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**Service users' experiences of the treatment decision making process in psychosis: a phenomenological analysis.**

Running head: Treatment decision-making in psychosis

Diana Stovell<sup>1</sup>  
Alison Wearden<sup>2</sup>  
Anthony P. Morrison<sup>1</sup>  
Paul Hutton<sup>3</sup>

<sup>1</sup>Division of Clinical Psychology, School of Psychological Sciences, University of Manchester

<sup>2</sup>Manchester Centre for Health Psychology, School of Psychological Sciences, University of Manchester

<sup>3</sup>Department of Clinical and Health Psychology, School of Health in Social Science, University of Edinburgh

*Corresponding author*

Dr Paul Hutton

Department of Clinical and Health Psychology

School of Health in Social Science

University of Edinburgh

Doorway 6, Medical Building

Teviot Place

Edinburgh, UK

EH8 9AG.

Email: [paul.hutton.cf@ed.ac.uk](mailto:paul.hutton.cf@ed.ac.uk)

Phone: +44 (0)131 651 3953

*Declaration of interest*

A.P.M. is a member of two National Institute for Health and Clinical Excellence guideline development groups: Psychosis and Schizophrenia in Children and Young People, and Psychosis and Schizophrenia in Adults (partial update). The other authors report no conflicts of interest.

*Author contributions*

DS conceived of and designed the study, carried out data collection and performed the analysis. AW, APM and PH contributed to conception and study design, project management and data analysis. All authors contributed to writing the final draft of the manuscript.

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*Ethics committee approval*

This study received approval from the North West UK NHS Research Ethics Committee.

## **Abstract**

### **Objectives**

We aimed to explore the treatment decision-making experiences of individuals with psychosis, and their implications for increasing service users' autonomy through clinical practice and research.

### **Design**

A qualitative design was used to explore in depth service users' experiences of treatment decision-making.

### **Method**

People with non-affective psychosis took part in semi-structured interviews that sought to elicit rich descriptions of their subjective experiences of treatment decision-making encounters. These were analysed using Interpretative Phenomenological Analysis (IPA).

### **Results**

The interviews of seven service-users with multiple experiences of treatment for psychosis were analysed. Four themes emerged around influences on treatment decision-making: (1) a need to feel listened to; (2) psychotic experiences, treatment and stigma; (3) communication and support; (4) differing conceptions of recovery. There was an over-arching theme of empowerment.

### **Conclusions**

Influences on participants' empowerment emerged at multiple levels, from their sense of self-worth to prevailing social constructions around psychosis. Service users' participation in decision-making about treatment for psychosis might be enhanced where clinicians are able to pay close attention to disempowering aspects of their experience. The development of more comprehensive models of decisional capacity may support this endeavour.

## Introduction

Where service users with mental health problems are judged to lack treatment decision-making capacity, there is support in law (Mental Capacity Act 2005: Code of Practice, 2007), and agreement in the literature (Dawson, 2015; Richardson, 2012) that everything possible should be done to support them to make their own decisions about treatment. For people with psychosis, the development of necessary strategies to support and restore decisional capacity will require a much better understanding of the factors which help or hinder it. We also need to consider whether our existing conceptualisations of decisional capacity are satisfactory. The accepted view that capacity denotes a preserved ability to appreciate, weigh up, remember and communicate decision-relevant information has been criticised for being overly cognitive in focus (Breden & Vollmann, 2004; Tan, Hope, Stewart, & Fitzpatrick, 2006), with relative neglect of the potential contribution of emotions, values, situational context and relationships to autonomous decision-making (McDaid & Delaney, 2011; Series, 2015; Tan et al., 2006). Repeated compulsory admissions for people with psychosis have been linked to a wide range of systemic influences (Loft & Lavender, 2015), which might also suggest the need of broader models of decisional capacity.

Research into the meaning and determinants of capacity, in the context of psychosis, however, is limited. Correlates of reduced capacity with schizophrenia have been identified, which include positive and negative symptoms, medication non-adherence or refusal and poor 'insight' (Candia & Barba, 2011; Okai et al., 2007). Group metacognitive training has recently been found to improve cognitive processing of treatment-related information (Naughton et al., 2012), though individuals' appreciation of the personal impacts of treatment decisions remained unchanged. The wider psychosis and recovery literature, meanwhile, has identified a broad range of influences on how individuals make sense of the world, such as systematic cognitive biases (Broome et al., 2007); emotional distress; experiences of current and past social adversity (e.g. Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001); and personal meanings of recovery (e.g. Pitt, Kilbride, Nothard, Welford, & Morrison, 2007). This and the literature calling for more comprehensive models of capacity (e.g. Breden & Vollmann, 2004), suggest that close examination of people's experiences of treatment decision-making with psychosis may be needed to understand the factors involved. Careful qualitative analysis of such experiences may have implications for the development of conceptualisations of capacity with psychosis, and associated interventions to improve it.

## Method

Ethical approval was obtained from the UK National Research and Ethics Service (13/NW/0244).

### *Design*

Interpretative Phenomenological Analysis (IPA), a qualitative method that uses in-depth, semi-structured interviews, was used to explore service users' experience of decision-making around treatment for psychosis. IPA seeks a detailed 'insider perspective' on the phenomenon of interest (Conrad, 1987), recognising the contribution of cognition, affect and the social context to individuals' sense-making (Smith, Flowers, & Larkin, 2009). The researcher's interpretative

perspective is acknowledged (Smith et al., 2009), here, influenced by critical social psychology, clinical psychology and work in recovery-oriented clinical services.

### *Recruitment and Participants*

In keeping with IPA methodology, a small homogenous sample was sought (Smith et al., 2009). Participants had to be 18-65 years old, have experience of treatment for a schizophrenia-spectrum condition and the ability to talk about this in depth. Those with a moderate to severe learning disability, currently in crisis, receiving in-patient care, experiencing psychosis that was primarily organic in origin or substance-induced or currently lacking capacity to consent to take part in research, were excluded. Participants were recruited through care coordinator referrals from Community Mental Health Teams (CMHTs) and Early Intervention in Psychosis Teams (EIPs), and self-referrals from voluntary mental health organisations. Each participant gave written, informed consent and received £10 to cover expenses.

### *Procedure*

Interviews took place at home or on NHS premises, and lasted one to two hours. The interview schedule was developed in consultation with experienced researchers, the IPA literature (Smith et al., 2009) and a service-user focus group. It consisted of open-ended questions about participants' experience of treatment decision-making situations (see supplementary material). It included questions about their feelings; sense-making; coping; influence of symptoms; helpful and unhelpful aspects of experience; and sense of self and others. The interview schedule was used flexibly so as to honour participants' particular experiences. Interviews were recorded and transcribed verbatim. The first author kept a reflective diary throughout the research process.

### *Analysis*

In keeping with IPA methodology (Smith et al., 2009), the first researcher listened to each participant's interview and read the transcript a number of times, noting features of seeming significance. Emergent themes were then iteratively grouped and re-grouped, and ultimately organised in a table under theme and sub-theme headings, alongside illustrative files of transcript excerpts. The second researcher periodically provided feedback on the emerging analysis and, later in process, the theme structure was discussed at two meetings of the research team, with consensus being reached through discussion. The first researcher returned, at intervals, to complete readings of the transcripts to check that the work remained grounded in participants' experience. Decision-making and analytic procedures were recorded throughout.

## **Results**

Eleven individuals with experience of treatment for psychosis were interviewed and seven interviews were analysed. Three participants were unable to provide in-depth reflections on their experiences, respectively due to minimal experience of treatment for psychosis, severely blunted affect or extreme tangentiality; their interviews were excluded from the analysis (see limitations). One participant's interview was excluded due to insufficient clarity of speech for transcription. Included in the analysis were four males and three females (mean age 49; range 38-58). Six were involved with a CMHT and one was receiving only out-patient psychiatric care. None was in paid employment, all but one were single and all were white-British. Five had experienced hospitalisation with psychosis. (Table 1) Figure 1 summarises the four themes and sub-themes, under the overarching theme of empowerment.

*Key for quotations:* / denotes a second-long pause; underlining denotes emphasis.

*Theme 1: A need to feel listened to*

Nearly all participants described experiences of disempowerment arising from feeling that they had not been listened to during treatment decision-making.

*Sub-theme 1.1: Importance of listening with respect, compassion and empathy.*

Participants' experiences of disempowerment included feeling that professionals weren't listening, didn't believe them, didn't take their distress seriously and lacked compassion:

*I think he [psychiatrist] saw me as nothing, like a, like a / like I was just saying it // saying that like when I see things and he was like trying to make it out as if I wasn't really... (Participant 8)*

*...they were just making decisions. // There were no warmness...there were just no emotion... it was stressful you know, very stressful...sometimes I just felt like a // like an effigy, you know in the corner... (Participant 1)*

A number of participants noted the positive contrast when they did feel heard:

*...what a difference, what a difference. He used to consult about me medication...ask me how I'd found it, and he, he seemed as though he genuinely cared and was interested.... (Participant 10)*

Respect and seeking a 'human connection' were seen as fundamentally important, with some participants valuing continuity in their relationships with clinicians.

*Sub-theme 1.2: Disempowerment by system and process.*

A number of participants described experiencing the treatment system as disempowering and de-humanising. They recounted feeling 'insignificant', 'like being in a lost parcel department', like 'some alien patient in the corner' and 'an outcast' (respectively, Participants 1, 6 and 4):

*...sent pillar to post, you know like that was going here, trying to get help there and they were sending me back there and he wasn't listening to me and then I was sent to somewhere, and I, I thought, I don't know what, what's going on. (Participant 8)*

*Sub-theme 1.4: Feelings related to power*

Most participants described having experienced feelings of disempowerment within treatment decision-making situations. The most notable examples were in descriptions of tribunals, being turned away from services when feeling suicidal or being sectioned, as exemplified by Participant 7:

*Erm, so, I coped in the hospital with feeling of /// being sort of like, bashed over the head and told I'm hopeless at living life, that's how it felt, and I withdrew, and I became numb. (Participant 7)*

Conversely, feelings of empowerment were more often related to recovery-oriented decisions, as when Participant 1 achieved a qualification in English:

*...they give me an opportunity..., it's all part of the care, you know... they made a decision... I felt elated...like, you know, screaming me head off and jump in streets..(Participant 1).*

*Theme 2: Psychotic experiences, treatment and stigma.*

Experiences of psychosis seemingly affected treatment decision-making situations for participants both directly, via symptoms and medication; and indirectly, with influence of past treatment experiences, negative beliefs about psychosis, low self-worth and perceptions of being negatively judged by others.

*Sub-theme 2.1: Reduction in agency and self-efficacy with distressing psychosis.*

Psychotic experiences eroded participants' agency and self-efficacy in treatment decision-making directly, through the severity of their distress, undermining influence of hallucinations and feeling physically unwell. Participant 8's hallucinatory experience seemed to exacerbate, for her, a pervasive sense of invalidation:

*...he [auditory hallucination] used to say, he [psychiatrist] don't believe you...I was getting upset about it, 'cos I thought, is this really happening and no one believes me... (Participant 8)*

Elsewhere, the effects of medication appeared paradoxically to compromise individuals' capacity to influence further treatment decisions:

*But it can tranquilise you too much. And, // that made me feel vulnerable because I was heavily tranquilised...(Participant 7)*

*Sub-theme 2.2: Influence of treatment-related experiences and beliefs.*

Participants' approaches to treatment decision-making were influenced by their past experiences of, and beliefs about, treatment. These included aversive, even traumatic treatment experiences; beliefs about the nature of symptoms and the appropriateness of treatment; and experience of limited treatment options. Participant 6 reflected on the effects of treatment-related trauma:

*...after me, the, the mistreatment...I thought that trust had gone forever... I need to trust those people again, and if I don't, I'm allowing what happened...to influence my .. the rest of my life, you know, treatment I'm receiving. (Participant 6)*

*Sub-theme 2.3: Power of negative constructions of mental illness.*

Participants articulated many 'taken-for-granted' meanings or social constructions around psychosis. They made associations between psychosis and being 'not normal', a 'basket case', a 'nutter' and 'a danger' (Participants 4, 10 and 7). These sometimes reduced their confidence to raise concerns about their treatment. The disempowering effects of social constructions seemed more insidious, however, where they appeared to be 'taken-for-granted', going unnoticed and unchallenged. Participant 10, for example, was surprised that her psychiatrist

treated her with the respect he would afford anybody else. This suggested that she might not expect to be involved in collaborative decision-making.

*I think he thought I wasn't a basket case and I did have some sort of intelligence... and erm, we just conversed, er, like you know with someone you meet on the street. (Participant 10)*

*Sub-theme 2.4: Stigma, shame and low self-worth.*

The effects of self-stigma and low self-worth on treatment decision-making were more immediately apparent for some. For Participant 8, it had very clear impacts on her low level of assertiveness in pursuing the treatment she needed.

*...I don't want to be a burden, I don't want to be where they've got to come and they don't really want to talk to me. And then I just say, oh leave it then, and I just have to cope with it meself. (Participant 8)*

Psychosis-related shame was much slower to emerge for Participant 1, however. He was reluctant to discuss a decision to seek treatment, seeing this as reinforcing a shaming illness identity that was undermining of his recovery. For Participants 4 and 10, an apparent desire to feel socially accepted by professionals, seemed to reduce their capacities to assert their needs. Both revealed unmet needs late in their interviews, which they had expressed only tentatively or not at all in clinical encounters, such as Participant 4's wish to discuss psychotherapy:

*R: You've mentioned a few times about not being offered psychotherapy...and that sounds like it's quite important to you...*

*P: Well, you see the thing is, I've mentioned it a few times, not like banged on any doors, but I've mentioned, it's never been offered, it's never really been discussed... (Participant 4)*

*Sub-theme 2.5: Feeling negatively judged by others.*

Some participants described feeling negatively judged by professionals, in relation to their actions, choices and treatment decision-making capabilities. 'Normal' choices appeared to be pathologised, and this adversely affected some participants' confidence and feelings towards clinicians during treatment decision-making. Of note was Participant 7's implied suggestion that decisional incompetence might be assumed in the context of psychosis:

*I think on first meeting someone, erm, a more thorough investigation should be done into what their belief system is and whether or not they // they are coherent. I was coherent, I was just, erm, psychotic at the same time as well. (Participant 7)*

*Theme 3: Communication and support*

Participants described experiences of disempowerment in treatment decision-making where they had not felt adequately informed or supported, or had had difficulty communicating their needs within the context of unequal power dynamics.

*Sub-theme 3.1: Power dynamics, from the implicit to the coercive.*

Participants expressed variously the view that psychiatrists hold immutable power, have authority over their patients, are of higher status and are the main drivers of treatment decision-making. Participant 1 said, for example:

*...that's the decision they make. You can't influence 'em, or else, there'd be corruption wouldn't there? (Participant 1)*

These dynamics surfaced implicitly in participants' use of language. Participant 4's tentative tone, for example, suggested that he might feel any input he had in decision-making to be a concession.

*I go and see Dr [psychiatrist]...and they're nice with me...almost with a bit of like, you know, like you've got a bit of input if necessary...So you've got almost like some sort of influence.... (Participant 4)*

Elsewhere, however, these dynamics were described explicitly. There was mention variously of 'that barrier with the doctor'; being 'palmed off'; being 'overridden'; being 'completely at your [psychiatrists'] mercy'; being 'dictated to'; and that 'doctors are supposed to know best' (respectively, Participants 1, 8, 7, 6, 4 and 5). Three participants also described experiences of coercion:

*...it was either [participant's name] you've got three days, it's either an injection or you take your medication, so I took it... (Participant 7)*

#### *Sub-theme 3.2: Power dynamics in sharing and use of knowledge.*

Participants experienced disempowerment through the ways that knowledge was shared and regarded. They felt excluded from the content of multi-disciplinary discussions about them; the rationale for decisions; and information about psychosis, medication and other treatment options. Disempowering influences included the protocol of formal treatment decision-making situations, invalidation of participants' concerns about treatment, and the assumption of the primacy of doctors' knowledge over participants' expertise about themselves. Participants' fear and agitation, unquestioning trust in professionals and apparent taken-for-granted acceptance of not being fully informed about treatment seemingly posed further barriers to accessing information:

*I didn't understand what he was telling me ...I thought, I don't know what you're talking about, but I felt frightened to say. (Participant 8)*

#### *Sub-theme 3.3: Importance of self-representation.*

Being able to communicate their needs to clinicians during treatment decision-making was very important to most participants, but also frequently challenging because of psychosis-related distress, effects of medication and difficulties with assertiveness or self-expression.

Two participants spoke of being turned away from services repeatedly when in crisis. The impact of this was particularly serious for Participant 6:

*Well, you're pretty much at a loss really/// I tried to commit suicide... (Participant 6)*

There was a notable contrast where Participant 10 felt her clinician to be very much attuned to her needs:

*...whatever I needed, if (CPN) thought it was good for me, he will make sure I got whatever I needed. (Participant 10)*

#### *Theme 4: Differing conceptions of recovery*

Participants seemed to vary in their degree of recovery orientation, that is, in how far they sought autonomy, considered a range of influences on their well-being, prioritised their values and goals and maintained a hopeful outlook.

##### *Sub-theme 4.1: Seeking autonomy.*

All participants expressed preferences for at least some level of autonomy in their treatment. Where they varied greatly was in their approach to, and effectiveness in, bringing this about. Participant 1 exercised autonomy in pursuit of recovery-oriented life goals but had had no say in his medical treatment over a long service-use history. Participants 4 and 8, meanwhile, were constrained in their pursuit of recovery-oriented interventions by low levels of assertiveness and support. Participant 10 uniquely described valuing autonomy within the medical system, whilst showing little interest in pursuit of recovery-oriented life goals. It seemed as if respect for participants' preferences for managing their well-being, was crucial to empowerment within treatment decision-making, as suggested by Participant 7:

*I prefer independence and, taking some form of action to resolve and feel comfortable with me, within myself, and // all of that was ignored. (Participant 7)*

##### *Sub-theme 4.2: Relationship to the medical model*

A key influence on participants' feelings of empowerment appeared to be their relationship to the medical model. Participant 7 had a like-minded psychiatrist who supported her choice of non-medical ways of coping.

*... I think my psychiatrist understands that I'd rather struggle and try and work out me emotions that are distressing...rather than, erm, saying, it's like I can solve that problem with a magic pill. (Participant 7)*

Participants 8 and 10, at times, concurred with their psychiatrists in viewing medication as an appropriate default option for managing distress. Whilst Participant 10 found security in the medical framework, Participant 8 did so in the absence of desired support with alternative treatment options. The medical model seemed generally to prevail unless participants exercised considerable personal resources to resist, and here lay potential for frustration and hopelessness:

*...what can you achieve with an half hour chat with somebody who's like really medically qualified?...It's handy to have that safety net, but in terms of actually making you better // it isn't really is it? (Participant 4)*

##### *Sub-theme 4.3: Seeking treatment congruent with values and goals*

All participants spoke about their values and goals in relation to treatment decision-making. Here again, clinicians' regard for these preferences seemed to affect participants' feelings of

empowerment. Some participants felt their values were completely overridden, particularly in in-patient settings. In contrast, Participant 1 described a sense of considerable empowerment through being supported by services to realise his goals:

*I passed me English language...it's best thing I'd ever done...for the staff to let me // express meself and for them to put faith in me to go to college...it's that freedom again.... (Participant 1)*

*Sub-theme 4.4: Hope, an influence and an outcome in treatment decision-making*

*...when you're crumbling //...you don't need to receive the message that it's always going to be the status quo, where you are now...everybody's got the ability to get better, really, and it would be nice to be told that... (Participant 7)*

All participants felt hopeless, at times, in relation to treatment decision-making, due variously to highly restrictive decisions made entirely by others, negative messages imparted by clinicians (as above), limited intervention options and persistently being offered treatment that was antithetical to the participant's understanding of their experience. Participants varied in the degree to which they were able to overcome feelings of hopelessness. Participant 6 noted how hopelessness, induced by traumatic treatment experiences, was an influence on subsequent encounters with clinicians. Conversely, more positive clinical encounters induced hope in Participant 4 that recovery was possible:

*... nowadays, /...even with like diagnosis like I've got, psychosis, you know, you're treated more like...a person... that underneath it is sort of normal, and will maybe one day recover...(Participant 4)*

Sadly, however, he also described this hope as being thwarted by limited intervention options. Hope seemed therefore crucial, yet vulnerable to a host of influences within treatment decision-making.

## **Discussion**

Several authors have argued that existing conceptualisations of treatment decision-making capacity are overly cognitive in their focus, and neglect the role of emotions, values, lived experience, and context (Breden & Vollmann, 2004; McDaid & Delaney, 2011; Series, 2015; Tan et al., 2006). Our phenomenological analysis of treatment decision-making, as experienced by people with psychosis, is consistent with this view. It adds to the findings of previous studies, however, by highlighting the importance of issues of power. We suggest that the concept of treatment decisional capacity in psychosis needs to be extended even beyond the social model advocated by McDaid and Delaney (2011), to encompass the power dynamics operating within the social context of treatment decision-making situations.

Multi-dimensional conceptualisations of empowerment, which take into consideration intrapsychic, interpersonal and socio-political factors, could inform how we define capacity [e.g., (Rogers, Chamberlin, Ellison, & Crean, 1997; Segal, Silverman, & Temkin, 1995)]. Participants in our study appeared to experience disempowerment in treatment decision-making related to all three levels, reflected respectively in signs of a sense of low self-worth and self-efficacy; feeling not listened to; and with influence of unequal power dynamics and

negative social constructions of psychosis. Our findings suggest, as have others' [e.g., (Hui & Stickley, 2007)], that effects of policy initiatives [e.g., (Department of Health, 2012)] to empower patients in treatment decision-making are frequently not reflected in the experience of service users with psychosis. Contributory factors to this may be the disempowering use of language (Hui & Stickley, 2007) and the sometimes conflicting models of mental health problems espoused by service users and professionals (Colombo, Bendelow, Fulford, & Williams, 2003), both operating at implicit levels.

Dominance of the medical model appeared to be disempowering where those inclined towards a recovery orientation were unsupported by clinicians, and struggled to pursue their recovery goals unaided. These findings accord with those of Colombo et al. (2003) who found that service users experienced disempowerment where they did not endorse the medical model of mental health problems, generally found to be espoused by psychiatrists, and struggled to challenge its assumptions.

#### *Clinical and research implications*

Increased awareness of the often implicit, unequal power dynamics within which treatment decision-making takes place would seem to be crucial to ameliorating factors that might undermine service users' potential for participation. These dynamics may account for reduced capacities in well-intentioned clinicians to listen carefully, with compassion and respect to patients and their narratives; and in patients to engage with trust and assertiveness in interactions wherein their values, goals, needs and wishes might be attended to. Clinicians might start to challenge these hitherto implicit or 'taken-for-granted' power dynamics by being particularly attentive to service users' values in relation to recovery. Sensitivity to aspects of individuals' experience that might undermine their potential for participation, such as emotional distress, negative treatment decision-making experiences and beliefs, self-stigma and low self-worth, is also needed. Service users have reported that such responsiveness is, of itself, a source of empowerment and an aid to recovery (Grealish, Tai, Hunter, & Morrison, 2011). In time, it is hoped that such endeavours, on the part of clinicians, might be supported by research to elucidate models of decisional capacity that capture more comprehensively the multi-layered influences on decision-making for people with psychosis.

#### *Limitations*

IPA assumes human capacities to share reflections on experiences of personal significance (Smith et al., 2009), but this was not possible for some participants, resulting in impoverished data that precluded meaningful analysis. This represented a weakness in recruitment procedures; reliance on care coordinators' judgments about who met inclusion criteria proved not wholly reliable. It may also highlight a limitation to IPA methodology, wherein the perspectives of already-disempowered individuals may be rendered invisible. Although homogeneity of sampling is recommended IPA practice, the study's cultural specificity should also be acknowledged.

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**Table 1 Participant characteristics**

Participant number	Age	Gender	Ethnic background	Marital status	Employment status	Current level of care	Duration of psychosis (years)	Experience of mental health system
1	50	Male	White-British	Single	Unemployed	CMHT	30	3 hospitalisations, (one very lengthy), experience of 4 antipsychotics, community care for past 10 years.
4	46	Male	White-British	Single	Unemployed	CMHT	20	Never hospitalised, experience of 6 antipsychotics.
5	38	Male	White-British	Single	Unemployed	CMHT	12	3 hospitalisations, all under section, 1 antipsychotic throughout.
6	58	Male	White-British	Single	Unemployed	CMHT	30	8-9 hospitalisations, 2 under section.
7	46	Female	White-British	Single	Unemployed	Psychiatric out-patient	24	Service involvement for 14 years, 2 hospitalisations, both under section.
8	51	Female	White-British	Single	Unemployed	CMHT	6	2 hospitalisations when young, service involvement since with different diagnoses.
10	55	Female	White-British	Married	Unemployed	CMHT	22	Never hospitalised, experience of numerous antipsychotics.

Note: Participants 2, 3, 9 and 11 were excluded from the analysis for reasons specified in the text

**Figure 1 Empowerment: Themes and subthemes**

