Whereas with no money you tend to stay in</p>	<p>learning how to speak again.</p> <p>Cos your teeth help you shape your words and it's a massive change but they had to go.</p> <p>Wanting to have more control over money I suppose spending money too fast cos money helping to pass the time by spending every now and again spending too much at once ending up skint getting in a mental rut then skimping by spending too much time skimping by budgeting better enjoying life more not bingeing learning my lesson be helpful</p> <p>breaking the day up you know going to the café for a coffee staying in when no money</p>	<p><i>Strategies that he uses to cope, often bring other problems with them. Hard to find personal strategies not involving other people that don't have a negative impact as well and which also feel out of control.</i></p> <p><i>Strategies can form a difficult cycle.</i></p>
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<p>and I tend to spend too much money in one go and my money doesn't last long anyway. I only get a bit of money anyway. If it could last a bit longer I'd probably be better off. That's something I wish I could make myself do. To have more control over my money spending skills.</p>	<p>spending too much money in one go not making money doesn't last long getting little bit of money anyway making it could last a bit longer would make me better off wishing I could make myself do having more control over my money spending skills.</p>	
<p>You can't really control other people you know. I'd like to have more company sometimes but then again I like to have my aloneness sometimes. I like being by myself for a quiet 5 minutes but the grass is always greener isn't it.</p>	<p>Not controlling other people you know liking more company sometimes liking to have my aloneness sometimes. liking being by myself for a quiet 5 minutes acknowledging the grass is always greener</p>	<p><i>Realising complexities in relationships; these are not within his control. He also needs to be alone sometimes.</i></p>
<p><i>Yes, so it's sort of choosing whether you want to be with other people or on your own.</i></p>		
<p>Yeh and it depends on their situation as well doesn't it but other than that no, I can't think of other things that I'd like to have more control of. Just, I'd like to be more in control of my health but that tends to be a matter of mystery, what I'm going to feel like, when I'm going to feel like and how I'm going to deal with everyday things.</p>	<p>depending on their situation not thinking of other things that I'd like to have more control of being more in control of my health considering a matter of mystery, what I'm going to feel like, when I'm going to feel like and how I'm going to deal with everyday things. Not knowing Not controlling Feeling that it just happens preparing for it eating properly</p>	<p><i>experiencing his psychological health as unpredictable and out of his control, making it harder to cope with and to understand. Struggling to find personal meaning and explanations and to relate distress to experiences.</i></p> <p><i>Preparing for distress by looking</i></p>

<p>You just don't know and you can't control it cos it just happens. You can prepare for it you know by eating properly and drinking enough and making sure you've got enough tobacco.</p>	<p>drinking enough having enough tobacco.</p>	<p><i>after himself physically and in an embodied sense, but this seems disconnected from thinking about his emotions.</i></p>
<p><i>Yeh so it's kind of looking after yourself generally.</i></p>	<p>making you feel much better</p>	<p><i>valuing and caring about self physically and with compassion; taking action in this embodied way might be easier than reflecting on emotions, but still affects psychological wellbeing. This is something he can do by himself.</i></p>
<p>Yeh, it makes you feel much better when you've looked after yourself and had a shower. It makes you feel much better about yourself rather than just festering away and making excuses not to do this and not to do that. When you get up and do these things you feel a lot better about yourself.</p>	<p>looking after yourself having a shower feeling much better about yourself not festering away and making excuses not to do this and not to do that getting up doing these things feeling a lot better about yourself.</p>	<p><i>valuing and caring about self physically and with compassion; taking action in this embodied way might be easier than reflecting on emotions, but still affects psychological wellbeing. This is something he can do by himself.</i></p>
<p><i>It makes you feel worth looking after doesn't it.</i></p>	<p>Saying no to everything is no good is it saying yes to things trying and do it.</p>	<p><i>Importance of remaining active and positive in his approach. Requiring agency and energy.</i></p>
<p>Saying no to everything is no good is it, you've got to say yes to things and try and do it.</p>	<p>Saying no to everything is no good is it saying yes to things trying and do it.</p>	<p><i>Importance of remaining active and positive in his approach. Requiring agency and energy.</i></p>
<p><i>It sounds like you've got lots of motivation for doing things.</i></p>	<p>trying to do little things here</p>	<p><i>Small actions can make a difference and build on one another. Shows that he can make changes himself.</i></p>
<p>Yes I try to do little things here and little things there and it all adds up and it's not a bad life really you know. Lifes not so bad and you have to thank yourself lucky that you've got a good state of health.</p>	<p>adding up recognising not a bad life really you know thanking yourself lucky that you've got a good state of health. thinking to myself there's always worse</p>	<p><i>Comparing himself positively</i></p>

<p>I always think to myself there's always worse and you've got to be thankful for small mercies.</p> <p><i>Yeh that's true.</i></p> <p>Don't let the bastards grind you down</p> <p><i>Have you noticed changes in control over time, you said you were in hospital and now you've got your own place.</i></p> <p>Yeh I was walking around destitute and living in some crazy world, homelessness and poverty to middle of the road, happy and sort of like free and content situations and I've had pretty mad and ill situations where I've been messed up on medication and drugs and felt terrible about it you know. It was pure luck that I sort of...it's the luck of the devil really to come out of it alive really. I think myself lucky to be alive sometimes and grateful to still be around cos so many people in my past haven't made it this far. People just drop by the wayside all the time, they drop like flies, there's always somebody dying.</p>	<p>being thankful for small mercies.</p> <p>walking around destitute living in some crazy world, homelessness and poverty to middle of the road, having happy and sort of like free and content situations having pretty mad and ill situations where I've been messed up on medication and drugs feeling terrible about it you know. Thinking that pure luck Describing as the luck of the devil really coming out of it alive really. thinking myself lucky to be alive feeling grateful to still be around knowing so many people in my past haven't made it this far. Knowing people dropping by the wayside all the time dropping like flies, there's always somebody dying.</p>	<p><i>to people with physical health difficulties again; contradictory feelings about his position.</i></p> <p><i>(who are the bastards?)</i></p> <p><i>experiencing world as unpredictable and people as fragile and vulnerable; life events often due to luck or fate.</i></p> <p><i>moving between different worlds; a sane world and crazy world. If one loses place in sane world then they can lose everything.</i></p> <p><i>Vulnerability of self and people and relationships which can be easily lost.</i></p>
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<p><i>So I guess in terms of being able to make choices and things now, it sounds like you're much more able to make choices.</i></p> <p>I used to be a lot younger see and I used to just race around and I used to find it hard to relax. I'd always be on my feet and doing something see, but these days</p> <p>I tend to be able to relax a bit more, as if my body just grew old. It stopped just wanting to run away from everything and felt more comfortable and easily able to deal with other people and not just have to keep on fleeing situations. It's like you notice older people are more relaxed whereas younger people are bouncier, it's just part of life but this is it, at a young age I ended up by myself and</p> <p>I found it hard to find some sort of ground control and just ended up in dire straits all the time. Everything just kept going wrong.</p> <p><i>So you just were always moving or running away from things</i></p> <p>Yeh I always just used to want to run away, I just</p>	<p>being younger racing around finding it hard to relax. Being on my feet and doing something see relaxing a bit more, growing old stopping wanting to run away from everything and feeling more comfortable dealing with other people more easily not fleeing situations. noticing older people are more relaxed noting younger people are bouncier understanding it's just part of life ending up by myself when younger</p> <p>finding it hard to find some sort of ground control ending up in dire straits all the time finding everything just kept going wrong.</p> <p>wanting to run away,</p>	<p><i>Changing as part of a natural embodied process; psychological changes occurring as his body changes and he feels more grounded and solid.</i></p> <p><i>Struggling to find any secure sense of self or stability as things (and himself) are constantly shifting.</i></p>
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<p>sort of liked living out in the open and I'd give up addresses to have no address and live rough and that and was seen to be not the clever thing to do and the system would intervene like, the social services would intervene.</p> <p>Cos I'd be unkempt and mute and that you know. I was happy at that moment but looking back I'm glad they did cos I wasn't in a right state of mind you know, I was probably in some strange mental state.</p> <p><i>So when you were in that place you had other people coming in and taking control of things a bit.</i></p> <p>Yeh they intervened like and said we're here to help you and you need to comply or we'll force medication on you. So I complied like cos they don't like it when you won't connect with civilisation, when you live like a wild animal. I ended up dropping out all the time and living like a drop out.</p> <p><i>So you'd comply for a little bit and then drop out again?</i></p> <p>Yeh yeh, something would go wrong and I'd</p>	<p>liking living out in the open giving up addresses having no address living rough and that questioning whether a clever thing to do intervening of system</p> <p>being unkempt and mute being happy at that moment looking back I'm glad they knowing not in a right state of mind you know thinking probably in some strange mental state.</p> <p>Hearing "we're here to help you" needing to comply having medication forced complying cos they don't like it when you won't connecting with civilisation, living like a wild animal dropping out all the time living like a drop out.</p>	<p><i>wanting to have an alternative lifestyle and freedom but sense of a system bigger than him restricting him; can't fight it.</i></p> <p><i>Questioning of his feelings and what to believe about what makes him happy, or what is happiness. Idea that other people can make that decision for him,</i></p> <p><i>Having his choices and freedoms restricted but feeling he had to comply or he would get into trouble with the system. Conflicting feelings between belonging to society and dropping out.</i></p>
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<p>just drop out instead of doing anything about it. I'd end up taking the easy way out and just walking away. Like dealing with everyday problems, like trying to cope in a flat by myself, The council and police would be at the door asking why I was messing around with so much recycling and not going to work and not taking my medication and things like that and then ending up thinking sod this place I can't cope with this questioning. I'm going to find somewhere else and then end up losing that place and not being able to find somewhere else and ending up with nowhere.</p>	<p>finding something would go wrong dropping out instead of doing anything about it. taking the easy way out walking away.</p> <p>dealing with every day problems trying to cope in a flat by myself, being asked why I was messing around with so much recycling not going to work not taking thinking sod this place not coping with this questioning. finding somewhere else losing that place not finding somewhere else ending up with nowhere.</p>	<p><i>Conflicting ideas, avoiding problems or living alternative lifestyle?</i></p> <p>.</p> <p><i>Wanting to escape conventional expectations but being pressured and pursued, making need to escape even stronger. Can't find peace. Conflicting sense of support; needing relationships but sometimes these are oppressive.</i></p>
<p><i>What's the most helpful thing you think that services can do for people?</i></p> <p>Giving them somewhere to live, somewhere to live, somewhere to eat, somewhere to sleep, somewhere to go to the toilet and wash and somewhere to clean your clothes. When you're in services you have to be able to rely on some accommodation and a stable place to live. It's a basis to a good start to your mental health getting better. Living rough in</p>	<p>Giving them somewhere to live, having somewhere to live, having somewhere to eat, sleeping, having somewhere to go to the toilet washing and cleaning your clothes. relying on some accommodation having a stable place to live.</p>	<p>.</p> <p><i>Meeting physical needs essential as basis to begin meeting psychological needs; sense of an embodied, holistic self</i></p>

<p>derelict buildings and caravans and things like that, like I have done in the past and when I look back I must have been a right lunatic like, just to believe in the voices that I was listening to in them days. Why the hell I believed in any of that nonsense I don't know, all sorts of bizarre crazy stories that I was conjuring up in my mind and following and believing like that someone was getting raped or something like in the car park in the middle of the night and getting out of bed from a derelict building and going into the multi storey car park to find out and there was nothing going on at all, It was all noises like and kids shouting and things like that. All these noises make voices.</p> <p><i>It's enough to make you feel anxious when you're hearing all these voices and you don't feel particularly safe.</i></p> <p>When you can't move, when you're stuck there listening to them that's when you start getting anxious. And coffee, coffee makes me worse. It makes me anxious a lot. It strains my heart, that's a nasty thing. That's when</p>	<p>Knowing a basis to a good start to your mental health getting better. living rough in derelict buildings and caravans</p> <p>looking back I must have been a right lunatic like, believing in the voices listening to them questioning why believing in nonsense I don't know, all sorts of conjuring up bizarre crazy in my mind</p> <p>believing like that someone was getting raped or something like in the car park in the middle of the night getting out of bed from a derelict building going into the multi storey car park finding out there was nothing going on at all,</p> <p>understanding it was all noises like and kids shouting</p> <p>hearing these noises make voices.</p> <p>Not moving Feeling stuck listening to them getting anxious. coffee making me worse. making me anxious a lot. straining my heart, finding a nasty thing.</p>	<p><i>Questioning the voices of his past and understanding this as being madness rather than relating to his emotional state or personal experiences.</i></p> <p><i>Making voices from noises and showing hypersensitivity in how his body responds to noise.</i></p> <p><i>Connecting physical and emotional experiences; becoming trapped both physically and mentally and being caught up in cycle of</i></p>
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<p>I start to worry about myself. I can't think about anything else.</p> <p><i>Is there anything that services have done that have been unhelpful in helping you feel in control and manage?</i></p> <p>Missed appointments and things like that. When someone hasn't turned up. When I was trying to get somewhere to live from hospital the social worker never turned up and I had to wait another 2 or 3 months for another appointment. So that sort of thing where somethings gone wrong, I don't know what you call that, but on the whole most of the services that have been in some way a connection to my being helped have done all right.</p> <p><i>That's really good</i></p> <p>Yeh I've had no problems really I find my feet again somewhere, even the services to the homelessness people is a godsend just the same as services for the mentally ill is a godsend as well. but I don't know what it would be like to not have to use the services and to fend for myself cos there's no limit to the</p>	<p>worrying about myself. Not thinking about anything else.</p> <p>Having people miss appointments trying to get somewhere to live from hospital the social worker never turned up waiting another 2 or 3 months for another appointment. finding somethings gone wrong,</p> <p>experiencing most of the services as helpful</p> <p>having no problems really finding my feet again somewhere, believing services to the homelessness people is a godsend finding services for the mentally ill is a godsend as well. Not knowing what it would be like to not have to use the services</p> <p>fending for myself</p>	<p><i>worry. Knowing strategies that are unhelpful but still following them; lack of alternatives.</i></p> <p><i>Waiting for something to happen or for services to do something, lack of personal agency to make change.</i></p> <p><i>Frustrating if services unreliable but also deferring responsibility to services rather than taking any action, passivity.</i></p> <p><i>Feeling of helplessness to create change himself and needing services.</i></p>
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<p>amount of help you benefit from is there, you could be living on your own or with someone even and receive help in a 2 bedroom council flat and it would be of benefit to you then as well. It's just where I've found myself in situations where I've ended up destitute just managing but as soon as I stop managing properly people intervened and showed me the way.</p> <p><i>So people have come in and helped at the right times for you.</i></p> <p>Before it's too late and you end up dead.</p> <p><i>Have you had any support from psychology or counselling?</i></p> <p>No I used to chat to the art therapist at the hospital. She was a counsellor as well, she was a good listener you know, it was like having counselling. It was like talking to a counsellor but I haven't had an arrangement with a counsellor or to talk to her like I would if I did have. I've had chats with psychiatrists and GP's but I haven't really had no psychologists. I don't really know what a</p>	<p>believing benefiting from all the help there is living on your own or with someone even and receiving help in a 2 bedroom council flat and it would be of benefit to you then as well finding myself in situations where ending up destitute just managing stopping managing properly then people intervened and showed me the way.</p> <p>Accepting intervention before it's too late ending up dead.</p> <p>chatting to the art therapist at the hospital. She was a counsellor as well, she was a good listener you know, it was like having counselling. like talking to a counsellor not having official counsellor not talking to her like would if his counsellor chatting with psychiatrists and GP's but I haven't really had no psychologists. Not knowing what a psychologist is,</p>	<p><i>Perceiving that things reach a point where he cannot manage and needs direction but seems like he is being 'taken in hand' rather than a shared and collaborative intervention.</i></p> <p><i>Believing he could have died without intervention. Seriousness of his situation and distress.</i></p> <p><i>Receiving very limited talking therapy and no planned therapeutic intervention.</i></p>
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<p>psychologist is, someone who assesses your thoughts then is it?</p> <p><i>That can be part of it but also to help people understand their thoughts and feelings and cope with them better. I wondered if it was something that got offered but it doesn't sound like it does.</i></p> <p>No I don't know much about that anyway.</p> <p><i>Does it feel like we've missed anything, like there's anything else that's important?</i></p> <p>I don't know, no it feels all right. I can't think of too much more to think of.</p> <p><i>Is there anything else that helps you to feel more empowered and in control?</i></p> <p>You can't control death can you? I've had a lot of bereavements in my life, or I did have at a lot at one time, all in the space of a few years so I had a lot of emotional distress. You can't control it cos once they're dead that's it. It's too late then, but you can control like you know do the best you can with your mental health if you look after yourself.</p>	<p>wondering what a psychologist is</p> <p>Not knowing much about that anyway.</p> <p>Not controlling death having a lot of bereavements in my life, having a lot of emotional distress. Believing once they're dead that's it.</p>	<p><i>Thinking about aspects of life and relationships that you can and can't control; distress comes from natural life cycle and trying to control what is within his power.</i></p>
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<p>the doctor, they don't want to give it to me.</p> <p><i>Does that stop you doing anything that you want to do?</i></p> <p>It stops me doing anything really full stop.</p> <p><i>When you feel anxious?</i></p> <p>Yeh, I feel totally disabled and totally sort of incapacitated. It leaves me drained as well when I'm overcome with an attack. I tend to lay down a lot to try and de-stress myself, like if I've had too much coffee and that makes it worse and I wait for the coffee to wear off and then I feel better again. But then I feel like another cup of coffee again. You just get addicted to drinking coffee, it's a vicious circle really. Its not a very nice feeling.</p> <p><i>No it sounds like you have to recover a bit physically when you feel really anxious like that.</i></p> <p>Yeh that's right. My mind can cope with it but its my body. It causes you worry, you worried about yourself. There's not a lot I can do about the anxiety. It's hard to explain where it comes from. It starts of as</p>	<p>needing different medication for anxiety finding it very difficult to get it off the doctor</p> <p>stopping me doing anything really full stop.</p> <p>feeling totally disabled and totally incapacitated. Feeling drained as well Being overcome by an attack. laying down a lot de-stressing myself having too much coffee making it worse waiting for the coffee to wear off feeling better again. wanting another cup of coffee getting addicted to drinking coffee finding self in a vicious circle really. not feeling nice.</p> <p>copng with it with mind but not my body. worrying about yourself. Not believing not a lot I can do about the anxiety. Struggling to explain where it comes from.</p>	<p><i>both as medical and to be treated rather than understood, (not so much trying to make sense of voices in this narrative).</i></p> <p><i>Reaching complete lack of agency and passivity.</i></p> <p><i>Feeling controlled, limited and incapacitated by anxiety as though this overwhelms him and is beyond his control.</i></p> <p><i>Repeating unhelpful strategies, 'finding self,' again a feeling of passivity and direction.</i></p> <p><i>Trying to make sense of the anxiety and connecting his</i></p>
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<p>worries really, about anything, anything at all. Even just small problems develop into some sort of strain. I think a lot of it is drinking coffee that does it. I don't doubt the coffee causes me a lot of anxiety but it's the way the anxiety starts in the first place. It makes me wonder where it comes from. I can understand schizophrenia a bit but with anxiety I don't know what to do with myself. It just feels so uncomfortable.</p> <p><i>So sometimes it feels like the anxieties harder to cope with than the voices?</i></p> <p>Than the voices, yeh. I've learnt to cope with voices over the years even down to turning them around and making them into better voices, good voices.</p> <p><i>How do you that?</i></p> <p>Just listen to it until it changes.</p> <p><i>Do you?</i></p> <p>Yeh.</p> <p><i>So how might that work? What might happen?</i></p> <p>Well say there's a tap dripping and the dripping noise is making a sound</p>	<p>starting of as worries really, about anything developing small problems into some sort of strain thinking a lot of it is drinking coffee knowing the coffee causes me a lot of anxiety wondering where it comes from. understanding schizophrenia a bit but with anxiety I not knowing what to do with myself when anxious feeling so uncomfortable.</p> <p>learning to cope with voices over the years turning them around making them into better voices, good voices.</p> <p>listening to it until it changes.</p> <p>hearing a tap dripping</p>	<p><i>physical and psychological experiences.</i></p> <p><i>Anxiety causes a lot of distress and lack of control over this; in some ways harder than voices to manage.</i></p> <p><i>Feeling uncomfortable in his mind and in his body.</i></p> <p><i>Gaining some control to change voices and turn them into better voices.</i></p> <p><i>Listening to the voice and having a process that changes it.</i></p>
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<p>and the sound starts distorting and sounds like a voice or something and say it's going on about paedophile or something like that as if it wants you to believe that you are that but you know you're not so your innocent to it so the distortion will go away and the tap will just be dripping again. It's like a warp in my memory, it's like the way I think about things. Its likes brain damage really, like the same tap you can listen to it in a different aspect. If you listen to it calling you a sick name or something, that's what starts of the voices but then you can readjust your mind to listen to it and make it, so you can hear it say something else.</p> <p><i>So how do you think that works, is it because you start thinking of something else and goes to the tap and changes how you hear it or how would you explain it?</i></p> <p>Yeah that's sort of right. I ignore what originally happened but then I start thinking about something else, the tap will just keep on going on about something else instead.</p>	<p>hearing dripping noise is making a sound hearing sound becoming distorting hearing sounding like a voice or something hearing it going on about paedophile or something believing wanting me you to believe that you are knowing you're innocent making distortion will go away hearing tap just dripping again. warping in my memory, a way of thinking about things. Comparing to brain damage really Listening to different aspects of tap dripping listening to it calling you a sick name or something, starting off the voices readjusting your mind listening making it, so you hearing it say something else.</p> <p>ignoring what originally happened thinking about something else</p>	<p><i>Maintaining a positive sense of self when he is hearing a voice can change the voice to a positive voice or a noise, so gaining control and some power.</i></p> <p><i>Having knowledge and awareness of sound but questioning whether it is in his head or real. Strong, stigmatising label of brain damage.</i></p> <p><i>Struggling to understand these experiences and to make sense of the voices and where they come from, what is the reality of them;</i></p>
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Or it will keep going on about the same thing but it will turn it round, cursing it by calling it what it called you,

So your able to play around with them a bit and make them...?

Make you laugh yeh. But they shouldn't exist really cos it's a tap dripping really isn't it. It just sounds like something else. But when it first starts trying to affect you mentally, that's when it's to blame but is it all in my own head or is it really there, I don't know like you know. Sometimes it's not there, all that's there is a dripping noise but how does it sound like a voice. I don't know, it's as if there's voices everywhere. I don't know where they come from but as soon as I find somebody who I can talk to and there not voices, there a real person. There not like noises and delusions where I'm thinking where did that come from and how did it do that. Is it in my own head or is it really there. They can't be there and they can't be in my own head either. The tap is dripping but is sounds like a voice. Is it a voice in my own head or is it a tap

hearing tap will just keep on going on about something else instead. hearing it keep going on about the same thing turning it round, cursing it calling it what it called you,

Making me laugh yeh. knowing they shouldn't exist really cos it's a tap dripping really isn't it. Understanding it sounds like something else. Hearing it at first starts trying to Effecting me mentally, blaming questioning is it all in my own head or is it really there, not knowing not always hearing it only hearing a dripping noise questioning how does it sound like a voice. Not knowing Describing as hearing voices everywhere. I don't know where they come from but as soon as I finding somebody talking to someone and there not voices, there a real person. There not like noises and delusions where I'm thinking where did that come from and how did it do that. Is it in my own head or is it really there. Questioning they can't be there and they can't be in my own head either.

making him question himself. Not a strong and consistent sense of identity.

Hearing sounds in different ways but which plays with his mind. Hypersensitivity and transforming nature of and to noise.

Trying to make sense of a puzzle, a sense that he and the world is a puzzle to himself.

<p>distorting noise but how does it distort the noise. Where does the dripping noise turn into a voice. Its beyond me, it's crazy like you know. It's something to do with being mentally unwell I reckon. I've got nothing better to do than listen to taps drip. But in our house we've got this conservatory and there's all these leaks and rain drops make a noise and there's one over there and one over there and its like trying to make that sound like a voice (bangs leg rhythmically).</p> <p><i>So it sort of gets distorted.</i></p> <p>I can make a noise like a voice but its me tapping my leg that makes a sound. All these sounds plays your mind up I think.</p> <p><i>So part of you knows its just you banging a chair or a tap dripping but another bit of your mind can distort it or ear it as something else.</i></p> <p>That's right yeh. And it can drive you mad and all of sudden you get a voice from nowhere, where there's no tap dripping or nothing. There's just a voice from somewhere</p>	<p>Knowing the tap is dripping Hearing like a voice. Questioning is it a voice in my own head or is it a tap distorting noise Wondering how does it distort the noise. Wondering where does the dripping noise turn into a voice. Not understanding Describing as crazy. Explaining as something to do with being mentally unwell nothing better to do than listen to taps drip. But in our house we've got this conservatory and theres all these leaks and rain drops make a noise and theres one over there and one over there and its like trying to make that sound like a voice (bangs leg rhythmically).</p> <p><i>So it sort of gets distorted.</i></p> <p>making a noise like a voice knowing its me tapping my leg that makes a sound. Thinking sounds playing my mind up</p> <p>Driving me mad Getting voice from no where, where there's no tap dripping or nothing.</p>	<p><i>Struggling to rationalise experiences and to make links with a 'rational' knowledge.</i></p> <p><i>having his mind taken over by his imagination or subconscious</i></p>
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<p>and my imagination or my subconscious or something just taken over my mind. Curses and that, its like a curse, voices in my head,</p> <p><i>What's your relationship with your voices like? Do you get on with any of them. Do you talk to any of the? Do you dislike them?</i></p> <p>Some of them I hate. I just tell them to fuck off. But other ones make you laugh. Chirpy voices. I started ignoring the voices and listening to the birds instead but the birds make a noise and their noise sounds like a voice as well. It's like the birds are chatting to you, but its them chirping really. There not making a voice. It's always the same. Everything turns into a voice. Apart from a voice is a voice when you get somebody to talk to. That's the reality of it all. Finding a voice to relate to. Its solitude that does it like, going stir crazy.</p> <p><i>Have any of your voices ever been helpful?</i></p> <p>Yeh they pass the time. Occupy your mind. I used to listen to voices sometimes telling me what to do in situations</p>	<p>hearing a voice from somewhere explaining as my imagination or my subconscious or something just taken over my mind.</p> <p>Feeling it's like a curse, voices in my head</p> <p>Hating some of them telling them to fuck off. Laughing at other ones Having some chirpy voices ignoring the voices listening to the birds instead but the birds make a noise and hearing their noise sounds like a voice as well.</p> <p>Comparing to birds are chatting to you, Knowing it's them chirping really.</p> <p>Knowing they're not making a voice. Turning everything into a voice. Apart from a voice is a voice when you get somebody to talk to. That's the reality of it all. Finding a voice to relate to.</p> <p>going stir crazy by solitude.</p> <p>passing the time with voices occupying your mind.</p>	<p><i>or something unknown that feels so hard to understand; not connecting this with a trauma or with his experiences.</i></p> <p><i>Feeling he is cursed; ideas of ill fortune rather than linking to his personal history.</i></p> <p><i>Relating to different voices in different ways but voices feel inescapable. Only being sure of reality when he is with a person. People help him construct a different sense of reality and of himself.</i></p>
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<p>and just go with the ideas that they used to put in my head and it could be quite beneficial really, it could be detrimental as well like saying everythings got to be put back where you found it. Crazy really.</p> <p><i>So it really depends what their saying</i></p> <p>Yeh cos like who says it as well, cos with a voice comes an illusion. Like an illusion will speak to you and you think is that a ghost or did I just see, what am I seeing. Is there anything there, can anybody else see it. Nobody ever says look at that person over there, nobody else can see it, it's just me imagining it.</p> <p><i>Does that bother you?</i></p> <p>Yes it bothers me that does. The illusions all the time. That's solitude doing that. Like being lost in a world of thoughts. Thoughts rather than being able to communicate with somebody.</p> <p><i>Yeh like thoughts and imagination rather than connecting with..</i></p> <p>Reality yeh. But it's drifting into mental illness</p>	<p>listening to voices sometimes telling me what to do in situations going with the idea that they used to put in my head being quite beneficial really being detrimental as well hearing everything's got to be put back where you found it. Understanding as crazy really.</p> <p>Effecting by who says it as well. Putting a voice with an illusion. Hearing an illusion speaking to you thinking is that a ghost or did I just see, asking what am I seeing. Asking is there anything there, can anybody else see it. Comparing with what other people see Reconciling that just me imagining it.</p> <p>Illusions bothering me Blaming on solitude doing that being lost in a world of thoughts. Experiencing thoughts rather than communicating with somebody.</p>	<p><i>Finding voices help him pass the time and occupy his mind, but a feeling of him not owning his thoughts. Having more positive relationship with voices sometimes, but this is most common experience with them.</i></p> <p><i>Finding it hard to trust his own senses and perceptions or to rely on his judgement.</i></p> <p><i>Relating to voices as people sometimes.</i></p> <p><i>Becoming lost: losing self in a world of his own thoughts and illusions (losing sense of identity and concrete sense of place and time). Needing connection with people to be brought out of this world.</i></p>
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<p>seeing illusions and that. The worse they get the worse you get with them, stop shaving and stop cutting your hair and changing your clothes. Motivation goes right down.</p> <p><i>Is that when you're being drawn into that other world?</i></p> <p>Drawn into like depression really. Voices driving you away. You can't find anybody to relate to and then the solitude causes you to become emotionally stressed and schizophrenia really. Turned into a schizophrenic. Hearing voices and seeing delusions and just battling away with the paranormal what ain't there.</p> <p><i>Its like chasing shadows almost</i></p> <p>Yeh yeh, you start to see different people in your own shadow. Some of its ugly, some of its beautiful. It depends what you like looking at doesn't it. If you see beauty in something it's a good thing and if you see ugliness you don't want to be looking at that.</p> <p><i>No you get lots of artists and creative people and</i></p>	<p>Reality yeh. drifting into mental illness seeing illusions and that. Deteriorating as voices get worse stopping shaving stopping cutting your hair stopping changing your clothes lacking motivation.</p> <p>Drawing into depression Voices driving you away Not finding anybody to relate to and then the solitude causes you to become emotionally stressed and schizophrenia really turning into a schizophrenic. Hearing voices and seeing delusions battling away with the paranormal what ain't there.</p> <p>Yeh yeh, you start to see different people in your own shadow. Some of its ugly, some of its beautiful. It depends what you like looking at doesn't it. If you see beauty in something it's a good thing and if you see ugliness you don't want to be looking at that.</p>	<p><i>Drifting into mental illness and becoming disconnected from reality with lack of agency or power (feels like no narrative to understand his experiences)</i></p> <p><i>Becoming overwhelmed by voices as these separate him from other people making it hard to connect so he becomes 'schizophrenic' and loses sense of himself.</i></p> <p><i>Being with other people helps him know sense of himself. Linking voices to spiritual world, not integrating these as reflecting part of himself.</i></p> <p><i>Recognising beautiful and fantastic in some illusions, but emphasis is on the unpleasant.</i></p>
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<p><i>actors who use voices in a really creative way.</i></p> <p>I see some good illusions you know. I've seen some pretty fantastic illusions of people doing things or vast illusions of one thing or another and voices that go with it at the same time. But I've had some bad things as well, like sick things come into my mind. They always start from voices somewhere that cause me to think about things I don't want to think about. Rather than looking at illusions that look enviable like or something you can copy or do properly, like live the experience rather than the hell.</p> <p><i>I guess that's one of the differences cos if it's a nice thing it doesn't cause the distress but if its</i></p> <p>No</p> <p><i>Really distressing that's upsetting.</i></p> <p>It is upsetting yeh. It's uncomfortable, its disturbing. It can disturb you. It can leave you disturbed. That's what I get, I get disturbed by things I do. I don't know what to do about them. You just have to wait for them to go away. That's all I can think of really.</p>	<p>seeing some good illusions you know. seeing some pretty fantastic illusions of people doing things seeing vast illusions of one thing or another and voices that go with it at the same time. having some bad things as well, sick things coming into my mind. starting from voices somewhere causing me to think about things I don't want to think about. looking at illusions that look enviable like or something you can copy or do properly, living the experience rather than the hell.</p> <p>No</p> <p>Feeling upset, uncomfortable and disturbed. Disturbing me not knowing what to do about them. waiting for them to go away. Finding something to take your mind off it. triggering off anxiety</p>	<p><i>Experiencing a lack of control and ownership over his thoughts. Dominating sense of difficulties and ugliness caused by voices and horrible thoughts.</i></p> <p><i>Thoughts affecting his sense of himself, hard to create a distance from them.</i></p> <p><i>Feeling disturbed by these experiences but not knowing what to do except wait for them to pass; little active response that is helpful and a sense of helplessness</i></p>
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<p>Find something to take your mind off it. It triggers off anxiety and it tends to make it worse by drinking coffee. I don't know what it is about coffee. Its just a drug I'm addicted to I reckon.</p> <p><i>Its got caffeine in it so maybe it's the caffeine in it that makes you feel a bit jittery.</i></p> <p>Yeh I think it does. I've had some pretty nasty experiences on it.</p> <p><i>Have you tried decaf coffee?</i></p> <p>Yeh but it doesn't taste the same.</p> <p>What time is it.</p> <p><i>Okay shall we leave it there. Does that feel okay.</i></p> <p>Yeh it was good wasn't it.</p>	<p>making it worse by drinking coffee not knowing what it is about coffee. Feeling addicted to coffee</p> <p>having some pretty nasty experiences on coffee</p> <p>not tasting the same. What time is it?</p>	<p><i>here.</i></p> <p><i>Feeling that no control over drinking coffee.</i></p>
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Table 6: Coded Narrative Account

Amanda	Closed coding	Open coding
<p>I have perceived my voices to be through my ears and also in my head. I have perceived them as being other people: the abuser when I was a child; a woman who I perceive as being weak; and one inner voice who communicates through feelings, as the Almighty universal force, or God.</p>	<p>Perceiving voices to be through my ears and in my head Perceiving them as being other people</p>	<p><i>Perceiving voices as alternatively real and imaginary; as other people who are separate from her Different characters, real or imagined, that influential on her.</i></p>
<p>The voices sometimes seemed to be another entity, but when I later explored my voices I realised that this entity was in fact my human spirit within; so now I perceive it to be within me, part of me and also part of the universal life force which is in us all.</p>	<p>Exploring voices Realising voices were her human spirit</p>	<p><i>Exploring voices and Making sense of them as being connected and part of her; part of her human spirit. Becoming more integrated. Changing her relationship to voices. Perceiving voices to be internal and part of universal life force.</i></p>
<p>I had two voices at onset: a male dominant voice which evoked fear in me, and the weak timid voice of a woman. Later, on exploration, I realised that the male voice was that of the abuser when I was a child; and the weak, timid voice was that of myself, the child, expressing how vulnerable I felt- how hurt, humiliated and worthless.</p>	<p>Hearing two voices initially Feeling hurt, humiliated and worthless. Exploring who voices represent Identifying child's voice as representing herself Expressing her hurt and humiliation through child's voice</p>	<p><i>Developing an understanding of the voices and who and what they represented.</i></p>
<p>The voice was of a woman yet the feelings were of the child I was when the abuse took place. I later learned that this was because the</p>	<p>Learning that feelings she had as a children were still in her Finding an explanation Bringing up children alone Having to be strong</p>	<p><i>Manifesting powerful emotions through the voices Understanding voices as reflecting a process of</i></p>

<p>feelings were still in me. But, being a strong independent woman bringing children up alone, I could not express them. I had to be strong. So in order for these extreme and powerful emotions to be expressed, they manifested themselves as a voice within.</p>	<p>repressing feelings understanding that powerful emotions were manifest as a voice</p>	<p><i>separating and integrating different parts of herself. Making sense of what the voices reflect of her past experiences</i></p>
<p>I was 5 years old. The voice was kind and caring and comforting. I was being sexually and mentally abused at the time. The relationships with my voices has always been related to suppressed emotions and the identity of my human spirit.</p>	<p>hearing voices when 5 years old being sexually and mentally abused understanding relationship with voices as relating to suppressed emotions and her identity</p>	<p><i>Relating voices being part of her and her identity, not separate from her (and so less threatening) Voices becoming stronger when she is experiencing traumatic times in life. Gaining personal growth and understanding of herself through voices (seeing positive function) Linking relationship with voices with suppressed emotion and identity of her spirit</i></p>
<p>Whenever I have been through traumatic experiences in my life, the voices have always seemed stronger, yet they have led me through a time of personal growth and understanding myself on a deeper level.</p>	<p>experiencing traumatic phases hearing stronger voices Experiencing personal growth and understanding of self through voices</p>	<p><i>Making link with trauma and the strength of the voices Perceiving positive aspects to her voices in terms of self understanding</i></p>
<p>I had an unhappy childhood. There was abuse, neglect, long periods of separation from my mother, whom I loved dearly, and then there was the death of my best friend, carol, at the age of 8. At 9 my older sister took her own life with an overdose and I was the one who found her.</p>	<p>Experiencing an unhappy childhood Having long periods of separation from loved mother Loving her mother Grieving for death of best friend Grieving for death of her sister</p>	<p><i>Feeling unloved and unsafe Voices reflecting her insecurities and feelings of being inadequate which she indirectly relates to feeling unloved. A lot of self-awareness.</i></p>
<p>I never felt safe or loved (only by my mother). I never felt supported,</p>	<p>Feeling unsafe and unloved Feeling loved by mother</p>	

<p>apart from the odd teacher who showed concern. The voices talk of abuse, self-doubt, insecurities and my inadequacies.</p> <p>These voices would obviously cause me discomfort and sometimes extreme stress, according to how I was able to handle the powerful, strong emotions they would release.</p> <p>Influence The voices have made me commit violence; they have evoked strong feelings of suicide; they have depressed me; they have created changes to my lifestyle and my negative thinking.</p> <p>Relationship At first, I denied the voices were real. This brought utter conflict within me and fear, extreme fear, which would result in panic attacks and physical ailments.</p>	<p>Hearing voices talk of abuse, self-doubt, insecurities and my inadequacies</p> <p>Releasing distress as voices released strong emotions Experiencing discomfort and sometimes extreme distress</p> <p>Committing violence because of voices Feeling depression because of voices Changing lifestyle and thinking negatively because of voices</p> <p>Denying voices were real initially Fearing voices Feeling conflict, Experiencing panic attacks and physical ailments</p>	<p><i>Strong, powerful emotions being released through voices Which she could not release another way. feeling distress through this release of emotion (so emotion that causing distress, not the voices) Reflecting on how the voices express her internal world An awareness that she has been negatively affected by the voices despite the comfort they have also brought. Reflecting on how level of stress related to how well she could regulate emotions</i></p> <p><i>Feeling controlled by the voices; locating responsibility for negative moods and thinking in voices</i></p> <p><i>Conflict through denying voices were real. Is the fear of voices being real or not real, or is fear of the emotions? Denying reality of voices leading to internal conflict, terror and somatisation</i></p>
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<p>Then once I accepted the voices were real, my relationship changed. They completely took over- I felt like a puppet, they were completely in charge. I felt like a robot controlled by them.</p>	<p>Accepting voices were real Taken over by voices Feeling like a puppet or robot Feeling controlled by the voices</p>	<p><i>Losing her own will and identity when she accepted they were real. She stopped feeling in control and instead voices in control. Assumption that if they're real they must be powerful? Accepting reality of voices leading to experience of feeling controlled by the voices</i></p>
<p>Later I learned how to gain control by setting times when they could talk to me.</p>	<p>Learning to control voices by setting the times when they could talk to me</p>	<p><i>Gaining control over the voices by making boundaries and rules (taking agency here, what led her to be able to begin doing this; gap in the process here)</i></p>
<p>Explanation I believe my voices are suppressed emotions that are denied within myself. When this happens over prolonged periods they manifest themselves as having characteristics, my logical mind conjures up characters associated with these characteristics. Other people relate to these experiences, especially if they have experienced it personally, but, as yet, I have not met anyone who has accepted my explanation</p>	<p>Believing voices were suppressed emotions that are denied within myself Emotions manifest themselves as having characteristics Conjuring up characters associated with characteristics These characteristics becomes voices Developing an explanation Meeting no one who accepts her explanation</p>	<p><i>Observing the process she goes through in making sense of voices and her emotions. Making sense of voices as being a representation of her suppressed emotions.</i></p>
<p>Coping My coping strategies are to review my emotions daily; deal with my emotions through a series of explanations; to be mindful of what I'm feeling and why.</p>	<p>Developing coping strategies Reviewing my emotions daily Dealing with her emotions by explaining them Being mindful of what I am feeling and why</p>	<p><i>Coping by being in touch and connecting with her emotions (sense of increased integration through this process).</i></p>
<p>Most of all, to strive towards self-respect, self-</p>	<p>Striving towards self-respect and self worth</p>	

<p>worth and more importantly, self acceptance; to learn to acknowledge the good and bad inside myself and to bring change to the things which are negative-and learn to accept who I am.</p>	<p>Learning to acknowledge the good and bad inside myself Bringing change to things that are negative Learning to accept who I am</p>	<p><i>Developing self worth and self understanding, accepting good and bad, accepting herself</i></p> <p><i>Accepting all parts of herself as part of an integrated whole.</i></p>
<p>Mental health</p> <p>I have never been labelled as a typical voice hearer, nor have I been given the label of 'schizophrenic'. If I had I would never have accepted it as it is a label that has nothing to do with my experience. I was however, admitted to a psychiatric ward for 3 months through them being aware that I heard voices.</p>	<p>Recognising that not labelled schizophrenic Rejecting label of schizophrenia Becoming a patient in psychiatric hospital</p>	<p><i>Not making sense of voices through the label of schizophrenia which doesn't connect with her experiences.</i></p>
<p>I was diagnosed with another label: post natal depression. During my stay there it didn't feel like it was an environment where I could talk about my voices: voices were looked upon as delusional.</p>	<p>Receiving label of post-natal depression Keeping quiet about voices Identifying in hospital that voices would be considered delusional (not seem safe to talk about them?)</p>	<p><i>Recognising that voices were unacceptable and potentially stigmatising, even amongst professionals. (A sense of needing to keep quiet)</i></p>
<p>I received Chlorpromazine and an injection which once resulted in a locked jaw. Medication was eventually reduced and by the time of my discharge I was drug free and have remained so for some 13 years until the present day.</p>	<p>Receiving medication Experiencing side affects Reducing medication</p>	<p><i>Remaining drug free despite hearing voices.</i></p>
<p>I looked elsewhere because in my heart I</p>		

<p>knew the answer to finding out what the voices were lay elsewhere-not in the psychiatric system.</p> <p>The first time I came into contact with people who showed an interest in my voice hearing experience was the Hearing voices network in Manchester. The information they supplied was about advertising conferences, self-help group meetings and events within the network.</p> <p>I used the information by going along to the meetings and conferences and actually becoming an active member of the network.</p> <p>No one other than myself could help me recover from the problems I had with my voices. But there were people who helped support me; these were other voices hearers who shared their experiences with me during self-help meetings where I was the leader of the group.</p> <p>I was just providing the opportunity and allowing voice hearers to explore experiences, myself included. We created an atmosphere of well-being and healing. We could relate to each other through our experiences.</p>	<p>Finding out what voices were outside psychiatric system</p> <p>Coming into contact with people interested in voice hearing at hearing voices network Going to meetings and conferences Becoming an active member of the hearing voices network</p> <p>Becoming an active member of a group</p> <p>Needing to recover myself from problems with voices Feeling supported by other voice hearers Sharing experiences</p> <p>Enabling voice hearers to explore experiences</p> <p>Creating an atmosphere of well-being and healing Relating to other voice hearers through shared experiences</p>	<p><i>Looking to understand and make sense of her experiences outside the medical model (takes some confidence and independent reflection to do this)</i></p> <p><i>Connecting and sharing with people who understand which normalises experiences. (Sense of other people coming into her narrative).</i></p> <p><i>Developing an active and dynamic role with a sense of agency.</i></p> <p><i>Appreciating both her own agency and developing sharing relationships in the process of recovery.</i></p> <p><i>Creating safe, supportive and trusting relationships to nurture and heal together. Having something to offer to other people; increasing sense of agency and worth.</i></p> <p><i>Developing personal understandings between our voices and our life histories and ourselves to make meaning from experiences.</i></p>
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<p>Working together with other voice hearers I learnt a lot about my own voice hearing experiences. Out of that I compiled focusing/self-help techniques to help other voice hearers to explore their voices and to find their own individual experience and meaning.</p> <p>There was no set background theory' only our own experiences. As part of the process of looking within ourselves and our voices, we naturally develop an understanding between our voices and our life histories.</p> <p>And so it starts to make sense, the more we explore our voices the more we discover and start to understand.</p> <p>With this I used my own strengths, priorities (children) and positive capacities to recover from my problems with my voices. This process involved acceptance, change and the future.</p> <p>Acceptance I attended the self-group and became an active member of a voice hearer organisation I accepted my voices as real I stopped trying to get rid o them, but accepted them as personal</p>	<p>Working together with voice hearers helped learning about own voice hearing Compiling focusing/self-help techniques Helping other hearers explore their experiences Finding their own individual experience and meaning</p> <p>Looking within ourselves and our voices Developing an understanding between voices and life history</p> <p>Making sense Exploring voices Discovering and understanding</p> <p>Using my strengths, priorities and positive capacities to recover from problems with voices accepting</p> <p>attending the self-group and becoming an active member of a voice hearer organisation accepting my voices as real</p>	<p><i>Making connections between our histories and the heard voices to understand self.</i></p> <p><i>Utilising own strengths to move from position where voices are problematic, to a position where can both accept and consider change.</i></p> <p><i>Accepting voices as belonging to her and becoming more fully integrated.</i></p> <p><i>Taking ownership of her voices through relating voices to her own emotional and internal life.</i></p> <p><i>Reclaiming personal power through being able to acknowledge difficult experiences.</i></p>
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<p>I became conscious of my ownership of my voices I stopped looking for a cause outside myself I looked for a solution inside myself I explored what had happened in my life which might have a relationship with my voices I accepted those emotions which I did not like and could not easily master</p> <p>Change I stopped suppressing my emotions I am now able to reflect on my horrible experiences I am able to acknowledge having problems which lead to the voice hearing experience I have reclaimed my personal power I have created hope for the future</p> <p>Future I have found myself a job and loyal friends I relied on myself to change my life I learned to be proud of myself I proved myself in my job, with friends and with bringing up children alone I changed my attitude towards being abused. I stopped blaming myself, punishing myself and doubting my self worth.</p> <p>Self-help groups I have attended and led self-help groups</p>	<p>stopping looking for a cause outside myself looking for a solution inside myself exploring what had happened in my life which might have a relationship with my voices accepting those emotions which I did not like and could not easily master</p> <p>stopping suppressing my emotions reflecting on my horrible experiences acknowledging having problems which lead to the voice hearing experience reclaiming my personal power creating hope for the future reflecting on experiences that related to voice hearing finding myself a job and loyal friends relying on myself to change my life learning to be proud of myself proving myself in my job, with friends and with bringing up children alone changing my attitude towards being abused. stopping blaming myself, punishing myself and doubting my self worth.</p>	<p><i>Changing her relationship with herself and recognising she could take agency over her life.</i></p> <p><i>Changing relations with herself and other people so that she could speak freely, receiving validation of her experiences.</i></p> <p><i>Noticing her progress and acknowledging these gains.</i></p> <p><i>Talking about herself with compassion, not shame and accepting all parts of herself.</i></p>
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<p>The following aspects were helpful in my recover</p> <p>I had an opportunity to speak freely about my voices</p> <p>My experience was accepted as real and not only Negative</p> <p>I learned ideas and coping strategies It was a first step to coping better</p> <p>I became less isolated with my voices</p> <p>I no longer had to deny or keep quiet about my experiences</p> <p>I felt supported</p> <p>I came into a non-judgemental atmosphere</p> <p>I gained positive reinforcement from small gains that I made</p> <p>I learned about the relationship between my voices and what I had suffered in my earlier life</p> <p>I could cope better with my daily life</p> <p>I started a job again</p> <p>And most important, I found self-acceptance</p> <p>My life now</p> <p>I do still hear voices but I can cope with them now. My experiences with my voices are not always positive but now I understand what makes them negative so they don't have the power they once possessed. I am more self-confident.</p> <p>I don't have a partner or intimate friends but this is through choice as I just</p>	<p>attending and leading self-help groups</p> <p>speaking freely about my voices</p> <p>finding experience accepted as real and not only negative</p> <p>learning ideas and coping strategies</p> <p>becoming less isolated with my voices</p> <p>ending denial and silence about my experiences feeling supported coming into a non-judgemental atmosphere gaining positive reinforcement from small gains that I made learning about the relationship between my voices and what I had suffered in my earlier life coping better with my daily life</p> <p>starting a job again</p> <p>finding self-acceptance</p> <p>coming into non-judgemental environment where could speak freely about voices</p> <p>accepting oneself</p> <p>hearing voices still but coping with them now. understanding what makes them negative so they don't have the power they once possessed. being more self-confident.</p>	<p><i>Reducing power of voices by understanding what their negativity represents about the self.</i></p> <p><i>Choosing and controlling relationships to meet her needs and prioritising developing her relationship with herself.</i></p> <p><i>Developing hobbies and interests beyond hearing voices.</i></p> <p><i>Finding personal sense of security and safety helps her to feel more secure and safe.</i></p> <p><i>Having a sense purpose in life to feel fulfilled and validated.</i></p> <p><i>Developing the inner strength and personal stability to depend on herself rather than relying on professionals for support.</i></p>
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<p>want time to discover myself more.</p> <p>I have a job I enjoy: walking with the elderly as an activity organiser (for which I am paid monthly).</p> <p>I have lived in the same rented accommodation for the past 25 years. It is a lovely home with a beautiful garden. My finances could be better as I am not fully self-sufficient: I still receive a family income supplement.</p> <p>I do have hobbies: walking, DIY and gardening, so I keep quite busy. I have friends I can call on when needed, as they can on me. I do have purpose in life: to live each day to the full. I do not take medication.</p> <p>I am not dependent on others for interaction. I have not used mental health professionals or mental health services since 1993 when I was sectioned. The only involvement I have had is as a professional mental health trainer. I was an active member of the hearing voices group, as a self help group leader, mental health trainer and counsellor right up to 2006.</p> <p>I now just concentrate on living each day to the full and taking it as it comes.</p>	<p>Choosing not to have close relationships Spending time discovering self</p> <p>Having a job I enjoy</p> <p>Renting a lovely home Receiving family income supplement</p> <p>Having hobbies Keeping busy Having friends can call on if needed Being there for friends if needed Having a purpose Living each day to the full No longer taking medication Having a purpose and fulfilment</p> <p>Not involved with mental health services</p>	<p><i>Focusing on herself in the moment rather than planning ahead.</i></p> <p><i>Experiencing the oppressiveness of psychiatric service as more damaging and traumatising than the voices themselves.</i></p>
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<p>It hasn't taken me into mental health circles for the past several months and, as a result, I have felt much more positive.</p> <p>Hearing voices and mental health environments do not mix-you just become restricted. Speaking on a personal level, I feel mental health environments are much more distressing and destructive than any voice hearing experience.</p> <p>But one never knows where life will take one. I feel I have been on a remarkable journey of self-discovery with my voices-an ongoing journey.</p>	<p>Concentrating on living each day to the full Taking it as it comes</p> <p>Finding being in a mental health environment more distressing than voice hearing experience Being on an ongoing journey of self-discovery</p>	<p><i>Sharing the journey with her voices to discover, understand and progress together in a sense of partnership.</i></p>
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University of the
West of England

Participant Information Sheet

The role of empowerment in recovery from severe psychological distress; a grounded theory exploration.

You are being invited to take part in a research study. This information leaflet is designed to advise you about what participation would involve. This is to help you decide whether you would like to take part. Please read it carefully and write down any questions you have or any further information you would like. You may also wish to discuss this with other people before coming to a decision.

Who are the researchers?

I am Kate Fenton, a trainee counselling psychologist completing my 5th and final year on the Professional Doctorate in Counselling Psychology at the University of the West of England. I am completing this research project as part of my training. I am also employed as an assistant psychologist and as a therapist at Maples Community Care. My research project is supervised by Andrea Halewood, a Senior Lecturer in the Department of Psychology and Wayne Gardner, a Senior Lecturer in Health and Social Science.

What is the research about?

This research is to explore the process of recovery for people who have experienced severe psychological distress. I want to find out what people have found helpful and unhelpful in managing their distress during this time and what has been empowering (increasing the amount of power that people feel they have over their life) or disempowering (decreasing the amount of power that people feel they have). This is important because research suggests that severe psychological distress can affect how independent and in control over life events people feel they are able to be. Further research is necessary to help understand what change is needed to encourage people to regain control. This research will be based on the opinions and views of people who are personally aware of the impact of this experience.

Why am I being contacted?

To understand more about this, I want to talk with people who have experienced severe psychological distress about what has helped them feel more or less in control. We would also talk about which areas of life people have felt more able to make choices about or felt less able to make choices about. A staff member has

suggested that you may be able to help with this research and I am contacting you to tell you more about the study and to ask whether you may be interested in talking with me.

Who can participate?

Adults can participate who have experienced hearing voices, or seeing hallucinations, or who sometimes experience ideas and beliefs about reality that are very different from those of other people, and who have found these experiences upsetting. Some people have these experiences and do not find them especially disturbing. To take part in this research, these experiences must have caused psychological distress. People can also take part who experience extreme mood swings from feeling very elated, to very low in mood. Again, this needs to be something that causes some distress. It is important that people who take part in this research are currently feeling stable, have access to professional and personal support, and are able to give informed consent.

What does participation involve?

I would like to talk to you about your own experiences. Our conversation will last for about an hour but you can end the interview at any time should you wish to. I will need to record your interview so that I can listen to our conversation again and to make sure that I do not forget important things that you say. If there are any questions that you do not want to answer, that is absolutely fine. Whatever you have to contribute will be interesting and helpful and there are no answers that are right or wrong. I may ask if I can speak with you at a later date to check that I have understood your experiences fully after looking through my interview notes, but you can let me know if you would not like me to do this. Similarly if you would like to contact me after the interview if any additional ideas arise as a result of the interview then that would be very helpful.

If you are interested we can meet again near the end of the research to talk about the findings. This is if you wish to be more involved and there is no expectation that you should do this.

How will information be used?

All information will be made anonymous which means that anything that could identify you will be removed from my research study, both in written form and in any presentations I may give about the results of my study. As part of my report, I may need to include extracts from our conversation but again any identifying material will be excluded to maintain confidentiality and to protect your identity and that of others. Your personal information will be stored separately from the interview material to protect your identity. All information will be locked in a secure place. However, if information is disclosed that reveals that you or other people may be at risk from abuse or harm, this may need to be passed on to relevant professionals. This would be discussed with you before any agency was contacted.

Do I have to take part in this research?

No, it is up to you if you want to take part and you may want to talk to someone about it before you make a decision. If you decide to participate but then change your mind, you can withdraw at any time without giving a reason. You may withdraw during the interview itself if you change your mind about taking part. If you decide you would like to withdraw after completing the interview, please contact me and all your data will be removed from the study. However, once the research has been submitted it will not be possible to withdraw your data. I would like to emphasise again that all information will be confidential and all participation in the research is voluntary.

Are there any risks or disadvantages involved in taking part?

Yes. Participation in research of this kind can raise difficult or uncomfortable issues as you discuss your experiences. You may find it upsetting to talk about your experiences or it might make you feel annoyed or angry to think about some situations you have been through. If you do feel upset during the interview, we can take a break, miss out certain questions if they are particularly distressing, or we can stop the interview altogether if you wish. In addition you may find yourself feeling distressed after the interview due to discussing these issues. For this reason it is really important that you consider whether you are feeling vulnerable at present, and whether you have sufficient support around you to help you cope with thinking about difficult experiences.

The interview can take place on two different dates if that feels more manageable for you. Support staff will be aware that you have spoken with me and are happy to talk with you about any concerns following the interview, if you feel that you need further support. You may also contact my supervisor or myself about any concerns you may have about the study either prior to your interview or following it. I will provide numbers of relevant helplines in case these may be helpful. I would recommend that you inform your GP or health professional that you are taking part in this research, but again, this decision is up to you.

What are the benefits of taking part?

While there are no immediate benefits to you in taking part in this study you may find reflecting on your experience helpful. You will also be contributing to an under researched area which will be of benefit to others. Research has the potential to change services and the way that professionals work with people and the findings will have implications for the practice within mental health services. It will also improve understanding of what factors encourage relationships to have a positive impact for people.

What should I do if I have a complaint?

If you have any issues or complaints around any aspect of this research you can contact my supervisor and director of studies, Andrea Halewood, whose details are listed below.

You may also contact Tony Ward who is the programme leader for the doctorate in counselling psychology at University of the West of England, Department of Psychology, Faculty of Health and Applied Sciences, Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY. He can be contacted on telephone number 0117 3283109. His email address is tony.ward@uwe.ac.uk

Tony Ward is not involved in this research and is an independent contact.

What should I do now?

If you wish to take part in this research, please contact the staff member who has informed you about my research and I can arrange a time that is convenient for us to meet at the Maples resource centre.

If you have any questions about the research please feel free to contact my research supervisor whose details are;

Andrea Halewood, Department of Psychology, Faculty of Health and Applied Sciences, Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY. She can be contacted by email on andrea.halewood@uwe.ac.uk. Andrea's telephone number is 0117 3283889.

You can contact me on my work telephone number which is 0117 9085000 or you can email me at kate2.fenton@live.uwe.ac.uk

Thank you for taking the time to read this and for considering taking part in my research.

This research has been approved by the Research Ethics Service, National Institute for Social Care and Health Research Academic Health Science and the University of the West of England.



University of the
West of England

CONSENT FORM

The role of empowerment in recovery from severe psychological distress: a grounded theory exploration.

The researcher is Kate Fenton, Trainee Counselling Psychologist, based at Department of Psychology, Faculty of Health and Applied Sciences, Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY. Contact details are

kate2.fenton@live.uwe.ac.uk

Please initial box

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

2. I understand that my participation is voluntary and that I am free to withdraw, without giving reason.

3. I agree to take part in the above study.

Please tick box

Yes

No

4. I agree to the interview consultation being audio recorded

5. I agree to the use of anonymised quotes in publications

I am aware that the information I am providing will be treated as confidential. However, if I disclose information that reveals that myself or other people may be at risk from abuse or harm, I understand that this may need to be passed on to relevant professionals. This would be discussed with me first.

Name of participant

Date

Signed

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Name of researcher

Date

Signed

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This research has been approved by the Research Ethics Service, National Institute for Social Care and Health Research Academic Health Science

Demographic Information

Are you male or female or transgender

Are you aged between 18 and 30 years

Are you aged between 30 and 45 years

Are you aged between 45 and 60 years

Are you are between 60 and 75 years

Are you above 75 years

The role of empowerment in recovery from severe psychological distress: a grounded theory exploration.

Participant Debrief sheet

Thank you for taking part in this research. It has been very valuable talking with you.

I hope that this has been a positive experience for you. However, if any of the areas we have discussed have been distressing or have raised difficult issues, support staff at Maples Community Care are happy to talk with you about these. If you need to contact me to discuss any issues arising from the research my email address is kate2.fenton@uwe.live.ac.uk

I have included contact details for relevant helplines below in case these may be helpful for you.

Helpline details

Rethink Mental Illness

Support and advice for people living with mental illness.

Phone: 0300 5000 927 (Mon-Fri, 10am-2pm), Website: www.rethink.org

Depression Alliance

Charity for sufferers of depression. Has a network of self-help groups.

Website: www.depressionalliance.org

CALM

CALM is the Campaign Against Living Miserably, for men aged 15-35.

Phone: 0800585858 (daily 5pm-midnight).

Website: www.thecalmzone.net

Bipolar UK

A charity helping people living with manic depression or bipolar disorder. Website: www.bipolaruk.org.uk

Samaritans

Confidential support for people experiencing feelings of distress 24 hours a day National Helpline: 08457 909 090 Local helpline: 0117 983 1000

Textphone: 07725 90 90 90

Sane

national out of hours mental health helpline offering specialist emotional support and information to anyone affected by mental illness.

Phone: 0845 767 8000 (daily, 6pm-11pm). SANEmail email: sanemail@org.uk

Website: www.sane.org.uk

Mind

Promotes the views and needs of people with mental health problems.

Mind information line

For information on mental health

Phone: 0300 123 3393 (Mon-Fri, 9am-6pm, except bank holidays). Website: www.mind.org.uk

Mindline Helpline

A free confidential helpline giving a safe place to talk if you or someone you know is in distress.

Phone: 0808 808 0330 (8pm-midnight, Weds to Sun).

Bristol Mind:

for local information about mental health

Admin team: 0117 980 0370 (9am-5.30 Mon, Weds and Thurs. 9am-4pm Tues).

Cruse Bereavement Care

Emotional support to anyone affected by a bereavement.

Phone: 0844 477 9400 (Mon-Fri, 9am-5pm, except bank holidays. Extended hours on Tues, Weds and Thurs when open until 8 pm).

Website: www.crusebereavementcare.org.uk

Rape Crisis

Phone: 0808 802 9999 (daily, 12pm-2.30pm, 7pm-9.30pm).

Website: www.rapecrisis.org.uk

Victim Support

Phone: 0845 30 30 900 (Mon-Fri, 8am-8pm. Weekends, 9am-7pm, bank holidays 9am-5pm).

Website: www.victimsupport.org

Beat

Provides helpline and online support and a network of UK wide self-help groups to help people beat eating disorders

Phone: 0845 634 1414 (Mon-Fri, 1.30pm-4.30pm and Mon and Weds evenings 5.30pm-8.30pm).

Website: www.b-eat.co.uk

OCD (Obsessive Compulsive Disorder) Action

Support for people with obsessive compulsive disorder. Includes information on treatment and online resources.

Phone: 0845 390 6232 (Mon-Fri, 9.30am-5pm)

Website: www.ocdaction.org.uk

OCD UK

A charity run by people with OCD, for people with OCD. Includes facts, news and treatments.

Phone: 0845 120 3778 (Mon-Fri, 9am-5pm)

Email: support@ocduk.org

No Panic

Voluntary charity offering support for sufferers of panic attacks and OCD. Offers a course to help overcome your phobia/OCD. Includes a helpline.

Phone: 0800 138 8889 (daily, 10am-10pm)

Anxiety UK

Charity providing support if you've been diagnosed with an anxiety condition.

Phone: 08444 775 774 (Mon-Fri, 9.30am-5.30pm)

Website: www.anxietyuk.org.uk

Relate

Relationship Counselling, open to everyone aged over 16.

National helpline; 0300 100 1234

Local Helpline: 0117 942 8444

www.relate.org.uk

Family Lives

Provides information, guidance and support on any aspect of family life.

Phone: 0808 800 2222 (daily, 7am-midnight)

Website: www.familylives.org.uk

British Association of Counselling and psychotherapy (BACP)

List of approved counsellors

General enquiries: 01455 883300 (8.45am-5pm Monday to Friday)

www.bacp.co.uk

Womankind

Provides women with free or affordable counselling, psychotherapy or ongoing support.

Helpline: 0845 458 2914 or 0117 916 6461 Mon-Fri 10am-12pm, Tues and Weds afternoon 1pm-3pm and Mon and Tues evening 8pm-10pm.

Address: Bristol Women's Therapy Centre, 3rd Floor, Brunswick Court, Brunswick Square, Bristol, BS2 8PE

Email: info@womankindbristol.org.uk

www.womankindbristol.org.uk

Talking Money (formerly Bristol Debt Advice Centre)

Advice, support and information about finance

Helpline: 0117 954 3990 (Mon, Tues, Thurs and Fri, 9.30am-5pm, Weds 1pm-5pm).

Office at, 1 Hide Market, West Street, St. Philips, Bristol, BS2 0BH (open for general enquiries).

Bristol Drugs Project

For accurate information about drugs and alcohol

Phone: 0117 987 6000 or visit 11 Brunswick Square, Bristol, BS2 8PE

Opening times for both services: Monday - Friday 9am to 8pm / Saturday 10am to 5pm

Email: roads@bdp.org.uk

www.bdp.org.uk

Once again many thanks for your kind help

Kate Fenton

This research has been approved by the Research Ethics Service, National Institute for Social Care and Health Research Academic Health Science