

# How can medication be used in support of Recovery?

The views and experiences of people taking medication, carers and workers

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## Abstract

**Background:** Recovery based practice is being widely adopted in mental health services. Medication is a frequently provided intervention but there is uncertainty about its role and value as a support for Recovery.

**Aims :** In order to inform good practice guidance, we sought the views and experiences of people taking medication, carers and mental health workers on the relationship between medication and Recovery.

**Method:** Participants completed interviews or questionnaires about medication and Recovery. Data was analysed using thematic analysis

**Results:** People with lived experience described how medication could both support and interfere with personal recovery and identified the importance of being able to make informed choices. Crisis plans were felt to support this. Some workers raised concerns about the conflict between respecting choice and maintaining safety.

**Conclusions:** A change in practice is needed to be consistent with Recovery values. This could include more individualised approaches and engaging people in shared decision making. The implementation of good practice guidance will need to engage with workers' concerns about managing risk.

**Declaration of interest:** none

## Introduction

Recovery has been described as an individual process of finding hope and meaning, developing agency and positive identity, empowerment and citizenship (Anthony, 1993). It does not necessarily require clinical recovery through symptomatic improvement. Practices that support Recovery have been widely recommended and endorsed as a basis for mental health service provision (CSIP et al., 2007, Department of Health, 2011, Shepherd et al., 2008). A number of NHS Trusts have made explicit commitments to implementing Recovery based practice (Maddock & Hallam, 2010). Locally, this has resulted in attempts to operationalise Recovery principles in relation to a number of areas, through producing good practice guidance (Roberts et al., in press).

Medication is an intervention that is almost universally provided by mental health services (Healthcare Commission, 2007). However, there are a number of conflicting discourses about its role and value. Despite a growing emphasis on involvement and choice in healthcare (NICE, 2009) the priority of mental health workers is often to ensure compliance with medication (Britten et al., 2010). Although psychiatrists may describe themselves as person centered they may emphasize adherence, considering this to be in the person's best interests (Seale et al., 2006). These practices reflect the use of an evidence base that centres on the outcomes of randomised controlled trials. However, the robustness of this evidence base and the theoretical assumptions underpinning it has been challenged (Kirsch et al., 2008, Moncrieff, 2008, Whitaker, 2004). Furthermore, such research is concerned with symptomatic improvement and therefore does not necessarily reflect outcomes related to Recovery.

Conversely, the Recovery approach is based on the evidence of lived experience and personal narratives. A range of perspectives about medication emerges from such sources. Many people describe medication as essential, often to get difficult symptoms under control or achieve stability, thus allowing the use of other strategies to improve wellbeing. Others describe medication as undermining recovery. Unpleasant side effects can interfere with personal self-management strategies and be experienced as outweighing any benefits of medication. Whatever the benefits that they have derived, many people express feelings that the professional response is too dominated by medication and there is not enough support available to explore alternatives, such as psychosocial interventions or self-management strategies. Concerns about medication have also been compounded by the response of workers to people's reluctance to take it. There are descriptions of how this has left people feeling pathologised and having little choice or control, with, in some instances, the use of compulsory treatment which has left people angry and traumatised (Coleman, 1999, Cordle et al., 2010, Davidson & Lynn, 2009, Deegan, 2005, Hornstein, 2009, Lapsley et al., 2002, Mead & Copeland, 2000, Read, 2009, Rethink, 2009, Scottish Recovery Network, 2007).

The need to resolve these competing discourses raises a number of questions about how medication can be provided in a Recovery orientated way: what role could medication have in supporting Recovery and how can it be provided in a Recovery based way? What obstacles might there be to adopting genuinely collaborative practices and crucially how can Recovery based practice be maintained at times when people are unable to make choices or when their choices might compromise the safety of themselves or others? In order to develop good practice guidance which addresses these questions, we initiated a project, led by both practitioners and people with personal experience of medication (either taking it themselves or in a caring role). So that the guidance would be driven by the lived experiences and preferences of people taking medication and their carers (who were often involved in medicines management processes) we began by carrying out a survey of their views and experiences. We also sought the views of other mental health workers, in order to harness ideas from a workforce that was being supported to adopt Recovery based practice and identify any conflicts that the guidance would need to engage with. This paper reports the findings of our survey.

## Method

### *Participants*

People with lived experience were recruited through service user and carer involvement workers, nursing staff at the in-patient rehabilitation and secure services and posters in waiting rooms. Twenty-six people who were currently taking medication and nine carers responded.

The project was publicised to workers through a local conference on Recovery and an item in the Trust online newsletter, distributed by e-mail to all employees. Seventeen mental health workers responded.

Participants had been in contact with the full range of adult mental health service areas provided by the Trust, with some having been in contact with more than one area. The distribution of participants is shown in Table 1.

**Table 1. Number of participants with previous contact with different service areas**

	<i>Services for common mental health problems</i>	<i>Services for longer term mental health problems</i>	<i>Crisis &amp; In-patient services</i>	<i>Forensic services</i>	<i>Not specified</i>
<i>Takes medication</i>	4	13	14	8	2
<i>Supporter</i>	3	3	5	0	4
<i>Worker</i>	2	4	2	3	10

### Procedure

A questionnaire was developed in consultation with representatives of local service user groups which could be used as the basis of an individual interview, a group discussion or completed and returned anonymously. The questionnaire contained one numerical rating scale and a series of open questions about the role of medication in Recovery, experiences of interacting with mental health workers in relation to medication and how Recovery principles could be applied to the use of medication, both at times when a person was stable and able to be involved in decisions and at times when they may lack capacity or present a risk. Different versions of the questionnaire were produced for people who take medication, their supporters and mental health workers.

Participants were offered the choice to participate in an interview, take part in a group discussion or to receive a copy of the questionnaire and return it either by e-mail or freepost. Interviews took place either in the participants' own homes or at a local base for mental health services. Interviews lasted between one and two hours. One discussion group was held at a voluntary sector resource centre. People who were taking medication and carers were paid £5.73 per hour and any travelling expenses for participating in an interview or discussion group. The distribution of participants opting for each response format is shown in Table 2.

**Table 2. Number of participants using each response format**

	<i>Individual interview</i>	<i>Group discussion</i>	<i>Written questionnaire</i>
<i>Takes medication</i>	26	0	0
<i>Supporter</i>	3	4	2
<i>Worker</i>	0	0	17

### ***Analysis***

The ratings given on the numerical scale at the beginning of the questionnaire were compared using a Kruskal Wallis one-way ANOVA by ranks. The qualitative data was analysed using thematic analysis (Braun & Clarke, 2006). This involved initially coding the data and then searching for themes or patterns that best represented the views within the whole data set. Illustrative quotes were extracted to support and give validity to the themes identified.

### **Results**

#### ***Quantitative data***

Participants were asked to rate on a scale of 1 to 10 how important generally they thought medication was to a person's recovery, where 1 was not at all important and 10 was extremely important. The mean scores for each group are shown in Table 3.

**Table 3. Mean ratings (and standard deviations) of the overall importance of medication for recovery**

	<i>Takes medication (N=26)</i>	<i>Supporter (N=9)</i>	<i>Worker (N=17)</i>
<i>Mean (s.d.)</i>	6.58 (2.48)	6.44 (2.13)	6.82 (2.42)

The Kruskal-Wallis test found no significant differences between the groups ( $H(2) = 1.99, p > 0.05$ ).

#### ***Qualitative data***

There was considerable consistency in the themes that emerged from the responses of people who were taking medication, their supporters and mental health workers. The responses of people taking medication and carers reflected both previous experiences and ideas about how practice could be improved, whereas workers' responses reflected only the latter. These themes could be grouped into four super-ordinate themes: the role of medication, the limitations of medication, medicines management processes and crisis management.

#### ***Role of medication***

Participants in all three groups described medication as useful intervention and, for a small number, it was felt to be essential, with a sense that finding the 'right' medication was fundamental to addressing the person's problems:

“To get your life back so that you can have complete control. [You] only can do that with the right medication.” (Person Taking Medication 12)

For others it was a short-term strategy, to reduce overwhelming distress or create stability and thus provide a foundation for a recovery process involving other strategies:

“[I] needed to be stabilised so I could engage in reality.”(PTM5)

“Helps the person overcome the crisis and re-engage in any of the activities, work, relationships they enjoy and value. The medication use would facilitate other aspects [of recovery].”(Worker 4)

The varying priority that was given to medication reflected the range of experiences and values held by participants and illustrated that Recovery is an individual process.

#### *Limitations of medication*

Participants in all three groups also identified the potential of medication to hinder Recovery. For people taking medication and carers this was mostly related to side effects, which in some cases were experienced as being worse than the original problem and were often described as interfering with someone’s ability to use other strategies to establish a meaningful and fulfilling life:

“Envisioning a bubbling, gurgling, leaping, scintillating clean mountain stream in summer sunshine and turns it into a bowl of dirty dishwater. That is what it did to my mind.” (PTM21)

“My son has changed from a physical lively character to an overweight demotivated character.” (Carer 4)

Concerns were also expressed about the risks of being on many different medications, dependency or medication exacerbating the original problem.

Workers also identified that medication could undermine Recovery through disempowering and pathologising people’s experiences, rather than valuing their personal meanings and giving them responsibility:

“Its very nature indicates that emotions are symptoms of something wrong, like an illness process and locates the action set away from the individual and in the hands of the expert prescriber.”(W5)

Many of the people taking medication indicated that they would like the option to reduce their medication or not take it at all and most of the carers and workers suggested that medication usage should be minimised. However, some workers expressed the opinion that medication was of fundamental importance. People in all three groups identified exploring alternatives to medication as desirable, with many of the people taking medication and carers wanting opportunities to talk and understand the cause of the problem, often naming psychological therapy as a helpful intervention. Other beneficial approaches identified were learning to manage stress, individual coping strategies and spiritual healing:

“When someone is stable the medical profession should be looking to not involve medication and instead look creatively at other ways to maintain stability.” (PTM25)

“Medication can help but the person may have other coping strategies that they have used before for themselves and have helped.” (W13)

#### *Medicines management processes*

People taking medication and carers described many negative experiences of communicating with workers about medication. These typically involved not being listened to and having little choice or control, with concerns or preferences being over-ridden by expert opinion or pathologised by being labelled as part of someone’s mental health condition. People expressed considerable frustration and distress in describing these experiences, as well as a sense of helplessness and fear that protests could lead to involuntary treatment:

“Very frustrating giving your layman’s opinion and then being told that you are not right. They then tell you why and you have to take on board their professional opinion.” (PTM6)

“My son started to fall over and they told him to stop play acting. He then had a grand mal seizure and had to go to the main hospital. It was obvious that it was the meds causing the problem, we were just ignored.” (C2)

People also described not being given enough information about medication, particularly about side effects and some believed that these had not been explained because the doctor was worried that they would start imagining them. Concerns were also expressed about a lack of review after a medication had been prescribed to see if it was effective or could be reduced. It seemed as if this was also associated with an over-reliance on medication as an intervention rather than exploring other approaches for recovery:

“Just stick a needle in and forget about you for a few years.” (PTM21)

People also described some positive experiences, which were characterised by feeling listened to and understood, being given good information (including a worker’s honest opinion) and being involved in decision making. One person had negotiated an individual strategy to medication use with her psychiatrist:

“I have been given medication purely to take when going into a manic episode. The choice is mine to take...However, with less risky episodes the possibility of managing the episode without medication should be an option.” (PTM25)

Corresponding with these experiences, the suggestions that people taking medication and carers made for how practice could be more recovery-orientated involved being able to trust their mental health workers, being listened to and taken seriously, being provided with information and offered choices, while still receiving guidance from someone with medical expertise:

“Have genuine consultation and sharing of ideas and information but do not overload the user and the doctor needs to make a professional judgement.” (C2)

Workers similarly identified a need to listen to people’s views and experiences in relation to medication and offer information and choice. This was in the context of recognising that people were individuals and therefore responses would need to be personalised:

“Workers trying to get a clear understanding of the person’s values (in general) but specifically around medication.” (W14)

“Provide adequate information regarding pros and cons of taking medication generally and specifically to the individual.” (W3)

### *Crisis management*

People taking medication and carers primarily identified the use of crisis plans as a way of maintaining a person’s involvement in decisions about medication at times when they were unable to safely make choices for themselves. However, there were concerns that these were not always taken into account by workers and could be over-ruled. The involvement of family members who knew a person well or a trusted person to act as an advocate was also suggested:

“Advanced statements can help but I have seen these overridden by the doctors who can persuade the service-user when they are vulnerable.” (C2)

Workers gave a spectrum of responses, reflecting the need to balance managing crisis and associated risk with Recovery principles. This was described by one worker as “tricky” (W10). Most workers described possible strategies for trying to maximise someone’s continued involvement in decision making as well as using crisis plans and other sources of information about a person’s values and preferences and what had previously been effective for them to inform decisions. Some suggested continuing to offer choice as far as possible, albeit from a more limited range of options:

“People are almost always able to give an indication- we draw the line too early.” (W5)

“It is still about conversations and trying to understand the person’s perspective.” (W10)

Some workers felt that during crisis it was necessary to suspend taking a Recovery based approach in order to prioritise managing risk. This was mostly in the context of trying to address the crisis situation as quickly as possible so a wider recovery process could be resumed and offering the person hope that they would ultimately regain control:

“May be necessary to treat illness as a priority. If acutely unwell, it is unrealistic to concentrate on many of the recovery principles.” (W9)

## Conclusion

There was considerable consistency between people taking medication, carers and workers in views about how medication could be used to support Recovery, with all three groups rating medication highly in its importance. There were also many similar themes in the descriptions of the lived experience of medication to those found in other sources, with medication being helpful at times but also hindering recovery both through adverse effects and processes around it that undermined individual autonomy and responsibility. There were some suggestions from workers of how people could be involved in making decisions about medication and these were borne out by some good experiences that were described.

There was variability in all groups in the emphasis given to the importance of medication. For people with lived experience, this is likely to reflect the individual nature of the recovery process. Workers, however, are likely to have been making this judgement in relation to what they understood to be beneficial for people with mental health difficulties in general. This reflects one of the major challenges that Recovery poses to mental health services, which have traditionally delivered care on the basis of what is known to be effective for groups of people rather than responding to individual preferences and experiences. There has also been a focus on symptom remission, for which medication may be seen as necessary rather than the more complex process of Recovery, which is likely to involve other priorities and a range of supports.

The majority of responses indicated a need for a change in practice in relation to medication in order to reflect Recovery principles. Principally, this would seem to require a transformation from mental health workers as experts directing someone's treatment to collaborators, supporting people in learning about the different options that are available to support their Recovery. (CSIP et al., 2007). This could be extended to learning about and weighing up the costs and benefits of medications, alongside other strategies. Pat Deegan has identified that a shared decision making approach to prescribing, in which both parties are seen as experts, one in relation to theory and evidence and the other in relation to their lived experience and preferences, is supportive of Recovery values (Deegan & Drake, 2006). Through developing peer-run 'decision support centres' she has demonstrated how such an approach can be successfully adopted in out-patient psychiatric settings (Deegan et al., 2008). The suggestions made by most of the workers in our survey would be supportive of a shared decision making approach.

Workers that were less supportive of such an approach mostly expressed concerns about the management of risk and there was a sense that Recovery based practice might need to be suspended at times of crisis. Deegan (2006), in common with our participants with lived experience, suggests the use of crisis plans. However, the reality faced by many workers is that such plans are not available and the need to intervene at such times is likely to have contributed to the situations that were a source of frustration and distress for people with lived experience of medication. Some workers identified that more could be done to involve people in decisions at times of crisis, continuing to try and identify and respect their preferences and offer choices as far as possible. A similar approach has been described by Roberts et al. (2008), indicating that Recovery principles can still guide practice at times of increased risk.

In identifying that the responses of workers were broadly supportive of adopting a Recovery based approach, we are aware of the limited size of our sample. It seems likely that our participants were mostly workers with a commitment to Recovery (although for some it was clear they were responding because of their concerns about Recovery based practice being associated with increased risk). This suggests that there is a need to engage with the wider workforce, in capturing their interest in how Recovery principles can apply to the use of medication.

The themes from our survey suggest a need to develop practice guidelines that emphasise individualised approaches, shared decision making (and how this can be maintained at times of increased risk) and the use of crisis plans. It also seems likely that, if such guidance is to be successfully implemented, workers will need support to manage the dilemmas associated with the constructive risk taking that is core to Recovery.

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