TITLE: Perspectives on medicine adherence in service users and carers with experience of legally sanctioned detention and medication: a qualitative study.

ABSTRACT

Aim
To explore and analyse perceptions of service users and carers on adherence and non-adherence with medication in mental health care.

Background
Mental health medication adherence is considered problematic and legal coercion exists in many countries.

Design
This was a qualitative study aiming to explore perceptions of the medication adherence from the perspective of the service user (and carer where possible).

Participants
Eighteen service mental health service users (and six carers) with histories of medication non-adherence and repeated compulsory admission were recruited from voluntary sector support groups in England.

Methods
Data were collected between 2008 and 2010. Using qualitative coding techniques, the study analysed interview and focus group data from service users or carers with experience of compulsory powers under mental health law.

Results
The process of medication adherence or non-adherence is encapsulated in an explanatory narrative. This constitutes their struggle to negotiate acceptable and effective routes through variable quality of care. Results indicated that service users and carers eventually accepted the reality of their own mental illness and their need for safety and treatment. They perceived the behaviour of professionals as key in their recovery process. Professionals could be enabling or disabling with regard to adherence with medication.

Conclusions
This study investigated service user and carer perceptions of medication adherence and compulsory treatment. They described a process perceived as variable and potentially doubly faceted. The behaviour of professionals was seen as crucial in collaborative decision making on medication adherence.

Key words: medication, mental health service users, medication adherence, service user perspectives, grounded theory
Why is this research needed?

- There is continued concern at poor service user adherence with anti-psychotic medication
- Globally, the law is being extended to attempt to increase medication adherence.
- The increase in potentially coercive legal measures raises concerns about engagement and working collaboratively with service users

What are the three key findings?

- Participants described difficulty in accessing care that enabled effective medication adherence.
- Adherence is enabled when service users/carers perceive professional behaviour as therapeutic, collaborative and competent but impeded by unhelpful professional behaviour.
- Professional therapeutic and collaborative decision making is described by service users and carers in this study

How should the findings influence policy, practice research and education?

- Understanding service users and carer perspectives on adherence is helpful in shaping professional/service user interaction.
- Policy and practice should focus on understanding factors that enable and hinder collaboration regarding medication.
- This research suggests that there is a need to further explore the nature of potentially coercive care and develop measures to enable professionals and service users to collaborate and share decision making.
Introduction

Service users, who experience mental disorder or distress, may in certain circumstances, be medicated without their consent. Concern about medication non-adherence is common in many countries and legal intervention has increased across most of the western world\(^1\). However, legalised compulsory treatment in mental health practice is contentious and opinion is divided regarding its therapeutic value or justifiability\(^2\).

Additionally, caring for people placed on compulsory treatment orders raises questions around types of professional behaviour considered acceptable to mental health service users (and carers) in this position. There is inherent tension in providing care within a context of surveillance and potential restraint. This represents a significant challenge for professionals and mental health service users where medication adherence is an issue. Consequently, it is necessary to examine medication adherence from the perspective of service users (and their carers) previously compulsorily medicated under mental health law. Understanding service user views can help professionals deliver care sensitively and competently where medication adherence may be compromised.

This paper focuses on a study of those who have been subject to British mental health legislation following partial or non-adherence with medication. Using interviews and a focus group it explores the perceptions of twenty four participant service users (and carer where possible) on medication non-adherence. This was not a comparison of service user and carer perspectives but focused on understanding the medication adherence process in each case.

Background

Failure to take prescribed medication is common in many long term conditions and contentious since the time of Hippocrates, 2000 years ago\(^3\). Although, many mental health service users are prone to non-adherence, most concern is
directed at severe mental illness such as schizophrenia. A review of the literature concludes that the situation has not improved over the past thirty years.

Initially, compulsory medication was confined to inpatient settings. However, as community care became the norm in the developed world, the case was made for extending the mental health act beyond the hospital setting. Since inception there has been anxiety about the adequacy of community care for service users. This often focuses on whether medication regimes are maintained and potential for dangerous behaviour should service users become disordered following non-adherence.

Internationally, there is concern at the various costs of non-adherence with antipsychotic medication. These are associated with poor outcomes for individuals and problematic financial implications of repeated hospitalisation for health services. In Britain, a succession of mental health service user homicides occurred throughout the late 1980s and 1990s. Recently, other cases have attracted press attention. Media and public perception is that a combination of poor supervision and medication non-adherence are causal. Despite this, there is little evidence to support this perspective with numbers of attacks small and decreasing. Nevertheless, concern remains about the various problems associated with medication adherence.

Considerable evidence exists that 2nd generation drugs influence weight gain with associated health problems for certain individuals. Medication may be accepted by many as necessary in mental health conditions. Yet, there is still much research required on understanding these associations in order to achieve most effective prescribing and condition management. Service users have expressed concern about weight gain and subsequent effects on lifestyle and health status.

Therefore, alongside legal measures to increase medication adherence there are calls for more collaborative decision making with mental health service users. A
recovery framework with its inclusive approach is advocated and service user involvement prioritised\textsuperscript{17}. Over the past decade, professionals have been urged to develop concordance with service users regarding medication choices\textsuperscript{18}. Collaborative decision making is defined as ‘a process of engagement in which health professionals and patients (and their loved ones) work together…to understand clinical issues and determine the best course of action’\textsuperscript{19} (p1).

Conversely, concepts of service user involvement, collaboration and concordance fit uneasily into a mental health system holding powers of compulsory medication. Mental health service users and professionals find themselves in a somewhat paradoxical position. Health professionals must perform a caring and collaborative role whilst simultaneously policing and enforcing medication adherence.

Studies clearly identify the people most likely to be non-adherent with medication as ethnic minority, male, single status, and under 40 years of age\textsuperscript{20, 21}. Studies in the 1980s and 1990s suggested that increasing compulsion resulted in improved medication adherence\textsuperscript{22}. However, research exploring service user perspectives suggests anxiety at being compulsorily medicated\textsuperscript{23}. Using content analysis with thematic and domain identification, they found the majority had negative feelings about their involuntary treatment\textsuperscript{24}. The experience of involuntary treatment exacerbated service users’ feelings of stigma and powerlessness.

A study on Supervised Discharge Orders with service users produced mixed views about the order. Many believed themselves to be disempowered by such orders but others recognised the value of reciprocal benefits such as accommodation\textsuperscript{25}. In other research, the opinions of patients, their carers, mental health professionals and community agency representatives were sought about the use of Community Treatment Orders (CTOs) in Saskatchewan, Canada\textsuperscript{26}. In-depth interviews and focus groups were used to collect data from service users, carers, mental health professionals and community agency
representatives. Again, results indicated mental health service users had contradictory feelings about CTOs.

Where collaboration decision making with service users with Bi-Polar disorder was prioritised, better adherence rates were recorded. 306 participants were randomly assigned to a collaborative care programme or to conventional care with a 3 year follow up period. Those assigned to collaborative care still had a 40% improvement in medication adherence at 3 years compared to those assigned to conventional care. The authors clarify that these findings are not generalisable as participants were all army veterans. In addition, the intervention was multi-faceted and they note, more work is required to examine which aspects are important. However, this study does indicate that collaborative engagement with service users is a fruitful area to explore.

Medication satisfaction, particularly regarding side effects, is an important aspect of adherence. Subjective satisfaction was explored using the Treatment Satisfaction Questionnaire for Medication (TSQM) with 121 stabilised service users. Participants also rated their symptoms using the Brief Psychiatric Rating Scale (BPRS). Those taking 2nd generation anti-psychotics reported better satisfaction levels but there was little difference in symptom ratings between those on first and 2nd generation medication. The study acknowledged methodological limitations in that it was multiply centred with some small numbers for certain drugs. Nonetheless, it adds to work in the field and reflects findings generally on medication satisfaction at the time. This issue is now reflected in national guidelines on the treatment and management of schizophrenia with 2nd generation anti-psychotic recommended. However, as noted earlier, these are now known to be accompanied by other health problems. Obesity, Diabetes and Cardiac problems are risks with an associated early mortality rate for mental health clients. The subjective experience of weight gain was explored with 18 service users in a qualitative and constructivist study. Analysis using the constant comparative method emphasised the complexity of weight management and its deleterious effect on individual lifestyle.
There is now dispute as to whether increased legal coercion ensures improved outcomes. Epidemiological research utilized a survival analysis on 265 CTO cases with matched controls and 224 consecutive controls. Patients were studied over a 12 month period to monitor readmission rates and occurrence of any forensic episodes. The CTO group had a significantly higher readmission rate with 72% readmitted in comparison to 59% and 52% respectively of the control groups. Also, a pilot study of CTOs and hospital utilization rates in Australia found that their effect was limited.

It is claimed that it is difficult to carry out well controlled methodologically sound quantitative research in this area where the subjects may be psychologically distressed. Others comment that although a number of non-experimental studies have been carried out in Australasia, Canada and the United States 'it is problematic to generalize from findings because of variations in methodologies, legal frameworks and the contexts' (p. 495).

Thus, mixed results emanate from empirical evidence regarding outcomes of legally enforced adherence measures, with later studies suggesting less evidence of efficacy. Existing qualitative research suggests that experience of coercion is complex and requires further exploration. Service users generally find coercion distressing yet there is limited evidence of effectiveness in improving outcomes. There is concern at the ethical implications of implementing more coercive measures on existing evidence. It is crucial to understand more about the subjective impact on those likely to be the subjects of compulsory powers.

**Aim and Objectives**

Aims and objectives were deliberately open in accordance with qualitative coding techniques, based on grounded theory. This research aimed to explore and analyse perceptions of service users and carers on adherence and non-adherence with medication in mental health care. Prior to data collection, an
advisory group of six individuals with a history of non-adherence and compulsory admission gave advice regarding types of questions to ask.

The research objectives were to understand: Box1.

1. Service user and carer perceptions of care when adherent with medication
2. Service user and carer perception of care when non-adherent with medication
3. How service users and carers characterise the process of adherence and non-adherence
4. How service users and carers perceive the process of detention and compulsory medication within mental health services
5. Service users’ and carers’ views and opinions on whether and how they could be helped to adhere with medication

**Design**

The initial phase of the research analysed interview data (individual or pairs where the service user wished to include their carer). The second phase checked out emergent findings with participants either individually or in a focus group. It was important that findings in a study on service user perspectives were recognisable to participants. Data generation and analysis was conducted using qualitative coding based on grounded theory techniques. There is much debate about the grounded theory method originally developed in the 1960s. Many agree that adaptations to the classic method are acceptable and even desirable provided systematization and transparency are maintained. This study used analytic techniques as recommended by Strauss and Corbin. However, it does not adhere to the classic grounded theory of ‘literally ignoring the literature’ (p.37). It is conducted in line with acknowledgement that existing
theoretical and experiential perspectives of researchers will influence findings socially constructed together with participants\textsuperscript{40}.

**Participants**

Sampling was initially purposeful and inclusion criteria were adults with a history of legal compulsion to take medication due to partial or non-adherence with mental health medication (at least two compulsory admissions). Exclusion criteria were those who might be actively distressed and/or on compulsory treatment orders at that time. It was important that the study interviewed people who had time to reflect upon the process of medication adherence. Participants were recruited through local voluntary sector support groups so potential participants could feel reassured about speaking freely with no direct connection to their treatment team.

Following presentation of the project, participants volunteered. Only those who had previously been sectioned under mental health law on more than one occasion were selected. A number of people volunteered, despite never having been legally detained and medicated. These explained that they had nonetheless felt coerced into medication taking. This was an interesting development and as Pilgrim\textsuperscript{2} notes, fits with literature on mental health service user perspectives but unfortunately did not fit inclusion criteria for this study.

Although statistical representation is not the objective of qualitative research it is necessary to have some form of portrayal of the cultural group most likely to be subject to compulsory medication (as the literature demonstrates)\textsuperscript{41}. Therefore it was also important to ensure young, black men were represented\textsuperscript{21}. This was achieved (see Table 1).

**Data Generation**

Initial purposeful and then theoretical sampling guided the ongoing iterative process of selection of participants for data generation. The period of data collection was 2008-2010. Data were generated through individual interviews and
a focus group with twenty four participants in a large English city. Originally, study design intended to focus on interview data alone. However, the design was modified in response to participant request and a focus group convened for member checking purposes.

Participants were recruited through local voluntary sector support groups. Interviews were conducted at the support group’s premises, the interviewee’s home or a convenient local hospital according to participant preference.

Data were collected by the first author and analysed with authors 2 and 3. Individual (or joint, consisting of one or more carers, according to service user preference) interviews were carried out with fourteen service users and six carers. (This was not a comparison of service user and carer perspectives but focused on understanding the medication adherence process in each case). The iterative process of grounded theory suggested certain areas for further exploration (one minority ethnic group family and another white English grouping). In the final respondent validation phase, to consider, influence and validate emerging findings one service user and carer pairing were re-interviewed, another service user re-interviewed alongside three new carers nominated by him and a focus group convened. (This constituted three already individually interviewed and four new participants with a similar history of non-adherence with mental health medication).

Interviews were largely unstructured, in line with the grounded theory approach. Consequently, as indicated above, areas for exploration were initially identified but the interview process followed advice to pursue information provided by participants as opposed to adhering to rigid formats. The interviews were sound recorded and transcribed.

**Data Analysis**

Data were analysed using the constant comparative method. Open, axial and selective coding took place in line with advice from Strauss and Corbin.
Charmaz and Dey. Line by line scrutiny took place using the Win Max Pro computer programme to generate multiple open codes. This breaks down the text into literally hundreds of open codes. (see diagram 2) These are generally ascribed titles reflecting the in vivo data. After generating a large number of open codes, axial coding selected those that seem to best connect and to be most promising for further elaboration. These became categories and were further refined using the coding paradigm as illustrated by diagrams 1-6. Categories also are described in terms of their properties and dimensions (descriptions and degrees). Therefore categories emerged and developed from open coding by connecting similar open codes, redefining these and subjecting them to examination in terms of causation, context, consequences and strategies employed. Data generation and analysis were iterative however, there were two main phases. Initially, interview data was gathered and analysed. Emergent findings were presented to service user and carers and to a focus group for respondent validation. Data from this phase was then fed in to form final analysis.

**Validity and Reliability**

Credibility and trustworthiness are necessary in terms of transparency of process in qualitative research. Use of grounded theory coding techniques combined with the WinMax software package enables visibility of data generation and analytic procedures.

Author 1 is a nursing lecturer but previously worked as a community psychiatric nurse, involved in monitoring medication adherence. However, participants were not previously known to any of the authors. The researchers believed that despite occupational history of medication monitoring and adherence encouragement they were open to possible alternative service user perspectives. A number of measures to reduce the possibility of existing views overly influencing findings were taken. As described above, respondent validation with participants was carried out to allow participants to consider, challenge, influence and validate the authenticity of findings. Their input had considerable influence
on the weighting put on certain aspects of final analysis of findings as will be highlighted later in this paper. Also, at points throughout the process, codes were further subjected to examination by comparison with experienced colleagues. Authors 2 and 3 were part of the process in open, axial and selection of final categories. It is also argued that inclusion of carers’ views aids triangulation, in adding source diversity to the data.

**Ethical Review**

The project proposal was submitted to the United Kingdom National Research Ethics Service and ethical approval was obtained from XX committee. Adaptation of study design to include a focus group was also approved at a later stage by XX committee. Participants were provided with information sheets explaining the rationale, risks and potential benefits of taking part in the research. Participants were assured that they could decline or cease participation at any point with no adverse consequences. Information regarding the standards of confidentiality and anonymity in any published findings was explained. Arrangements were made to ensure that support would be available should they become distressed.

**Results**

Data were transcribed and examined line by line to produce multiple open codes.

**Developing the story through axial coding**

After data were open coded, they were grouped and further subsumed under more conceptual and inclusive axial codes to form categories. Category building raises theory to more abstract and conceptual levels. Processes around medication and use of compulsory powers were selected as categories and subjected to scrutiny regarding causal, contextual factors, strategies employed and resultant consequences using the coding paradigm as recommended by Strauss and Corbin (see diagram 1). The following string of linked categories provides the narrative of the pathway through mental health services for those in this study that had compulsory medication.
There are two potential care pathways in the double edged process of mental health medication adherence (see figure 1). It commences with the category: need mental health care but service user refuses treatment

Participants described:

‘the times my husband and I begged them to come out and have a look at her so I told them and I didn’t pull any punches, they didn’t listen to us’. (Carer D: 95 yr old Caucasian)

‘I had him at home for 7 months talking gibberish at the TV, no help’ (Carer C: 43 yr old Caucasian)

‘I can’t tell when I’m going wrong but my Mum can see it’ (Service User S: 28 yr old African Caribbean male)

‘I’d be sitting here on the stair all night, I’d phone the doctor in the morning and say he’s not well, they say is he harming anyone? Is he a harm to himself? I’d say no, then the doctor would say to me that they can’t do anything until he hurts somebody or hurts himself. I had to phone the Samaritans in the middle of the night sometimes they told me I’d have to wait until he did something; that was my greatest fear, that he’d do something to someone’ (Carer S: 89 yr old African Caribbean female;)

Open codes relating to this part of the process were:

- Compulsory powers can be necessary
- The only way to get help
- Unresponsive services
- Crisis management involving emergency services

Carers reported a distressing experience of needing help but having difficulty accessing care (see diagram 1). The service user would not accept voluntary care and mental health services seemed unresponsive. Their strategy was to gain access to treatment through the emergency route and service users were sectioned using mental health legislation (sectioned’ is the common term used to describe being placed under a section of the mental health act in the UK)

At this stage, service users found themselves: losing a credible identity (due to being sectioned), claiming:
‘they make all these decisions based on I don’t know what, because they don’t listen to me well when I’ve been sectioned and I felt like my rights had been taken away from me (Service User N 45 yr old Caucasian female)

‘they talk about me behind my back, then they tell me what the team decided’. (Service User C: 23 yr old Caucasian male)

‘I used to be someone, went to college, had a job, now I’m just a patient’ (Service User P: 26 yr old African Caribbean male)

‘I’m just another black woman with schizophrenia’ (Service User K: 34 yr old African Caribbean female)

Open codes relating to this category are:

- Stigmatised
- Just a patient
- She used to work
- Not worth being listened to
- Defined by mental illness

Becoming a ‘sectioned’ patient within the context of a society that stigmatises mental disorder results in the consequence of a loss of voice (see diagram 2). The identity of a sectioned patient is a discredited identity. Service users in this study sought means of regaining control.

At this stage, service users still deny their mental disorder but recognise that professionals reward compliant behaviour. In order to cope and regain some control they resort to the category: playing the game: (appearing to be a compliant patient) explaining:

‘well I take it (medication) because I feel it helps to keep me on an even keel and I do feel it is helpful to keep me on an even keel but I do think, I may miss a day or miss two days and I don’t always take it every single day but for them (professionals), they think it’s compliance and you must take the medication every single day.’ (Service User K: 34 yr old African Caribbean female)
This next participant initially seemed to be a potential deviant case. She claimed that she had not had any disagreement with professionals regarding medication issues. However, she had been detained and medicated without consent. On further exploration, she explained that she had strategies for avoiding confrontation.

‘I’m good at being compliant, my friend got into trouble but I didn’t argue,’ (Service User Q: 32 yr old African Caribbean female)

She observed that appearing to behave in a certain manner yielded results. She managed to get herself discharged as soon as possible by mimicking demeanour she believed the professionals perceived as ‘well’.

I manipulated my way out of the section I didn’t talk about the things that were hounding me, I sort of avoided subjects that were extreme.’ (Service User Q: 32 yr old African Caribbean female)

Others explained how they manipulated dosages to allow them to cope with their lives but also appear adherent.

‘I can’t take the full dose with two young children to bring up but you can’t tell them’ (Service User B: 43 yr old African Caribbean female)

Open codes relating to this category are:

- Hospitalisation is unpleasant
- Feeling physically unwell as a result of medication
- Try to take back some control
- Appearing adherent
- Complexity/partiality of adherence

Service users described feeling powerless but recognising that that medication adherence was expected of them (see diagram 3). They described how medication could be difficult to tolerate, leaving them feeling physically unwell and overly sedated. They felt that professionals often did not fully appreciate this and therefore hid their partial adherence from professionals. Nonetheless, the appearance of being compliant enabled discharge as a consequence.
However, over time and with repeated relapse service users reluctantly accept their experience as illness requiring treatment including medication. This resulted in the category: **accepting mental disorder**, explaining:

‘it could have been a one off, I wouldn’t have believed I needed the medication after the first admission but now I know and I know that each relapse makes it worse’ (Service User O: 38 yr old Caucasian male)

‘Now she knows she’s ill now and she takes her medication and she knows she has to and it actually helped her.’ (Carer D: 95 yr old Caucasian female)

I know now that I’m ill, I’ve proved it to myself now, I was in the hostel for about a year I reduced the medication with the knowledge of the people around me and after a year. They said ‘let’s see what happens’. After about 3 months I relapsed’ (Service User S: 26 yr old African Caribbean male)

The open codes for the category of **accepting mental disorder** are:

- Initial denial
- Acknowledging reality of mental illness
- Reluctant acceptance of need for medication
- Proved it to myself

Having accepted their mental disorder as a reality, participants recognised they needed to take medication. An acceptable medication regime helps to prevent relapse and stabilise life (see diagram 4).

However they found the process of obtaining effective treatment complex and adherence difficult to achieve. They described their perception of encountering two potential reactions in professionals: **collaborative decision making mode** or **non-collaborative mode**

Regarding **Collaborative decision making enables co-operation** they reported:

‘I think my CPN takes on board what I say she’s quite good, I can like test the waters with her and then we will think about it and not just on one
single answer but look for a variety of avenues to follow. Weight gain is an issue with some of the medication’ (Service User N: 34 yr old African Caribbean female)

‘well they tried to help me they tried to change my medication, they tried to change it to one that didn’t give me weight gain, tried to be, at times, supportive of me when I had mental health problems and issues’ (Service User Y: 36 yr old African Caribbean female)

‘There was one Chinese Dr, she listened and she got me on the right medication’ (Service User D: 52 yr old Caucasian female)

Open codes for this category are:
• Good professional care is appreciated
• Treating service users and carers with respect
• Partnerships with patients
• Adherence is possible but requires enabling
• Good professional care enables adherence

Collaborative decision making enables co-operation results in the consequence of medication adherence (see diagram 5). Where professionals listened and invited collaboration in decision making, they were perceived as more likely to understand the issues and offer acceptable medication regimes. Service users and carers in this study described being able to trust these professionals to hear their concerns. They wished to maintain contact and they felt they could adhere with medication where they had been involved in the process.

However, service users and carer participants also described meeting professionals in the opposite category. In the respondent validation phase, participants challenged emerging findings, stressing the need to highlight the less collaborative elements of care: non-collaborative mode disables co-operation:

‘I had to sort out the side effects myself, I said but they didn’t do anything’ (Service User Q: 32 yr old African Caribbean female in focus group)

‘my psychiatrist at present says, you know, the nurses aren’t there to
speak to you, I thought that's not very good’ (Service User G: 45 yr old Caucasian female)

‘they treated us like the opposition’
(Carer D: 95 yr old Caucasian female)

‘seeing only the illness, not the person’ (Service User O: 24 yr old African Caribbean male in focus group)

‘they just risk manage and give medication’
(Service User W: 55 yr old African Caribbean male in focus group)

‘I could just pretend to take the medication, people could go underground’
(Service User O: 33 yr old Caucasian male)

The open codes for this category are:

- Lack of necessary information
- Side effects not managed
- Took years to get the right medication
- Over medicated
- Treated like a nuisance/problem, not a patient

Participants described professionals who would not listen, would not address their side effects and did not offer to work in collaboration (see diagram 6). They described the difficulties of reaching a situation where tolerable and helpful medication regimes could be attained. Medication adherence was described as compromised when professionals seemed reluctant to listen to their genuine concerns. The possibility of co-operating with treatment was perceived as unlikely in these situations.

Therefore, the story involves initial resistance to intervention but eventual acceptance of a mental health disorder due to experience of repeated relapse when non-adherent with medication. Requests for help can meet with what feels like an inadequate response from services. When help is offered, service users and carers find that the service user seems to lose the right to be heard as a result of their sectioned status. They learn to pretend adherence to regain some sense of control but they also come to accept their experience as illness. They
want help to deal with this illness but find that they there are two potential care pathways. Whether they receive competent and therapeutic care is dependent upon the attitudes and communication styles of the professionals they meet. In turn, this influences their ability to co-operate with care. Where they have been listened to and care is provided in a collaborative manner, they can co-operate and adhere with prescribed medication. Where not listened to, care can take the form of intolerable medication regimes. The task is to work through the system to find the professionals who will listen and provide helpful care.

**Core Category: The doubled edged process of mental health medication adherence.** (see figure 1)

In grounded theory, one existing or new core category eventually emerges through selective coding as the overarching explanatory narrative. Within this study, the tale of related categories has two potential outcomes; **collaborative decision making mode enabling co-operation** or **non-collaborative mode disabling co-operation**. This study suggests that the core category: **the double edged process of mental health medication adherence** encompasses and explains the process of reaching a situation where medication adherence becomes possible. Ambiguity was a feature of mental health care and service users and carers could not rely on that care to be acceptable and effective. Service user feedback suggested that the researchers needed to weight this aspect more heavily. Therefore, the final category emphasises the potential paradox of the process of medication adherence.

**Discussion**

As discussed in the literature, mental health services should care for service users but also fulfil a social control function. Professionals need to be aware of their dual roles and inherent power. Neglect of the listening and caring facets of mental health provision may result in service users feeling unable to co-operate with treatment. Previous research has demonstrated that increasing coercion may not improve outcomes.
Policy and practice emphasise the need to work collaboratively with service users. Yet, despite recognizing their need for treatment (including acceptable medication), service users in this study, described not being able to depend on provision of consistently helpful mental health care. In other areas of service provision too, it has been suggested that care can be double edged. The different faces of provision labelled as care for older people may differ so much as to be completely conflicting in both nature and in result, claims Simms. Others also describe policies and practices that are double edged with unintended consequences. Although these aim to provide something beneficial, at the same time their very existence may make the experience worse for the recipients of that service.

With many groups who have chronic or long term conditions, there are implicit issues of dependency and unequal power relations in their dealings with health services. There is concern at how mutual respect is compromised in the professional/service user relationship where the threat of legal compulsion is always present. It is important that ‘the patient’s objective inequality’ is not ‘transformed into a humiliating situation’. It is acknowledged that although the professional/service user relationship can never be one of equals, it can attain a helpful position of mutual respect. The task of collaboration can be problematic between groups with differing perspectives. It is therefore imperative that professionals strive to understand how medication adherence and collaboration with care is perceived by service users and carers. This study emphasises the need to recognise that care combined with compulsion can be a double edged sword. Excessive concentration on medication adherence alone can be counterproductive. Service users in this research indicated that adherence is enabled by collaborative care with professionals who listen to them and enable them to take helpful medication.
Limitations

This is a relatively small scale study and makes no claim to generalise. Findings are substantive to the group studied. However, they do support and add detail to other research in this area. Service users were not part of the research team but were part of the advisory and feedback process.

Conclusion

Mental health law on medication adherence has been extended in many parts of the world. Therefore, mental health professionals and service users have new challenges in managing interaction around adherence. There is a need to increase awareness of factors influencing service users’ ability to tolerate and be helped by medication. This research focused on interview and focus group data from those who had experience of mental health law and compulsory treatment. It explains the process of attempting to find effective care and tolerable medication from the service user perspective. Service users (and their carers) accept their need for assistance but too often struggle to find it offered in a satisfactory manner. Ultimately, both service users and practitioners are or should be seeking a co-operative and constructive relationship. This outcome has proved difficult to achieve as highlighted by the documented concern about medication non-adherence and compulsory treatment in most of the developed world. Service users and carers have very real concerns about the benefits and effects of medication and require help in managing adherence. The findings of research, such as this, should enable service users’ perspectives to be heard and practitioners to hear.

References


### Table 1 - Demographic characteristics of participants

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Figure 1. The Doubled Edged Process of Mental Health Medication Adherence

- Deny mental disorder but 'play the game' to escape from hospital
- Need mental health care but service user refuses treatment
- Lose credible identity due to being 'sectioned'
- Lose credible identity due to being 'sectioned'
- Staff respond in non-collaborative mode
- Enables cooperation and adherence with medication
- Enables cooperation and adherence with medication
- BUT repeated relapse leads to acceptance of mental disorder and accept help
- Staff respond in collaborative decision making mode
- BUT repeated relapse leads to acceptance of mental disorder and accept help
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- Need mental health care but service user refuses treatment
- Deny mental disorder but 'play the game' to escape from hospital
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