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How included are mental health service users in decisions about their medication?

In this review I discuss four papers that concern decisions about medication in mental health services. Three papers mention a form of decision-making that should give service users equal power with the clinician - 'shared decision-making' - and one uses an empowerment framework. Even so, I will suggest that the first paper (Angell and Bolden, 2015) shows how mental health service users can be disempowered in a meeting with a psychiatrist who appears to be taking the service user's concerns into account. The second paper (Delman, Clark, Eisen and Parker, 2015) suggests how young people in mental health care can begin to have more say as they get older but also shows what stands in the way of them doing so. The third paper (Mikesell, Bromley, Young, Vona and Zima, 2016) shows how service users and professionals both have dilemmas about shared decision-making, and seems to conclude that things cannot change much. The fourth paper (Morant, Kaminsky and Ramon, 2015) helps explain why the 'shared decision-making' model does not transfer easily from physical to mental health care. Professionals, they suggest, need to address the problem of disempowerment and stigmatising of service users in mental health care, as well as the wider organisational constraints, changing the organisation if necessary.

What happens when a psychiatrist and a service user meet to talk about medication?

Angell and Bolden (2015) describe medication as "a cornerstone of treatment" in psychiatry (p. 44). However, prescribing happens behind closed doors. It was not clear how much 'shared decision-making' was happening, an approach recommended by Drake and Deegan (2009). Angell and Bolden (2015) suggest that in mental health there may be particular barriers to shared decision-making, such as when the service user had not wanted help from mental health services. Also, psychiatrists are assigned the task of risk management, which is often seen as ensuring that people are on medication or continue with it. This goes against the idea that it is up to the service user to decide. Indeed, the service user's resistance to taking medication may be viewed as a sign they are 'ill' and cannot make that decision. However, Angell and Bolden (2015) wondered if the long-term nature of some service users' relationships with mental health services might provide the opportunity for trusting relationships to develop between psychiatrists and service users, making it more possible that medication decision-making could be shared.

Recording discussions between service user and psychiatrist

Angell and Bolden (2015) used the research method of conversation analysis to look at recorded discussions between service user and psychiatrist to see how the medication decision was made. Conversation analysis enables us to see how people influence others in their conversations. So it is ideal for looking at how psychiatrists might persuade service users that they should take more or less of a medication.

Angell and Bolden (2015) audio-recorded conversations between one psychiatrist and 36 different service users in one-to-one meetings to discuss their medication. The meeting was with the team psychiatrist in a multi-professional assertive community treatment service in an American city. Participants had been seen for an average of 12 years and most had a diagnosis such as 'bipolar disorder' or 'schizophrenia'.

How a psychiatrist talked to service users

Angell and Bolden (2015) noted that the psychiatrist used two ways to persuade service users to agree to her suggestions regarding medication. They called these “client-attentive” and “professional authority” (p. 47).

‘Client attentive’ persuading: This was where the psychiatrist referred to the service user’s reported experiences, such as muscle tremor. The psychiatrist recognized this as a side effect, suggested it may be due to one of the two medications the service user was on, and recommended lowering one of them.

Using ‘professional authority’ to persuade: This was where the psychiatrist used either her knowledge from professional training, or for example blood tests. In the same meeting as described above, these tests enabled the psychiatrist to inform the service user that the level of lithium was low, and Depakote high, so she could suggest it was the Depakote that caused the service user’s tremor. The service user wished to reduce the lithium but the psychiatrist argued to keep it the same and lower the Depakote. The psychiatrist suggested that this would help with the tremor.

In the article by Angell and Bolden (2015) there are seven short extracts from recorded conversations between a service user and the psychiatrist, and in all of them the psychiatrist by far speaks the most. This may be just because the authors chose sections that demonstrated how the psychiatrist justified her decision about medication. However, the sort of things the service user said in these extracts were things like “What, eh”, “Okay”, “Yeah”, or partial sentences such as “That don’t mean-“. Angell and Bolden (2015) also report that the psychiatrist’s decision was “rarely challenged by clients” (p. 54).

Occasionally a service user said more, but the psychiatrist seemed skilled at using service users’ own experiences to persuade them of her decision. Angell and Bolden (2015) show how she sometimes used a service user’s own words and her knowledge of the person to justify her decision. In one example she reminded a man of his negative experiences when he was on a lower dose of an antipsychotic medication. Using someone’s own words can be persuasive because it gives them the impression that they have been heard. In this instance the service user still disagreed with the psychiatrist’s refusal to decrease his medication. The psychiatrist then predicted that his distressing experiences would come back if she did so. Angell and Bolden note that the psychiatrist spoke as if from an ‘expert’ position, saying things like, “What we find is usually...” (p. 52).

Did the psychiatrist really involve service users?

Angell and Bolden (2015) suggest that the psychiatrist was using persuasion in a caring way “to achieve consensus” (p. 54) but they also remind us that she has the authority to decide about medication. The point about the psychiatrist’s authority seems key, in that it could be argued that the apparent ‘consensus’ was not real, since Angell and Bolden (2015) themselves point out that service users tended not to challenge the decision. In their study there was no evidence of alternatives to medication being suggested. Angell and Bolden (2015) concede that what they observed did not fit the vision of truly shared decision-making, but they suggest that perhaps such equal partnership is not easily possible because neither doctors nor patients are used to it. This does not strike me as a credible argument for maintaining an unequal *status quo*. I wonder what the service users would have said about their experience of these meetings with the psychiatrist, had they been asked. It may have felt disempowering when the psychiatrist used her knowledge of their history and what they had told her about their problems in order to justify why her decision was

right. Arguably this is not good for people's mental well-being, since it could undermine any belief that they may be able to have their opinions about their own care taken seriously.

What helps young people to share decisions about their medication?

Delman et al. (2015) point out that many young people would like a more active part in decisions about treatment, and that not having this can make them less likely to use services. They highlight the tendency of young people not to take medications because of unpleasant 'side effects' such as rapid weight gain. Delman et al. (2015) suggest that a theory called the Finfgeld empowerment model (Finfgeld, 2004) could be helpful. It has two levels, they tell us: choosing and negotiating. Choosing means the service user chooses between different options. Negotiating is more active, as it involves reaching a compromise if there is disagreement.

Delman et al. (2015) describe an approach called 'positive youth development', aimed at empowering young people to become more involved in decisions about their futures. The approach is based on the Finfgeld (2004) empowerment model, which recognises problems with the health care system itself, the service user's level of confidence and commitment, and how staff in the system may help the service user to overcome these obstacles in order to take a more active role in decision-making. This leads, ideally, to service users feeling more empowered and to greater overall well-being.

The study involved interviews with 24 young adults in mental health care in one American state about their views on how much they felt involved in decisions about their medication. They were between the ages of 18 and 30 and all had a diagnosis of a serious mental illness. Participants were only included in the study if they had asked their current psychiatrist for a specific medication or had disagreed with the psychiatrist and come to a negotiated decision. Most participants were white and two thirds were female.

Delman et al. (2015) identified five things that young people said were helpful for their active participation in medication decisions, and three barriers to active participation.

What made participating in medication decisions easier?

Psychiatrist interest in service users' wishes: Participants said that it helped when their psychiatrist listened and asked them for their opinion. In one case the psychiatrist agreed to go along with the participant's wish to come off medication, and discussed a plan to do it in a safe way.

Support from other staff: Staff of various services were helpful, for example those in a group home who offered to coach participants before they saw the psychiatrist, or attend the meeting and advocate for them. Most participants had meetings of only 15-20 minutes with the psychiatrist, and some said that it was helpful to inform the psychiatrist about what was on their mind through their counsellor or CBT therapist.

Personal growth: Many participants felt that over time they had become more confident due to long experience with psychiatrists and therapists, although some thought this was due to the support and encouragement of other staff.

Confidence: Some participants felt that their psychiatrist helped them to be more confident by inviting them to give their opinions, and some talked about gradually gaining knowledge through education or their own reading and searching the internet. Successful negotiation of medication decisions in itself also boosted confidence.

Psychiatrist availability: Some young people said that their psychiatrists made an effort to get more time for meetings with them, although this was not easy. Some psychiatrists made themselves available by phone between appointments, which the participants found very helpful.

What made participation in decisions difficult?

Lack of psychiatrist time: In contrast to the above, participants often talked about previous psychiatrists being less available. Participants had felt they did not listen or there was not enough time to explain about unpleasant 'side effects' and that they had to go along with the psychiatrist's wishes.

Psychiatrist lack of interest: Again referring mainly to previous psychiatrists, participants felt that psychiatrists were in a rush, had no real interest in their longer-term goals, and that they ignored concerns about unpleasant effects of the medication.

Service users' low self-efficacy: During their time in child and adolescent mental health care, participants had the experience of their parents and psychiatrist making decisions. They were not aware of their right to refuse medication or to change their psychiatrist, and had not developed any sense of being able to negotiate in decisions. Some reported being glad they now had more confidence to do these things.

How can people be more included in their medication decisions?

Although Delman et al. (2015) demonstrate that psychiatrist behaviour is sometimes a barrier to young people having a say in their medication, they also point out organisational constraints that make it difficult for psychiatrists to give people more time. Psychiatrists' traditional tendency of paternalism is also a problem, Delman et al. (2015) suggest, making them reluctant to trust the judgment of service users who have a diagnosis of serious mental illness. However, Delman et al. (2015) have demonstrated conditions under which some young adults can have more say in decisions about medication. They suggest that psychiatrists need training in how to invite people to take a more active role, and how to negotiate compromises when there is disagreement. They see a role for peer support workers in coaching service users before they meet with their psychiatrist. They suggest parents may welcome greater involvement in supporting the young person's development and more active decision-making.

What do professionals and service users think about how medication decisions are made?

Mikesell et al. (2016) interviewed both service users and professionals about how medication decisions were made. They explain the 'shared decision-making' model as having three parts:

- Unbiased information
- Collaboration
- Mutual respect

Mikesell et al. (2016) focus on the information part of decision-making. The participants in this American study were two administrators, three team leaders (one to one interviews), 25 clinicians who were case managers (focus groups), 14 service users and 6 family members (focus groups). They were all connected with two services in California. Service users tended not to have health insurance

and the clinics were publicly funded. The researchers asked participants whether they thought service users had difficulty deciding about medication, and whether they felt that a decision-aid tool could help. The decision tool provided information about different medications, including 'side effects', and aimed to help people come to their decision. The professionals who prescribed medication were all psychiatrists but none took part in the study. Service users all had a diagnosis of "either a psychotic or mood disorder" (Mikesell et al., 2016, p. 709). Four of the 14 service users were white, and eight were men.

Mikesell et al. (2016) reported three themes: being client-centred, exchanging information, and a theme of expertise. Regarding the need to be client-centred, all participants seemed keen that service users were involved and empowered in decision-making about medication. Service users felt that the decision tool would help them in this. Clinicians stated that there was no coercion and that service users had the right of choice. However, when it came to how choice could happen, things became more complicated.

Double messages about information given to service users

Information should be clear and unbiased: Both professionals and service users thought that information given to service users about medication should be full and nothing should be held back. Professionals thought they should help service users to tell psychiatrists about 'side effects' and support them to negotiate about decisions. They expressed concern that service users did not always have full information – for example not knowing that their weight gain was likely to be due to having been on a certain medication for some years. They suggested other service users could provide information from their experiences. Service users felt that finding out more about medications and their 'side effects' could be empowering.

Problems about communicating information: In contrast to their assertions that they gave full and clear information and that there were "no head games" (Mikesell et al., 2016, p. 711), professionals also said that information about side effects was concealed. They would not want to tell a young person or their parent that they could gain weight rapidly on starting a medication. Mikesell et al., (2016) describe this concealment as a sense of "therapeutic obligation" (p. 711). Professionals suggested that the decision tool could be confusing because it gave too much information, and some service users took a similar view, or thought they might focus only on the negative things such as the 'side effects'. Even so, 'side effects' may reduce their compliance, service users suggested, but they might not tell the psychiatrist for fear of disapproval.

Mutual mistrust about 'expert' knowledge

What service users know: There was general recognition that service users know about their 'symptoms' and how their medication affects them, and it was helpful for professionals to listen to this. However, service users tended to express doubt that they could make sensible decisions when they were in crisis, and some also felt they could not trust themselves to know when they were well. One professional viewed service users as unable to do what most people would do in terms of finding information or knowing their rights, but did not appear to advocate empowerment.

What professionals know: Whilst sometimes both professionals and service users suggested that service users placed too much faith in professionals' knowledge, service users also indicated that it could be difficult to question their authority. A professional acknowledged that a peer support worker had been most helpful in resolving one situation they had encountered. Service users would sometimes look up information on the internet or someone else did, for example a spouse, after the

meeting with a psychiatrist, and then they made the decision whether to take the medication. Service users were not impressed by the apparent “trial and error” mode of working out which medication would be best, or which combination. However, it was difficult to do anything other than go along with the doctor when they felt dependent on them.

Losing the big picture?

Mikesell et al. (2016) wonder if the shared decision-making model, when applied in mental health, should allow for the professional to persuade service users to take medication. However, this overlooks the real issue of harmful ‘side effects’ that may take a toll on physical health over time. Risk management appears to be seen only in narrow terms of current mental health ‘symptoms’, and not at all in terms of long-term physical health, even to the extent that risks to physical health may be concealed from service users. Mikesell et al. (2016) note that professionals work in contexts where alternative treatment may not be available, limiting the options they can offer. Indeed their role is partly to ensure compliance, which is incompatible with fully shared decision-making. Mikesell et al. (2016) cite Makoul and Clayman (2006) in suggesting that unbiased information may not always be advisable in mental health, although it can be an ‘ideal’ to aim for when circumstances allow. This leaves open the question of when the professional will deem the service user to be capable of shared decision-making, and this may continue to be over-ruled by the focus on ‘symptoms’ and lack of a wider perspective on service users’ lives and goals.

Can shared decisions about medication become routine? A UK perspective

Morant et al. (2015) suggest the need to take a wider perspective, looking at the organisational constraints on professionals rather than just the doctor-patient encounter. They note that shared decision-making is promoted in UK health policy but that in mental health it seems slow to take hold, in keeping with reports from America. They point out that service users have reported both benefits of medication and unpleasant and harmful effects. Harms include “weight gain, drowsiness and mental clouding, reduced libido, involuntary movements and diabetes” (p. 3). These problems can be as difficult as the original mental health difficulties, and explain why there is a high rate of non-compliance with prescribed psychiatric medication, Morant et al. (2015) suggest. Psychiatrists, they say, need to recognise people’s ability to self-manage their medication.

There is a problem of over-prescribing of medication, say Morant et al. (2015), with failure to reduce medication after a crisis is over, and prescribing more than one medication at a time, which increases the negative effects. The helpfulness of antipsychotic medication, they suggest, has been exaggerated (Moncrieff, 2009; 2013). Furthermore, Morant et al. (2015) cite studies suggesting that people may not need much medication if they have the right support (Romme, Escher, Dillon, Corstens and Morris, 2009; Seikkula, Alkare and Altonen, 2011). Yet the problems persist, with psychiatrists not really involving people in medication decisions.

Morant et al. (2015) present a modified theory of shared decision-making that includes the wider mental health system, the GP, carers, and support forums and social networks. It also incorporates the long-term relationships between the service user and the service or a psychiatrist.

Professionals can change what they do

There is a need, suggest Morant et al. (2015) for professionals to be ready to discuss openly the limits to shared decision-making in mental health care, such as the organisational concern with managing risk. Morant et al. (2015) suggest that over time, as a therapeutic relationship develops

between a professional and a service user, it may become more possible for the professional to use a coaching approach, encouraging service users to talk about their life and long-term goals and take a more active part in decisions. However, they also note the possibility for service users to feel progressively more disempowered over time if professionals continually use coercion such as depot. Morant et al. (2015) suggest family carers and members of internet forums or people's wider social network may be able to support service users' active decision-making, and that this should be encouraged. Other mental health staff can also support and coach people to ask for what they want, but they may need training to increase their confidence in their understanding of medication. GPs may be equally reluctant to advise, leaving it to the 'expert' psychiatrist.

Changing the culture

In relation to the culture of mental health care, Morant et al. (2015) suggest that the tendency to see mental health problems as mainly medical and requiring medication needs to be changed because it stops professionals seeing other causes and other solutions. Professionals, they suggest, also tend to be too pessimistic about people's long-term future, and fearful of reducing medication in case of relapse, while missing the risk that medication poses to people's long-term physical health. They also have a role of keeping society safe by controlling people's behaviour, say Morant et al. (2015), and they are influenced by the pharmaceutical industry. All these forces need to be looked at if there is any hope of changing things.

Training

The issue of service users' own wish for less autonomy when in crisis also needs to be acknowledged, say Morant et al. (2015). However, they suggest that coercion and control spill over too much into times when service users are able to be actively involved in decisions. Psychiatrists may need reassurance that it is not time-consuming to involve service users in decisions, say Morant et al. (2015). There was one randomised controlled trial of shared decision-making in inpatient settings, say Morant et al. (2015), but staff did not continue using it after the end of the trial. They suggest that training in shared decision-making should be available both to care-coordinators and service users themselves. Discussions could be structured around computer information and decision tools. Service users could meet with a peer worker before meeting the psychiatrist, so that the psychiatrist will not need to spend more time with the service user.

More research might help things change

Morant et al. (2015) suggest there is more research needed, especially on the role of peers, other staff, and family members, and on situations where the service user is in crisis. The things in the wider system that help or hinder shared decision-making need to be studied. Staff other than psychiatrists need greater knowledge about medication, and all need to learn more about how service users can and do successfully manage their medication and use other resources. Professionals may think they use shared decision-making while service users do not perceive it that way, say Morant et al. (2015). A gradual reduction of medication with support is better than the service user unilaterally deciding to stop medication because they have lost faith in the professional's ability to listen, they suggest. Service reconfiguration may be needed to truly support shared decisions. Using their expanded model of shared decision-making may help make this possible, Morant et al. (2015) suggest.

Conclusions

There is growing research suggesting that the positive effects of psychiatric drugs have been exaggerated and that they have long-term harmful effects. It seems imperative, therefore, as Drake and Deegan (2009) suggested, that decisions about medication are shared and not imposed on service users. Risk management should include the risk of long-term harm to physical health and survival. Alternatives to medication need to be more widely available, especially psychological therapies. The social deprivation that causes people on-going stress needs to be addressed. Mental distress has come to be viewed as a medical problem when it is in fact a social problem. It needs psychological and social solutions, not drugs (British Psychological Society, 2014). The articles discussed here demonstrate that the mind-set of viewing mental distress as a medical problem and seeking to impose narrow medical solutions needs to shift a lot more. The study by Delman et al. (2015) seemed a little more hopeful in that an empowerment model seemed to help young people to develop more confidence to negotiate decisions with their psychiatrist, although these young people were selected on the basis that they had done this. It is impossible to know how many other young adults still felt deeply disempowered in the surrounding mental health system. Morant et al. (2015), writing in a UK context, seemed to have some promising suggestions for changing the culture and organisation of mental health services. However they do not underestimate the barriers to change, which are political and social, and not just about funding.

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