DOCTORAL THESIS:

"…it depends on the risk." CONSTRUCTING 'ANTIPSYCHOTIC' MEDICATION 'REFUSAL' IN COMMUNITY 'MENTAL HEALTH' SERVICES

Submitted to the University of Hertfordshire in partial fulfilment of the requirements

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ABSTRACT

Aim

Antipsychotic medication is the predominant intervention used for psychosis in the UK. However, there are risks associated, it is not always effective and service-users express ambivalence towards taking it. The research aims to explore community mental health professionals' perspectives on working with people with psychosis who express antipsychotic 'medication refusal'.

Method

A mixed-methodology was utilised. A survey of community mental health professionals was undertaken (N=74) to enquire about frequency of medication refusal and actions taken by professionals. Four uni-professional focus-groups were held to discuss the topic. The resulting data was subjected to a discursive analysis.

Findings

Antipsychotic medication refusal was presented as a common experience by participants, with service-users often stopping against advice. A substantial proportion of survey participants reported experience of supporting service-users without using antipsychotics or to come off, with good rates of success. 'Risk talk' was a prevalent feature of the focus-groups: a range of 'risk' repertoires were drawn on by participants to warrant particular actions.

Implications

Government initiatives relating to service-user choice, empowerment and recovery in mental health are in opposition to more pervasive 'risk' discourses. The notion of 'risk' in relation to antipsychotics needs further consideration, with professionals made more aware of its social construction and alternative conceptualisations of psychosis and antipsychotics.

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1. INTRODUCTION

1.1. BACKGROUND

Antipsychotic medication is the primary intervention recommended for psychosis-related diagnoses in the UK [National Institute for Health and Clinical Excellence (NICE) 2009]. Although service-users often report finding medication helpful, there are associated difficulties and the potential for harmful effects are well known (Gardner, Baldessarini and Waraich, 2005). Service-users frequently do not take medication as prescribed, can discontinue taking it against medical advice, and are often dissatisfied with professionals' responses when requests for support with coming off are made (Read, 2005). This research aims to explore community mental health professionals' perspectives on working with people with psychotic experiences who express that they do not wish to take or wish to come off antipsychotic medication. In order to save space, I will summarise this notion as 'medication refusal'[1].

1.2. PLAN

May (2001) argues for a more reflective approach in psychology, as the objectivity usually promoted can create a distance between the professional and their experience. In acknowledging the influence I bring to the research, I will write in the first person. I will provide an account of how I came to this research, my position in relation to the research topic and theoretical assumptions underpinning my approach. I will move on to provide definitions and background information on antipsychotics before setting out competing accounts surrounding the utility of antipsychotic medication. I will move on to explore the notion of 'compliance' to and discontinuation of antipsychotics. I will end by exploring some of the contextual factors surrounding decision-making about medication before outlining the rationale for the research[2].

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1 A negative connotation is not implied

[2] I will follow a convention of denoting contested terms in single quotation marks and true quotes in double quotation marks.

1.3. INSPIRATION

There are several strands which have brought me to this topic. As a child I had limited exposure to my grandmother's occasional mental health 'breakdowns', diagnosed as 'manic depression': they were concealed behind closed hospital doors, but I remained curious. My curiosities led me onto a path into clinical psychology. As my career has progressed, influenced by critical literature (e.g. Smail, 2005; Bentall, 2004), my scepticism about pathological accounts of 'mental illness' has grown. More recently, hearing service-user accounts at a conference of abominable treatment from mental health services, further encouraged me to undertake some critically-informed research. A further influence was hearing my partner (a community mental health nurse) talk about his frustrations in working with service-users who stop taking medication and the lack of other options available.

I began to explore the literature on medication-free approaches and encountered Mind's research exploring service-users experiences of coming off medication, which was critical of medical professionals' responses (Read, 2005). I began to wonder about this issue from the perspective of mental health professionals, which led me to conceive of this as a potential idea for my doctoral research.

No research is value free, even if it claims to be so (Fox & Prilleltensky, 1997). In the interests of reflexivity (Yardley, 1997) I will explicitly state my position in relation to the topic. I am sceptical of biomedical models of mental health and consequently about the purported benefits of chemical solutions. I believe that there should be choice in the interventions people in distress are offered. I believe that the focus in mental health should be broadened beyond the individual to wider contextual factors including family, institutions, and wider societal issues of inequality. The reader should note my position and what I bring as a researcher as they judge the following account.

1.4. THEORETICAL ASSUMPTIONS

1.4.1. Social Constructionism

The research is positioned within a *social constructionist* framework. Social constructionism has developed as a critical alternative to traditional psychology. It is a broad school and includes individuals taking a variety of positions on reality, personhood, language, personal agency *et cetera* (Burr, 2003; Parker, 1998). Burr (2003) has detailed common assumptions which underlie a social constructionist approach: a critical position towards taken-for-granted knowledge about the world; viewing assumptions about the world as historically and culturally specific; viewing knowledge as being constructed and sustained by social processes (i.e. interactions between people); and the view that different constructions of the world sustain or exclude particular social actions.

1.4.2. Critical Realism

Radical social constructionists take a relativist view of the world: a "truth" is always relative to a discursive or cultural frame of reference. This position is open to criticism that moral relativism can ensue with no rationale to advocate one construction over another (Burr, 2003). Willig (1998) has commented on the tendency of social constructionist researchers to absent themselves from making recommendations for improvement to practice, for fear of reifying particular constructions. She argues that the absence of taking a position can act to support oppressive constructions: inaction is an action. She takes an overt political position in her work, but notes that analysis should be reflexive and historically sensitive. She situates herself within a *critical realism* frame. A critical realist position might also be situated within social constructionism (Burr, 2003), but proposes that there are structures (i.e. biochemical, social structural, economic *et cetera*) underlying observable phenomena; these can never be directly accessed only known through their effects (Willig, 1998): what is true is not the same as what is held to be true (Collier, 1998). Constructions of the world are based on the underlying structures which constrain what it is possible to say and do (Parker, 1999).

1.4.3. My position

I would orientate myself closer to the critical realist position. Firstly, this arises from the topic in question: medication has real physical effects on people. However, these can be constructed in different ways and there are diverse discourses surrounding medication and practice, which have different effects (Harper, 1999a). Secondly, this is *applied* research: I work within a *real* health service which exerts influence on practice and consequently the lives of service-users by virtue of the assumptions made about the world inherent in it. I would see that the key purpose of research is to lead to 'improvements' in practice and the experiences of service-users. This will ultimately involve advocating for some constructions over others.

1.5. REVIEWING LITERATURE

Given the breadth of literature surrounding psychosis and medication, a full literature review of the field is not feasible within the constraints of this thesis. I will give priority to research which has sought to empirically examine stakeholders' perspectives in relation to the topic of enquiry, which will exemplify the different available constructions of the issue. I will also address competing accounts from the professional literature, alongside some examination of the service-context within the NHS. My aim is to present sufficient literature to establish a robust rationale for undertaking the research and provide enough context for the reader to understand and evaluate the research.

1.6. 'PSYCHOSIS'

For Bentall (2004) 'psychosis' refers to 'madness' or severe psychiatric disorders in which an individual appears to lose touch with reality. 'Psychotic' experiences refer to unusual perceptive experiences, for example voice-hearing in the absence of an external stimulus ('auditory hallucinations' in medical terms) and unusual or 'paranoid' beliefs held by an individual but not shared by others in their social environment ('delusions' in medical terms) [The British Psychological Society (BPS),

2000]. The ICD-10 Classification of Mental and Behavioural Disorders (ICD-10; World Health Organisation, 1992, p2-3), defines "psychotic" as:

> ..the presence of hallucinations, delusions, or a limited number of severe abnormalities of behaviour, such as gross excitement and overactivity, marked psychomotor retardation, and catatonic behaviour.

The medicalisation of 'madness' in the nineteenth century sought to establish the biological origins of mental distress and establish it as the jurisdiction of doctors (Pilgrim and Rogers 1999). This construction is still dominant: psychotic experiences are conventionally seen as 'symptoms' of underlying 'mental illness', listed as items on psychiatric diagnostic criteria for a range of 'mental disorders', the most common of which is 'schizophrenia'. The ICD-10 describes nine sub-types of schizophrenia and eighteen related disorders. Psychosis also features within several other categories of disorders outside of schizophrenia and its related "disorders", including "disorders due to psychoactive substance use" and "mood disorders".

The validity, reliability and utility of 'schizophrenia' has been critiqued in detail by many authors, including in the last decade Boyle (2002) and Bentall (2004) and there are a range of alternative, but subjugated constructions of psychosis available. Boyle and Bentall suggest that the investigation of 'psychosis' should be done outside of the outdated and unscientific concept of 'schizophrenia'. This is also advocated by the BPS Division of Clinical Psychology (BPS[3], 2000). As such, I will refer to 'psychosis', rather than diagnostic labels, (unless these were used by particular literature referred to).

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[3] This is unsurprising given that Boyle and Bentall were contributory authors.

1.7. 'ANTIPSYCHOTIC' MEDICATION

1.7.1. Background

The use of antipsychotics in 'treating' psychosis is so prevalent that researchers report difficulties attempting to conduct research with drug-naïve patients (Bentall, 2009). NICE (2009) guidance is that antipsychotics should be "offered" to people newly diagnosed with "schizophrenia", "schizoaffective disorder", "schizophreniform disorder" and "delusional disorder", during acute episodes of the "disorder" and for one to two years after to prevent relapse (NICE, 2009). Bentall (2009) suggests that in practice, many people with psychosis are told that they should continue medication indefinitely to prevent 'relapse': known as *maintenance treatment*.

1.7.1.1. Definitions

Chlorpromazine was the first 'antipsychotic' drug to be introduced in the 1950s. First known as "major tranquillisers" and "neuroleptics"[4] they were only later referred to as 'antipsychotics' (Moncrieff, 2008). The current British National Formulatory[5] (BNF-58; British Medical Association and the Royal Pharmaceutical Society of Great Britain, 2009) lists 23 oral and 6 depot[6] preparations of antipsychotic drug. They are recommended for the relief of "florid psychotic symptoms", to "prevent relapse" in "schizophrenia" and as tranquillisers:

> …to calm disturbed patients whatever the underlying psychopathology, which may be schizophrenia, brain damage, mania, toxic delirium, or agitated depression. (p 194).

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[4] Meaning *nerve-seizing*; a name which is preferred and argued by some authors to be more accurate descriptions of their mode of action (Moncrieff, 2008; Breggin, 1993)

[5] The British National Formulatory is a reference book for prescribers, pharmacists and professionals which is published biannually and purports to provide evidence-based up-to-date information on the selection, prescribing, dispensing and administration of all medicines available under the NHS.

[6] 'Depot' preparations of antipsychotics are long-acting form of the medication administered via an intra-muscular injection in the buttocks, often as an out-patient, by a Community Psychiatric Nurse. Some authors have alluded to the potential for this to be a humiliating experience for service-users (Day and Bentall, 1996).

1.7.1.2. Mode of Operation

Antipsychotics are purported to alleviate the 'symptoms' of psychosis through blocking dopamine D2 receptors (BNF-58, 2009). This thesis has led to the enduring and often reformulated (tautological) hypothesis that "schizophrenia" (or more recently only the 'positive' psychotic symptoms of schizophrenia) is caused by abnormalities of dopamine in the brain, which antipsychotics operate to reverse (Howes & Kapur, 2009): a theory that has filtered into common psychiatric discourse so that psychiatric drugs such as antipsychotics are often promoted by health professionals as correcting a "chemical imbalance" (Double, 2005; Moncrief, 2008). This argument has been challenged. Johnstone (2000) suggests it is a form of "backward logic" akin to suggesting that headaches are caused by a lack of aspirin. Furthermore, the mode of operation on 'symptoms' of the various antipsychotic drugs is less than clear, for example all antipsychotics act on multiple neurotransmitters in addition to dopamine and not all bond potently to D2 receptors (Miyamoto, Duncan, Marx and Lieberman, 2005). Certain antipsychotics in particular are "dirty" drugs which act at multiple receptors (Healy, 2005). In a review of modern antipsychotic drugs, Gardner et al. (2005) argue that

> "pharmacocentric and circular speculations about altered dopaminergic function, have not led to a better understanding of the pathophysiology or causes of the several still idiopathic psychotic disorders, nor have they provided a non-empirical, theoretical basis for the design or discovery of improved treatments for psychotic disorders."

1.7.1.3. 'Side Effects'[7]

The original antipsychotics of the 1950s (e.g. chlorpromazine and haloperidol) were associated with severe and undesirable neurological effects, associated with their action on dopamine receptors, known as *extrapyramidal side-effects*; referring to changes in voluntary movement (Gardner, Baldessarini and Waraich, 2005). Arguably the most serious extrapyramidal side-effect, due to its lasting nature following discontinuation of medication, is *tardive dyskinesia*, which chacteristically involves spasmodic movements of the jaw and tongue.

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[7] Harper (1999) regards 'side-effects' as a euphemism for direct but unintended effects of medications.

Other 'side-effects' include endocrine and metabolic effects, such as weight gain, hyperlipidemia and hyperglycaemia leading to diabetes; elevated prolactin levels leading to changes in sexual functioning, lactation and breast swelling; and cardiovascular effects, such as raised blood pressure, tachycardia, stroke and sudden cardiac death (Gardner et al., 2005).

1.7.1.4. 'Second Generation' Drugs

Demand for drugs with better "side-effect profiles" led to the re-launch of Clozapine in the late 1980s; an 'atypical' antipsychotic, in that it did not seem to produce extrapyramidal side-effects (Gardner et al., 2005). It was also claimed to produce improvements in a significant proportion individuals who had been unresponsive to conventional antipsychotics (Kane & Meltzer, 1988). Clozapine had previously been found, however, to cause potentially fatal agranulocytosis[8] and was re-launched only for use with individuals with "treatment resistant schizophrenia" who had not responded to other drugs, with close monitoring and regular blood testing required.

Following the reintroduction of Clozapine, further 'atypical' antipsychotics were launched in the 1990s including Olanzapine, Resperidone and Amisulpiride (Miyamoto et al, 2005). They were initially claimed to have similar benefits to Clozapine in terms of efficacy and side-effect profiles but without the risks (Healy, 2005). The terms 'typical' and 'atypical' antipsychotic have been superseded in most literature by "first-generation" and "second-generation" antipsychotics, due to the recognition that the so-called 'atypical' antipsychotics do not constitute a homogenous class of drugs, have diverse pharmacological actions and most still have the propensity to cause extrapyramidal side-effects; certain of the newer drugs also have a greater propensity for producing metabolic abnormalities (NICE, 2009; Gardner et al., 2005). Although the first NICE guidance on the treatment of schizophrenia recommended that an 'atypical' antipsychotic be prescribed as the

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[8] An acute condition involving severe and dangerous lowered white blood cell count.

first line of treatment in newly presenting cases of schizophrenia (NICE, 2003), the most recent guidance (NICE 2009) does not recommend second-generation above first-generation drugs: the drug should be chosen depending on what seems most appropriate for the individual.

1.7.2. Accounts of Utility

In this section a range of accounts about the utility of antipsychotics will be presented, drawing on the professional literature and research examining service-user perspectives.

1.7.2.1. *Professional Literature*

Bentall (2009, p220) states that there is "no doubt" about the short-term benefits of antipsychotics in producing quick relief from psychotic symptoms. However, not everyone with psychosis is considered to "respond" in a therapeutic way. Bentall states that the proportion of "non-responders" is difficult to estimate, but draws on Kane (1989) to suggest rates of between a quarter and a third of individuals.

When chlorpromazine was first synthesised by Laborit in the 1950s, it was its propensity to induce a state of "disinterest" in one's surroundings which led to it being trialled on psychotic patients and subsequently being found to have useful effects for this patient-group (Mckenna, 2007). Subsequent claims were made that these drugs work by having specific effects on the underlying pathology of schizophrenia and psychosis. Mckenna (2007) cites a National Institute of Mental Health study (1964) as providing evidence that antipsychotics have selective effects on the symptomology of schizophrenia, beyond purely sedation and tranquillisation. He points to findings that the improvement on symptoms such as hostility, aggression and anxiety were less than for symptoms such as delusions and hallucinations. Moncrief (2008) disputes that neuroleptics act specifically on the mechanisms underlying psychosis, which she terms a "disease-centred model", she argues that other types of drugs (such as benzodiazepines) can produce similar

effects on psychotic symptoms, but have received little investigative effort. She proposes a "drug-centred model", which views psychotropic drugs as *inducing* particular psychological states which must be judged for their usefulness and balanced against adverse effects.

Healy (2005) provides a similar argument. He disputes that antipsychotics are "antischizophrenic": like coffee or alcohol they tend to have similar effects on anyone taking them. He argues that the effect they have is to produce a feeling of detachment or a "who cares" feeling, which is why they appear to get rid of psychotic symptoms such as voices and delusions. The voices or beliefs are usually still there, but the person is less bothered by them and able to concentrate on other things. In this sense he argues for their utility at appropriate doses and places the patient's subjective experience of the helpfulness of the drug at the centre of the prescribing process.

Breggin (1993) is more scathing of antipsychotics, citing them as "the most dangerous medications ever used in medicine" (p.108). He argues that so called "antipsychotic" drugs act as "chemical lobotomies" which do not provide specific treatment for particular symptoms, but rather act to generally blunt and subdue individuals and reinforce the patient's role as the "helpless sick person". He argues that both antipsychotics and psycho-surgery act on the brain dopaminergic pathways leading to the frontal lobes and limbic system. Antipsychotics are thus argued to produce their desired effect by impairing normal brain functioning. He cites research which suggests that for a significant proportion of individuals these impairments are permanent. Similarly, Healy (2005, p256-257) suggests that professionals and service-users need to be aware of the potential for permanent changes in brain systems following treatment with antipsychotics. He suggests that "the act of therapy changes people forever….starting and stopping treatment is not the same as not starting." A recent review of the research on the impact of antipsychotics on brain structure concludes that antipsychotics have the potential to produce

structural changes in the brain, but methodological flaws and inconsistencies mean that research findings have yet to produce a clear picture (Navari and Dazzan, 2009).

Antipsychotics and other physical treatments are widely heralded as having enabled the de-institutionalisation of the 1960s and subsequent establishment of community psychiatric care. Black (2005) states that psychiatric hospitals were emptied following the discoveries of ECT, Lithium and Chlorpromazine. Other researchers question this version of history. Johnstone (2000) agrees that the introduction of drugs such as neuroleptics and de-institutionalisation occurred at about the same time, but cites evidence to suggest that numbers of psychiatric inpatients had already started to fall. Healy (2005) suggests that it is difficult to disentangle the relative influences which led to community care, but suggests that the use of drugs engendered a willingness for more risks to be taken in discharging people. Harper (1999b) observes that outside of the hospital, diagnosis and medication serve to fix people in a *conceptual* and *ideological* space, as opposed to the physical separation in the asylums. He suggests that medication continues as a form of physical regulation through *Dispensary Power* which replaces the confinement and physical restraint of the past.

1.7.2.2. Service User Perspectives

Studies utilising a range of methods have been undertaken to investigate service-users attitudes towards and experiences of taking antipsychotics, which I will detail in this section.

Rogers and Pilgrim (1993) surveyed service-users' views of taking antipsychotics, 57% reported finding them helpful; 62% reported that side-effects had been severe or very severe. They note that qualitative data suggested substantial levels of ambivalent and negative attitudes towards the drugs, which was not necessarily reflected in overall quantitative ratings. They conclude that on-the-whole service-users are critical of these drugs. Similarly, Day, Bentall and Warner (1996) found that service-users have complex relationships with medication which are not simply pro

or anti. They conceptualised four types of "subjective attitudes" towards antipsychotics:

1) "unquestioning, uncomplaining, dependent": expressed dependence on drugs and strong belief in the authority of the doctor;

2) "autonomous, sceptical": expressed a negative attitude towards drugs and a concern for being autonomous;

3) "balanced appraisal": concerned about side-effects, but acknowledging the benefits of medication;

4) "autonomous responding": medication seen as beneficial, but did not express dependence on it.

They suggest that clinicians being sensitive to service-users' attitudes towards medication would have a positive impact on the therapeutic alliance, which in turn can improve outcomes.

Rogers, Day, Williams, Randall, Wood, Healy, and Bentall (1998) undertook a detailed exploration of the meanings service-users attach to medication, interviewing 34 service-users on long-term regimes of antipsychotics. They present qualitative findings, exemplifying their claims with extracts from the interviews but the method of qualitative analysis is not described. There were a range of reported costs and benefits associated with taking antipsychotics. Benefits included "calming" effects, control of specific symptoms such as voices or unwanted thoughts and as an aid to coping with particular situations. Problems included side-effects and the impact that these had on participants' abilities to engage in daily activities. Side-effects most frequently reported included "drowsiness, tiredness, sleepiness", followed by restlessness and lack of motivation. Some participants reported that there was little to choose between the undesirable effects of the medication and psychotic symptoms. The authors suggest that participants had developed knowledge of how much medication they needed and would vary it themselves by raising or lowering the dosage in particular circumstances. Participants did not see antipsychotic medication as being akin to medication taken for other conditions, because of the

potential sanctions for not taking it. Participants were aware of mental health legislation and expressed a fear of coercive treatment if they did not take their medication. Some participants reported being persuaded to take their medication by mental health professionals in the community. There was also expression of the stigma associated with mental health problems and the authors describe that participants perceived a "social contract" whereby taking medication enabled them to live in the community. Similar recommendations are made to those emerging from the Day et al., study: professionals should acknowledge service-users own definitions of their situation and self-management strategies, with the goal of working collaboratively together. They suggest that future research might be invested in rethinking the nature of patient/professional encounters around medication

Carrick, Mitchell, Powell and Lloyd (2004) undertook a qualitative study of the experience of taking antipsychotics, using grounded theory. A core category of "maximising Well-being" emerged. Well-being was defined in terms of normality of feeling, function and appearance. A struggle was presented in trying to reduce both side-effects and illness symptoms which were both seen as detracting from "well-being". Medication was viewed in terms of "sufferance" to be "put up with" for sufficient benefits. Clear views were expressed as to whether medication was "worth it" overall, which differed from person to person. More than 60 side-effects were mentioned and in common with Rogers et al.'s findings, tiredness was most common, but was reported to not be taken seriously by doctors. As in Rogers et al.'s study, there was a concern that hospitalisation was a likely consequence of non-adherence and that choices were limited. Recommendations similar to those detailed in the other studies are made: in order to achieve a cooperative partnership, doctors need to clarify service-user goals. Service-users are argued to be best-placed to evaluate effects of treatment and the optimum balance of side-effects and symptoms.

1.7.3. Summary

This section has examined accounts of the utility of antipsychotics. We can see from the varying accounts presented here, that this is a contested topic amongst both professionals and service-users. Antipsychotics are not useful in a straightforward way and there are many levels of complexity. Research looking at service-user perspectives recommends that professionals take steps to acknowledge the uniqueness of service-user positions and that service-users have expertise in judging and managing their own medication-related behaviour.

1.8. MEDICATION 'COMPLIANCE'

1.8.1. Why medication is deemed necessary

Service-user adherence to antipsychotics as prescribed is usually presented as being essential to maximise therapeutic outcomes in individuals diagnosed with schizophrenia (Velligan, Lam, Glahn, Barrett, Maples, Ereshefsky and Miller, 2006) with non-adherence and medication discontinuation presented as significant "management" issues (Awad, 2004) and as predictive of "relapse" (e.g. Robinson, Woerner, Alvir, Bilder, Goldman, Geisler, Koreen, Sheitman, Chakos, Mayerhoff, and Lieberman, 1999). As we have already seen, service-users do not find medication straightforwardly beneficial and outcome-measures from some medication trials support this. For instance the Northwick Park Functional Psychosis Study found that although "maintenance treatment" with antipsychotics reduced the risk of "relapse" compared to those treated with a placebo, there were better occupational outcomes for participants in the placebo group (Johnstone and Geddes, 1994).

From a sociological perspective, Pilgrim and Rogers (1999) comment that psychiatric patients' non-compliance with medication is seen as a significant social problem, tied up with ensuring the success of community care. They suggest that the media has depicted medication as a valid means of managing and controlling people viewed as a threat to the social order. The need for compliance stems not only from public pressure but is a key component of the management of mental health problems.

These observations have been borne out with the recent addition of *Community Treatment Orders* (CTOs) to mental health legislation (Mental Health Act, 2007, Ch. 4). Such orders can compel individuals with "mental disorder" who have previously had a hospital admission to comply with medical treatment in the community, with consequent recall to hospital if the terms of the order are not met. The rationale being "to prevent risk of harm to the patient or others".

1.8.2. Language

In contrast with increasingly restrictive mental health legislation, the discourse in the professional literature has moved from "compliance", implying service-user passivity and obedience to the practitioner; to "adherence", argued to infer a collaborative relationship between the service-user and practitioner (Singh et al., 2006) and "concordance", defined as the degree to which clinical advice and health behaviour agree (Mitchell & Selmes, 2007). Recent NICE guidance ("Medicines adherence", 2009) uses the term "adherence", defined as:

> " ....an agreement between prescriber and patient about the prescriber's
> recommendations...the extent to which the patient's action matches the
> agreed recommendations." (p. 4)

Day and Bentall (1996) are sceptical about whether simple changes in terminology can address the problem of "paternalism" inherent in the notion of "compliance".

A distinction is made in recent adherence literature between unintentional (e.g. misunderstanding instructions or forgetting) and intentional non-adherence (deciding not to follow recommendations) (NICE, 2009). "Intentional non-adherence" is further divided into "medication refusers", "irregular compliance" and "medication discontinuation" against recommendation (Velligan et al., 2006; Mitchell & Selmes, 2007). It is suggested that the majority of individuals diagnosed with schizophrenia would fall into the "irregular" category, but there has been little research on overt medication refusal (Mitchell & Selmes, 2007). In relation to medication discontinuation, several large scale trials have found particularly high rates of

medication discontinuation: the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE), which compared first and second generation antipsychotics, found that 74% of participants discontinued the study medication before 18 months (Swartz, Stroup, McEvoy, Davis, Rosenheck, Keefe, Hsiao, Lieberman, 2008).

1.8.3. Adherence to antipsychotics

Given the importance placed on antipsychotics as a 'treatment', much effort has been invested in examining the reasons for non-adherence, in order that rates might be improved. As such, there is an a priori assumption in most "adherence" literature that non-adherence is a negative thing to be reduced.

Reviews of the literature relating to antipsychotic medication adherence acknowledge that there has been little agreement regarding how adherence is operationally defined and best measured (Velligan et al., 2006). This variability has led quoted rates of non-adherance in individuals diagnosed with schizophrenia to range from 20% to 89% with an average of 50%; depot medication is often recommended as a solution (Singh, Massey, Thompson, Rappa and Honeywell, 2006). Adherence to prescribed medications is not only an issue for psychiatry: the NICE guidance relates to the prescribing of medication generally. NICE suggest that between a third and half of all medicines prescribed for long-term conditions are not taken as recommended.

A recent UK national household survey has examined adherence to psychiatric medication using structured interviews (Cooper, Bebbington, King, Brugha, Meltzer, Bhugra and Jenkins, 2007). Overall, 34% of those prescribed a psychiatric drug reported that they were not fully adherent. The rates of self-reported non-adherence in individuals diagnosed with psychosis were not significantly different from those taking other types of psychiatric medication. For those taking antipsychotics, side-effects were more commonly cited as reasons for not adhering than for other

medications. Across the whole sample, not wanting to take medications or not thinking they were needed were major reasons given for non-adherence.

1.8.4. Discourses of "compliance"

David Harper (1999b) explored the discourses surrounding medication in a chapter of his PhD thesis. His research involved individual interviews with service-users and the psychiatrists, GPs and nurses involved in their care. The interviews were subjected to discursive analysis alongside an analysis of wider literature. Harper identified two opposing discourses as being available in relation to non-compliance: *Non-compliance as not following medical advice* and *Non-compliance as an assertion of agency and choice*.

Within the first discourse, he argues that failure to take medication is constructed by professionals as being an effect of the illness (in terms of 'insight') and as morally irresponsible. Compliance is seen as inherent in the service-user as apposed to the doctor-patient relationship, and is seen in either/or terms, rather than as on a continuum. The result is that the responsibility for 'compliance' is located with the service-user.

In the second discourse, prescription regimes are seen as a result of negotiation or a power struggle between the doctor and service-user which may be constructed in terms of: defiance of medical authority, a breakdown in the doctor/service-user relationship, a self-protective response, a valid decision or as self-medication. Within this discourse, responsibility for non-adherence is located in the doctor-patient relationship or the doctor's actions, and negotiation is warranted. Withdrawal of service-user cooperation is warranted if such negotiations are unsatisfactory. This might be expressed through the service-user reducing their dose or refusing to take medication. Within this discourse, service-user expertise and rights are valued and they are able to assert agency through making decisions about their medication

regime. The research discussed in the next section might be seen in terms of the second discourse.

1.8.5. Coming off Medication

As we have seen in the studies detailed in Section 1.7.2.2, service-users provide sophisticated accounts as to the costs and benefits of medication and some take the decision to stop taking it.

1.8.5.1. *Mind's research (Read, 2005)*

The mental health charity Mind conducted research with 204 individuals who had attempted to come off a variety of psychiatric medications. Participants were interviewed using a structured questionnaire, with a smaller sample partaking in in-depth interviews. Twenty one of the sample had tried to come off antipsychotics. The most common reason given for deciding to come off medication was adverse effects (60%) followed by not wanting to take medications long term (53%) and feeling things were better so medication no longer needed (37%). Of the 21 participants in the study who had been taking antipsychotic medication, over 60% tried to come off their drugs either against medical advice or without informing their doctor. The reason given for not telling the doctor was usually because of fear of opposition or compulsion. The study participants rated psychiatrists and GPs as being the least helpful people in terms of offering support with coming off medication (particularly by those who wanted to come off antipsychotics) and counsellors/psychotherapists as being most helpful. The results suggested that there are not clear rules predicting likelihood of success and that doctors are not good at predicting who is able to safely come off.

The authors encourage more debate of the issues between interested parties; call for further research to be undertaken around withdrawal from psychiatric drugs; and suggest training for professionals on understanding service-users perspective on psychiatric drugs. Limitations of the research include the small sample size,

particularly in relation to antipsychotics, the lack of 'scientific' peer-review (although the results have been presented and discussed in public forums) and insufficient detail in the report about the analyses undertaken. However, the research raises important questions for the role of professionals in working with this issue.

1.8.5.2. Advice on "Coming off"

David Holmes is a clinical psychologist working in a Community Mental Health Team (CMHT) who has written in professional and service-user literature about coming off antipsychotics. He notes that there is little help available for people who want to try to come off medication and has written a list of "top tips" for coming off based on his clinical experience (Holmes & Hudson, 2003).

Writing in a clinical psychology professional practice journal after encountering Mind's research on "coming off" Holmes (2006) expresses curiosity as to how psychologists respond to people talking about medication and expressing that they want to stop taking it. He suggests that psychologists might be useful professionals for service-users to talk to about this issue and outlines the way he works with service-users who raise medication issues. For service-users who express curiosity in coming off, he recommends a structured joint brainstorming exercise where the pros and cons of continuing or coming off medication are explored. He also recommends books to service-users to read to help inform their decision. He suggests that the written result of the brain-storming exercise can be shared by the service-user with family or other professionals involved in their care, which can promote a climate of collaboration. Holmes suggests that although coming off medication can be a 'risk', so are other potentially helpful or stressful things in life. He concludes with a call to psychologists to use their relatively powerful positions to advocate for people who want to come off psychiatric drugs.

1.8.6. Minimal/Non Medication Approaches

There is a small body of research which has explored minimal or non-medication approaches to working with psychosis. Bola (2006) notes the limited number of good quality studies which have allowed comparison between initial treatment of first-episode schizophrenia with and without medication. In his review of the literature, he identified seven studies with sufficient methodological robustness, where a medicated group was compared with a non-medicated group (including drug placebo, therapeutic mileau, and psychotherapy). Only four of these involved random assignment to groups. Calculation of effect sizes showed no advantage for early treatment with antipsychotics over non-medication approaches. Calton, Ferriter, Huband, and Spandler (2008) undertook a systematic review of the published literature on the "Soteria Paradigm": a therapeutic community alternative to hospitalization, for those diagnosed with schizophrenia. The authors define the core principles of this approach as:

> the provision of a small, community-based therapeutic milieu with significant lay person staffing, preservation of personal power, social networks, and communal responsibilities, a ''phenomenological'' relational style which aims to give meaning to the person's subjective experience of psychosis by developing an understanding of it by ''being with'' and ''doing with'' the clients, and no or low-dose antipsychotic medication (with all psychotropic medications being taken from a position of choice and without coercion).

They found that the outcomes of this paradigm were comparable with standard treatment, therefore no disadvantage was incurred by the lack of antipsychotic treatment. In a further article, Carlton & Spandler (2009) discuss a range of other minimal-medication approaches. These include, a psychosocial approach developed in Finland, the outcomes of which were that for the experimental group (psycho-social, minimal-medication approach): 43% had never taken medication (compared to 6% of the standard treatment group), there was significantly less hospitalization and fewer psychotic symptoms. They conclude by calling for greater consideration of the provision of minimal-medication approaches in the UK.

The findings from the research described here serves to challenge the conventional assumption that compliance with antipsychotic medication is always necessary.

1.8.7. Summary

This section has explored issues around the notion of medication 'compliance'. The mainstream of psychiatry, convinced of the necessity for continued antipsychotic treatment, direct research towards improving rates of compliance. However, there are alternative discourses centred on choice, with a minority of bodies and professionals advocating for supporting service-users to come off medication and minimal-medication approaches.

1.9. MAKING DECISIONS ABOUT MEDICATION

This section will further explore some of the issues and contexts surrounding decision-making about antipsychotic medication, including: the legal framework, government agendas and the context of medical consultations.

1.9.1. Choice, Consent & Recovery

1.9.1.1. Informed Consent

The notion of informed consent to treatment has become a central issue in medical ethics and there are particular issues in relation to mental health. According to Davis (2009), consent must be obtained in order for a treatment to be given lawfully and can only be meaningful if a full explanation of the treatment has been given: an individual is able to refuse a treatment, without undue pressure being placed. However, legislation allows rights to be overridden in particular circumstances: where an individual is deemed to lack *mental capacity*[9] to make the decision, in

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[9] The Mental Capacity Act (2005) states that a person is unable to make a decision if he or she is unable to: understand the information relevant to the decision; retain the information for long enough to be able to make a decision; use or weigh up the information as part of the process of making the decision; communicate the decision by any possible method, such as talking, using sign language, squeezing someone's hand and so on.

which case decisions are made by professionals in the *best interests* of the person, in consultation with the individual's family and friends; and if an individual is detained under certain sections of the Mental Health Act (2007). However, legal powers must not be used as a threat to coerce an individual into consenting.

Healy (2005) discusses the complexities around informed consent. He suggests that there are factors which can undermine the notion of voluntary consent to treatment, including: the pressures involved in medical consultations preventing full discussion of treatment options; the way in which treatment options are presented; the diverse views which different mental health professionals might provide on the nature or purpose of the treatment; and the reluctance by professionals to present the lack-of-certainty about particular treatments. Carlton & Spandler (2009) contend that in order to give consent, individuals must be aware of the range of choices available and that often the only choice on offer is medication.

1.9.1.2. Choice

The notion of "consumer choice" has become increasingly prevalent within NHS government directives in the past ten years. The Department of Health white paper (DoH; 2006) *Our health, our care, our say: a new direction for community services* states the government's plan to develop more personalised health and social care services which make information available to service users, provide greater choice about the help and support available and give service-users more power to influence the standards of local services. It stipulates the requirement for services to seek service-user views and involve them in decision-making.

Research detailed in Sections 1.7.2.2 suggests that service-users often feel coerced into complying with medication regimes. Other research has investigated the extent to which service-users feel involved in decisions about being prescribed antipsychotics (e.g. Paton and Esop, 2005; National Schizophrenia Fellowship, 2000).

The main findings being that a substantial proportion feel that they are not provided with sufficient information about the medication prescribed to them and are not involved with the decision-making about choice of drug.

1.9.1.3. Recovery

The notion of "recovery" in mental health has grown in recent years and is argued to have its roots in the USA in users' personal stories of recovery from mental illness which challenge the idea that recovery from severe mental health problems is uncommon (Wallcaft, 2005). Some of the key ideas integral to the concept of recovery include forging new ways of living based on self-agency, self-help, hope, developing coping strategies and sharing these with others (Ramon, Healy and Renouf, 2007). These ideas might be seen to fit with Harper's identified discourse: *Non-compliance as an assertion of agency and choice*.

The DoH has utilised the concept of recovery in agendas for service provision, for instance: *The Journey to Recovery– The Government's vision for mental health care* (DoH, 2001) argues that a positive and optimistic approach needs to be taken towards those who use mental health services which enables individuals to have access to resources which they believe are critical to their own recovery.

1.9.2. Medical Consultations

Seale, Chaplin, Lelliot and Quirk (2006) examined the discussion of antipsychotics in psychiatry outpatient appointments. This research is useful in highlighting some of the issues around decision-making in relation to antipsychotics.

Qualitative interviews were held with 65% of consultant psychiatrists across two mental health trusts (N=21) on the topic of out-patient consultations involving antipsychotic discussion. The results were analysed using thematic content analysis. The psychiatrists positioned themselves as taking a "patient-centred" approach within consultations, through use of understandable language, greater provision of

information about treatment options, and more negotiation of decisions. They also expressed a preference for co-operative relationships, where decision-making was shared. This was reported to be achieved by listening to service-users views and experiences, showing empathy and understanding, being honest and being "human". Most presented medication as being the most important treatment for people diagnosed with schizophrenia. Participants raised issues about the dilemmas involved in discussing the adverse effects of medication with service-users, in terms of how much information to provide and the impact this might have on compliance, own lack of knowledge, and fear of litigation. There were also reports of the use of manipulative strategies, such as bargaining, deception in the service-user's "best interest", and the use of persuasion. The participants described at times the need to take a more directive or coercive approach, particularly if service-users were thought to lack "insight" or be "very psychotic".

In discussing the findings, the authors observe that despite preferences for shared decision-making, the inherently asymmetrical nature of the relationship whereby the psychiatrist assesses the service-users' competence to take decisions, can mitigate against this. The dilemma between sharing information with service-users and encouraging treatment might also undermine a commitment to shared-decision making. The authors recommend that further research be undertaken examining the conditions which place psychiatrists in the position of such a heavy reliance on medication.

1.9.3. Summary

In this section we have seen that apparently progressive policies relating to informed consent, choice, recovery and service-user involvement may be undermined at the point of service, when it comes to antipsychotic drug treatment, due to the conflicting roles and priorities of service-users and medical professionals.

1.10. RESEARCH RATIONALE

We have seen that there are contested issues in the area of antipsychotic medication use and 'refusal'. Research suggests that service-users want to have more choice in how and if they take antipsychotics and if this is not supported may stop without medical supervision. We have seen in research with psychiatrists that there are apparent dilemmas in working with conflicting agendas in mental health. Psychiatrists, in the main, are the only professional group prescribing antipsychotic medication[10]. However, given that mental health teams (in their various guises) in the community are multidisciplinary, mental health professionals of various disciplines work directly or indirectly with service-users taking antipsychotic drugs and many are expected to monitor medication as part of their role. It is unclear whether the same dilemmas might be present for mental health professionals from other disciplines, as to date little research effort has been directed at this. It might be expected that different disciplines draw on different frames of reference for working with such issues. This research aims to address questions of this nature.

1.11. RESEARCH AIMS

The research aims to explore antipsychotic 'medication refusal' from the perspective of community mental health professionals. There are two aspects to the research:

a) An exploration of the accounts the professionals give of:
   - How often service-users express 'medication refusal'
   - What actions they take in response
   - How often they have supported service-users without medication or to come off medication
   - Confidence in working with these issues
   - The relative influence of different stake-holders in decision-making in relation to this issue
   - Availability of non- medical approaches

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[10] Although in recent years mental health nurses have been able to train to achieve some prescribing rights

b) Harper (2008) notes that in the field of mental health, discourse analysis has been useful in exploring contested issues. We have seen that antipsychotic medication is such an issue. As such a critical examination will be undertaken using a discursive framework of *how* professionals talk about these issues. This will pay attention to the accounts professionals give of their actions, the discursive resources drawn on and the functions these serve.

2. METHODOLOGY

2.1. DESIGN

2.1.1. Theoretical Assumptions

A social-constructionist approach does not advocate a particular research methodology: both qualitative and quantitative methods may be used (Burr, 2003). However, the assumptions underlying a social constructionist approach guide the kinds of questions asked and methods used to answer them. Consequently, particular methods have been more widely taken up than others: discursive approaches in particular (Section 2.1.3).

Although guided by social constructionist assumptions, I have made methodological decisions based on pragmatic grounds. Within pragmatic approaches, the research question guides the choice of method, which is then judged on whether the purpose was met. This can lead to bespoke research designs combining different methods (Teddlie & Tashakkori, 2003).

2.1.2. A Mixed Methods Approach

As indicated in Section 1.11 I was interested to investigate the different accounts professionals give in relation to frequencies and actions taken around 'medication refusal', as well as *how* professionals talk about these issues and account for their actions.

My interest in quantifying some of the issues (for example how frequently service-users express medication refusal) was a result of being unable to find any existing research quantifying this phenomena from the perspective of professionals in the course of their day to day work, other than the "compliance" literature detailed in Section 1.8.3. It was also in part a 'tactical' consideration, acknowledged by Yardley (1997), in that numbers are often seen to provide stronger arguments and can be more influential on practice/policy (e.g. hierarchies of evidence used to construct

clinical guidance: DoH, 1999): Parker (2007) points to the use of opinion polls in emancipatory research in South America. My interest in *how* professionals talk about the issues and account for their actions in relation to 'medication refusal' stems more clearly from a social constructionist position in which the use of language to construct the world is examined.

A two-pronged approach therefore is employed:

a) A small-scale survey of professionals, through means of an online questionnaire, inviting professionals to give an account, in largely quantifying terms, in relation to antipsychotic 'medication refusal' (see Section 2.2.1.)

b) A series of focus groups of professionals, which provided a more open forum for professionals to provide accounts on the topic of enquiry, to be analysed discursively (as detailed next).

2.1.3. Using Discursive Methods

In this section I will outline discursive methods of analysis and the approach I plan to utilise.

2.1.3.1. Discourse Analysis

A diverse range of activities are referred to as 'Discourse Analysis' (DA). The confusing and varied nature of the field is in part a product of analytic traditions developing in different academic disciplines (Hepburn & Potter, 2007). I will concentrate here on DA approaches which have developed within psychology. Discursive approaches in general question the assumption that language is merely neutrally descriptive of a "real" world. Discourse is seen as constructing reality and reality is collectively produced through social processes: discursive approaches study aspects of the constructive process and its products (Wetherell, 2001). The terms discourse analysis and discursive analysis will be used interchangeably.

2.1.3.2.   Discursive approaches in psychology

2.1.3.2.1.   Potter and Wetherell's approach

DA in psychology has its roots in a critique of traditional social psychology, originally articulated by Potter and Wetherell (1987). In this seminal text, Potter and Wetherell drew influence from linguistic philosophy, ethnomethodology, the sociology of science, semiotics and post-structuralist thought to propose a discursive approach which challenged assumptions at the heart of traditional psychology such as the notion of 'attitudes'. For instance, they suggest that an 'attitude' is a discursive act in a specific context which serves a particular function rather than a stable internal state.

They define discourse in an open way as "all forms of spoken interaction, formal and informal, and written texts of all kinds" which they contrast with a Foucauldian definition where discourse refers to "broader, historically developing linguistic practices" (p6-7). (I will come back to this). Within their approach, discourses or texts are approached "in their own right" rather than, in the realist tradition, as a route to something beyond, such as cognition, attitudes or events. They view language as being both "constructed" and "constructive": it is built from available resources (words, categories, common ideas, broader explanatory systems) and it builds versions of events and actions. Variation in peoples' accounting is to be expected, as talk is used for different purposes in different contexts e.g. blaming or justifying. DA aims to demonstrate the discursive processes involved in constructing the 'world out there'. Potter and Wetherell use the notion of the *interpretive repertoire* to refer to what might be termed in other DA analytic traditions as a discourse. Interpretive repertoires are defined as:

> recurrently used systems of terms used for characterizing and evaluating actions, events and other phenomena……constituted through a limited range of terms used in particular stylistic and grammatical constructions. Often….organized around specific metaphors and figures of speech (tropes)…(p 149).

2.1.3.2.2. Discursive Psychology

Edwards and Potter (1992) developed Potter and Wetherell's original approach in a particular direction, which they called *Discursive Psychology* (DP). Under this rubric they initially undertook to further critique traditional fields of psychological research such as memory and attribution theories. Their concern is with the *social action* being done with talk: how are events described and explained? how are factual reports constructed? how are cognitive states attributed? They are also concerned with issues of *stake*: the way that peoples' discourse is organised to resist actual or potential attempts to infer that they have particular interests. They draw on the idea of *rhetoric* as being a feature of everyday talk and suggest that rhetoric can be examined in order to identify the alternative arguments or versions of events which are being undermined. They outline nine *rhetorical devices* which are utilised by people in constructing factual accounts: summarised in *Table 1.*

Table 1: *Rhetorical Devices presented by Edwards and Potter (1992, p160-163)*

Device	Purpose
Category Entitlements	People in particular categories are expected to know certain things and the veracity of their account can be warranted by virtue of the category membership.
Vivid description	Used to create the impression of "perceptual re-experience" or indicate that the speaker has particular observational skills. Can also be used to package contentious or problematic events.
Narrative	Related to *vivid description*. Can be used to increase the plausibility of an account. Offers an opportunity for fusing memory and attribution or event description and causal explanation.
Systematic Vagueness	Converse of vivid detail. Can provide a barrier to easy undermining whilst at the same time proving the foundation of an inference.
Empiricist Accounting	Has characteristics of scientific talk and writing: treats phenomena as agents in their own right and either deletes the observer or treats them as a passive recipient.
Rhetoric of argument	Constructing claims in the form of a logical or well-known argument type which makes them external to the speaker.
Extreme case formulations	Can be used to make a claim or report more effect by drawing on extremes of relevant dimensions of judgement (Pomerantz, 1986)
Consensus and corroboration	A major way of warranting the factuality of an account by depicting it as agreed across witnesses or assented by independent observers.
Lists and contrasts	Lists, particularly three-part lists can be used to construct descriptions which appear to be complete or representative. Contrasts formulate a 'factual' version against a more threatening or unconvincing alternative.

Although in Potter & Wetherell's original approach they undertook analyses of interview data, proponents of DP promote the notion that data collected should be "naturally occurring" talk or text. The premises being that: the research setting is not influenced by the researcher's own categories, it avoids encouraging people to see themselves as disinterested observers of their own actions, it avoids the problems

inherent in making inferences from the research arena to the topic or practice, it is a rich record of life in practice (Hepburn and Potter, 2007). Other researchers have acknowledged the ethical and practical difficulties in obtaining such data (Willig, 2008). Harper, O'connor, Self & Stevens (2008) in reference to clinical psychology research, have suggested that semi-structured interviews can be suitable for DA research which aims to "map out" discursive resources available to speakers.

2.1.3.2.3.   Foucauldian Discourse Analysis

Foucauldian Discourse Analysis (FDA) is associated with post-structuralist theory. It is concerned with language and the role it plays in constituting elements of life (Willig, 2008). In psychology, the strand of DA articulated by Ian Parker has its roots in FDA (Willig, 2008). Parker (1997) argues that as DP has developed beyond Potter and Wetherell's initial approach, it has become distanced from issues of politics or power, making it less critical and more akin to mainstream psychology. He critiques the avoidance in DP of locating micro discursive practices in wider discourse. The kind of DA articulated by Parker (2005) is concerned with the oppressive versions of the world created by discourses, e.g. medical discourses define what is sick. He espouses a historically informed analysis which enquires as to how particular language has come to organise particular social bonds (*genealogy*). A key concern is with power and its operation to *position* people through language. Discourse is seen to locate people in *subject positions* which convey certain rights to speak and constrain what might be spoken (Parker 1997). Davies & Harré (1990) also utilise the notion of *positioning* whereby discursive practices locate particular subject positions and particular subjectivities: individuals can position others or they can position themselves through what is said. This is not necessarily an intentional process.

2.1.3.3. My approach

Wetherell (1998 p388) notes the two DA camps in social psychology: approaches rooted in ethnomethodology and conversation analysis, which undertake a "fine grain analysis" of the "action orientation" of talk e.g. DP; and those developed in the post-structuralist tradition informed by Foucauldian approaches where the focus is on discourse, power and subjectification. She argues for an integration of influences from both strands which will provide "the most productive basis for discourse work in social psychology". Taking this on board and in line with other DA research carried out within clinical psychology (e.g. Stevens & Harper, 2007; Harper, 1999) I plan to draw on aspects of each of the strands of DA summarised here. Hence in my analysis I will pay attention to the following features of talk, which might be considered three layers of analysis:

- The rhetorical devices used by participants in constructing their accounts and the functions these serve

- The *interpretive repertoires* drawn on by professionals in their talk and the subject positions and opportunities for actions these produce and constrain

- The relationship between the discursive features and wider societal discourses (in the FDA sense).

2.2. DATA COLLECTION

2.2.1. Questionnaire

2.2.1.1. Construction

The questionnaire (Appendix 1) was constructed to invite professionals to give an account of their practice and present a position on issues in relation to 'medication refusal'. I did not regard the questionnaire as a means of obtaining the "truth" about what goes on in services, but as a means of communication between the participants and myself (Marks, 2004) through which participants would construct a particular version of reality in the context of myself as a Trainee Clinical Psychologist (known or unknown to them) inviting such a response. The questionnaire includes questions asking for numerical responses, multiple-choice scenario questions and some open-

ended questions. In utilising a questionnaire which invited participants to select from pre-determined responses, I was aware that I was placing my own constraints on the accounts it was possible for professionals to provide and artificially de-contextualising the issues. To balance this to some degree and to provide participants with opportunity to 'resist' my constructions, I provided free space for participants to give alternative responses and comment generally on the topic and research.

2.2.1.2. Piloting

The questionnaire was piloted by two community mental health nurses (working in a CMHT and a community forensic team) who were invited to feedback on how "user-friendly" it was, how long it took to complete and any questions which were not clear. It was also looked at by a clinical psychologist (working in an early intervention in psychosis team) and reviewed by the multi-disciplinary "research governance" committee of a local NHS Trust. Minor adjustments were made to the questionnaire following feedback by these parties.

2.2.1.3. Format

The questionnaire was converted and distributed in an electronic format using the internet company "Survey Monkey" as detailed in Section 2.4.2.1.

2.2.2. Focus Groups

2.2.2.1. Rationale

The premise of the focus group is that a small number of people engage in an informal group discussion, focused on a particular topic or range of issues, which might be presented in various forms (e.g. a vignette, a film). I will briefly outline here why focus groups were selected as the means of data collection.

Focus groups are argued to be more 'naturalistic' than individual interviews and can be used flexibly within diverse theoretical frameworks, including constructionist

approaches (Wilkinson, Joffe & Yardley, 2004). They are suggested to be particularly useful for exploring "sensitive" topics, for instance Wilkinson describes her work on women's beliefs about causes of breast cancer (Wilkinson, 2008). Kitzinger & Barbour (1999) suggest that focus groups enable researchers to examine perspectives as they operate within a social network and explore how accounts are articulated, censored, challenged and changed through social interaction.

2.2.2.2. Constitution

There are advantages and disadvantages about the degree to which groups are hetero or homogenous. However it has been argued that a group which has a shared experience is often the most productive (Kitzinger & Barbour, 1999). Macnaghten & Myers (2007) add that it is also helpful if group participants share a certain way of talking. Madill, Gough, Lawton and Stratton (2005) suggest that for a student DA project, a minimum amount of interview data should be 3-4 hours. Based on these assumptions, I planned to hold four *uni*-professional focus-groups, which reflected the main professional groupings in community mental health teams: psychiatrists, nurses, social workers and psychologists. I hoped that this approach would create the conditions for diverse discursive resources to be drawn on by participants.

2.2.2.3. Vignette & Moderator Schedule

In order to provide a focus for discussion in the groups, I developed a case vignette of a service-user expressing that they were going to stop taking their antipsychotic (Appendix 2). I constructed the vignette influenced by case examples in published books about psychosis and real cases I had heard about. I aimed the vignette to be accessible and familiar to professionals across the different disciplines and types of community team. The vignette was reviewed by a community mental health nurse and a clinical psychologist for accuracy, plausibility and accessibility. Minor amendments were made following feedback. I did not intend that the vignette would be the only focus of the discussions, but that it would ease participants into discussion around the topic of interest. I developed a flexible interview schedule to

use as "group moderator" alongside the vignette to direct discussions in the groups around the topic and encourage opportunities for differing accounts to be made (Appendix 2).

2.2.2.4. Time & Venue

One focus group was held on university premises and the others were held on NHS premises. They were arranged at locations which were suitable to the professionals involved. Two of the groups were held at lunchtime and participants were provided with lunch, the other two were held late afternoon and participants were provided with refreshments. I had allowed for each focus group to run for approximately an hour to an hour and a half. The first two groups (social workers and nurses) lasted for just over an hour and the last two groups for just under an hour (psychiatrists and psychologists).

2.2.2.5. Session Plan

The sessions began with welcoming participants, reiterating the information in the Participant Information Sheet (Appendix 3) followed by signing consent forms, basic ground rules for the discussion and participants reading the vignette. I subsequently invited discussion through posing questions on the interview schedule.

2.2.2.6. Role of moderator

As moderator, although I posed initial questions, I took a relatively less "interventionist" stance (Macnaghten & Myers, 2007) in allowing participants to lead the discussion in a relatively free way. However, I monitored the degree to which participants appeared able to contribute and actively encouraged contributions from particular participants at times if it seemed as if some participants were being overly dominant. I also encouraged discussion and the expression of differing accounts through asking open question such as "have others had the same experience as X or..?". Additionally, I took a "curious" position by at times encouraging participants to elaborate on their contributions or asking for clarification on points made.

2.3. ETHICS

Given the nature of the study and that the participants were all qualified health professionals, no significant ethical concerns were identified. Participants were provided with sufficient information about the research in order to make an informed decision whether to participate (See Appendix 2, 3, 4, 5). All focus group participants signed a consent form (Appendix 6). Ethical approval was sought and obtained from the Hertfordshire Research Ethics Committee (Appendix 7). No objections were expressed and the committee approved the research without any amendments. In order to approach NHS staff, approval was sought and obtained from the Research and Development departments of the four Mental Health NHS Trust from which participants were recruited. The trusts were located in the Eastern and London strategic health authority regions. In order to protect the confidentiality of participants, the Trusts will not be named here.

2.4. PARTICIPANTS

2.4.1. Selection Criteria

The inclusion criteria were: a qualified mental health professional from any discipline, working in an NHS community mental health team which undertakes care-coordination for individuals with psychosis. Eligible teams were Community Mental Health Teams (CMHTs), Early Intervention in Psychosis Teams (EIPT), Assertive Outreach Teams (AOT) and Community Forensic Teams (CFT). Individuals working in teams undertaking short-term crisis work, but which did not care-coordinate were not eligible to participate, as I anticipated that a different range of issues would be presented in acute mental health service provision.

2.4.1.1. Survey

The aim was for the questionnaire to be completed by a variety of professionals in the different teams detailed above, so that a diversity of accounts could be collected. As there was no plan to undertake inferential statistical analysis on the data

collected, there was no target number of questionnaires to be completed beyond this aim. In sampling terms, it might be considered a "self-selecting" sample.

2.4.1.2. Focus Groups

It was planned that four uni-professional focus groups would be held which would reflect the main professional groupings in community mental health teams; namely psychiatrists, nurses, social workers and psychologists. As such, participants were recruited to the focus groups purposively on this basis. Pragmatic decisions were made about when to undertake focus groups based on dates which were suitable to the majority of potential participants within the time-scale of the project. As such not everyone who volunteered and was eligible to take part was ultimately able to do so.

2.4.2. Recruitment

2.4.2.1. Survey

Several strategies were used to recruit participants from the four NHS Trusts to complete the questionnaire. Whilst undertaking the research, I was on placement within an Early Intervention in Psychosis team in one of the NHS Trusts involved. I used the contacts that I had through my position in this team and existing contacts through previous work in local services, to cascade information about the research and stimulate interest from potential participants, mostly through email. In addition the following strategies were used:

1. Team managers were emailed and asked to distribute the email advert to team-members.
2. The advert was distributed through Trust e-newsletters.
3. A short pitch about the research was made to four local teams, with email follow-ups.
4. The research advert was distributed to the national membership of the British Psychological Society, Division of Clinical Psychology, Faculty of Psychosis and Complex Mental Health.

2.4.2.2. Focus Groups

Recruitment to participate in the focus group part of the research was done through the questionnaire. The questionnaire asked respondents whether they would be willing to participate further in the research by taking part in a focus group, and if so for them to provide an email address. Questionnaire respondents who expressed an interest and were located locally were contacted and sent an invitation letter (Appendix 5). If they continued to express an interest, they were sent the study information sheet (Appendix 3). Reminder emails were sent as necessary. Focus groups were arranged when there were a sufficient number of eligible volunteers available for each group. For logistical purposes, recruitment to the focus groups was undertaken from only one of the participating NHS Trusts.

2.4.3. Participant profiles

2.4.3.1. Survey

Seventy four questionnaires were completed. *Table 2* provides information on participant demographics of interest. It shows that there were a good spread of participants from the full range of professionals groups, types of team and number of years of experience. Of note is the relatively small number of psychiatrists participating compared to the number of Clinical Psychologists and Mental Health Nurses. Forty three respondents (60%) indicated that they had a particular interest in issues related to "antipsychotic medication, medication withdrawal or non-medical approaches to psychosis" (see Appendix 10) and as a whole, participants indicated that they undertook a broad range of duties as part of their professional role in their team (see Appendix 9). Participants provided information on the size of their caseloads, how many of their caseload had had psychotic experiences and how many were prescribed antipsychotics. This data is summarised in *Table 3*.

Table 2: *Profile of Survey Respondents*

Demographic of interest	Number of Respondents	Percentage of total
1. Team Type ▪ CMHT ▪ EIPT ▪ AOT ▪ CFT	29 34 10 1	39% 46% 14% 1%
2. Professional Status ▪ Psychiatrist ▪ Clinical Psychologist ▪ Mental Health Nurse ▪ Social Worker ▪ Occupational Therapist ▪ Psychotherapist	6 31 24 9 3 1	8% 42% 32.% 12% 4% 1%
3. Number of years qualified ▪ 0-2 ▪ 2-5 ▪ 6-10 ▪ 11-15 ▪ 15-20 ▪ >20	6 15 15 9 13 16	8% 20% 20% 12% 18% 22%
4. Number of years working in a community team ▪ 0-2 ▪ 2-5 ▪ 6-10 ▪ 11-15 ▪ 15-20 ▪ >20	8 23 20 12 9 2	11% 31% 27% 16% 12% 2%

Table 3: *Summary of information about survey participants' caseloads.*

Measure:	Mean		Median		Range	
Size of caseload:	20		15		3 – 99	
	Number	Proportion of caseload (%)	Number	Proportion of caseload (%)	Number	Proportion of caseload (%)
Approx number clients on caseload with current or past psychotic experiences	16	78	12	77	1 - 99	7 - 100
Approx number clients on caseload prescribed an antipsychotic	12	59	10	63	0 - 75	0 – 100

2.4.3.2. Focus Groups

Table 4 provides a profile of the participants constituting the four focus groups. All participants worked in either a CMHT or EIPT. Attempts were made to recruit participants from other types of team, but this was not ultimately possible. The reader will note that there was the addition of an occupational therapist to the social worker group. This individual was keen to take part and we decided in collaboration that being part of the social worker group was the most suitable position, in the absence of a group specifically for occupational therapists.

When the focus groups were originally conceived, I had planned for groups to contain approximately five or six participants. However, in practice it was difficult to achieve these numbers. I decided in collaboration with my research supervisors to run groups with a minimum of three participants; Wilkinson (2008) suggests that focus groups can be run with as few as two participants, although between four and

eight is the norm. The first focus group, which was for nurses, was run with three participants. I found that this worked well and rich discussion was had, so I was not concerned about later groups being this small.

As I have previously mentioned, decisions about the constitution of the focus groups were made pragmatically: the result was that some individuals knew each other in groups, some worked in the same team, and some were meeting other group members for the first time. Additionally, I knew some participants, worked alongside some, and had never met others before. These contextual factors may have influenced the ease with which some participants felt able to take part or felt excluded and the kinds of conversations which took place.

Table 4: *Profile of focus groups*

Focus Group	Team	Participant Code	Profession	Seniority In Team	Number of years qualified	Number of Years in a community team
1	All EIPT	N1	Nurse	Band 6	2-5	2-5
		N2	Nurse	Band 6	15-20	11-15
		N3	Nurse	Band 6	15-20	11-15
2	4 from EIPT; 1 from CMHT	SW1	Social Worker	Level 2	2-5	2-5
		SW2	Social Worker	Senior	6-10	6-10
		SW3	Social Worker	Senior	>20	15-20
		SW4	Social Worker	Not known	>20	15-20
		OT	Occupational Therapist (OT)	Senior	15-20	15-20
3	2 from EIPT; 1 from CMHT	MD1	Psychiatrist	Consultant	11-15	2-5
		MD2	Psychiatrist	Staff Grade	>20	0-2
		MD3	Psychiatrist	Speciality Doctor	11-15	6-10
4	All CMHT	P1	Psychologist	Consultant	15-20	15-20
		P2	Psychologist	Band 8A	2-5	2-5
		P3	Psychologist	Band 8A	2-5	2-5

2.5. DATA ANALYSIS

2.5.1. Questionnaire Data

The numerical results from the questionnaire were analysed descriptively using Microsoft Excel and the summarising facilities provided by Survey Monkey. Open-ended responses were examined and categorised. Extracts have been drawn on where relevant in order to examine and comment on positions taken by participants.

2.5.2. Focus Group: Stages of data preparation and analysis

Please refer to Section 2.1.3.3 for more information about the mode of DA utilised.

2.5.2.1. Recordings

Focus group sessions were recorded using a digital voice recorder. I listened to the recordings in their entirety as soon as possible after the groups were held, making initial notes on ideas which sprang to mind.

2.5.2.2. Transcription

I transcribed the first two focus groups in some detail, noting errors of speech, stutters, false starts, overlapping speech, pauses of three seconds and over, intakes and exhalations of breath, laughter and other non-verbal features, and clear emphases in speech. Punctuation was added to ease readability. Due to the time consuming nature of the transcription process and the time constraints on the study, the last two groups were transcribed by a private company (Appendix 8). I checked these transcripts closely against the recordings, corrected errors and added the features of speech detailed above. The transcription conventions used are detailed in Section 3.3.2. I made further notes of interesting features as I transcribed (See Appendix 15 for an example transcript[11]). After the transcripts had been prepared I initially read through each one as a whole at least once, paying attention to what was going on in the talk and making more notes.

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[11] This will be removed from publicly available versions.

2.5.2.3. Coding

Following the guidance of Potter & Wetherell (1987) the transcripts were read through and the text was divided into categories which were marked on the transcripts. This was an *inclusive* process, where instances of a category which were unclear or vague were still marked as such and extracts of text could be categorised under more than one category, as it was not clear at this stage how relevant different extracts might be. The process of coding is not seen as being part of the analysis, but as being a means through which the data can be divided into manageable chunks. An initial list of themes were identified as emerging from the data (Appendix 14). Relationships between the themes were explored and they were collapsed into broader categories. The extracts of text relating to these categories were electronically copied and pasted into separate category files for analysis.

2.5.2.4. Discourse Analysis

Potter & Wetherell (1987, p175) suggest that there is no method to discourse analysis in the traditional sense: it is a "broad theoretical framework concerning the nature of discourse and its role in social life". They suggest that profound changes in understanding take place through engagement with and repeated reading of the data. The analysis is seen as a fluid process of going back and forth between the stages of coding, analysis, validation, writing and back again. As I became increasingly familiar with the data, I found myself in a predicament: the data collected was rich with a multitude of potential themes to explore and many possible ways forward, such that I was unsure which path to take. This sense of confusion is apparently common, particularly for novice researchers (Harper et al., 2008). Potter and Wetherell (1987) suggest that the analysis should give *coherence* to the body of discourse and enable the reader to see how the discourse fits together to produce effects and functions. I noted that talk about 'risk' was a feature in every focus-group, was being used in rhetorically interesting ways and seemed to lend coherence to the body of data as a whole. I made a decision to narrow my focus somewhat and organise the whole analysis of the focus groups around the function of 'risk'.

3. RESULTS

3.1. SURVEY RESULTS

3.1.1. Introduction

In this section I will present the survey results. I have attempted to present the data in such a way that variability in the data are apparent for the reader to see.

3.1.2. How common is antipsychotic 'refusal'?

Forty nine participants (66%) indicated that at least one client on their caseload had expressed a wish to stop taking or not initiate antipsychotics in the past month (mean number of clients = 2; SD = 3). Sixty nine participants (92%) indicated the same for the past year (mean number of clients = 5; SD = 5). There was variation across respondents in terms of how frequent they reported this experience to be: *Figures 1 and 2* provide further details of the spread of responses. If we compare the proportion of reported incidences of clients 'refusing' antipsychotics in the past month with the number of individuals on antipsychotics on participants' caseloads (Section 2.4.3.1), we find a mean proportion of 17% (SD = 14; range = 0% - 60%) of clients 'refusing' per caseload.

3.1.3. Coming off antipsychotics

3.1.3.1. Past Year

Participants were asked to indicate how many of the clients in the past year who had expressed a wish to come of antipsychotics had started to do so. Forty nine participants (71% of those who had reported that a client had expressed a wish to stop taking antipsychotics) indicated that at least one of these clients had started to come off (mean number of clients = 3; SD = 2; range = 1 - 12). *Figure 3* provides further details of the variability in responses. On average participants reported that 40% of clients had started to come off antipsychotics with the support of the service, 60% had started to come off against advice.
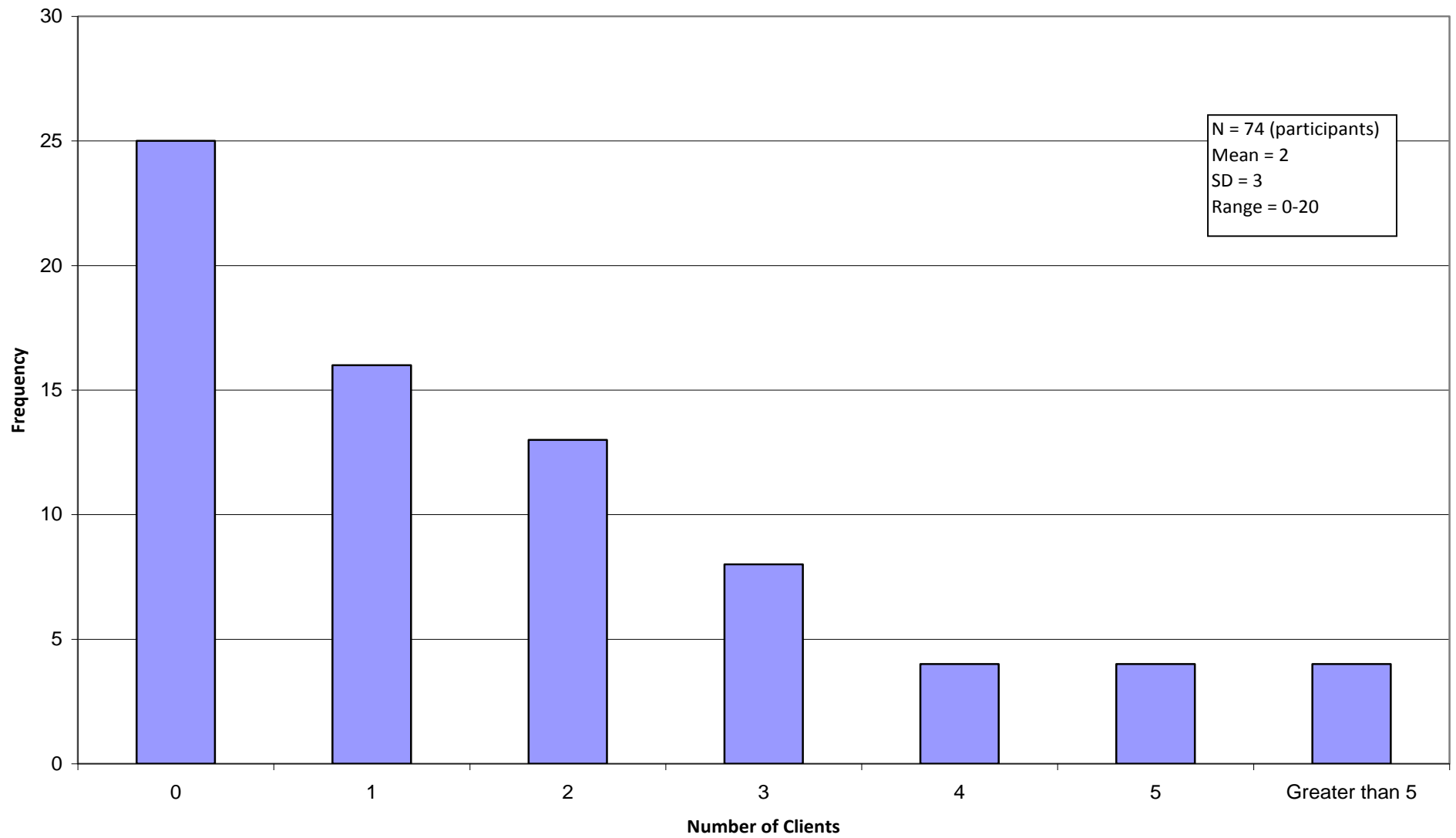
Figure 1: *Participant reports of number of clients expressing a wish to stop taking or not initiate antipsychotics in past month*
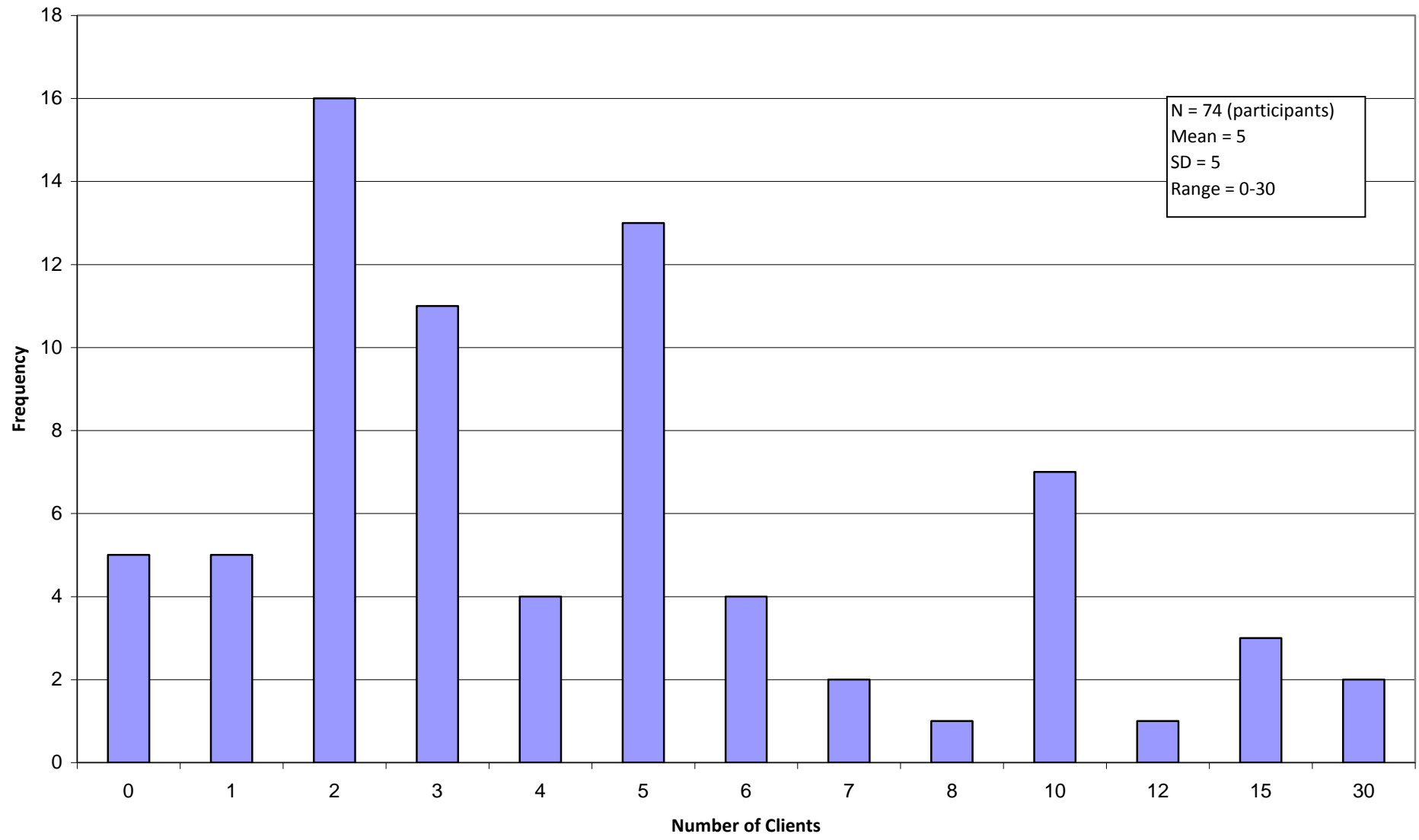
Figure 2: *Participant reports of number of clients expressing a wish to stop taking or not initiate antipsychotics in past year*
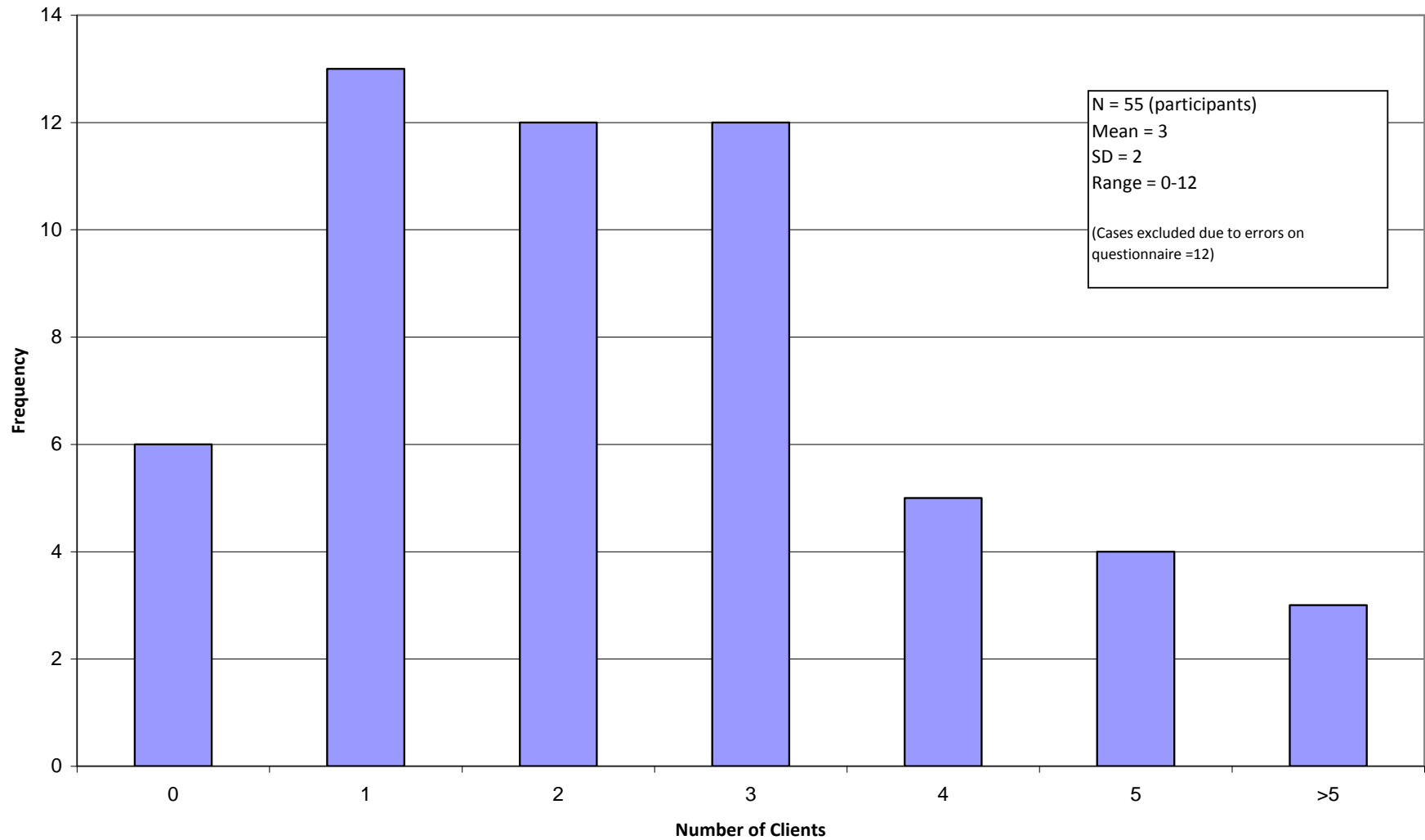
Figure 3: *Professional reports of how many of the clients who expressed a wish to come off antipsychotics in past year started to come off*

3.1.3.2. Past two years

Participants were asked to indicate how many clients they had supported to come off antipsychotics in the past two years. Forty four participants (59%) indicated that they had supported someone (mean number of clients = 5; median number of clients = 2; SD = 10). More details on the spread of the data are shown in *Figure 4*. As *Figure 4* shows, five participants reported supporting ten or more clients to come off (more information is provided about these participants in *Table 5*, which is discussed below), which appears to have inflated the mean, as such the median may be a more useful measure here.

A total of 208 clients were identified as having been supported to come off antipsychotics in the past two years. Participants were asked to rate the proportion of these clients which they deemed to have had a successful outcome for a "significant period of time". A standard definition of success was not provided: participants were free to define this. Overall, one hundred and eight cases were rated as successful (52%) and 98 were rated as unsuccessful (47%). The mean number of reported successful cases per participant was 3 (Median = 1; SD= 3; range = 0 – 18); the mean number of unsuccessful cases was 4 (Median = 0; SD=8; range = 0 – 55). As we can see in *Table 5*, Participant 67 reported that 55 cases were unsuccessful, which has substantially inflated the mean of unsuccessful cases and as such the median is a more suitable measure here. A further calculation was undertaken for each of the forty four participants as to their ratings of successful/unsuccessful for the cases they identified, as a percentage of the total number cases they supported to come off. The percentages were then averaged across the group: a 74% 'successful' rate was found across participants, with 55% of participants reporting 100% success; a 26% 'unsuccessful' rate was found with only 7% reporting 100% 'unsuccessful'.

Participants were asked to rate the proportion of cases where the medication discontinuation was initiated by them or by the client; the average proportions were 16% and 84% respectively.

From the perspective of exploring variation in responses and how participants have positioned themselves in relation to the questions being asked, it is interesting to take a closer look at the five participants who indicated that they had supported ten or more clients to come off medication: a more detailed profile is provided in *Table 5*. In this sample, a divide is apparent between the psychologists and psychiatrists in both the quantitative and qualitative data provided, with the three psychologists presenting a more optimistic position with regards to supporting clients to come off medication and the psychiatrists suggesting that only a small minority of people can manage without medication. For instance Participant 22 (Clinical Psychologist) presents a "coming off" success rate of 80% and comments: "I am developing a support pack with staff and service users, for people to use when they are planning to stop medication". Participant 54 (Consultant Psychiatrist) presents a success rate of 10% and comments: "I am not convinced that for all of them is treatment alternative to medication wise, as it could, in my opinion [….] progress illness faster..".

N = 44 (participants)
Total clients = 208
Mean = 5
SD = 10
Range = 1-60
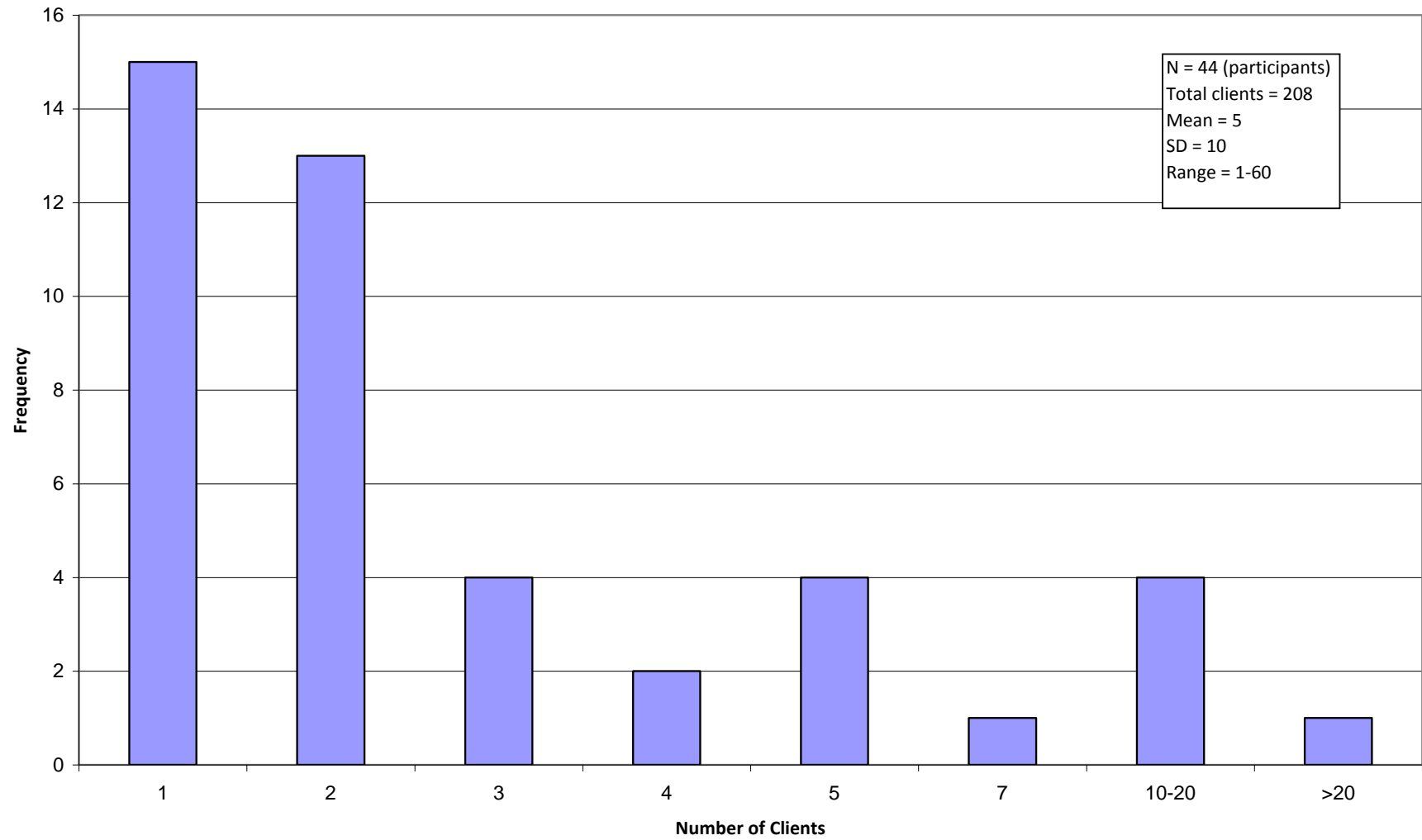
Figure 4: *Participant reports of how many clients they have supported to come off antipsychotics in past two years*

Table 5: *More detail on the five participants who reported supporting ten or more clients to come off antipsychotics in the past 2 years*

Survey Participant number	Profession	Team	Number of clients supported to come off in past 2 years	Number Successful/Unsuccessful		Number of clients with psychosis supported without antipsychotics in past 2 years	Comments made
19	Clinical Psychologist	EIPS	20	10	10	15	Nice guidelines suggest that following a first episode of psychosis, people take antipsychotic medication for at least 12 - 18 months. All people who use our service are informed of this and following this period many choose to reduce and stop it. People are supported to do this but also to restart it if they then experience early warning signs of further problems. Individuals feeling empowered and able to actively use medication in this way is one of the key outcomes of the service.
22	Clinical Psychologist	EIPS	10	8	2	12	I am developing a support pack with staff and service users, for people to use when they are planning to stop medication - but the decision to stop is seen as very much to be decided with the consultant psychiatrist. I think things are improving, but very slowly.
36	Consultant Clinical Psychologist	EIPS	20	18	2	10	These questions are difficult to answer because in our service clients may be prescribed neuroleptics for an initial time but then be encouraged to come off them for the remainder of their 3 years with the service

Table 5*: continued*

54	Consultant Psychiatrist	EIPS	10	1	9	30	Some questions of the questionnaire may be misleading or not easy to answer, because people with psychotic experience varies in their presentation and I am not convinced that for all of them is treatment alternative to medication wise, as it could, in my opinion anable tyo progress illness faster and lead quiker to chrinic state.
67	Consultant Psychiatrist	EIPS	60	5	55	5	what about being more specific re diagnosis. I think there will be a different approach to someone who has had a brief and self limited episode than what a person with a confirmed diagnosis of schizophrenia or bipoalr disorder needs. [….] What struck me was that we do not have any proper, reliable follow up studies in F23 to see how many of them will go on to develop further epsiodes or F20.

3.1.4. Professional perspectives on why people 'refuse' medication.

Participants who reported that they had worked with someone expressing 'medication refusal' in the past year, were asked to indicate the most common reasons people give. They were able to select up to four from a list of 13. They also had the option to indicate 'other' reasons. *Figure 5* depicts the results of this question. It shows that the most popular reason selected was "Adverse physical effects such as restlessness, un-controllable movements, weight gain, impotence etc.", followed by "Feeling too sedated" and "Feeling better/cured now".
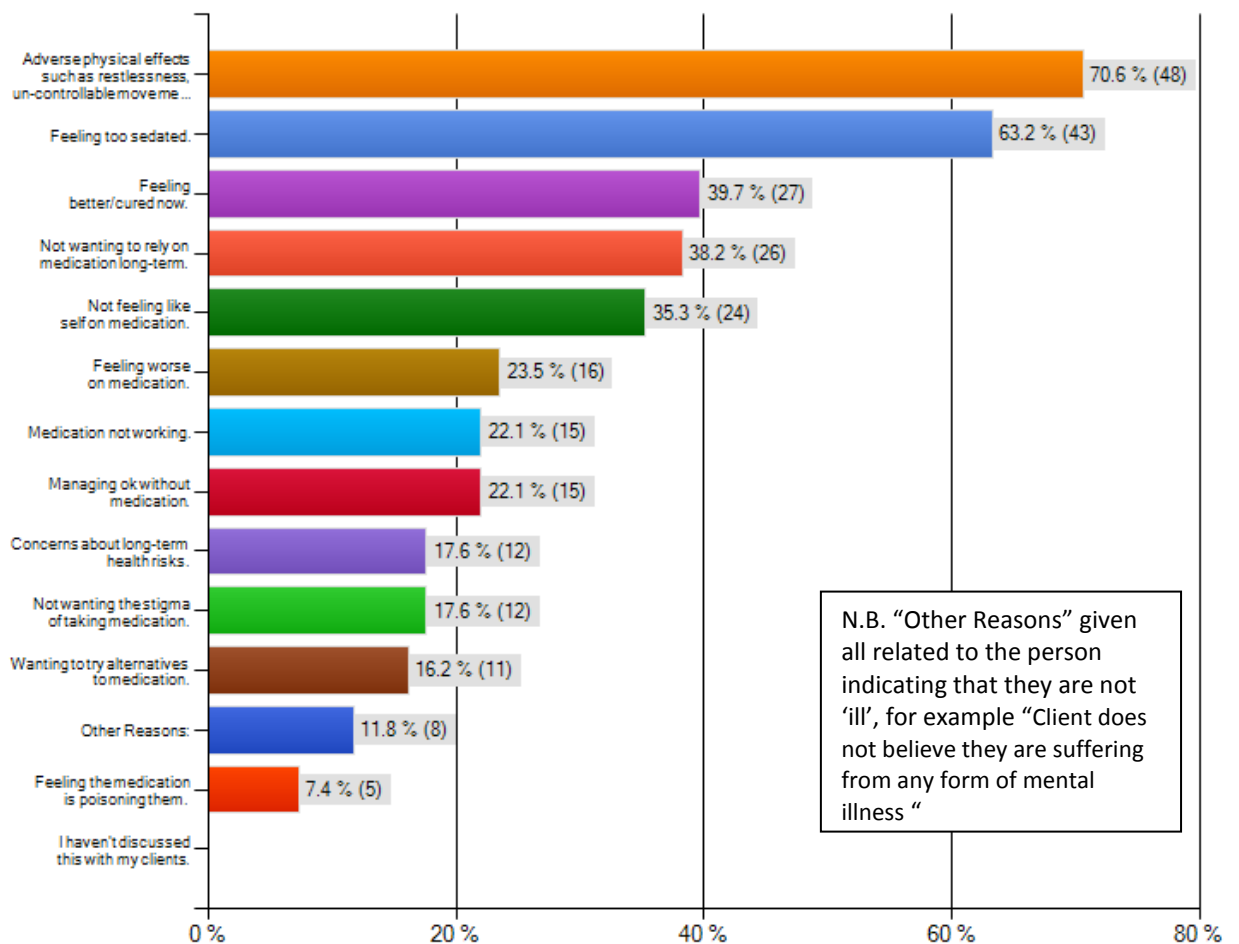
Figure 5: Participant selections of reasons people give for not wanting to take antipsychotics

3.1.5. Proposed actions taken if someone 'refuses' medication

Participants were asked to indicate what action they would take if a client expressed that they wished to stop taking or not initiate antipsychotic medication. They were able to select up to four from a list of 13. They also had the option to indicate 'other' reasons. *Figure 6* depicts the results of this question. It shows that the most popular choice was "Explore why..", followed by "Arrange or encourage an appointment with the psychiatrist" and "Discuss with the client the potential risks".
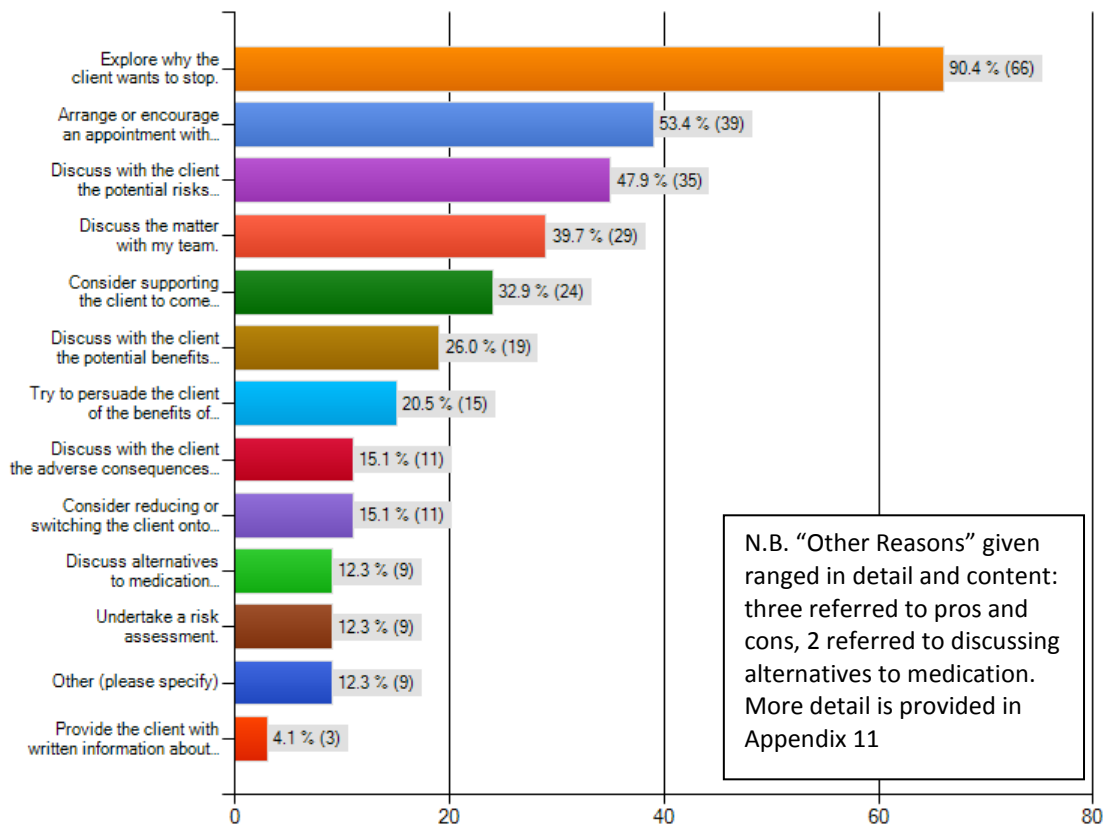
Figure 6: Participant selections of actions they would take if a client 'refused' medication

N.B. "Other Reasons" given ranged in detail and content: three referred to pros and cons, 2 referred to discussing alternatives to medication. More detail is provided in Appendix 11

3.1.6. Supporting people without medication

Participants were asked approximately how many clients with psychotic experiences they had supported without antipsychotics in the last two years. Fifty five participants (74%) reported that they had supported at least one person (Mean number of clients = 8; SD = 6; Median = 2; range = 0 -30). More details on the spread of the data are shown in *Figure* 7. Again we can see wide variation in participant responses on this question with numbers of people supported ranging from 0 to 30. This variation suggests that again the median is a better summary statistic here. More information about the one participant (Participant 54) who stated that they had supported 30 people is provided in *Table 5*.
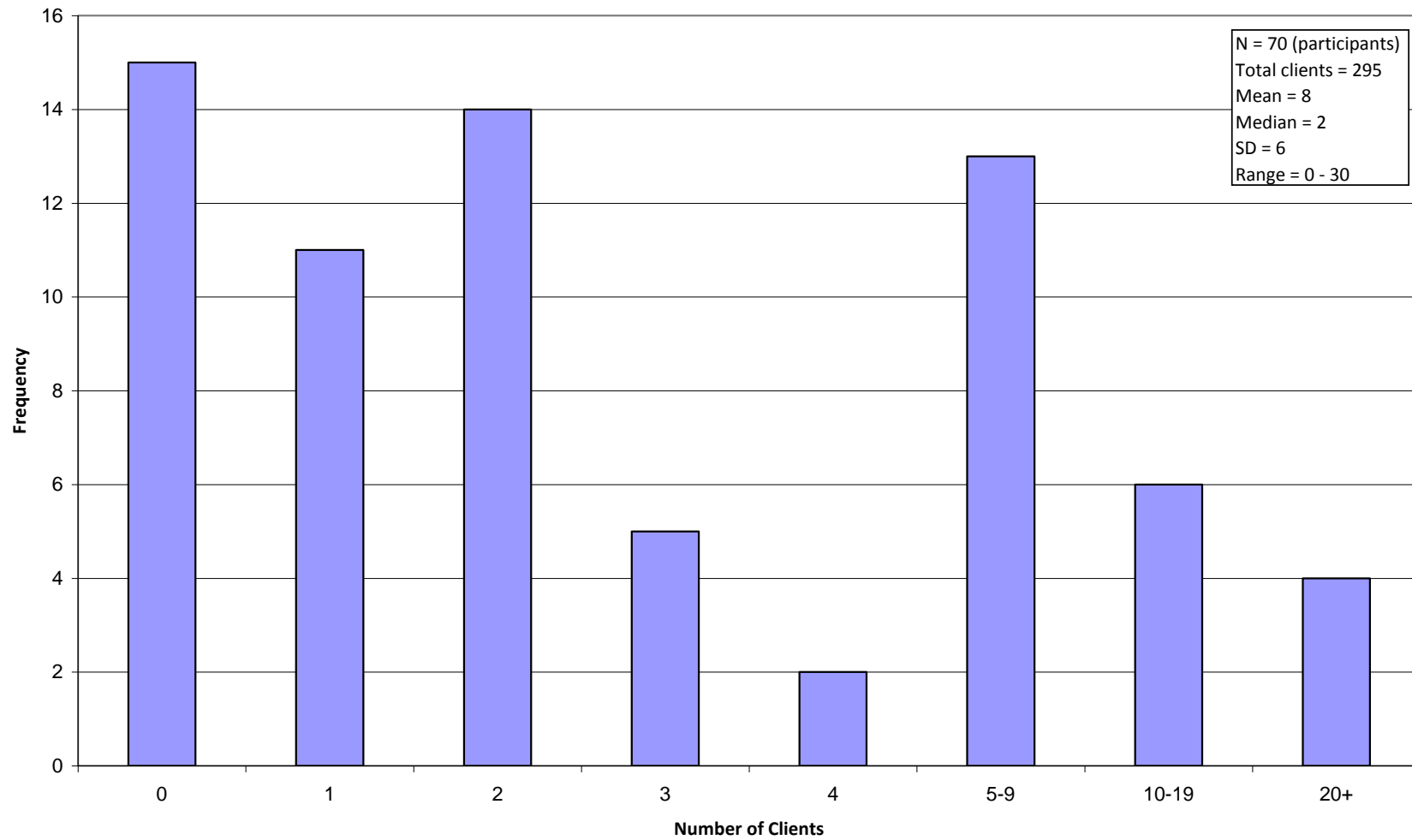
Figure 7: *Participant reports of how many clients they have supported without antipsychotics in past two years*

3.1.7. Confidence in working with these issues

Participants were asked to indicate on a five point likert scale from "not at all confident" to "extremely confident" their confidence in supporting clients to discontinue antipsychotic drugs. *Figure 8* shows the distribution of ratings. It suggests that on the whole participants position themselves as fairly confident in dealing with this issue, although a substantial minority (15) position themselves as not confident. Participants were asked to indicate what would increase their confidence. They were able to select up to three from a list of 8 options. They also had the option to indicate 'other' reasons. *Figure 9* shows the distribution of ratings. The most frequent choice selected was "Access to alternative interventions to support client", followed by "Resources to allow me more time to devote to supporting clients in this situation" and "More research evidence that clients are able to successfully able to manage without medication".
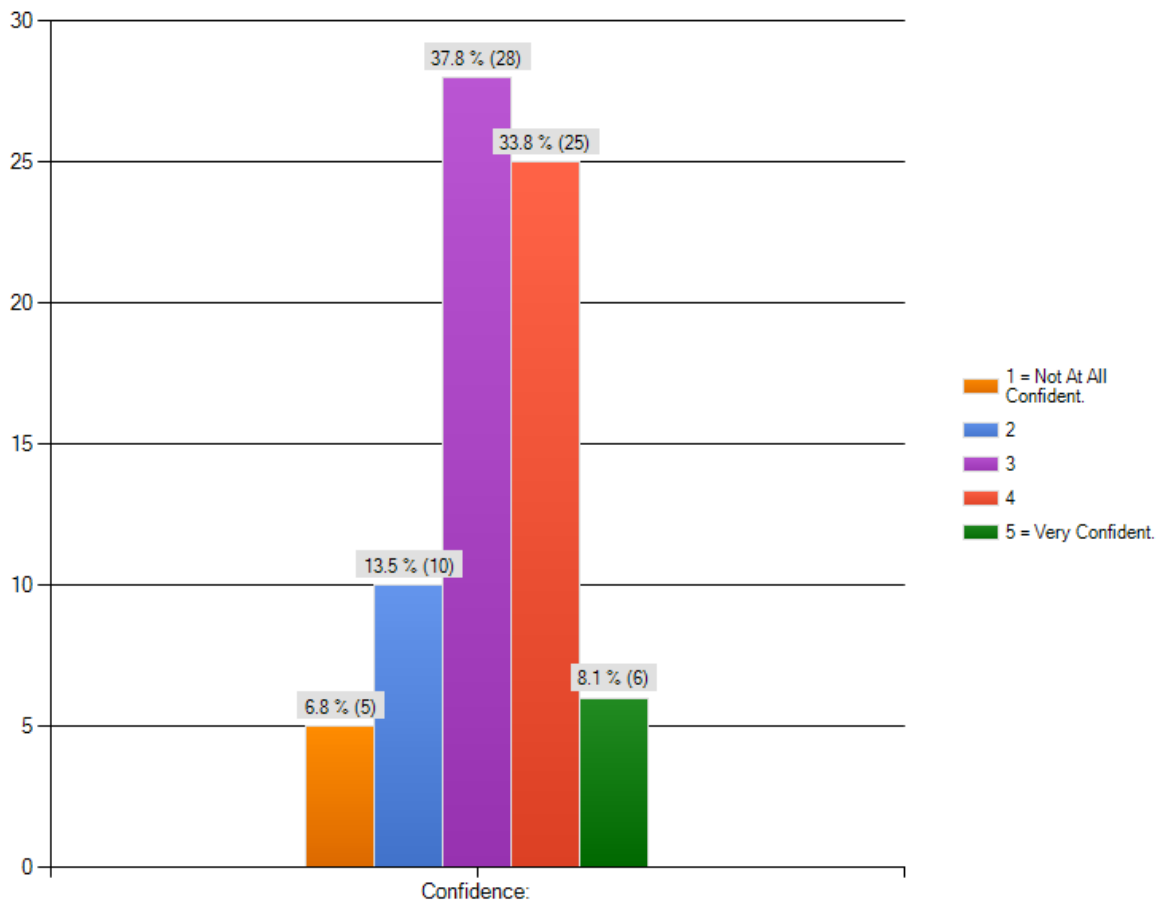
Figure 8: *Participant ratings of confidence in supporting clients to discontinue antipsychotics*
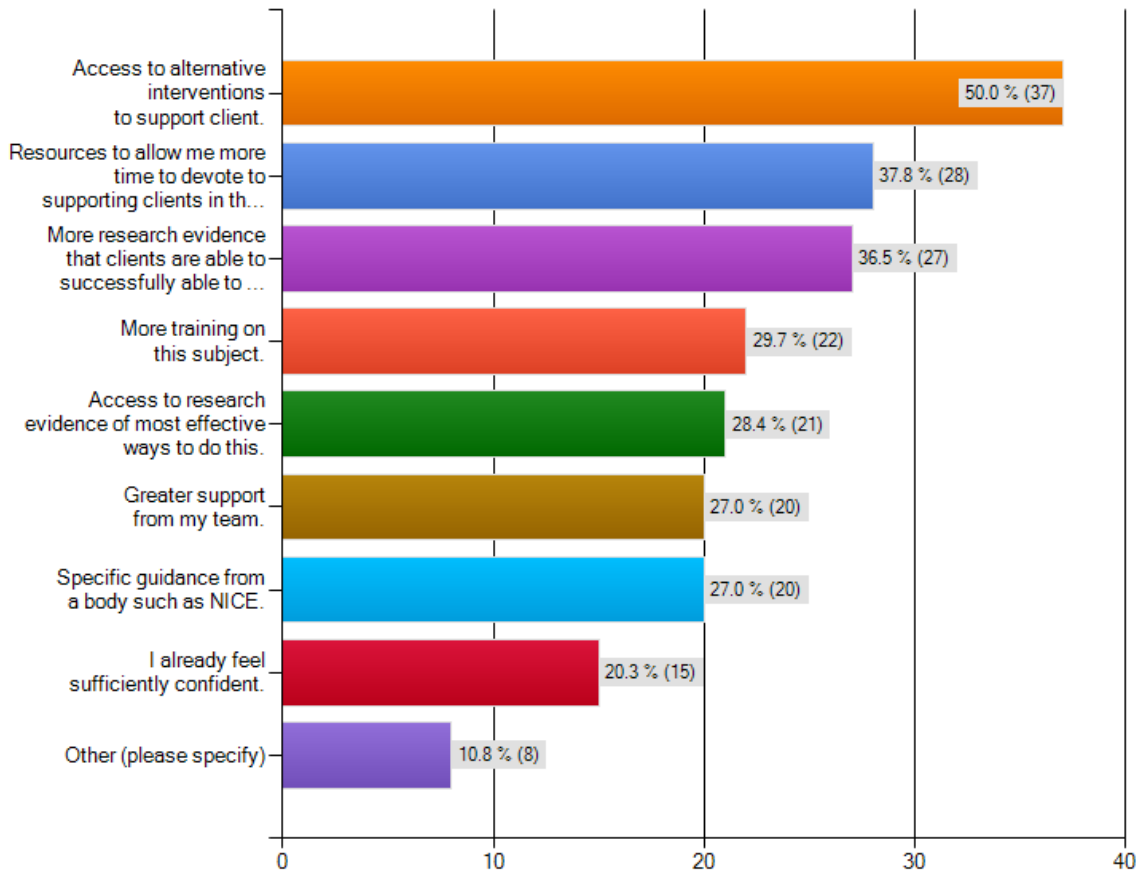
Figure 9: *Participant selections of what would help improve their confidence in supporting clients to discontinue antipsychotic drugs or manage psychotic experiences without drugs*

3.1.8. The relative influence of different stake-holders on decision-making

Participants were asked to rate to on a five point likert scale from 1 (minimal influence) to 5 (most influence), how much influence a range of stake-holders would usually have on the decision-making when a client expresses that they wish to stop taking or not initiate antipsychotic medication. *Figure 10* shows the results of this question in terms of relative proportion of each selection made for each stakeholder (see *Appendix 13*). *Figure 10* shows that there was considerable variation in responses. Overall, the client's psychiatrist was rated as having most influence (average rating of 4.27) followed by the client (average rating 3.87), followed by the care-coordinator (average rating 3.65).
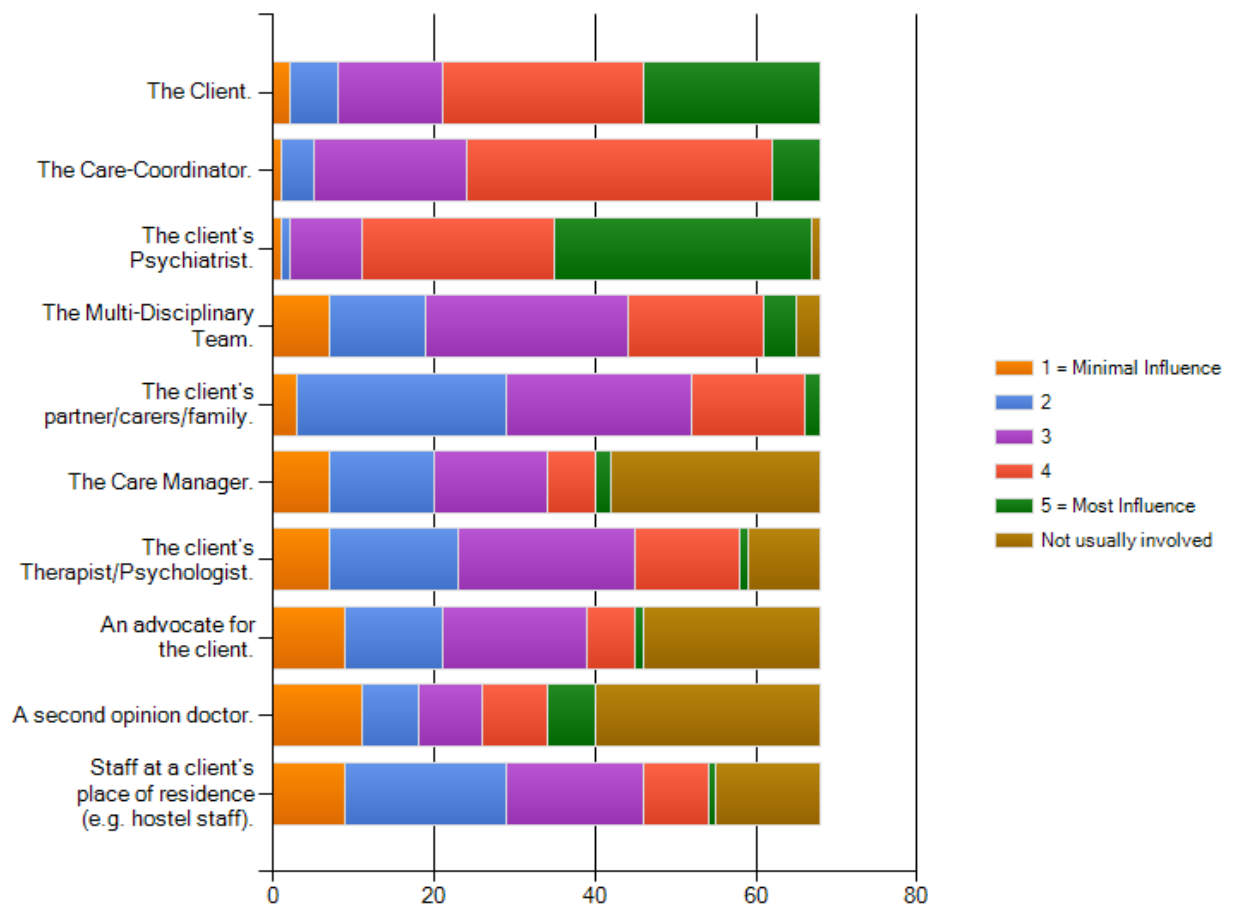
Figure 10: *Participant ratings of the influence of different stakeholders on decision-making in relation to clients 'refusing' medication*

3.1.9. Non-medical approaches

Participants were asked an open-ended question about the non-medical approaches or support services they provide or are available locally for clients with psychotic experiences. A wide variety of responses were provided: *Table 6* details the ten most frequently listed. Participants were also asked an open question about the non-medical services/approaches/extra resources they thought would be helpful to have locally. A wide-range of suggestions were made, some were suggestions of currently unavailable resources, many were related to improving quality, capacity or diversity of existing services. *Table 7* details the ten most frequently listed.

Table 6: *Most frequently mentioned non-medical resources available locally*

Approach or Resource	Frequency
1. "Groups" Specified and unspecified. Specified included: service-user support, sports, "recovery".	36
2. CBT	25
3. "Psychological Therapy" (unspecified) or Psychology	18
4. "Support" Approach or service.	16
5. Family Work Included "family interventions", Behavioural Family Therapy, Systemic Family Therapy.	14
6. "Hearing Voices" Approach or group.	13
7. Occupational Therapy	13
8. "Psychosocial Interventions"	12
9. Employment or Vocational Services	10
10. Day Centres/Services	9

Table 7: *Most frequently mentioned non-medical resources needed locally.*

Approach or Resource	Frequency
1. **Increased access to range of psychological therapies** Specified and Unspecified. Specified included: mentalisation approaches, counselling, family interventions, dialectical behaviour therapy, CBT.	21
2. **More community based activities** Statutory and non-statutory, including day centres, evening and weekend activities, OT activities, groups.	14
3. **More user-led approaches** Including support groups, peer support networks, buddy systems.	9
4. **Hearing Voices Groups**	8
5. **More support services** Including one to one support workers, befriending.	6
6. **Medication Support** More service-user information resources about medication, including coming off, medication support forums.	4
7. **Skills Training** Anger management, social skills, vocational skills.	4
8. **More carer/family support services**	3
9. **Increased tem resources/less paperwork**	3
10. **Alternative forms of service provision** Therapeutic community, respite facility as alternative to hospital.	3

3.2. SUMMARY

In this section I have presented the results from a survey of professionals about 'medication refusal'. A picture is presented by the participants of antipsychotic 'medication refusal' and discontinuation being a common occurrence. Although, there was wide variation in this. Discontinuation was reported to often occur against advice. A majority of participants reported that they had either supported someone to "come off" medication or supported someone without using antipsychotics. Success rates were reported to be relatively good. On the whole, the participants reported themselves as being fairly confident in supporting people without antipsychotics. Psychiatrists were constructed as being most influential in decision-making about medication discontinuation. A wide-range of non-medical interventions and resources were identified as being available to participants. Most participants indicated that access to a greater quantity and range of such resources would be helpful.

3.3. DISCURSIVE ANALYSIS

3.3.1. Introduction

The aim of this section is present the discursive analysis undertaken of the focus group data. Wood and Kroger (2000) discuss the dilemmas involved in how to organise a discourse analysis, with possibilities including structuring it around specific devises, strategies or functions and presenting it on a case by case basis or across cases. They add that data can always be returned to and worked up with additional claims at a future date. I decided to structure my analysis across groups, rather than examine each group in turn. I have, however, made observations about differences between groups where pertinent.

A concern within discourse analysis, is the relative importance placed on the *frequency* of occurrence of particular features in the data. Harper et al. (2008) suggest that the frequency of occurrence is less important than whether a feature is *culturally available*, who said it and in what context it was said. Bearing this mind, I have placed more emphasis on the availability and context of particular features rather than their frequency.

Mine is not a definitive reading of the data and other researchers might have directed their focus elsewhere and structured it differently. I am aware that the choices I have made mean that there are aspects of the data which have not been attended to, or have not been looked at in depth. I would hope to come back to the data at a later date to add to the analysis.

3.3.2. Reading: Some Assumptions

In presenting a discourse analysis, Potter & Wetherell (1987) state that a set of examples should be drawn on, along with detailed interpretations, to link specific claims to specific aspects of the extracts. The goal being that the reasoning process from the data to the conclusions is documented and can be evaluated by the reader. I aim in my analysis to make the basis of the claims I make transparent through a

detailed examination of extracts drawn from across the four focus groups. Each extract will be presented with original line numbers from the transcript, so that the reader can get some sense of where in the transcript the extract was taken from. In referencing features of the extracts presented I will refer to line numbers in brackets: (50-51). Harper (2008) notes the importance of acknowledging the researcher's contributions in order to provide context to interviews: I have attempted to make my role clear in the extracts used and situate each extract in the discursive context in which it occurred. I have at times drawn on wider professional literature to clarify, backup or contest claims being made: this will be expanded on in Section 4.

The basic principle underlying a discursive approach is that talk fulfils many functions and has different effects (Potter and Wetherell, 1987); that is not to say that this is necessarily an intentional process and individuals may be entirely unaware of what is being done through their talk much of the time.

To aid the reader, *Table 8* summaries the transcription conventions used in the extracts and the codes representing the participants.

Table 8: *Symbols and conventions used in extracts*

Transcription Symbols		Participant Codes[12]	
[square brackets]	Overlapping Speech	M:	Moderator (myself)
Number in brackets (4)	Pause [13]		
//	A turn follows rapidly from another with no perceptible gap (latching)	N1:	Nurse 1
(xxxxx)	An utterance which is impossible to understand and could not be transcribed.	N2: N3:	Nurse 2 Nurse 3
((text))	A non-speech element such as laughter or a descriptor e.g. ((whispered))	SW1: SW2: SW3: SW4:	Social Worker 1 Social Worker 2 Social Worker 3 Social Worker 4
Wor-	Utterance is broken off	OT:	Occupational Therapist
Emboldened	A clear emphasis on the word	MD1:	Psychiatrist 1
[.....]	Excision: some data omitted	MD2:	Psychiatrist 2
co::lons	Indicates an extension of the preceding vowel sound	MD3:	Psychiatrist 3
.hh	Intake of breath (number of hh indicates length)	P1:	Psychologist 1
Hh	Out breath (number of hh indicates length)	P2: P3:	Psychologist 2 Psychologist 3
…….	Speech tails off		

[12] See Section 2.4.3.2 for more information about the participants
[13] Only clear pauses of >3 seconds were transcribed.

3.3.3. 'Risk Talk'

Participants talked implicitly and explicitly about a range of, often conflicting, 'risks' as being present in the course of their work. I have attempted in my analysis to map out the main resources which appeared available to be drawn upon by the participants in the focus groups in talking about 'risk', in relation to the overall topic of discontinuing antipsychotic medication. I have summarised this 'map' in *Table 9*. The different strands which I have identified and made claims about are not necessarily distinct from each other, rather there are overlaps and complex links between them. In this analysis I will not be examining the 'truth' or 'reality' of the 'risk/s' discussed, rather I am interested in the different ways in which 'risk' features in the professionals' accounts to achieve certain rhetorical effects, how it constructs and positions different stake-holders and how it warrants certain courses of action and excludes others.

Table 9: *Map of 'Risk Talk' Analysis*

Function	Resources
1. **Constructing people with 'psychosis' as risky**	▪ The *risk to self or others* repertoire ▪ A Biomedical Construction ▪ Adding to the risk: Substance Abuse ▪ The *diagnosis as a measure of risk* repertoire
2. **Constructing Professional 'Responsibility'**	▪ 'Risk' as a 'disclaimer' ▪ The '*we can take more risks these days*' repertoire ▪ The *Professional Anxiety* repertoire ▪ The *Duty to Society* repertoire ▪ The Dilemma Device
3. **Constructing 'Coercion' Vs 'Freedom & Choice'**	▪ The '*Working in Partnership*' repertoire ▪ Persuasive Talk ▪ A question of 'insight'?
4. **Constructing 'Risks' to Service-Users**	▪ Legitimising Vs Minimising the 'risks' of Medication ▪ The 'risks' of psychosis

Table 9: *Map of 'Risk Talk' Analysis*

3.3.4. Constructing people with 'psychosis' as risky

Participants constructed people with 'psychosis' as posing 'risks' to themselves, their families, "others" and to professionals. I will explore these claims in this section.

3.3.4.1. The risk to self or others repertoire

Participants often referred in a characteristic way to service-users posing risks to themselves or others, which I have termed the *risk to self or others repertoire*. *Extract 1* might be seen as an example of this. It is taken from the beginning of the nurses' focus group when I first invite participants to comment on how they would respond in the vignette scenario of 'Mark' expressing that he is going to stop taking his antipsychotic medication (Appendix 2).

> *Extract 1: Nurses*
>
>   3. N1: You really have to assess the risk, in terms of eh,
>   under the mental health act. If, if the risk was great enough. (4)
>   M: What, what factors do you think you'd need to consider in that
>   respect?
>   7. N1: Um, thi this seems ((laughs)) very familiar to me [cos]
>   M: [mm]
>   N1: I've got a patient who I've been through this with and he's on erm
>   oral Risperidone as well and it was the same um dosage as well. Erm,
>   11.   ((hhh)) His current mental state? Does he remain psychotic? Is he
>   functioning? Erm. Is he in any distress? Is he a risk um of harming
>   others? Or is he (4) he his current mental state.

Nurse 1 (N1) begins her account in an *empiricist*[14] style referring vaguely to "the risk" which "you really have to" "assess" (3). 'Risk' is constructed matter-of-factly here as a unitary thing which is 'out there' to be routinely and objectively "assessed" in order to make decisions "under the mental health act". The lack of elaboration about *what* 'the risk' is and *how* it is assessed gives the impression that there is an implicit understanding by others present of what is meant. The pause of 4 seconds at the end

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[14] Please refer to Section 2.1.3.2.2 for a definition of this rhetorical device

of line 4 suggests that N1 has completed her contribution: further explanation is not required. This way of talking helps to rhetorically construct *consensus*[15] amongst those present, which, alongside the *empiricist* style, strengthens N1's account. Her use of the pronoun "you" and modal "*have* to" (3; my emphasis) add to the consensus effect. This is orientated to by the other two members of the group who both later on in the discussion refer back to this, for example: "again it depends on the risk" (Nurse 2, 17); "And it's again m- my obligation is to assess that risk" (Nurse 3, 443). N1 appears to orientate to my question (lines 5-6) as a challenge to the consensus, which she responds to by elaborating and further strengthening her case (as discussed below).

Reference to the 'mental health act' clarifies, for 'those-in-the-know', that N1 is talking about 'risks' posed by service-users such as Mark and consideration of hospitalisation "if the risk was great enough" (4). Reference to the mental health act and associated terms was a common feature of this repertoire. In making reference to the legislation of the mental health act, N1 explicitly positions herself in the mental health professional role, a role from which she is entitled to speak about 'risk' and its 'assessment', adding authority to her account. This could be contrasted to a service-user, such as Mark, whose authority in talking about such issues could be undermined by their non-professional status or by positioning them as 'mentally ill' (as I show below).

After my question (lines 5-6) N1 switches from the initial *empiricist* style to a first person *narrative* account; referring to her familiarity with a scenario like Mark's. Her claim that "I've got a patient who I've been through this with" (9) acts to strengthen the plausibility of her subsequent account. N1 returns to the *empiricist* style by *listing* the "factors" involved in assessing risk. Lists are used as a rhetorical device which can give the impression of a complete description; I found that lists of this kind often featured in the *risk to self or others repertoire* and added to the impression of a

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[15] Please refer to Section 2.1.3.2.2 for a definition of this rhetorical device

carefully considered sequence of actions, inoculating against possible criticism that such decisions are made hastily.

Shorter forms of this repertoire were also present in the focus groups, for example as demonstrated by Psychologist 2 (P2) in *Extract 2.*

Extract 2: Psychologists

256. P2: [.....] Well it's

risk, it's going back to risk I suppose. Both for him and his family and

other people.

It appears that this repertoire can serve as a 'bottom line' argument which can be drawn on by professionals to justify their actions, including potentially coercive 'treatment' and as such is extremely difficult to challenge. The repertoire obscures the power differentials between professional and service-users to define the 'risk'. A similar repertoire, '*The life-saving repertoire*', was identified by Stevens & Harper (2007) as a justification for compulsory treatment in their discursive investigation of professionals' accounts of ECT.

3.3.4.2. A Biomedical Construction

'Psychosis' was almost always constructed by participants in biomedical terms and even if this was not done explicitly, the language used implied this. There were numerous references to "illness", "disorder", "unwell", "relapse", "patient", "treatment", "diagnosis" in all groups. One effect of this is that it builds a case for the obviousness of a biomedical solution, i.e. medication. An exception could be found in the Psychologist group where Psychologist 1 (P1) refers specifically to a psychoanalytic model of psychosis where it is seen as an "adaptation…to..some…profound internal conflict" (33) and there is some discussion about the idea of "therapeutic community". However, P1 goes on to say "who knows about the legitimacy or validity of ideas like that" (964-965) and the dominant construction appears to hold strong.

In *Extract 1* (9) we see N1 move from the legal to the biomedical: N1's use of the term "patient" helps to mark this, implicitly defining her contrasting role as 'nurse' and the expertise inherent in this. Reference to "mental state," "psychosis" and "functioning" (11-13) serves to locate the 'risk' within underlying mental illness. This provides several functions: it challenges the rationality of Mark's apparent decision to stop taking his medication; it again demarks this as an arena where the expertise of a mental health professional such as N1 is needed and her abilities to 'assess' such 'risks'; and it warrants the continued use of 'antipsychotic' medication, if necessary through coercion. We see a similar argument constructed by MD1 in Extract 3.

Extract 3: Psychiatrists

462. MD1: [.....] he

was never, I understand, **aggressive** before, **explicitly** never
followed by police or something like that, but, but behaviour
seems, if he will deteriorate, it is potential, potential **risk** yeah.

466. ((.h)) So in this case, exactly, I would say that, in ideal world there
would be two people to go go go to see the client

In this extract we can see that although MD1 concedes that Mark was "never...aggressive" (463) she suggests that there are future risks if he were to "deteriorate". Mark is positioned without agency at the mercy of presumed pathological processes and as such the 'risk' is an unknown quantity. MD1 suggests that as an apparently precautionary measure against the risk Mark might pose to professionals, two professionals should be visiting him. Although her reference to "ideal world" suggests that this may not happen in practice. The construction of 'risk' here as being variable and perhaps difficult to measure contrasts with N1's account in *Extract 1* where 'risk' is constructed as something which is objectively measurable, suggesting the flexibility of risk repertoires. However, both forms of the argument can serve to warrant caution and potentially more restrictive intervention. The

argument for the variability and unpredictability of risk, by virtue of the assumed disease process, potentially warrants greater levels of restriction to more people.

3.3.4.3. Adding to the risk: Substance Abuse

We saw in *Extract 3* the construction of service-users being a risk to professionals. Service-users with a psychosis could be further constructed as being more 'risky' to professionals by reference to their potential alcohol or illegal drug use, as demonstrated in *Extract 4*.

> *Extract 4: Social Workers*
>
> 1051. SW3: [....] if you visit
>
> someone, and they're **not** taking drugs or **not** abusing alcohol, if they are taking their medication, you're on a fairly safe bet that when you go and see them at home, you you you feel fairly erm,
>
> 1055. y'know certain that that erm y'know they're going to be reasonably OK. **However** if if they're **regularly** taking or abusing drugs and alcohol, who knows what you're gonna find when you//
>
> SW1: //Mm//
>
> 1059. SW3: //come to the doorstep really [....]

In this extract Social Worker 3 (SW3) appears to make two main points: (1) if someone is taking their medication, they are predictable and less risky (1051-1056); (2) if someone regularly uses alcohol or drugs they become an unknown quantity and pose potential 'risks' to visiting professionals (1056-1059). Although we can see that SW3 is somewhat hesitant in his first claim: "you you you feel fairly erm y'know" (1054-1055) and *hedges* his argument ("fairly" and "reasonably") possibly suggesting the problematic nature of this claim.

Service-users here are attributed agency: they can take or not take prescribed medication and can take or not take drugs and alcohol. Being attributed agency allows for judgements to be made about whether behaviour is 'responsible' or 'irresponsible'. The implication here is that taking prescribed medication is

responsible and taking drugs or alcohol is *irresponsible*. There are thus discursive resources available for professionals to blame service-users for their actions and 'riskiness'. There was also an alternative repertoire of optimism around service-users with a diagnosis of 'drug-induced psychosis'. Here 'psychosis' could be located as a consequence of drug-taking with the presumption that if drug-taking stopped, the psychosis would relinquish, without the need for long-term antipsychotic 'treatment': "very often they'll come off the medication and never relapse as long as they look after themselves by not taking drugs again" (Nurse 1; 498-499). Again the service-user is being attributed agency and responsibility: in this case for preventing future ill health. We can also see here the influence of 'diagnosis', which is elaborated on in the next section.

3.3.4.4.   The diagnosis as a measure of risk repertoire

'Diagnosis' was a further resource available for participants to draw on in their construction of 'risk' posed by service-users. *Extracts 5 & 6* demonstrate the different ways in which this might be done.

> ### Extract 5: Psychologists
> 173.   P1: […] but I find myself **over** responding or
>   responding in a more erm **active** way with clients in this position
>   (compared) to clients with other diagnoses.
> .   M: Right.
> 177.   P1: The diagnosis becomes a very **heavy** part of the ((.hh))//
>   M: //Mm//
>   P1: //gravitational field.

In *Extract 5*, Psychologist 1 (P1) is responding to my question about the relative influence of 'risk' in responding to Mark's case (following a prior discussion of 'risk' by the group). In his first person account he positions himself without agency "finding" himself "**over** responding" to the "diagnosis" (173-175) which is attributed agency. The metaphorical comparison to "gravity" (177-179) constructs a psychosis

diagnosis as a powerful force over which one has no control but can observe its effects. As such P1 is suggesting that he is an innocent bystander and cannot be held accountable for his presumption of 'risk' and subsequent "**over** response". The term "over respond" is vague and perhaps glosses actions which P1 might not want to be associated with as a psychologist, who might usually construct himself as an ally of the "client" (as psychologists do elsewhere in the focus group). In locating agency within 'diagnosis' he is able to inoculate against possible criticism for his "over response".

One could also read P1's account as locating agency in psychiatrists who would be the authority giving the diagnosis. If we read it this way, we can see that this account is denying responsibility for constructing service-users with a psychosis diagnosis as risky and allocating blame at the door of psychiatry. Given this reading, it is interesting to compare this account with Psychiatrist 3's (MD3) account in *Extract 6*.

Extract 6: Psychiatrists

950. MD3: But that's why it's important, the assessments, get the initial
             assessment//

     MD1: //Yeah yeah yeah//

     MD3: //as soon as possible, you should **know**, what kind of patient you

954.   are going to treat.

     MD1: Yeah ((softly))

     M: And what ((hh)) I don't know, what, what would you be thinking in,
             in terms of, w- would it point you in different directions?

958. MD3: O- o- Obviously take more risks, because um, maybe just that it, it's
             a transitory situation, err, stress disorder, uh, acute something,
             acute, lets say psychosis in a person who otherwise is not
             psychotic.

962. M: Mm.

     MD3: There are, psychiatry is not a, so clear as all//

     MD1: //Yeah yeah//

     MD3: //so we can make mistakes all the time, uh, [we..]

966. MD2: [No litmus,] litmus test they call it you know//

     M: //Mm//

     MD2: //you can't test it, this problem.

     MD3: But if you are in front of you (xxxx) a paranoid schizophrenic

970.   patient//

     MD1: //Mm//

     MD3: //you know that this guy has to take medications//

     MD1: //Yeah//

In *Extract 6* MD3 like N1 in *Extract 1* constructs 'risk' as being something which can be objectively assessed, in this instance by virtue of the diagnosis: "you should **know**, what kind of patient you are going to treat" (953-954) because depending on the diagnosis you can "O- o- Obviously take more risks" (958). MD3 then makes a rhetorically interesting argument in which he shows what Antaki and Wetherell (1999) term "concessions". He shows concession to the possible counter-argument that diagnosis is unreliable: "psychiatry is not a, so clear" (963); "we can make mistakes" (965). He is joined in this concession by Psychiatrist 2 (MD2): "No litmus,

litmus test" (966). We can then see what has been termed a *concessionary marker*: "But" (969). This marks the end of the concession and indicates that what follows is contradictory. He goes on to restate the original proposal that diagnosis indicates risk, by using the example of "a paranoid schizophrenic patient" (969), which he is suggesting is a clear-cut diagnosis, concluding categorically that such a patient "has to take medications" (972). The use of the modal "has" again sets the scene for potentially coercive action.

Antaki and Wetherell suggest that including a concession strengthens an argument by making it less open to challenge. MD3's argument is further strengthened by his *category entitlement*: as a psychiatrist he has the authority and expertise to make such diagnoses. We can also see here elements of a tautological argument: how do you know this person is risky: because he is a paranoid schizophrenic: how do you know he is a paranoid schizophrenic: because he behaves riskily. We can see how it would be very difficult for a service-user to challenge the case being made here.

3.3.5. Constructing Professional 'Responsibility'

We saw in my analysis of N1's account in *Extract 1* that she presented 'risk assessment' as being an obligatory part of her 'role'. In this section I will further examine the accounts the participants gave about their 'roles' in relation to 'risk', particularly in constructing professional 'responsibility'.

3.3.5.1. 'Risk' as a 'disclaimer'

Hewitt and Stokes (1975) frame a 'disclaimer' as a verbal device which is used 'ward off' potential attributions of an undesirable identity or characteristic in what is about to be said, for example "I'm not racist but". Focus group participants seemed to draw on 'risk' as a disclaimer, as I have underlined in *Extracts 7&8*.

Extract 7: Nurses

382. M: So if in, you talked *N3* about, theres some instances where, people

do stop taking their medication. ((.hh)) Would there be situations

where you would actively, support that or or agree to disagree//

N3: //Erm//

386. M: //But//

N3: //There are situations where I would actively support that//

N1: //Mm

N3: <u>And obviously you take in mind the risk, the legal status,</u>

Extract 8: Psychologists

250. M: So there's **part** of you that would want to support what he's saying,

but//

P2: //Mm//

M: //part of you that feels like there's nothing there to support that//

254. P2: //Yeah//

M: //that decision, for him.

P3: Yes, that I I would want to um, make sure that he would. <u>Well it's risk, it's going</u>

<u>back to risk I suppose.</u> [....]

The form of the disclaimer I identify is somewhat different to the classic form described by Hewitt and Stokes, but none-the-less appears to serve the same function, in this case as an apparent attempt to defend against the accusation of not behaving responsibly. In both of these examples Nurse 3 (N3) and Psychologist 2 (P2) use the 'risk disclaimer' when I question their position on potentially supporting service-users who want to stop taking medication. It appears that to readily take a supportive position in this respect can be problematic for professionals and my reading is that this is because of the potential for this position to be constructed as professionally *ir*responsible.

3.3.5.2. The 'we can take more risks these days' repertoire

The 'talk' drawn out from the groups and presented so far has on the whole constructed 'risk' as something to be avoided and this was the dominant construction. However, there were accounts where 'risk *taking*' was talked about. *Extracts 9* and *10* are examples.

Extract 9: Social Workers

417. M: So given the **boundaries** of the systems in which you work, do you feel you can **respond** as you'd like to in these this kind of situation?

(4)

SW1: Yeah, I, ((hesitantly)) [think so yeah]

421. OT: [I feel I feel I think we,] I personally do I think we can take some more **risk** because we're practitioners and we're given more **autonomy** as practitioners nowadays than, than we **used** to. I think it was very much dictated by medical staff and I think that we have more, control over that. I I might I might be having a different

425.   experience than other people.

Extract 10: Psychiatrists

1054. MD2: I mean in the current situation, you've got more **resources** at the moment, that we can follow them regularly you know, so we can take a **chance** you know, take a **risk**//

M: //Mm//

1058. MD2: //to reduce the medication and **see**, how they respond, whether it gets worse or whatever (xxxx xxx xx). Previously it used to be so **difficult** people used to be on depot medication, Modecate or Haldol and they carried on for many, many years, even if they were

1062.   symptom **free**//

M: //Mm//

MD2: //they were settled. But they used to go and the GP used to give them depot medication and (they were on it for twenty years). Even

1066.   though we have got recently atypical antipsychotic treatment, they carried on taking (all) injections. But because we are now monitoring, its more community team you know approach, so now we are monitoring more **closely**, so we can take more **chances** and

1069.   do the **experiment** as well.

In *Extract 9*, I ask the group whether they are able to respond to Mark's situation as they would want to (417-418), thus inviting a possible discussion of the service context in which they operate. The pause of 4 seconds and SW1's hesitant response

(419-420), suggests that this is a possibly problematic question. Occupational Therapist (OT) also begins hesitantly (421) and struggles to find her footing ("I feel" "I think"). She apparently continues more confidently: "I personally do" (421) but this, along with "I might be having a different experience than other people" (424-425) acts as a *hedging* disclaimer (Hewitt and Stokes, 1975). The function of this is to suggest uncertainty about what is being said: this is only *her* experience, which perhaps allows for some flexibility in her position, depending on the responses of others. OT's qualifier "*some* more risk" (my emphasis) adds to the tentativeness of her claim. The main thrust of her argument is that non-medical professionals like her have more say in issues related to medication than in the past which *could* lead to more risks being taken in working with service-users without medication. OT does not offer an explicit evaluation of whether this is a positive or negative change, but the suggestion is that this is a good thing.

In Psychiatrist 2's (MD2) account in *Extract 10* he also claims that more risk can be taken now than in the past with regards to *reducing* the amount of antipsychotic medication people take. He is more confident in his claims than OT, implying *consensus* with his use of the pronouns "you" and "we" and his accompanying detailed explanation as to *why* more risk can be taken now. He presents the case of a modern service with "resources" which allow service-users to be followed "regularly" (1054-1055) by the "community team" (1065) and that there is opportunity to "experiment" (1069) to "see how they respond" (1058). He also claims that this progress is due to changes in the way that medications are administered: the shift from "depot medication" (1060) to "atypical antipsychotic treatment" makes it easier for medication to be reduced. MD2 rhetorically strengthens the apparently factual nature of his account through the use of *contrast:* he vividly contrasts current practice with how things used to be: "people used to be on depot medication, Modecate or Haldol and they carried on for many, many years, even if they were symptom free" (1060-1062). MD2's account is rhetorically skilful in the way that current practice is owned and taken responsibility for through the use of "we" but he

distances himself and his psychiatry colleagues from other types of practice both temporally and through the non-agentive quality of his portrayal: "people used to be on" not "we used to put people on". MD2 goes on to locate responsibility for these past practices with GPs (1064-1065) and in doing so absolves psychiatry of any responsibility. MD2's account thus obscures possible counter claims that antipsychotics have always been available as oral preparations and that significant numbers of service-users are still prescribed depot medication by psychiatrists (one study found rates of between a quarter and a third: Barnes, Shingleton-Smith and Paton, 2009).

We can see that apparently progressive accounts of 'risk-taking' practice are actually rather weak accounts which operate purely through a comparison to previous practices: in OT's case prior medically dominated practice and in MD2's case previous over-use of depot medication. Another take on 'risk-taking' is demonstrated next.

3.3.5.3. The Professional Anxiety Repertoire

Participants drew upon the notion of "anxiety", "worry" or "stress" in particular ways in their accounts, which I have termed *The Professional Anxiety Repertoire*. Discursive psychology approaches examine how emotions are invoked in accounts and the discursive functions such invocations serve (Edwards, 1999). In *Extract 11* we can see an exchange between SW3, SW1 and OT, taken from a sequence in which they are talking about the greater choice given to service-users about taking medication in the early intervention in psychosis team, compared with other mental health teams.

> *Extract 11: Social Workers*
> 462. SW3: [..] there is an expectation that we will be working with clients//
>   OT: //yeah//
>   SW3: //with **quite** a **level** of being quite unwell actually//
>   SW1: //Mm [yeah, yeah]
> 466. OT: [Yeah uh yeah]
>   SW1: we can be very worried at home and [missing out on sleep]

OT: [((laughing)) yeah]

SW3: [((laughing)) (xxxx)]

470.   SW1:   yeah but yeah I certainly can get y'know can get very anxious//

OT: //Yeah//

SW1:   //and [you can]

SW3:   [Yes]

474.   SW1:   take it home with you but yeah you're still working with them in the community// ((sarcastic tone))

SW3 claims that "there is an expectation that we will be working with clients with **quite** a **level** of being quite unwell" (462;464). SW3 is talking collectively through his use of the pronoun "we" and as such is inviting *consensus* from his colleagues which they respond to. Although it appears initially that SW3 might be presenting a positive picture of a progressive way of working, as this exchange develops this reading is undermined. SW3 modifies the extent of his claim for the 'unwellness' of clients through the double use of "quite", perhaps to defend against perceived accusations of irresponsible practice (464) and locates decision-making as outside of his and his colleagues' hands through his suggestion that "we" must comply with "the expectation" (462). SW3 is constructing himself and colleagues as powerless and at the mercy of the "expectation" of unidentified forces 'out there' making demands on them. SW3's *vagueness*[16] about where the "expectation" is from might be seen as an implicit criticism of someone or something which SW1 and OT will be able to decipher from their shared local knowledge or it might be used as a device to guard against disputation.

SW1's subsequent response builds on this and suggests agreement with the premise of SW3's claim. However, she appears to dispute its moderateness by drawing on emotional lexis. The argument being made appears to be that, contrary to SW3's suggestion that there is an expectation to work with people who are "*quite*" "unwell", people are *so* unwell and *so* much of a risk that professionals "worry"

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[16] Refer to Section 2.1.3.2.2 for a definition of this rhetorical device.

about them at home, to the extent that they lose sleep (467). SW3 and OT orientate to this claim with laughter, suggesting that this is made as a joke (468-469). SW1's use of humour here may suggest an acknowledgement that what is being said is contentious. The acceptance of her contentious claim through laughter permits SW1 in her next utterance to restate her point in stronger language ("certainly"; 470) using the pronoun "I" this time. There is another pronoun shift to "you" as SW1 completes her contribution, which serves to distance her personally from what is said next (474-475). She uses humour again to apparently criticise the idea of 'community care' and the unreasonable demands this places on professionals like her ("you can take it home with you"; 472-474). Griffiths (1998) demonstrates how humour is used as a device in community mental health team meetings to resist medical dominance without overt challenge to authority. To overtly criticise the principles of service-user choice and community care would place SW1 in a problematic position, however the careful and complex use of humour and emotional lexis allows this critique to be made. The effect being to evoke empathy for the professionals who are bearing the weight of too much responsibility, indirectly blame the service-user for making an unwise 'choice' about medication and blame the system which allows this state of affairs. We can also see here that through the implied blame of service-users for choices they make, they are being attributed agency. This contrasts with the lack of agency attributed to professionals by SW3 at the beginning of the extract and the passive apparently natural "anxiety" response to unrealistic demands being placed on professionals.

3.3.5.4. The Duty to Society Repertoire

It was implied in some accounts that professionals have a responsibility to protect society from the risks posed by service-users. This theme was strongest in the discussions in the social worker group. An explicit example of this repertoire can be seen in SW2's accounts in *Extracts 12* and *13*.

Extract 12: Social Workers

1226. SW2: [.....] mainly I think we have expectation on

us that from society that that we're to keep people well and to

keep people safe ((.h)) and when when you ask what, what would

help, I mean, in the case of this Mark guy, y'know it would be nice

1230. to be able to try but but there's a lot of pressures on us

[....]

1235. through whatever

reason, medication seems to be y'know whether its that's its got

the evidence backing it or it but that seems to be the first line of

treatment really and that's what y'know erm that's the one we

1239. tend to use.

Extract 13: Social Workers

1266. SW2: [.....] an example would be and this is an extreme

example, but erm we get referred for someone in in a similar

situation erm who y'know he's responding like this, erm but saying

he's not going to take his medication er and this is extreme, erm

1270. and we er it got to a mental health act assessment and it and he

was clear so so so the worker and the doctors tried to, tried to erm,

s- support him with that so they didn't force the medication they

thought they'd keep things under review for a week and the wor-

1274. worst possible thing happened, he he erm he he was getting lots of

similar to people laughing about him//

M: //Mm//

SW2: and and he got in a car and drove to London and ran some people

1278. over//

SW1: //Oh//

SW2: //killed some people so. I mean y'know it was in all the national

newspapers and things like that//

1279. M: //Mm//

SW2: //and that that its not useful cos its so extreme [but]

M: [Mm]

SW2: y'know it is very hard to think, y'know you are working within (this)

1283. and you **do** have responsibilities and//

93

In *Extract 12*, SW2 is contributing to a discussion about alternatives to antipsychotic medication, invited by a question I ask about this. In contrast to SW3's account in *Extract 11* that there is an "expectation" to work with people with "**quite** a **level** of being quite unwell" (462-464), SW2 suggests that there is an "expectation" from society that "we're to keep people well and to keep people safe" (1226-1228). In the use of the word "people" in relation to safety, SW2 could be referring to keeping service-users "safe" from society or keeping society "safe" from service-users: his narrative in *Extract 13* suggests the latter (discussed further below). SW2 makes a weak concession that there may be alternatives to medication which might be helpful ("it would be nice to be able to try"; 1230), but due to the "pressure on us" (1230) medication is the best option. SW2 is vague about the "pressure" and about why medication is the best option. As we have already seen, *vagueness* can be used to evade scrutiny and rebuttal. The "pressure" may refer to pressures from society, from the service or pressures of workload, amongst others. The reference to "the evidence" (1237) has the rhetorical effect of adding credibility to the claim, but again the lack of specificity defies easy challenge. As we have seen in other accounts, SW2 seems to be denying agency in decision-making, on this occasion by suggesting that there are good reasons for the way things are currently and that he is in essence following the protocol of the service he works in: "through whatever reason […] that's the one we tend to use".

The main thrust of SW2's claim is that there is an expectation from society that mental health professionals have a responsibility to "keep people" with mental health problems "well" so that society is kept safe and that medication can do this. The implication here again is that potentially coercive medication 'treatment' is warranted. We can see a stronger case made for this if we examine *Extract 13.*

In *Extract 13* (in the context of a discussion about professional accountability which develops from SW2's account in *Extract 12*) SW2 tells a *story* which is used to

exemplify his argument in *Extract 12*. Although the terms narrative and story are often used interchangeably (Sarbin, 1986), the *story* has been characterised by some commentators as a particular type of narrative genre (for example: Kohler-Riessman, 1990; Mishler, 1986). Features of a *story* include: a temporal dimension; a beginning, middle and end; a 'plot', central to which are human predicaments and attempted solutions; and a coherence or connectedness of events (Sarbin, 1986; Gergen & Gergen, 1986). We can see that SW2's account in *Extract 13* contains all of these features, and narratives meeting this definition were a frequent feature throughout all of the focus groups: SW2's story was one of the shorter and less detailed examples*.*

Both the employment of the *story by* SW2 at this point and the way in which the tale is told have particular rhetorical effects. Kohler-Riessman (1990; p1197) argues that stories are particularly powerful in their ability to "pull the listener into the teller's point of view." Similarly, Edwards & Potter (1992) locate narrative as a device which can add to the plausibility of an account. We can see that SW2 makes a repeated claim about the story before and after telling it that it is an "extreme" example (1266, 1269, 1280). We have seen previously how the use of concessions like this can strengthen accounts (Section 3.3.4.4). The story is given authenticity by the suggestion that SW2 was a close observer to the events by virtue of being a member of the team in question: "we get referred for someone" (1267). We see SW2's story is gradually worked up through setting a typical scene of a referral to the service, the introduction of the service-user saying he won't take medication, a failed attempt to section the protagonist, and events subsequently culminating in a tragic and shocking ending as the unmedicated service-user gets into a car and runs over and kills "some people". The inevitable trial by press ensues. And the moral of the story is that "you **do** have responsibilities" (1283) as a professional because if you don't take responsibility, this could happen.

There is little context provided to the events or efforts to develop the main character, by providing a background history. This vagueness adds to the impression of a clear cause and effect between being "ill", not being medicated and high levels of risk.

3.3.5.5. The Dilemma Device

Extract 14 is interesting in the way some of the analytical observations made already in this section are drawn together in the form of a dilemma. Psychologist 2 (P2) is responding to a question from me to the group about whether they are able to respond as they'd want to in Mark's case.

> *Extract 14: Psychologists*
>
> 208. P2: It's an interesting question. It's all going through my mind is there's
> part of me that **would** encourage him to, if he really felt strongly
> against medication, I **would** encourage him to go with that. But then
> there's another part of me that thinks, yes, but I wouldn't be **there**
> 212.   as an emergency service if things went **wrong.**
>   P1: Yeah.
>   P2: And, so there's part of me that takes a- feels a responsibility towards
> the team as a whole [....]
> 224.   [....] **but** it's this emergency service, that
> we're actually **not** there all day or night,
>   M: Hmm.
>   P2: um, if there is then a **crisis.** So I suppose it's trying to be responsible
> 228.   for the team as a **whole**.

P2's initial response "its an interesting question" (208) might be seen as a delaying tactic, perhaps suggesting the problematic nature of the question. P2 goes on to present a dilemma between supporting and encouraging Mark in refusing the medication (209-210) and not wanting to cause difficulties for "the team" if it goes wrong (212-215). P2 goes on to repeat the terms of this dilemma (extract not included) before concluding with "So I suppose it's trying to be responsible for the

team as a **whole**" (227-228). We can see that P2 does some interesting rhetorical work in this extract as she struggles to position herself and give an account which, one might speculate, can guard against others potentially attributing her with an undesirable identity, such as: "irresponsible", "risk-averse", "a bad team-member", *et cetera.*

P2 presents an image of an argument between the two contradictory positions being played out in her "mind" (208). She talks metaphorically of embodying the dilemma: "there's part of me that would encourage him" (208-209), "there's another part of me that thinks, 'yes, but I wouldn't be there…'" (211). The metaphor allows P2 to vividly demonstrate the dilemma between the two positions, which creates the impression that there is a very difficult decision to be made here and that she wouldn't make it lightly. In demonstrating that she has an awareness of the different positions available, P2 is able to defend the position she finally takes as being the process of a series of reasoned arguments. If we look at the argument being made by P2, we can see that she draws on certain devices which serve to make her final position seem more reasonable. For example, she positions the alternative in terms of an *extreme case formulation* (Pomerantz, 1986)*.* She implies that the most likely consequence of Mark coming off his medication would be an "emergency" or "crisis", which she wouldn't be able to deal with because "we're actually **not** there all day or night" (225). The argument being made is that it would only be safe for her to support Mark to stop taking his medication if she could be there "all day or night". This talk of extremes helps P2 to rhetorically reach the conclusion that her responsibility lies with the team, but also that in taking this position she is acting in Mark's best interests because to allow him to go into crisis and not be able to do anything to support him would be irresponsible. P2 marks her conclusion with qualifiers ("suppose", "trying") which gives the impression that this is a position which she is reluctant to take.

It is important to draw attention here to a repertoire evident only within the psychologist group which might be seen as super-ordinate to other discussions held in this group. Much of the talk hinged on debating the relevance or usefulness of psychologists getting involved with matters to do with medication. I might term this repertoire the '*do we even have a role in this*' repertoire. This is exemplified by Psychologist 1's comment: "I think sometimes we're seen as being um err, unhelpfully **irrelevant** in these situations" (370-371). Although alongside this was a counter-repertoire along the lines of '*psychologists have valuable contributions to make*' which can be seen in Psychologist 3's comment: "hopefully um, kind of broaden the understanding of the issue" (517-518). The second repertoire appears to be reflected in Holmes account detailed in Section 1.8.5.2 and some of the questionnaire responses (Section 3.1.3.2).

3.3.6. Constructing 'Coercion' Vs 'Freedom & Choice'

I have already used the terms 'coercion' and 'coercive' in reference to points I have made in the preceding sections. It may be useful to draw on definitions at this point. The Oxford Dictionary (Hornby, 2000 p229) defines coercion as "the action of making somebody do something that they do not want to do, using force or threatening to use force". The rationale for coercive treatment under mental health legislation is bound up with the notion of 'risk' and we saw this being drawn upon explicitly in Section 3.3.4.1. The opposite pole to 'coercion' might be seen as 'freedom and choice'. In this section I will examine more closely the interplay between these poles.

3.3.6.1. The "Working in Partnership" repertoire

A repertoire of professionals *working in partnership* with service-users was drawn on throughout the focus groups. In *Extract 15* N2 is talking about how she would work with Mark.

Extract 15: Nurses

21. N2: [...] I think if he was managed in the community

I'd be looking at trying a different medication and getting him to

actually work **with** me towards finding the right medication. Because

I think even if somebody goes straight to hospital, um, they're forced

25. to take medication basically when they come home they can be non-

compliant again. So I think its about, them managing their own

medication and working in partnership together.

[....]

45. because its quite empowering for them//

M: //Mm//

N2: //to have a say rather than to have all of that taken out of their

hands.

N2 begins the account with a conditional "*if* he was managed in the community" (my emphasis; 21) suggesting that Mark being seen in the community is not a given: the possibility of hospitalisation is always there. The term "managed" is interesting in that it positions Mark as less powerful, but doesn't exclude the possibility of some agency (we see this below). The power inherent in 'managing' is not located in anyone at this point, but then is made clearer as N2 places herself in this position: as she moves to talk in the first person: "I'd be" (22), "work **with** me" (23). The phrasing "work with me" is prefaced by "getting him to" suggesting that this is something that will require some effort on her behalf and hints at coercion. N2 constructs the "work" which she and Mark will do as "finding the right medication" (23). This is counter to Mark's expression (in the vignette) that he does not want to take medication and doesn't like taking it. N2 has hence already formulated that the problem is that Mark is on the *wrong* medication and that the situation would be resolvable if the "*right* medication" (my emphasis) were to be found. She is thus taking a paternalistic position (Day and Bentall, 1996): she is the expert who knows better than Mark: medication is *the* solution to Mark's predicament. The notion of professionals knowing best appeared to be questioned by an anecdote told by N3 of a service-user who successfully came off his medication against N3's advice: "...its

over a year now er. Things have remained well. This, lads, been at university and got a degree in the mean time.." (304-305). The possibility of this potential *'service-users as experts' repertoire* to challenge the dominant repertoire of paternalism demonstrated in *Extract 15* was undermined as N3 went to add that "..but (actually) its hard to compare like for like really isn't it they're all different stories.." (305-307). Hence it is dismissed and minimised as a one-off, maintaining the dominant narrative.

N2 goes on to compare her approach with what would happen if Mark was sectioned and "forced to take medication" in hospital, as the problem would be that once he came home he could be "non-compliant again" (24-26). This part of the account is interesting rhetorically, firstly the comparison with the extreme coerciveness of hospitalisation serves to position N2's community approach as more humane and reasonable, and secondly N2 is formulating Mark's concerns as "non-compliance". As I discuss in Section 1.8.2, "compliance" is a dis-preferred term in the professional literature now, because of the implied passivity of the service-user and expectation of obedience to medical authority. There is then a further interesting move rhetorically, as N2 gives the impression of handing back full agency to the service-user: "its about, them managing their own medication" (26). N2 has thus proposed an interaction with Mark where she has set that the agenda is "finding the right medication", that Mark has to work with her towards this, which will then lead to Mark "managing" his "own medication". Mark "managing" his own medication infers agency and choice, but we can see that the inferred 'choice' is illusory because actually the expectation is that Mark complies by taking the medication others prescribe him to take. Attributing Mark agency here means that he can then be blamed for not taking the medication and not 'getting better' as opposed to blaming the medication for not having the desired effects. N2 then glosses the process she has described as "working in partnership together" (27). As "partnership" usually implies equality between partners, we can see that this is also illusory as N2 has already set the terms of the engagement. N2 adds to the gloss later by referring to

her approach as "empowering" (45). However we can see it is only constructed as such by virtue of its comparison to the opposite extreme: "rather than to have all of that taken out of their hands" (47-48).

3.3.6.2. Persuasive Talk

Participants' frequently talked implicitly and explicitly about "persuading" service-users to take medication: a practice which has been alluded to by service-users (Rogers et al., 1998; Section 1.7.2.2). An example of this can be seen in *Extract 16.*

> *Extract 16: Nurses*
>
> 479. N2: […] Wh- as I said
>
> earlier, I think what I would like to do is to try and y'know talk him
>
> into trying something different.

In *Extract 16* Nurse 2 (N2) is making reference to Marks's case. In this example N2 is talking explicitly about persuading Mark to take his medication: "talk him into trying something different" (480-481). N2's use of "y'know" (480) suggests that this is an accepted thing to do. In *Extract 17* we can see a typical account of how the persuasion might be done. Again Social Workers 3 (SW3) and 1 (SW1) are making reference to Mark's case. SW3 had said previously that he would take a "relapse prevention stance" (20-25) and he is responding to my question about how he would do that.

> *Extract 17: Social Workers*
>
> 29. SW3: [by going] over with him some of the, **symptoms** that y'know he's//
>
> SW1: //so the early warning signs?//
>
> SW3: //Yeh, the early [warning signs really]
>
> SW1: [Yeah]
>
> 33. OT: Yeah
>
> SW3: that are likely to occur//
>
> SW1: //yeh//
>
> SW3: //should he stop his medication really. So its its kindof (3)

37.   encourage him really//

   SW1: //yeah//

   SW3: //that y'know this could happen if you stop taking your medication

           and erm y'know remind go over with him really about some of

41.   those feelings that he experienced and er, I suppose its a kind of

           like a kindof subtle way of [trying to persuade him]

   SW1: [Mmm…..yeah] ((softly))

   SW3: to carry on.

In *Extract 17* SW3 begins his explanation with "by going over some of the symptoms" (29). Harper (1999) has coined the term *symptom-talk* which he defines as being a form of narrative where the focus is**:**

> a narrow range of observable and inferred phenomena (symptoms) and which views these phenomena as both possessing agency and being 'surface' signs or markers of 'deeper' pathology (i.e. illness or disease) within the individual. (p 132)

SW3's account here could be seen as an example of *symptom-talk*. His reference to "going over…symptoms" is formulated by SW1 as "the early warning signs" (30), which SW3 concedes. They are making reference to a recognised approach to working with "schizophrenia" presented by Birchwood, Spencer and Govern (2000) known as the "early warning signs approach to relapse prevention"[17]. "Early warning signs" or "relapse prevention" was made reference to several times in the groups. We can see that referencing a recognised "approach" serves to add credibility to SW3's account. SW3 suggests that he would make a case to Mark that if he does stop his medication "this could happen" (39) "this" being a resurgence of the presumed underlying illness in the form of "symptoms". In SW3's account, Mark, the medication and the "symptoms" are all located agency: Mark in how or whether he takes medication; the medication in keeping the "symptoms" under control; and the "symptoms" as an active process lurking beneath the surface ready to re-emerge

---

[17] This is an interesting integration of medical and psychological models developed by Clinical Psychologists. The premise behind this approach is that there are "early signs" indicating a "relapse" is imminent which individuals can be trained to recognise. They can then employ psychological strategies to help reduce the "relapse" occurring. This is done in the context of the service-user being on "maintenance medication" and further medication being initiated when "early warning signs" develop.

given the opportunity. The suggestion being that medication is the only way the "symptoms" can be controlled and Mark would be making an irrational decision if he did stop his medication.

It could be argued that SW3's proposed conversation with Mark is threatening, however SW3 formulates it as "a kindof subtle way of trying to persuade him" (42). This has echoes of the 'manipulative' and 'deceptive' strategies talked about by psychiatrists in Seale et al. (2006; Section 1.9.2). The need for "subtlety" is alluded to elsewhere, for example, Nurse 3 remarks: "one of the wor- most disempowering things you can do is to try to make it sound like its forced" (59-60). Perhaps the implication being that we are forcing you but we need to make it seem as if you have a choice.

In the example presented here, the accounts the participants have given of how they would talk to service-users about the possibility of stopping medication, have been weighted strongly in favour of continuing with medication with threats that likely consequences are relapse. In other accounts, hospitalisation, deterioration and dangerous behaviour were presented as likely consequences. There were instances in the psychologist group where there was allusion to a more 'balanced' discussion about medication, with reference to "pros and cons" as we can see in *Extract 18.*

Extract 18: Psychologists

303. P3: I think yeah, I think it should be to have those kind of discussions
        about pros and cons in the context of like relapse prevention work
        could be a useful part of the discussion.

Although, again in this extract we can see reference to "relapse prevention" (302), which might weight the "pros and cons" discussion in favour of medication.

3.3.6.3. A question of 'insight'?

Harper (1999b) shows that failure of service-users to take medication can be constructed by professionals as being an effect of their illness in term of lack of 'insight' and as such valid objections to medication can be "de-legitimised". I also noted this as a repertoire available to be drawn on by participants in this study, which further undermined the notion of service-users being able to make a 'choice', as in *Example 19*.

> *Extract 19: Psychiatrists*
>
> 590. MD1: [....] I always work uh what I
>   believe is in the best interests of client you know, so **I'm** trying to
>   work under the clinical excellence, ((.h)) it mean that, this guy
>   needs probably two or three trials [...] with
> 594.   enough uh dose of, of the medication, ((.h))and I'll have to do my
>   best to **treat** his err his case properly with the medication, until he
>   will take **insight** because there is a good uh, chance that he will
>   have **insight** when he will be symptoms free//
> 598.   M: //Mm//
>   MD1: //because, lack of insight is is one of the **symptoms**, so if he was he
>   will he will improve **insight** by the **medication**, then we can
>   increase adherence and compliance, you know? [....]
> 602.   this client, in my opinion, **needs** to be, to be on the
>   medication **because** after the trial of the medication, as I said under
>   the condition of the appropriate lengths and and dosage, he can
>   make a more **inform** and more valuable **decision** for himself,
>   whether he would like to stay on medication or **not**//

At the beginning we see the medical paternalism seen in previous extracts ("best interests of client"; 591). We also see reference to "clinical excellence" (592) which might be a shortened reference to NICE, which serves to add credibility. Prescribing medication is presented here as a process of trial and error, but with an optimism that it is possible to get it right: "two or three trials [...] with enough uh dose of, of

the medication" (593-594). This obscures the evidence that a substantial proportion of individuals receive no benefit at all from antipsychotics (Bentall, 2009).

MD1 constructs "lack of insight" as a "symptom" (599) which can be relieved by medication (600) which in turn will: 1) increase compliance (601) and 2) enable Mark to make an informed decision about continuing medication or not (605). This is a curious argument as increasing medication "compliance" and being able to decide to discontinue appear to be contradictory. MD1 manages this problematic contradiction by the temporal distance between the two claims and through using the disclaimer "in my opinion" (602). By finishing on the claim about informed decision, MD1 portrays her approach as reasonable: she is trying to give Mark the opportunity to think through the options without the influence of the "symptoms" which impair his judgement. What is implied is that without medication Mark is symptomatic and thus cannot be held responsible for not taking medication and cannot make an informed choice, but once medication is taken the presumption is that this will work to allay "symptoms", bring "insight" and hence he could be held responsible for not complying.

3.3.7. Constructing 'Risks' to Service-Users

Participants talked about various conflicting 'risks' which service-users might be exposed to, which I will examine here.

3.3.7.1. *Legitimising Vs Minimising the 'Risks' of Medication*

Participants talked about 'risks' associated with antipsychotic medication in a range of different ways which could serve different functions: 'risks' could be legitimised or minimised, and agency and responsibility for problems associated with medication could be located in different objects and subjects. It is worth noting that there was virtually no discussion of this nature within the psychologist group.

3.3.7.1.1. Minimising

Problems with medication were most often constructed in terms of "side-effects". Harper (1999) has problematised this term: *side* effects are actually *direct* effects of drugs, which are unintended. He argues that through the notion of the "side-effect", certain drug effects are constructed as proper and intended and other drug effects minimised as unintended and wrong. He suggests that this can serve to objectify the phenomena thus denying the subjective experience of the service-user, and locate responsibility away from professionals through the claim that these are unintended effects. In this study, participants were able to talk about "side-effects" in particular ways which further served to minimise these unintended drug effects.

Extract 20 Nurses:

90. N1: Cos that is
        quite a low dose and [all]
    M: [Mm]
    N1: antipsytot- antipsychotics and going to have side effects. (4) So,
94.   s'about finding out what's, wh- [what he thinks]
    M: [whats bothering him most?]
    N1: about it. Is it just side-effects cos other medication are also going to
        have side-effects (xxx) um, if he's not tolerating this then he's going
98.   to have problems with other medications as well

In *Extract 20* Nurse 1 (N1) is making reference to Mark. There are three points made in her account: 1) that antipsychotic side-effects are inevitable (91-93); 2) that Mark is not "tolerating" the medication (97); 3) that Mark's lack of tolerance would mean he would have problems with other medications (98). The claim that side-effects are an inevitable consequence of all antipsychotics has several implications: it serves to generally minimise their (the side-effects) importance and legitimise their acceptability, it 'lumps' all side-effects together as one entity which suggests that all are equivalently risky or unpleasant, and it suggests that side-effects are something that service-users just have to put up with. N2's suggestion that Mark is not "tolerating" the medication potentially contradicts her claim for the inevitability of

side-effects, as it suggests that it is something about Mark's physiology which is causing him in particular to experience these effects: Mark's body is thus to blame (and indirectly Mark), not the medication. The notion of tolerability could also be seen as a moral judgement which implies that Mark is too weak to cope with the medication or is exaggerating the negative effects. We can see here the flexibility of what might be termed "side-effect talk" which can be utilised to minimise or obscure the unintended effects of medication, deflect responsibility from medicine or the pharmaceutical industry and locate problems within the service-user. It can also warrant particular courses of action and impede others: N1's suggestion that if Mark cannot "tolerate" this medication he will be unable to "tolerate" others, could imply that it may be better for him to stay on the drug he is on, which serves to undermine any concerns he has expressed. Alternatively it could imply that it might be best for him to come off the medication and for alternative interventions to be tried. None of the groups drew on a *'there are viable alternatives to medication'* repertoire.

There were additional discursive strategies which were employed which served to minimise 'risks' or adverse drug effects. One device used was *contrast.* Taking antipsychotics could be compared with taking other types of medication, for example Social Worker 3 comments: "Normally I give some example of y'know if if I'm taking antibiotics, I don't like taking them.." (199-200). Stevens and Harper (2007) found that a similar strategy was employed in professional accounts of ECT where ECT was rendered just another medical procedure thus minimising potential controversies over its use. We have seen that service-users do not necessarily construct antipsychotics as equivalent to other kinds of medication (Rogers et al., 1998).

The language used to describe adverse drug effects could also serve to minimise them, for example "[not] very nice" (SW3; 206) and causing "problems" (SW2; 9) which could be compared with the more extreme "dangers of coming off medication" (SW2; 8). Furthermore, service-users could be accused of fabricating side-effects because they did not want to take medication as we see in Nurse 3's (N3)

claim that "I have one now who's and (he's he) he's effectively making up symptoms which he doesn't have which can be measured like by the LUNSERS[18]" (113-115). Not only does this serve to undermine the validity of service-user concerns, we can see that N3 appears to be using the term "side-effect" and "symptom" interchangeably which serves to blur the lines of causation: the effects can be attributed to the 'illness' rather than the medication.

Finally, the validity of service-user concerns about the 'risks' of medication could be denied as we can see in Psychiatrist 2's (MD2) explanation: "..we can explain to them that these antipsychotics are not, you know, making them dependant on them you know. They are not very highly tranquillisers or anything like that" (304-306). MD2 as a psychiatrist has the *category entitlement* to make such a claim and give it the appearance of being factual, which disguises the controversial or potentially misleading nature of such statements. For instance Healy (2005) discusses the controversies and semantics around the notion of 'dependence' in relation to antipsychotics which would question the factuality of MD2's statement. Johnstone (2000) has suggested that doctors often fail to pass on to service-users known hazards of medications.

3.3.7.1.2. Legitimising

Participants appeared to make value judgements about side-effects with some afforded more legitimacy than others. Participants talked specifically about certain side-effects as being particularly concerning, these included sexual dysfunction (in men), weight-gain (in women) and what might be categorised as sedation ("they find that they can't think clearly, they're tired" N1; 377-378). I will take one of these examples to explore in more depth. In *Extract 21* the group are discussing the problem of weight gain.

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[18] LUNSERS is an acronym for Liverpool University Neuroleptic Side Effects Rating Scale (Day, Wood & Dewey, 1995). This is a commonly used self-report rating scale.

Extract 21: Social Workers

729. OT: //Mm. I always wonder actually as a practitioner whether if

somebody prescribed **me** an antipsychotic//

SW2: //Yeah//

OT: whether I'd want to take it I mean//

733. SW3: //Mm//

OT: if some- if I put two stone on in weight by somebody [s- prescribe-]

SW2: [Yeah]

OT: I'm [((.h)) not convinced I would]

[.....]

741. OT: //[so] I have to work with within that as well um and listen to what

people have got to say when they//

SW2: //Yeah//

OT: //when you've seen them come in ((.h)) well I've worked in

745. inpatient settings when they've come in as a very tiny size **eight**

young lady, [going out]

SW2: [Yeah]

OT: as a size twelve to fourteen.

749. SW1: Mm. [And carry on taking on taking it as well isn't it?]

OT: [And how. And carry on taking it.] And I just think ooh um y'know. I

can understand why you would not want to take that [medication.]

SW2: [Yeah]

753. SW1: And wouldn't you be angry//

SW2: //Yeah//

SW1: that you'd been prescribed the **one** or the **two** that were most

typical to [put on weight. I mean I think that's kindof pretty.. xxx]

757. OT: [Absolutely, yeah, absolutely yeah]

The Occupational Therapist (OT) begins with "I always wonder" (729) with respect to what she would do if she was prescribed an antipsychotic. She is constructing an account where what she is about to say is based on rational *though*t rather than *emotion* (Edwards, 1999). She continues to build a *vivid, narrative* description of what might happen as a consequence of taking antipsychotics by drawing on several rhetorical strategies. She makes the proposition *if* she were to "put on two stone in weight" (734) which uses *quantification* to build an authoritative factual account

(Potter & Wetherell, 1994) of the real risks of taking antipsychotics. Perhaps as a defence against counter-claims that this is an exaggeration, she creates a *footing* of personal experience "when you've seen them come in" (744) and goes on to describe actual cases. She uses *extramatization* (Potter, 1996) combined with *quantification* again in her description: "a <u>very tiny</u> size **eight**" (745) which is then contrasted with "a size twelve to fourteen" (748). OT thus builds a picture of the dramatic effects antipsychotics can have in terms of weight gain, which is used as an explanation for her assertion that she would be reticent to take such medications herself ("I'm not convinced"; 736). On another level, what OT is doing here is constructing herself as a thoughtful and compassionate practitioner who takes the risks associated with antipsychotics seriously and can imagine what it must be like for service-users who are prescribed them.

We might imagine that OT's dramatic description of the risks associated with antipsychotics might lead her to go on to question their use, as to not do so would perhaps leave her open to the challenge that she is complicit in questionable practices. However, the conversation then takes an interesting turn when Social Worker 1 (SW1) joins in, which helps OT manage this predicament. SW1 takes up the conversation with "And carry on taking on taking it as well" (749), which OT then assents to (750). There is a suggestion here that the service-user should refuse to take the medication and by continuing to take it are to blame for the effects. The responsibility for the effects are thus located with the service-user not the professionals or the medication. However, as SW1 continues, it appears that some responsibility is located with psychiatry: "And wouldn't you be angry… that you'd been prescribed" (753-755); but the medication (and OT) is let off the hook with the suggestion that these problems are particular to specific drugs: "you'd been prescribed the **one** or the **two** that were most typical to put on weight" (755-756), which suggests that a simple switch would solve the problem. Again we can see here an optimistic portrayal of medication: it is possible to find the right drug; an argument which ultimately serves to minimise the risks.

3.3.7.2. The 'risks' of psychosis

Participants were able to draw on repertoires and devices which served to construct psychosis itself as being harmful to service-users.

One such repertoire available was the '*Untreated' Psychosis is Harmful Repertoire*, as demonstrated by Psychologist 3*: "*the message I've received about untreated psychosis and how damaging that can be" (182-183). This repertoire could be situated by participants in research and was a resource which could be drawn on to warrant the early use of antipsychotics as we see in *Extract 22.*

Extract 22: Social Workers

249. SW1: Mm. I think that that something else you can think about is that the
early intervention in psychosis international guidelines from the
research are to treat with a low dose of antipsychotic quickly to
stop kindof brain damage//

253. OT: //Mm//

SW1: //kindof happening and that that is the ethos of our team//

SW3: //Mm//

OT: //stop the extra cognitive dysfunctioning//

257. SW1: //yeah, [yeah and]

OT: [as a] result of the illness//

SW1 draws on the notion of "international guidelines" (250) which strengthens the credibility of the claim that not medicating can lead to "brain damage" (252). Although the claim is hedged somewhat with "kindof" (252;254) which allows SW1 some flexibility if she hasn't got the terminology quite right. SW1's account constructs a sense of urgency with the addition of the temporal dimension of "quickly". OT backs up SW1's claim, suggesting that antipsychotics can "stop the extra cognitive dysfunctioning" (256) caused by "the illness" (258). Again we can see a disease process being constructed here which can be effectively stopped by antipsychotics. The strength of this argument is in its simplicity: who wouldn't agree

that a pill which can stop "brain damage" should be used as quickly as possible? We can also see that comparing the consequences of not taking medication ("brain damage") against the previously identified adverse consequences of taking it (weight gain, sexual dysfunction, sedation) weights the argument in favour of taking it.

A similar argument is constructed through drawing on a repertoire which might be termed *Psychosis is distressing*. This repertoire constructs the experience of psychosis as awful, intolerable and uncontrollable. The implication being that the only solution is medication. We can see an example of this in *Extract 23*.

Extract 23: Social Workers

944. SW1: I've got a young guy who's in hospital at the

moment, and he has had like constant voices from the moment he

wakes up till the moment he goes to sleep, and apparently (well)

he's only just started to talk about it but he's had it for three years,

948. and they're talking about wanting to rape him and break his legs

and he can smell **blood** and **semen**//

SW2: //Mm//

SW1: and ((.h)) that's so horrendous to try and comprehend, in fact I can't

952. comprehend [what kind of living hell he's]

[....]

959. OK there are risks with the medication and a-, but it feels like its

worth trying that at the moment and certainly he' s agreeable

[....]

965. if we, can help that change, with medication

then I would be for that.

SW1 is using *narrative* and *vivid description* to demonstrate the awfulness of the psychotic experience. Her use of a 'real' case adds to the strength of her claim. We can see in the narrative discursive strategies like those used by OT in *Extract 21* such as *extramatization* ("<u>constant</u> voices from the moment he wakes up" 945-946) which are used to *work up* the claim being made. We also see the use of dramatic lexis such as "horrendous" and "living hell". The account builds up to the conclusion

that whatever risks are associated with medication, they can't compare to how awful the psychosis itself is and so are worth trying (959-960). Note here that SW1 constructs the service-user here as consenting to 'treatment' ("certainly he's agreeable"; 959) which is in contrast to a case such as 'Mark' who is not agreeable. As such the claim being made by SW1 is not particularly contentious. However we could imagine a similar account being extended to justify coercive 'treatment'.

3.4. SUMMARY

In this section I have presented an analysis of the construction of 'risk' in relation to the notion of antipsychotic medication 'refusal' as it appeared in the focus groups. I have illustrated how the fine level details of the 'talk' served to construct accounts as being valid. I have also demonstrated how repertoires were drawn on to position professionals, service-users and medication in particular ways which could warrant or legitimise certain actions and obscure others. In the final chapter I will discuss the findings in the context of wider discourses and other literature.

4. DISCUSSION

In this section I will examine the findings from the survey and focus groups in the context of wider discourses and literature. I will go on to evaluate the quality of the research and its limitations. I will conclude by discussing the findings in terms of the implications for different stakeholders.

4.1. FINDINGS IN CONTEXT

4.1.1. Survey

Diverse positions were presented by survey participants in relation to medication refusal. It was generally presented as a common encounter in their practice: almost all reported to have had some experience of it in the past year. Medication discontinuation was presented as often following expression of refusal and, as with Mind's research on "coming off" (Section 1.8.5.1), participants suggested that service-users often stopped medication against advice (60%). The most common reasons professionals gave for service-users not wanting to continue were similar to results reported from research with service-users: adverse physical effects, sedation, feeling better and not wanting to rely on medication long-term (Read, 2005; Cooper et al., 2007).

The most common actions the participants indicated that they would take in response to medication refusal were to explore the issue with the service-user, arrange an appointment with the psychiatrist and discuss the risks with the service-user. A minority (32%) endorsed the item: "consider supporting the client to come off". The psychiatrist was presented as being most influential in decision-making about medication refusal, just ahead of the client and care-coordinator. The psychiatrist appears to be constructed by colleagues as responsible for dealing with issues related to medication refusal. It is interesting therefore, that so few psychiatrists took part in the research. Johnstone (2000) has suggested that psychiatrists are used covertly by society as "police" for problems no one else want to deal with: perhaps colleagues are positioning them as such here. We saw that in

the focus groups, other professionals could position themselves in this way too, by drawing on a *Duty to Society Repertoire* (Section 3.3.5.4.)

Participants were able to take an optimistic position in relation to supporting people to come off medication. A majority of participants reported that they had had experience of supporting people to come off medication, or supporting people without using medication. A substantial proportion of attempts to support service-users to "come off" were presented as successful, thus challenging the pessimistic picture generally presented in the professional literature (Section 1.8). This contrasts with the reluctance of focus group participants to position themselves as actively supporting service-users without medication (e.g. Section 3.3.5.1).

4.1.2. Focus Groups

In my reading of the focus group discussions, the dominant construction of medication refusal which emerged centred around the notion of 'risk'. In Section 3.3.3, I mapped out the main features of what I have labelled 'risk talk'. Participants drew on various linguistic resources to 'work up' particular claims about 'risk' and its relationship to their practice.

I examined how the professionals' accounts served to construct service-users as both 'risky' and potentially *at* risk from disease processes and medication. Professionals positioned themselves as arbitrators of these competing 'risks', situated within a struggle between wider discourses of freedom and choice versus public protection and coercion. This has echoes of Seale et al.'s (2006) research with psychiatrists, where a tension was demonstrated between being "patient-centred" and sharing decisions about antipsychotic prescribing, and the need to judge service-users' competence to make decisions about medication.

I have shown in my analysis, that risk repertoires were powerfully tied up with biomedical, legal and medication-related repertoires, which could flexibly construct

subject positions for service-users. They could, for example, be positioned as passive recipients of pathological processes, dangerous and unable to make decisions, which could potentially warrant legally sanctioned or, what might be termed, 'veiled' (for example through 'persuasive talk': Section 3.3.6.2), coercive 'treatment' with antipsychotics to stop the pathological processes. Conversely service-users could be attributed with agency, able to make decisions about taking medication or not, or about other 'health-related' behaviours such as taking drugs and hence could be held *morally* responsible and to blame if 'wrong' choices were made (for example Section 3.3.4.3).

Similarly, professionals could position themselves with and without agency: as passive automatons following the policies, procedures and norms of the service or system, with the warrant to be held responsible if these were not followed (for example Section 3.3.5.4), or as active, autonomous practitioners making decisions (for example Section 3.3.5.2). A further position available for participants to draw on was an 'absent' position, as we saw in the psychologists group (Section 3.3.5.5). Thus responsibility and agency for decision-making could be handed to others. However, as Willig (1998) has argued: inaction is an action. In failing to take a position, one is positioning oneself as complicit in sustaining current practice.

It is important to keep in mind the notion that speakers are themselves *positioned* by the discourses in which they are embedded, and that discursive acts are constrained by the particular conditions in which speakers are located (Harper, 1995; Parker, 1992). Harper (1995) suggests that a discursive analysis should ask: *what interests are being served by the concept of X in this situation?* In order to broaden my analysis, it may be useful to examine *what interests are being served by the notion of 'risk' in relation to medication refusal*. In order to do this I will draw on theories of 'risk'.

Beck (1992) has referred to the *Risk Society*. His thesis is that contemporary western societies are moving to a "late modern" period where 'risks' have emerged due to globalisation, urbanisation and industrialisation. The prevention and minimisation of these 'risks' has become a central concern in contemporary society. Individual responsibility has become attached to 'risk', such that people are seen to both cause risk and be responsible for risk minimization. Lupton (2006) has outlined how other sociological writers have drawn on the Foucauldian notion of *governmentality* in relation to risk. Here, it is proposed that neo-liberal societies depend on the popular notion of individual freedom and rights, where external governance becomes internal self-government. Within this framework, risk discourses are a major apparatus through which self-regulation and personal responsibility are propagated. As the number of risk discourses grows, so do the number of risk-avoiding practices which citizens are required to attend to: ignoring 'risk warnings' is subject to moral judgement or stigma. Rose (1999) has theorised that psychology is complicit in these processes through its focus on the objective measurement of 'the individual'. Within a *governmentality* framework, power relations are at work in the way 'risks' are socially constructed. As Crowe and Carlye (2003) suggest, there is no fixed or inherent risk which is revealed through observation, rather meaning is attributed to some characteristics rather than others in the construction of a 'risky' individual.

It is interesting to apply the *governmentality* framework to the present research. We have seen how repertoires of choice and freedom were drawn on by professionals (Section 3.3.6.1.) These could be seen as neo-liberal discourses serving to conceal the concerns of the state to control social deviance and risk. Professionals were able to draw on these repertoires to attribute responsibility to service-users for 'health-related' behaviour (i.e. taking medication): failure to comply with 'health' advice could lead to moral judgement and coercive measures. In this respect professionals are acting as agents of the 'neo-liberal' state. Furthermore, we have seen how professionals are able to draw flexibly on biomedical, legal and medication-related repertoires in constructing risk.

Beck (1992) discusses the role of medicine in the *Risk Society*. The professionalisation of medicine in nineteenth century Europe took illness away from people, making it the jurisdiction of medicine, which had the power to define pathological conditions and develop "technology" to administer them without external scrutiny or governance. Beck argues that the professionalisation of medicine has created a *reflexive market strategy* where 'medical progress' continually defines new health risks, whilst at the same time producing new treatment innovations, which extends its arena of practice.

Kutchins and Kirk (1999) have detailed how increasing numbers of everyday behaviours or problems are becoming conceptualised as indications of mental illness by psychiatry, for example, not sleeping indicates Major Depressive Disorder; worrying is Generalised Anxiety Disorder; shoplifting is Conduct Disorder. One result of the increasing numbers of diagnosable mental disorders are more and more potential markets for the pharmaceutical industry to target with chemical cures as Johnstone (2000) and Moncrief (2008) have suggested. These authors present a picture of the pharmaceutical industry and psychiatry colluding to change the definitions and boundaries of chemicals and illnesses, based on business interests rather than 'scientific' decisions. Johnstone suggests that new drugs go through typical cycles of an accidental discovery with initial proclamations of miraculous effects leading to a buzz of excitement. As time goes on they are eventually recognised as no better than the treatment they purported to replace. As I discussed in Section 1.7.1.4, the 'atypical' antipsychotics might exemplify this process. A further contributor to the power of the pharmaceutical industry, highlighted by Johnstone (2000), is the control it extends over the 'scientific' literature. She suggest that medical journals often: rely on funds from drug advertisements for survival, have individuals on their editorial boards who have drug-company affiliations and publish drug company sponsored 'supplements' which are subject to less rigorous peer

review. Furthermore, Healy (2001) argues that trial outcomes which do not support a company's interests are frequently not reported.

In this context, the dominant institutions of medicine and the pharmaceutical industry serve to determine what is known about 'mental illness', its 'treatments' and the 'risks' involved. Professionals within their daily practice might thus be seen as pawns of this process as they draw on this apparently 'scientific' knowledge in their roles as arbitrators of risk. For example despite their now recognised failings (e.g. NICE, 2009) we saw that psychiatrists in the focus groups were able to draw on a repertoire of 'medical progress', where "atypical antipsychotics" were presented as advanced formulations compared favourably to previous treatments (see Section 3.3.5.2).

Going back to my initial question as to whose interests the notion of 'risk' in mental health serves, we can see that government, medicine and the pharmaceutical industry might be such beneficiaries.

4.2. CRITIQUING QUALITY AND LIMITATIONS

In this section I will evaluate the research in terms of its quality and limitations and comment on how fruitful combining the two types of method has been.

4.2.1. Survey

I have stated that I have not used the questionnaire in the way it might be traditionally used, which is to obtain a 'valid' measure of clearly defined phenomena. Rather, informed by social constructionist thinking, I have conceptualised it as a way of inviting participants to present positions on a topic. In using a questionnaire to do this, I have placed constraints around the possible positions which can be taken by participants, thus possibly obscuring variability: a criticism which Potter and Wetherell (1987) direct at such a methodology. However, pragmatically, I found that

using the survey alongside the focus groups *has* facilitated a broader exploration of the topic from a broader range of professionals and enabled me to capture some of the variability in positions available in relation to the topic. Furthermore, having asked survey participants to quantify the frequency of encountering medication refusal, I am able to conclude that professionals present this as a common encounter, which warrants a call for further research to be undertaken on the issue.

Specific limitations of the questionnaire which might be addressed if it were to be refined for further use, particularly within a realist framework, include perhaps for the matters of coming off medication and not wanting to initiate medication to be separated and examined separately. Also, I did not provide a definition of 'success' in terms of coming off medication, leaving it to participants to define: I see 'success' as being uniquely defined by a service-user within the context of their world. Other researchers might critique this (as did one participant) and wish to provide a constraining definition to allow comparison across different studies.

In terms of representativeness of the survey, a sample of 74 participants in survey terms is small, and as a self-selecting sample it could be critiqued as inherently 'biased'. My aim was not for representativeness and generalisability in a traditional positivistic sense, rather I aimed for a diversity of accounts to be collected from professionals working in different contexts. There was little representation by psychiatrists who, as the professional group with perhaps the most interest and power with regards to medication, might present particular positions in relation to this issue which have been missed. Furthermore, a disproportionate sample of participants were clinical psychologists, due to recruitment through a BPS special interest group. This may have increased the availability of success stories about coming off medication. However, as I have suggested in relation to the focus groups, psychologists are also able to take an 'absent' position on this.

4.2.2. Focus Groups

I have outlined why focus groups were chosen as a means to collect professional accounts in relation to antipsychotic 'medication refusal' (Section 2.2.2.1). In practice I found this to be a fruitful means to evoke and examine such accounts. Using groups rather than individual interviews allowed an examination of how particular discursive acts were *orientated* to by other members of the group, which was helpful in analysing the meanings which were being created within the groups (Potter and Wetherell, 1987). Although, focus groups do not constitute "naturally occurring" talk, they can demonstrate the discursive resources available for professionals to draw on and one might speculate that these resources are available for professionals to draw on in discussions with professionals and service-users.

It is important to reflect on my position as researcher and facilitator of groups and how I have contributed to the meanings which were constructed in the groups. Firstly, I constructed the vignette which was used as an initial focus for the groups and was focussed on the groups to varying degrees. This vignette is open to be examined and deconstructed in itself as one means of evaluating my influence on the groups. Secondly, participants may have anticipated that I take a particular position on the topic by virtue of my profession and this may have indirectly located participants in particular subject positions in relation to me and limited what might or might not be said. Thirdly, I may have directly positioned people through my contributions to the focus group discussions. I have tried to make this transparent in the extracts I have drawn on in my analysis.

4.2.3. Discursive Analysis

Potter & Wetherell (1987) have identified ways in which DA work can be evaluated, which the reader is able to apply to my analysis. The first is *coherence*: analytic claims should give coherence to a body of discourse and how it fits together, functions and accounts for exceptions. I have attempted to do this throughout my analysis, by drawing attention to discursive micro-features as well as broader patterns in the data

with reference to extracts as examples. Where there are exceptions I have demonstrated how these can be accounted for. The reader is thus able to judge my analysis and the claims I have made. A second criteria is *fruitfulness*: "the scope of an analytical scheme to make sense of new kinds of discourse and to generate novel explanations" (p171). The 'risk talk' I have presented and the devices and repertoires inherent in it may be useful in examining and illuminating analyses of talk in other settings, for instance general medical settings or professional settings where 'risk' is a feature.

A further criteria presented by Woods and Kroger (2000) is *plausibility*, by which they mean whether a set of claims is acceptable and makes sense in relation to existing 'knowns', including existing literature. The reader is invited to judge the plausibility of my claims through their knowledge about social life and through comparisons I have drawn between my claims and other literature.

4.3. APPLICATION

4.3.1. Applying Discursive Research

Harper (1995) has drawn attention to the problem of the straightforward application of DA research to practice: there are a variety of stakeholders with different stories to be told, however some are more dominant and powerful than others and the decision about which to privilege is political. Harper (1999a) draws on the concept of "usefulness" rather than application, in terms of whether suggestions lead to just and socially responsible outcomes. He has done this in his own research by focusing on specific stakeholders and suggesting the ways in which the research might be useful to them. This seems like a useful way to frame "applications" from this research. In doing this, in line with the critical stance I have taken in undertaking the research, I will privilege the concerns of service-users. Some suggestions I make might be liable for criticism as idealistic and it is likely that significant changes will be resisted by the powerful structures which hold mental health systems in place.

However small changes might snow-ball to make bigger changes to improve the experiences of service-users.

4.3.2. Service-users

Research findings might be most usefully disseminated to service-users through user newsletters, meetings and conferences.

We have seen how professionals are able to draw on complex discursive resources when talking about medication, and may use techniques of persuasion with respect to medication refusal. Service-users could be made aware that the arguments professionals might make in this respect, for example about risks of relapse and of "brain damage", are particular versions and that there are alternative accounts. Harper (1999a) suggests that training for service-users might facilitate this. Service-users also need to be aware of their rights, in order that they might challenge practices such as veiled threats. Mind publish information leaflets about rights under mental health legislation which are available online for service-users to access. Awareness of government initiatives on "choice" and "involvement" may provide further leverage for service-users in obtaining the services to suit their needs.

Service-users need to have access to independent advice about medications and how to safely come off them, as professionals may provide limited information. Questionnaire responses suggested that in some areas, groups were available for people who want to come off medication, where they can access support and information. Networks could be set up where service-users could support each other in this process, where those who had already been successful might mentor peers.

4.3.3. Professionals & Academics

Research findings might be most usefully disseminated to these parties through published literature and conference presentations. Also, participants of the research

were able to provide an email address if they wanted updates on the outcomes of the research.

Professionals might be made more aware of the effects that particular ways of talking about medication refusal might have on relationships with service-users and that the use of 'persuasion' might contravene mental health legislation. They might become more aware that: critiques exist of the 'truths' about psychosis and antipsychotics; the risk of bias in research relating to medication; that the notion of 'risk' is contested, not an absolute. Hearing about other professionals' successes with supporting service-users to come off medication might empower more professionals to take such 'risks' themselves.

Professionals may benefit from independent training about antipsychotic medication and coming off medication, in order that they might be able to provide the conditions for service-users to make truly informed choices.

Professionals sympathetic to alternative approaches to psychosis might join with service-users in networks where expertise and knowledge might be shared and political pressure might be placed to challenge medical dominance. For example, professional groups were able to join with service-user groups in an alliance to challenge proposals to change mental health act legislation. The topic explored here is under-researched and professionals, academics and service-users might join forces to carry out more research. Charities such as Mind might be able to support further research in this area.

4.3.4. Service Managers

Managers of services could be made aware that the promotion of risk-averse repertoires constrains innovative and true user-focused service provision. As demonstrated by questionnaire respondents, drawing on NICE guidance (2009) can be used to justify the support of service-users in attempting to come off

antipsychotics. Service audits might be undertaken to measure the extent to which service-users are given this option and rates of success in order to build up "practice-based evidence".

4.4. FURTHER RESEARCH

Further research could analyse "naturally occurring" talk between professionals, and between professionals and service-users in relation to medication refusal, in order to identify whether the repertoires and devices which were demonstrated in this study are used in "real" conversations. Hepburn and Potter (2007) have undertaken discursive research on child abuse helpline telephone conversations. They have been able to provide staff with feedback and training, based on analyses of their conversations. A similar approach could be undertaken in relation to this topic. A further useful piece of research would be a detailed account of a professional and service-user working together to come off medication.

5. CONCLUSIONS

This research set out to examine professional perspectives on working with medication refusal in psychosis. It has shown that this is a commonly reported experience for professionals and that there are diverse accounts which can be provided by professionals in relation to the topic. In particular, professionals are able to draw upon flexible repertoires of risk to account for their actions in relation to medication refusal and warrant particular courses of action. These can be situated in wider societal discourses of risk.

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7. APPENDICES

What happens if someone doesn't want to take antipsychotic medication?

Questionnaire

Information for participants

Participation

You are free to choose whether or not to participate in this research. By continuing to complete this questionnaire you are consenting to take part in the research project and the information you provide being subjected to analysis and publication. Your data will not be personally identifiable and will be kept confidential within the research team. You are free to withdraw at any time without any reason, simply exit the questionnaire and your data will not be saved. You are able to indicate whether you would like to receive information about the outcome of the research and whether you would like to participate further in the research.

Instructions

Please follow the instructions for each question. You may work in different settings, however the questions relate to working with clients living in the community only. The situations of all the people we work with are very different, however when answering the questions please think about what would usually happen.

N.B. The questionnaire will be predominantly administered online, filters will be applied so that persons attempting to participate who do not reach the inclusion criteria will not progress to complete the full questionnaire.

1. <u>About you</u>

The following information is required to make sure you are eligible to participate and so that we have an idea of the range of people participating and their locations. You will not be asked to give your name.

a) **What type of team do you work in?**
☐ Community Mental Health Team
☐ Early Intervention in Psychosis Team
☐ Assertiveness Outreach Team
☐ Crisis Intervention Team*
☐ Community Forensic Team
☐ Home Treatment Team*
☐ Community Assessment Team*
*Professionals working in these teams are not eligible to participate

b) **Which is your employing trust?**

_____

c) **You must be a qualified professional to participate. What is your profession?**
☐ Psychiatrist* Please specify seniority _____
☐ Clinical Psychologist
☐ Counselling Psychologist
☐ Mental Health Nurse
☐ Social Worker
☐ Occupational Therapist
☐ Psychotherapist
☐ Other: Please Specify _____

d) **How many hours a week do you contribute to the team?**
_____

e) **How many years post-qualification experience do you have?**
☐ 0 – 2 years
☐ 2 – 5 years
☐ 6 – 10 years
☐ 11 – 15 years
☐ 15 – 20 years
☐ 20+ years

f) **How many years have you worked in a mental health team in the community?**
☐ **0 – 2 years**
☐ **2 – 5 years**

☐ 6 – 10 years
☐ 11 – 15 years
☐ 15 – 20 years
☐ 20+ years

2. Role in the Team
The next questions are to give us an idea of the work you usually undertake in your team.

a) **What are the main roles you play in the team? (Please tick all that apply)**
☐ Care Coordinator.
☐ Undertaking assessments
☐ Prescribing Medication.
☐ Providing consultation to the team.
☐ Administering Medication.
☐ Monitoring Medication.
☐ Managing social affairs, e.g. accommodation, benefits etc.
☐ Providing short-term individual psychological interventions (1-10 sessions).
☐ Providing longer term individual psychological therapy to clients (more than 10 sessions).
☐ Running groups, e.g. anxiety management, relaxation etc.
☐ Developing Programmes to support clients in developing daily living skills.
☐ Managing the team.
☐ Acting as an Approved Practitioner.
☐ Care Manager.
☐ Undertaking risk assessments.
☐ Others: Please Specify:

_____

_____

b) **How many clients do you have on your caseload in the community team?**

_____

c) **Approximately how many clients on your caseload have a history of or currently have psychotic experiences?**

_____

d) **How many clients on your caseload are subject to Community Treatment Orders?**

_____ ☐ **Don't know**

e) **Do you have a special interest in issues relating to antipsychotic medication, medication withdrawal or non-medical approaches to psychosis?**

☐ No
☐ Yes: please specify:

_____

_____

3. Clients on anti-psychotics

The next questions specifically relate to working with people prescribed antipsychotic drugs.

a) **Approximately how many clients on your caseload in the community are currently prescribed an antipsychotic drug/s?**

_____ ☐ **Don't know**

b) **Approximately how many clients on your caseload currently (within the <u>past month</u>) have expressed that they wish to stop taking their antipsychotic drug/s?**

_____

c)

    I. Approximately how many clients have you worked with in the past <u>year</u> who have expressed at some point that they wish to stop taking their antipsychotic drug/s?

_____

    II. Of these approximately how many have begun a process of discontinuing antipsychotic drugs with the support of services?

_____ ☐ Don't know

    III. Of these approximately how many have stopped taking their medication against the team's advice?

_____ ☐ Don't know

d) **In your experience, what are the <u>most common</u> reasons people give for wishing to discontinue or not initiate antipsychotic medication?**

☐ Adverse effects such as restlessness, un-controllable movements, weight gain, impotence etc.
☐ Not wanting to rely on medication long-term.
☐ Concerns about long-term health risks.
☐ Medication not working.
☐ Feeling worse on medication.
☐ Not wanting the stigma of taking medication.
☐ Wanting to try alternatives to medication.
☐ Not feeling like myself or feeling too sedated.
☐ Feeling the medication is poisoning them.
☐ I haven't discussed this with my clients.
☐ Feeling better/cured
☐ Other reasons: Please Specify

e) **When a client you are working with expresses a wish to discontinue antipsychotic medication, which of the following actions would you be <u>most likely</u> to take?**

☐ Try to persuade the client of the benefits of continuing to take their medication.
☐ Discuss the matter with my team.
☐ Discuss with the client the adverse consequences of this, in terms of the risk of admission to hospital.
☐ Arrange or encourage the client to have an appointment with the psychiatrist.
☐ Explore why the client wants to stop.

☐ Consider reducing or switching the client onto a different medication.
☐ Discuss with the client the potential risks of stopping medication.
☐ Discuss with the client the potential benefits of stopping medication.
☐ Provide the client with written information about stopping medication.
☐ Discuss alternatives to medication with the client.
☐ Consider supporting the client to come off medication.
☐ Undertake a risk assessment.
☐ Others: Please specify:

_____

f)
I. Indicate who would <u>usually</u> be involved in decision-making about what to do when a client expresses that they wish to stop taking or not commence an anti-psychotic drug?
II. **Of those selected, please rate how much influence you think each has on the decision (1 = minimal influence, 5 = most influencial).**

	1	2	3	4	5
☐ The client.	☐	☐	☐	☐	☐
☐ The Care-Coordinator.	☐	☐	☐	☐	☐
☐ The client's psychiatrist.	☐	☐	☐	☐	☐
☐ The Multi-Disciplinary Team.	☐	☐	☐	☐	☐
☐ The client's carers/family.	☐	☐	☐	☐	☐
☐ The Care Manager.	☐	☐	☐	☐	☐
☐ The client's therapist.	☐	☐	☐	☐	☐
☐ An advocate for the client.	☐	☐	☐	☐	☐
☐ A second opinion doctor.	☐	☐	☐	☐	☐
☐ Staff at a client's place of residence (e.g. hostel staff).	☐	☐	☐	☐	☐

☐ **Don't know.**					
☐ **Others: please specify:** _____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐

g)

    I. Approximately how many clients in the last <u>two years</u> have you supported to successfully stop taking antipsychotic medication for a substantial period of time (if none proceed to section i)?

    _____

    II. What percentage were initiated by yourself?

    _____

    III. What percentage were initiated by the client?

    _____

h) **Please rate how confident you feel in supporting clients to discontinue antipsychotic drugs (1 = not at all confident, 5 = extremely confident)?**

☐	☐	☐	☐	☐
1	2	3	4	5

i) **What do you think would help you to feel more confident in supporting clients to discontinue antipsychotic drugs or manage psychotic experiences without drugs ?**

☐ Greater support from my team.
☐ Access to research evidence of most effective ways to do this.
☐ Specific guidance from a body such as NICE.
☐ Access to alternative interventions to support client.
☐ Resources to allow me more time to devote to supporting clients in this situation.
☐ More training on this subject.
☐ More research evidence that clients are able to successfully able to manage without medication.
☐ Other: Please Specify:

_____
_____
_____

j)

I. What non-medical approaches or support services do you provide/are available locally for clients you work with?

_____
_____
_____

II. What non-medical services/approaches/extra resources do you think would be helpful for your clients to be able to access locally?

_____
_____
_____
_____

4. The research

a) Would you like to receive further information about the research as it progresses?

☐ No
☐ Yes: please provide an email address where you can be contacted:

_____
_____

b) Would you be interested in contributing to the next stage of the research, which aims to explore these issues in more depth? This would involve taking part in a focus group or interview.

☐ No

☐ Yes: please provide an email address where you can be contacted:

_____

_____

How far would you be prepared to travel to take part in the next stage of the research?

☐ I could only take part if it was in my workplace or very near by.
☐ To the University of Hertfordshire in Hatfield.
☐ I am not restricted to how far I would travel.
☐ Other _____

_____

C) Please provide any further comments or suggestions you have about this topic area or the research:

_____

_____

_____

_____

_____

Thank you very much for your contribution to the research.

Appendix 2: Focus Group vignette & topic guide

Case Vignette

Mark is a young man living with his mother and younger brother. He has been involved with mental health services for several years and is currently prescribed Risperidone 2mg once daily.

After leaving school he began an apprenticeship as a plumber. Several months later, his family started to notice that he was becoming more withdrawn and neglectful of himself. He started spending more time alone in his room on his computer instead of attending work and socializing with his friends. He became increasingly unable to meet his work and college obligations and eventually dropped out. He lost touch with most of his friends and became anxious about going out in the local area. He would often not respond to his family's attempts to talk to him. At times he could be heard laughing and talking to himself in his room and could be verbally aggressive towards his mother and brother when asked about this. On one occasion he grabbed a knife from the kitchen and threatened to cut his wrists. When his mother had opportunity to enter his room, she always found the curtains closed and she could often hear that Mark was still up in the early hours of the morning.

After coming to the attention of services, Mark was assessed and given a diagnosis of Paranoid Schizophrenia. He was reluctant to talk to professionals and always appeared anxious and suspicious when brought to appointments. On one occasion he said that they had been followed to the appointment and were being watched, but denied hearing voices. Mark was initially prescribed Olanzapine, 5mg once daily, which he took for several months. His mother noted that he was less aggressive and more likely to talk to her and his brother, but was still withdrawn and suspicious. Mark complained to his mother that he felt restless and was putting on weight. He started to refuse to take his medication and became even more withdrawn, telling his mother that the family were not safe and insisting that additional locks were put on the front and back doors. His mother became increasingly worried about him and was not sure how to manage his refusal to take his medication. Mark was visited at home by his psychiatrist, who told him that he was worried about him not taking his medication and discussed whether he might feel safer in hospital. Mark insisted he did not need to go to hospital and agreed to try a different drug. He was prescribed Risperidone, 2mg once daily.

You have been working with Mark for several months and during this time on several occasions he tells you clearly that he does not want to take the medication. He tells you it makes him feel like he is separate from the world and that he always feels sleepy. He tells you he doesn't like taking medication and that his father has told him it can cause health problems. At your most recent appointment, he tells you he is going to stop taking it altogether.

Focus Group Moderator Topic Guide

1. Introductions and ground rules of session

2. Reading Vignette

3. Questions – to stimulate discussion and to be followed flexibly:

   a. How would you respond in this situation?

   b. What factors would you consider? Which are most important?

   c. Are you able to respond as you would ideally want to? What prevents or supports this?

   d. Do you think other members of your team would respond in the same way? How might they respond differently?

   e. Do you see your role as important in situations like this? Do others see your role as important?

   f. How often would you face this type of situation?

   g. Are there ways in which you think your practice could improve? What supports or inhibits this?

   h. How important are issues relating to antipsychotic medication management to your profession?

   i. How are individuals who are reluctant to take antipsychotic medication viewed? Do you think there are adequate alternatives?

Appendix 3: Information sheet for focus group participation

RESEARCH PARTICIPANT INFORMATION SHEET (Version 1)

Study title:

An exploration of community mental health professionals' perspectives on working with

people with psychotic experiences who do not wish to take antipsychotics.

Dear …………………………………….,

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you.

Please do ask us if there is anything which is not clear, or if you would like more information, and take time to decide whether you would like to participate or not.

What is the purpose of the study?

My name is Sally Westwood and I am a Trainee Clinical Psychologist at the University of Hertfordshire. I am conducting this research as part of my doctorate qualification in Clinical Psychology.

My research will be looking at the experience of working with adult service-users with a history of psychotic experiences who do not wish to take or wish to come off antipsychotic medication. Research has looked at this from the perspective of service-users, however my research is taking the perspective of mental health professionals. I am interested in all professional disciplines working in community teams, whether they prescribe and monitor medication as part if their role or not. Very little previous research has been carried out in relation to this subject and thus your contribution would be highly valued. It is hoped that the results will allow greater understanding of how professionals and services respond to this issue and changes which might need to be made to better meet the needs of professionals and service-users. The research will be submitted for publication when complete.

In order to gain an understanding of this issues, I am looking to recruit five to six psychiatrists, community mental health nurses, social workers and allied health professionals (occupational therapists, clinical and counselling psychologists, psychotherapists) working in mental health teams in the community to take part in uni-professional focus groups.

Why have I been invited?

- You are from a professional discipline which the research is interested in.
- You work in a community team with people with psychosis prescribed antipsychotics.
- You have expressed an interest in my project via contact by email or by telephone.

Do I have to take part?

It is wholly your choice as to whether you decide to participate or not. If you do decide to participate you will be given a copy of this information sheet to keep and you will be asked to sign a form recording your consent.

 If you do decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

To participate, you would be asked to take part in one tape-recorded focus group session lasting approximately 1 - 1½ hours. The setting is to be negotiated depending on who agrees to take part and may take place at the University of Hertfordshire or on NHS premises closer to where you are located. A fictitious case example will be presented at the session and you will be expected to discuss your response to this and issues surrounding the topic with peers from the same or a similar professional background to yourself. The resulting data collected will then be subjected to analysis.

If you consent, you may be contacted at a later date to ask if you wish to comment on our research findings. You are able to decline this offer without giving a reason.

What are the possible disadvantages of taking part?

Participating in the study will place a burden on your time. However, it is anticipated that this will not exceed two and a half hours including travel time.

Although topics to be discussed are not potentially distressing, reflection on your work in the focus group may cause you to consider different ways you could have understood a service user's difficulties or worked with a service-user. This may be a useful process, but might also evoke negative emotions. If any of the questions are experienced as being particularly sensitive, you do not have to answer them.

What are the possible benefits of taking part?

We can not promise that the study will help you. However, taking part will allow you to have time and space to reflect on your experiences and practice with peers. This process may allow sharing of good practice, and reassurance that others are faced with similar dilemmas.

The topic being explored is currently under-researched and it is intended that this research will be published in professional journals. As such it may help other professionals to reflect on their own practice and contribute to an understanding of how services or organisations respond to the issues and might need to change in order to better address the needs of service users and professionals.

What if there is a problem?

If you have concerns about any aspect of this study you should ask to speak to the researcher who will do her best to answer your questions (Telephone numbers: 07957 638954, 01992 313658). If you remain unhappy and wish to complain formally you can do so by contacting the

researcher's Academic Supervisor at the university, Dr Alex Harbourne (Telephone number: 01707 289449).

Will my taking part in the study be kept confidential?

All information collected about you throughout the course of research will be kept strictly confidential. Your name and other identifying information will be kept securely and separately from your tape-recording and the subsequent data-analysis. Your employer will not have access to any raw research data which may be able to identify you at any time.

Due to the time constraints on this project an approved transcription service may be used to transcribe your interview. In this case your recording will be labelled A, B, C etc. to protect identity. The service will sign a non-disclosure, confidentiality agreement.

Some parts of the data collected by this research will be looked at by authorised persons from the University of Hertfordshire (Sponsoring organisation) and the research team. Anonymised sections of the data collected may also be looked at by representatives from academic and professional assessment bodies in order to assess the quality of this doctoral research project. All will have a duty of confidentiality to you as a research participant.

Your recordings and any identifiable data relating to your participation will be kept for up to 5 years post research project submission (June 2015) according to the University of Hertfordshire's 'Good practice in research' guidelines. All identifiable data will be destroyed by the chief researcher after this time in accordance with university guidelines.

Are their any reasons where confidentiality may be breached?

Due to your professional status, you will be regulated by a professional body. The researcher is bound by the British Psychological Society code of conduct and as such this will be followed with regards confidentiality:

1. If you disclose information during the interview which leads to sufficient concern about your safety or the safety of others it may be judged necessary to inform an appropriate third party without formal consent.

2. Prior to this occurrence the researcher's project supervisor will be contacted to discuss any possible concerns, unless the delay would involve a significant risk to life or health.

What will happen to the results of this research study?

The results will be written up in the form of a thesis for the purposes of gaining a Doctoral qualification in Clinical Psychology. This will be publically accessible.

I may ask you if you would like to comment on the analysis of the focus group to help with the accuracy of the results. You can decline your involvement.

It is planned that the findings will be shared via academic publication and/or presentations. Participants will not be identified in any report or publication. Any quotes used will be fully anonymised. You have the right to decline the use of your quotes.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, dignity and well-being. This study has been reviewed and given a favourable opinion by the Hertfordshire Research Ethics Committee who have raised no objections on ethical grounds. The research has also been reviewed and agreed by the research and development committee within your employing organisation

Due to the academic nature of the research, this project has also been subjected to both a formal and a peer review by the University of Hertfordshire's Doctoral Programme in Clinical Psychology.

Further information and contact details

Should you have any further questions or any concerns during the study please do not hesitate to contact the researcher or her research supervisor using the contact details provided below.

If you are interested in potentially participating in this study please fill in the reply sheet included with this information sheet and return to Sally Westwood (Chief Investigator) via email.

Should you wish to complain about this study the Independent Complaints Advocacy Service (ICAS) supports individuals wishing to pursue a complaint about the NHS.

(http://www.dh.gov.uk/en/Managingyourorganisation/Legalandcontractual/Complaintspolicy/NHScomplaintsprocedure/DH_4087428)

Thank you for taking time to read this information.

Kind Regards,

Ms Sally Westwood   Dr Alex Harborne

Chief Investigator   Academic Supervisor
Trainee Clinical Psychologist   Clinical Psychologist & Research Tutor
University of Hertfordshire.   University of Hertfordshire
s.j.westwood@herts.ac.uk   a.harborne@herts.ac.uk
07957 638954   01707 289449
01992 313658

<u>Research</u>

Anti-psychotics: What happens if someone doesn't want to take them?

Calling all mental health professionals working in community teams!

Can you help?
As part of my Clinical Psychology doctorate at the University of Hertfordshire, I am undertaking some research into the experience of working with adult service-users with a history of psychotic experiences who do not wish to take or wish to come off antipsychotic medication.

Research has looked at this from the perspective of service-users, however my research is taking the perspective of mental health professionals and I am interested in all professional disciplines working in community teams, whether they prescribe and monitor medication as part if their role or not. Very little previous research has been carried out in relation to this subject and thus your contribution would be highly valued. It is hoped that the results will allow greater understanding of how professionals and services respond to this issue and the research will be submitted for publication when complete.

How can I take part?
I have developed a short online questionnaire to collect information about your experience of this matter. It doesn't matter how experienced you feel you are with this matter or not, I would like to hear from you. Please click on the following link to take part: [address]. It should not take you longer than approximately 20 minutes.

The second part of the research will consist of focus groups or interviews with a small selection of professionals and you can indicate on the questionnaire whether you are interested in taking part in one of these too.

What if I want to know more?
Please email me at: s.j.westwood@herts.ac.uk if you would like further information, or feel you could contribute to helping with the research in other ways.

Thank you for your time.

Sally Westwood
Trainee Clinical Psychologist
Doctor of Clinical Psychology Training Course
University of Hertfordshire

Appendix 5: Invitation to participate in focus group

C/O Doctorate in Clinical Psychology course
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB
s.j.westwood@herts.ac.uk
sallywestwood@nhs.net
07957 638954

11th July 2009

Dear …………………………………….,

Re: Research Focus Group - An exploration of community mental health professionals' perspectives on working with people with psychotic experiences who do not wish to take antipsychotics.

As part of my Clinical Psychology doctoral training, I am undertaking research into professionals' experiences of working with service-users with a history of psychotic experiences who wish to "come off" or stop taking antipsychotic medication. Research has been undertaken relating to this topic from the perspective of service-users, however there is little research exploring the perspective of mental health professionals. I am interested in professionals working in community teams, whether or not they prescribe and monitor medication as part if their role. It is hoped that the results will allow greater understanding of how professionals and services respond to this issue and as well as being written up as a doctoral thesis, the research will be submitted for publication.

You may have already taken part in the first stage of my research, which involved completing a questionnaire or you may have been contacted to help me by a member of your team. The second stage of the project involves taking part in a focus group discussion to explore the issues in more depth. This is what I would like your help with. I plan to hold four focus group discussions of different professional groups. The groups will be as follows: a group of psychiatrists, of community mental health nurses, of social workers and of allied health professionals (i.e. occupational therapists, psychologists, psychotherapists). I hope to recruit approximately 5-6 professionals to take part in each session.

To participate, you would be asked to take part in one audio-recorded focus group session lasting approx. 1 - 1½ hours. The setting is to be negotiated depending on who agrees to take part and may take place at the University of Hertfordshire or on NHS premises closer to where you are located. A fictitious case example will be presented at the session and you will be expected to discuss your response to this and issues surrounding the topic with peers from the same or a similar professional background to yourself. The resulting data collected will then be subjected to qualitative analysis.

If you are willing to consider participation or would like more information, please contact me using the details at the top of the letter. Thank you in advance for your time. I look forward to hearing from you.

Yours Sincerely

Ms Sally Westwood
Chief Investigator
Trainee Clinical Psychologist
University of Hertfordshire.

Supervisor: Dr Alex Harborne
Clinical Psychologist & Research Tutor
University of Hertfordshire
a.harborne@herts.ac.uk
01707 289449

Reply Sheet

(Please complete appropriate boxes and return by email to the researcher:
s.j.westwood@herts.ac.uk *).*

1.   ☐ *I am not interested in participating in this project.*

2.   ☐ *I may be interested in participating in this project but would like further information.*

   I consent to you contacting me on the telephone number/email address below.

3.   ☐ *I am interested in participating in this project.*

   I consent to you contacting me on the telephone number/email address below.

_____

My Details (Please Supply if you tick statement 2, or 3):

Name:

Telephone number:

Email address:

Preferred means of contact (please tick):

☐ *Email*
☐ *Telephone*

If telephone, suitable times for contact (E.G. Mondays 12-2pm):
Day: *Times:*
Day: *Times:*
Day: *Times:*

(Please complete appropriate boxes and return by email to the researcher:
s.j.westwood@herts.ac.uk*).*

Appendix 6: Focus Group Consent Form

RESEARCH PARTICIPANT CONSENT FORM (Version 1)

Title of Project: ***An exploration of community mental health professionals' perspectives on working with people with psychotic experiences who do not wish to take antipsychotics.***

Centre number:

Study Number:

Participant identification number:

Name of researcher: *Sally Westwood, Trainee Clinical Psychologist.*

To be completed by participant (Please initial each box):

		Initials
1.	I confirm that I have read and understand the information sheet date 15th July 2009 (Version: 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that I am free to decline entry into the study and I am able to leave the study at any time without reason?	
3.	I consent to the tape recording of my interview	
4.	I understand that relevant sections of the data collected by this research will be looked at by authorised persons from the University of Hertfordshire (Sponsoring organisation) and within the research team. Anonymised sections of the data collected may also be looked at by representatives from academic and professional assessment bodies in order to assess the quality of this doctoral research project. All will have a duty of confidentiality to me as a research participant	
5.	I agree to take part in the above study.	
6.	I agree to be contacted for my comments on the findings of the study. I am aware I can decline my involvement at any time.	
7.	I agree that anonymised quotes from my interview may be used in any publications.	
8.	I would like to receive a summary of the results from the study: ☐ Yes ☐ No	

Participant Signature: _____ Date: _____

Name: _____

Signature of Person taking consent: _____ Date: _____

Name: _____

Appendix 7: Ethical Approval Letter

NHS

National Research Ethics Service

Hertfordshire REC
East of England REC Office No 3
9th Floor, Terminus House
The High
Harlow
Essex
CM20 1XA

Telephone: 01279 418 439
Facsimile: 01279 419 246

28 September 2009

Miss Sally J Westwood
20 Horns Close
Hertford
Hertfordshire
SG13 8HL

Dear Miss Westwood

Study Title:	**An exploration of community mental health professionals' perspectives on working with people with psychotic experiences who do not wish to take antipsychotics.**
REC reference number:	09/H0311/97
Protocol number:	1

The Research Ethics Committee reviewed the above application at the meeting held on 23 September 2009. Thank you for attending to discuss the study.

Ethical opinion

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

Ethical review of research sites

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

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification

Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		21 August 2009
Participant Information Sheet	1	11 July 2009
Participant Consent Form	1	11 July 2009
Letter of invitation to participant	1	11 July 2009
Interview Schedules/Topic Guides	1	26 February 2009
Questionnaire: What if someone doesn't want to take antipsychotic medication?	1	13 February 2009
Advertisement	1	26 June 2009
Protocol	1	13 February 2009
Investigator CV	SJW	14 August 2009
Letter from Sponsor		19 August 2009
Transcription confidentiality/non-disclosure agreement	1	11 July 2009
Formative Feedback on research proposal		25 March 2009
Academic Supervisor's CV	AH	07 August 2009
UMAL Professional Indemnity		01 August 2009
REC application		19 August 2009

Membership of the Committee

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

Statement of compliance

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

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority

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

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
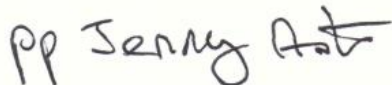
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0311/97	Please quote this number on all correspondence

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

Yours sincerely

pp Jenny A...

Dr Steve Eckersall
Chair

Email: jenny.austin@eoe.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers" (SL- AR2)

Copy to: Prof John Senior
Pro-Vice Chancellor (Research)
University of Hertfordshire
College Lane
Hatfield
Herts AL10 9AB

Ms Natercia Godhino
R&D Office
Cambridgeshire & Peterborough NHS Foundation Trust
Douglas House
18 Trumpington Road
Cambridge
CB2 8AH

HireATypist
For All Your Typing & Transcription

Hire A Typist will adhere to the following wording. If required we will sign and send you a copy of this for your records.

Confidentiality Agreement

The parties to this agreement are Hire A Typist, whose office is situated at 29 Sydney Place, Lockerbie, Dumfriesshire, DG11 2JB and Sally Westwood whose residence is situated at 20 Horns Close, Hertford, Herts, SG13 8HL.

Hire A Typist confirm that:

We will not divulge information howsoever learned about The Client's clients, The Client's associates or The Client's client's associates to the press or any party that may result in information being passed to the press in any country.

We will not divulge information howsoever learned about clients, The Client's associates or The Client's client's associates to any other competitor of The Client, The Client's associates or The Client's client's associates or party likely to do so.

We will take reasonable care of any information so obtained and held or transmitted by them on hard copy or digital format such that it is not readable in the public domain and will not end up in the public domain.

Any subcontractor used by Hire A Typist to carry out work on behalf of The Client will be required to sign similar undertakings.

Signed on behalf of Hire A Typist by

Jill Simeon - Partner
Hire A Typist

What are the MAIN roles you play in the team?

Role	%
Undertaking assessments	64
Undertaking risk assessments.	50
Care Coordinator.	49
Short-term psychological interventions (1-10 sessions).	42
Providing consultation to the team.	41
Longer term psychological therapy (more than 10 sessions).	41
Managing social affairs, e.g. accommodation, benefits etc.	35
Monitoring Medication.	32
Running groups, e.g. anxiety management, relaxation etc.	19
Administering Medication.	16
Care Manager.	10
Others (please specify)	10
Developing daily living skills programmes.	9
Managing the team.	8
Prescribing Medication.	7
Acting as an Approved Practitioner.	6

Appendix 10: Information on survey participants' responses in relation to the question:

Do you have a special interest in issues relating to antipsychotic medication, medication withdrawal or non-medical approaches to psychosis (If Yes please specify)?

P Number	Profession/ Team	Response
1	Clinical Psychologist AOT	all three
2	Clinical Psychologist AOT	Assertive Outreach clients are largely non-compliant with their prescribed medication, and therefore non-medical approaches are ofetn key to engagement and recovery
5	Mental Health Nurse EIPS	psi and bft and football
8	Clinical Psychologist CMHT	only during training
11	Mental Health Nurse EIPS	CBT
13	Clinical Psychologist CMHT	only in so far as i'm a psychologist so obviously interested in psychological approaches alongside psychiatric
18	OT EIPS	holistic, non-medical approaches, particularly meaningful activity. Also the importance of socail skills training in helping people experiencing psychosis

Appendix 10 Continued

19	Clinical Psychologist EIPS	First episode psychosis, at risk mental states for psychosis and psychological approaches to psychosis are all special interests.
20	Mental Health Nurse CMHT	Medication management Weight management Healthy eating
21	Mental Health Nurse EIPS	non-medical approaches to psychosis especially during crisis / acute presentations. reducing and coming off psychiatric medication (run a open space in community for people wnating to stop/ reduce their psychiatric medication).
22	Clinical Psychologist EIPS	Individual or group support and written information to support medication withdrawal
24	Mental Health Nurse EIPS	cbt, assisting clients to reduce or come off medication after a two year period if symptom free and after discussion with client and family
25	Mental Health Nurse EIPS	I am currently training as a non-medical independant prescriber
26	Psychiatrist EIPS	I'm interested in antipsychotic medication and non-medical approaches in mild psychosis (that is below the threshold for a diagnosis of a psychotic illness)
27	Mental Health Nurse AOT	Solution Foused Brief Therapy Mindfulness based approaches to strees reduction

29	Psychiatrist CMHT	as a clinician who deals everyday with patients taking antipsychotic medications it is absolutely pivotal a clear and deep understanding of every issue related to the compliance in this field. as a psychotherapist I am also very interested in understanding the role that antipsychotic medications have in keeping the patient within boundaries approachable to a psychotherapeutic interventios. and last but not least I am really interested in gaining a deeper knowledge about the rational underneath the patients` refusal for antipsychotic medications.
30	Clinical Psychologist CMHT	psychological approaches to understanding and coping with psychosis
31	Clinical Psychologist Community Forensic Team	CBT for psychosis, Hearing Voices approaches to working with voices, safe medication withdrawal and management of withdrawal effects, education (to service users and staff) about medication (costs/benefits/ longer term and unknown effects)
32	Clinical Psychologist AOT	Support service user choice re medication and promoting alternatives including psychological therapy, hearing voices group etc.
33	Clinical Psychologist CMHT	Psychological and alternative approaches to working with people suffering from psychosis
35	Clinical Psychologist EIPS	Non medication approaches Inc psychological therapy and understanding person's own view of difficulties and options for facilitating recovery
36	Clinical Psychologist EIPS	Concerns about the contribution of medication to 'classical' presentation of longer term psychiatry clients ('SMI' group) and if iatrogenic. Concerns about effects of neuroleptics on medication-naive brains of young people with first episode psychosis Terminology such as medication 'compliance' Perpetuation of the medical model

37	Clinical Psychologist CMHT	CBT
41	Clinical Psychologist CMHT	I am interested in the psychological management of psychosis.
44	Clinical Psychologist CMHT	CBT/FI for psychosis.
45	Clinical Psychologist AOT	As a Clinical Psychologist, one of my roles is to help people understand and cope better with their psychotic experiences
46	Clinical Psychologist CMHT	Non-medical approaches to psychosis - psychodynamic and cognitive perspectives
47	Clinical Psychologist EIPS	i thin it'd be interested to conduct RCT in which one of the branches is 'not onlong term antipsychotic medication' + alos interested in the potential role of alternative medication that have less SE e.g. antidepressant, anxiolytic
48	Clinical Psychologist EIPS	non-medical approaches to psychosis - psychological therapies
49	Mental Health Nurse CMHT	Looking more into the non-medical approaches
50	Social Worker AOT	No medical approaches

51	Social Worker CMHT	Trained in Psycho-social interventions for psychosis (including CBT, family interventions etc)
52	Mental Health Nurse EIPS	Non medical approaches to mental health
54	Psychiatrist EIPS	efficacy, side effects
55	Clinical Psychologist EIPS	I am interested in the neurosciences as they describe the physiology and behavioural role of Dopamine based systems.
56	Social Worker EIPS	As new team member although I am social worker I will take the traianing medication next month
57	Social Worker EIPS	I am a qualified as a systemic family thrapist and I am the Trainer for BFT within the team.
58	Occupational Therapist EIPS	I am interested in learning more about living with pschosis but without medication
62	Mental Health Nurse CMHT	All depending on the individual
63	Clinical Psychologist CMHT	Previously conducted doctoral reseach on cognition in psychosis. Also worked on research projects investigating psychological therapies for psychosis including group CBT for voices, Cognitive Remediation, and Motivational Interviewing for medication concordance in this client group. During training undertook specialist placements in psychological therapy (CBT/Family Intervention) for psychosis, including EIP service

64	Social Worker CMHT	post-Faucaldian/Lacanic :power relations and empowerment
67	Psychiatrist EIPS	all of the above
69	Mental Health Nurse EIPS	Nurse prescriber
71	Mental Health Nurse EIPS	I am a Nurse Prescriber so interested in all aspects of medication. I am also PSI trained so interested in non medical approaches.
72	Social Worker EIPS	Talking therapy allowing the patient to talk about the experience of being psychotic and exploring with them what they find helpful to manage their symptoms. Whilst medication helps some patients others do not find it helpful at all.
74	Mental Health Nurse EIPS	CBT
46	Clinical Psychologist CMHT	Non-medical approaches to psychosis - psychodynamic and cognitive perspectives

Appendix 11: 'Other Reasons' given by participants in response to question:

"If a client you are working with expressed a wish to stop taking antipsychotic medication, which of the following actions would you be MOST LIKELY to take? CHOOSE UP TO FOUR"

P Number	Profession/ Team	Response
7	Psychotherapist CMHT	Think "persuade" is too strong a word in above question -would discuss the benefits.
21	Mental Health Nurse EIPS	in addition to the three i have ticked as standard i would discuss alternative to medication, alternative medication choices (should the reason be side effects), explore why the client wants to stop, discuss the experience of others who coming off and provide written information on these, sign post to local group re. coming off medication, support the client to discuss the matter with others (psychiatrist, family etc.), provide written information about coming off.
30	Clinical Psychologist CMHT	would usually share with the client's care coordinator
31	Clinical Psychologist Community Forensic Team	I'd discuss with them coach/practise a) alternative ways of dealing with the issues that the medication was meant to deal with, and b) plan how to manage withdrawal or rebound symptoms and encourage them to see stopping medication as a months long process (up to 18 months) and an opportunity to develop their own personal resources
41	Clinical Psychologist CMHT	It will depend a lot on the client's history - so if it looks like the meds don't make much difference then I might recommend to my team we support them coming off. If they have ended up in hospital each and every time they have stopped them - then I'd probably try to persuade them to keep taking them, in either case I would think it appropriate fo rthem to be booked in with a psychiatrist for a medication review.
45	Clinical Psychologist AOT	I would discuss the pros and cons of stopping medication vs the pros and cons of continuing medication

59	Clinical Psychologist CMHT	Help the client think back about the context of being prescribed the medication to help develop a wider story about the medication and their relationship to it.
63	Clinical Psychologist CMHT	Explore costs and benefits of stopping meds and taking them
72	Social Worker EIPS	Discuss with the psychiatrist and arrange an appointment with them so the patient can discuss with the doctor all the pros and cons of coming off their medication.

Appendix 12: 'Other Reasons' given by participants in response to question:

"What do you think would help you to feel more confident in supporting clients to discontinue antipsychotic drugs or manage psychotic experiences without drugs? CHOOSE UP TO THREE"

P Number	Profession/ Team	Response
22	Clinical Psychologist EIPS	More experience within the team in the process of supporting clients to discontinue - it is only recently we have been offering this as an intervention / approach.
33	Clinical Psychologist CMHT	The bigger issue of use of medication and role of Psychiatrists within CMHTs (teams) - highly dominant culture of medical model. Therefore, various team members automatically refer to psychiatry as first point of call
34	Clinical Psychologist AOT	It depends what you mean by feeling confident - I'm very happy to support clients to explore what they want and make choices about medication. I'm not always confident it'll work out for them so there's a certain retiscence that seems appropriate to the risks of relapse.
36	Clinical Psychologist EIPS	A less risk-averse culture in other mental health teams we interface with
40	Social Worker CMHT	Getting rid of the blmae culture should anything go wrong.
41	Clinical Psychologist CMHT	It depends on the client ! In practice it is very difficult to do without the support of the psychiatrist gruding or otherwise.
55	Clinical Psychologist EIPS	Some of this is also about team culture - many team members seem to feel deskilled if the client does not want to take medication.

Appendix 12 continued

67	Psychiatrist EIPS	I think that there is a sufficient body of evidence that most people will have to take medications. Discontinuing antipsychotics is more about finding out who is from this lucky minority (10-20%) who can manage without medications. Most importantly, to make sure that those who do relapse cann acess help and medication asap when they need it again. Please refer to NICE and Cochrane.

Of the people listed below, in your experience, indicate how much influence each USUALLY has on the decision-making when a client expresses that they wish to stop taking or not initiate antipsychotic medication. Rate each on a scale of 1 - 5 (1 = minimal influence, 5 = most influence) or tick the last column if that person would not USUALLY be involved in the decision-making.

| | answered question | | | | | | 68 | |
| | skipped question | | | | | | 6 | |
	1 = Minimal Influence	2	3	4	5 = Most Influence	Not usually involved	Rating Average	Response Count
The Client.	2.9% (2)	8.8% (6)	19.1% (13)	36.8% (25)	32.4% (22)	0.0% (0)	3.87	68
The Care-Coordinator.	1.5% (1)	5.9% (4)	27.9% (19)	55.9% (38)	8.8% (6)	0.0% (0)	3.65	68
The client's Psychiatrist.	1.5% (1)	1.5% (1)	13.2% (9)	35.3% (24)	47.1% (32)	1.5% (1)	4.27	68
The Multi-Disciplinary Team.	10.3% (7)	17.6% (12)	36.8% (25)	25.0% (17)	5.9% (4)	4.4% (3)	2.98	68
The client's partner/carers/family.	4.4% (3)	38.2% (26)	33.8% (23)	20.6% (14)	2.9% (2)	0.0% (0)	2.79	68
The Care Manager.	10.3% (7)	19.1% (13)	20.6% (14)	8.8% (6)	2.9% (2)	38.2% (26)	2.60	68
The client's Therapist/Psychologist.	10.3% (7)	23.5% (16)	32.4% (22)	19.1% (13)	1.5% (1)	13.2% (9)	2.75	68
An advocate for the client.	13.2% (9)	17.6% (12)	26.5% (18)	8.8% (6)	1.5% (1)	32.4% (22)	2.52	68
A second opinion doctor.	16.2% (11)	10.3% (7)	11.8% (8)	11.8% (8)	8.8% (6)	41.2% (28)	2.78	68
Staff at a client's place of residence (e.g. hostel staff).	13.2% (9)	29.4% (20)	25.0% (17)	11.8% (8)	1.5% (1)	19.1% (13)	2.49	68

Appendix 14: Original Broad Categories Identified

Broad Categories

1. Risk

2. Reasons for not taking meds

3. Outcomes of stopping meds

4. Coming off meds

5. Insight

6. Actions taken/Interventions by professionals

7. Role of professional/s

8. Service Context

9. Professional anxiety

10. Alternatives to medication

11. Empowerment

12. Mental Health Act and hospitalization

13. Community work

14. Constructing medication

15. Diagnosis/Illness

16. Engagement/relationship

17. Relapse

18. Responsibility/Accountability

19. Decision-making about medication

20. Working in Partnership/Choice

Other Features

1. Case anecdotes

2. Talking from own experience

3. Constructing the "client"

4. Constructing "compliance"