Modern Mental Health

Critical Perspectives on Psychiatric Practice

Editor
Steven Walker

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load,

engendered by groups who espouse capabilities beyond the traditional: empathy, compassion, even love, they would say; practices that generate conversation, dialogue and collaborative action, and which have the capacity to see work as a system which is a flow of life. The Haven as an organisation has attempted to espouse such principles and, until now, has remained a living, learning and changing community.

A key part of this learning has concerned the need to reinforce and surround the organisation with robust structures for reflection. Hinshelwood has written at length, here in this book and elsewhere (Norton and Hinshelwood, 1996), about the potentially destructive impact on staff of working with severe personality disorder. This, of course, has an equal and opposite detrimental effect on the service users they are attempting to care for. The Department of Health (2007) has developed far-reaching programmes, such as the KUF, the Personality Disorder Knowledge and Understanding Training Framework (www.personalitydisorder.org.uk/training/kuf/), to aid the national workforce in understanding and best helping those with this diagnosis. Any staff team wishing to survive working with a client group who wrestle with unconscious impulses and employ savage mechanisms to cope, and who struggle with the ability to mentalise, must be able to create a team space for its clients in which to reflect, until they have developed the capacity to do so for themselves. This requires team openness, cohesiveness, trust, and a developed reflective capacity. At The Haven we call this triangulation or creation of the third space (Keval, 2003).

Scanlon and Adlam (2012) have opened an important dialogue concerning challenges to the therapeutic milieu and they examine many facets of the difficulties surrounding the care of those considered to have disordered personalities. In addition to their discourse regarding the internal pitfalls and challenges to services who work with severe personality disorder, they also reflect on the demise of some established organisations such as the Henderson Hospital, suggesting this was due to an oversimplification of the notion of the psychological complexities of personality disorder on the part of commissioners (Wrench, 2012). There is no doubt that this research study concerning The Haven shows that long-term work and long-term investment are vital. Something good and workable has been created. It emerged and grew in an organic way, informed by service users and responsive to organisational change. But it now exists in a difficult social and economic climate and is subject to the realm of necessity which is monetary, involving austerity measures and welfare reforms, which may leave little time and resources to acknowledge the psychological complexities of this diagnosis and the nature and length of the work needed to effectively respond to it.

Concerns currently exist regarding the future of health care and fears that recent legislation will open the door to turning health care into a market, without the proof that it is suitable for market mechanisms. The cost of health and social care may be considered unsustainable but this does not necessarily mean that a business model with a competitive ethos is going to provide a successful solution. As all sectors leap to respond to the next competitive tender, our greatest hope for the maintenance and proliferation of successful services in the future lies with the voice of service users. In relation to the dialogue with policy makers and commissioners, it is service users who are best able, with our support, to powerfully define themselves and their needs.

3 Exploring Shared Decision Making for Psychiatric Medication Management

By Emma Kaminskiy, Shula Ramon and Nicola Morant

Introduction

This chapter draws on two concurrent research projects[1] to explore how shared decision making is conceptualised by both practitioners and service users for psychiatric medication management. Selected similarities and differences in key themes between the stakeholder groups of psychiatrists, care co-ordinators and service users will highlight some of the crucial barriers, as well as some of the potential facilitating factors, to achieving a truly shared decision-making process that currently exist in UK mental health services. Shared decision making (SDM) promises to offer opportunities for recovery-oriented practice in mental health medication management, acknowledging the different forms of expertise needed in decision making and making explicit the ideal of involvement of both service users and practitioners in decision making. It is hoped that shedding light on the experiences and perceptions of the barriers and facilitators to SDM voiced by service users and practitioners will encourage reflection and change towards a more equal 'meeting of experts'.

There is a broad acceptance that there is an over-reliance on psychiatric medication in mental health treatment programmes in the UK (Healy, 2009). Most people's contact with psychiatric services revolves around medication-related discussions (Moncrieff, 2009). Yet there is a growing body of evidence which shows that the efficacy and helpfulness of antipsychotic medication, in particular, has previously been overestimated (Morrison et al., 2012). This, in conjunction with growing concerns over polypharmacy and the enduring and life-impeding side effects associated with many medications on offer, suggests that increased choice, involvement and open dialogue are essential to the psychiatric encounter.

The concept of SDM sits within the larger move towards recovery-based practice in mental health (Schauer et al., 2007), which, along with 'patient-centred care' is now considered to be core components of the UK mental health system (Department of Health, 2009b;

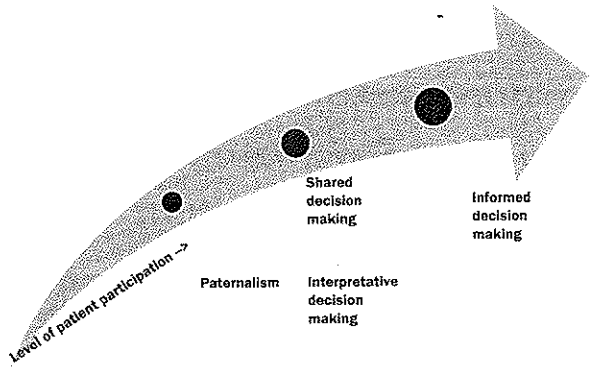

Figure 3.1 Shared decision making on the spectrum of service-user participation

National Institute for Mental Health in England, 2005). SDM for medication-related decisions, then, is one tool in a larger system or approach which focuses on giving the mental health service-user choice, freedom and partnership with practitioners in their individualised treatment plan (Davidson et al., 2010).

To date, very little research has been undertaken in mental health that explores service-user involvement in decision making and SDM relating to psychiatric medication. The studies that have been conducted show that mental health service users are keen to participate in decision making and desire greater involvement (Hamann et al., 2006; Loh et al., 2007). Practitioners also express a cautious willingness towards SDM (Patel et al., 2008). Positive impacts of SDM have been shown in terms of improved treatment adherence, satisfaction, knowledge, and involvement in decision making, reduced depressive symptoms and a trend towards reduced hospitalisation (Hamann et al., 2006).

In terms of levels of service-user involvement and responsibility in decision making, SDM has been proposed to occupy the middle ground between paternalism and informed choice (Figure 3.1). There is a considerable overlap between SDM and constructs with similar connotations, such as concordance, evidence-based patient choice, enhanced autonomy and mutual participation (Makoul and Clayman, 2009; Wirtz et al., 2006), and these concepts have been proposed to sit within the wider shared decision-making model (Coulter and Collins, 2011).

Charles et al. (1997, 1999) provide a useful and widely cited definition of SDM. Here, SDM includes four elements: (1) involving both practitioner and patient, (2) both parties sharing information, (3) both expressing treatment preferences, and (4) a consensus and agreement on treatment decision being reached. Expanding on this, Montori et al. (2006) argued that SDM may be carried out differently in chronic care conditions, where decisions may be delayed, or modified from visit to visit, without the delays leading to harm. Central to these broader conceptualisations of SDM is the importance of the relationship between the provider

and patient. Through information exchange and sharing of preferences, the parties come to know each other, trust is formed and service users are treated as individuals with expertise.

This chapter will explore how service-user involvement and SDM is conceptualised in the context of medication management in community mental health services in the UK today, highlighting similarities and differences between care co-ordinators', psychiatrists' and service users' perspectives. First, a more detailed picture of the context in which medication management in the UK mental health system takes place will be presented.

The landscape of psychiatric medication management in the UK

SDM as a strategy in the UK health system came first to primary care in the 1990s as an import from the United States. Clinicians have been asked to adopt it as a clinical practice principle. Its introduction was justified in terms of enhancing collaboration between patients and clinicians, with the aim of facilitating commitment to the relevant treatment decisions by both stakeholders. Much of the research conducted in primary care focused on observing the degree of SDM in doctor–patient consultations, and developing professional competencies for SDM (Edwards and Elwyn, 2009). In many of these studies, patients' views about their own experience, or about SDM were not elicited, and no training was provided to patients to help them participate in SDM.

SDM in the realm of mental health also arrived from the USA in the 2000s, but was developed mainly by service-user activists who also have clinical qualifications. It has evolved as an integral component of the recovery approach, with emphasis given to enhancing being in control of one's life. Being in control and having ambitions, as well as making one's own choices, are key elements in the recovery journey which is aimed at living well with the illness and beyond it (Anthony, 1993; Davidson, 2003). This new meaning of recovery implies the ability to be in recovery even if one continues to have symptoms of mental illness and crisis. It is predicated on the belief that people experiencing mental ill health have strengths as well as weaknesses, and that enhancing their potential strength is much more important than focusing on their deficit (Rapp and Goscha, 2012). This belief relates closely to the social model of disability developed by activists with physical disabilities in the 1980s in both the USA and the UK (Oliver, 1996).

The US emphasis has been on service users learning how to contribute to the process of SDM in the context of psychiatric medication management. This involves them using their experience of taking psychiatric medication as relevant information to be shared with their clinician, learning to be positively assertive in their contact with service providers, and treating psychiatric medication as one possible intervention among several which relate to personal medicine and well-being (Oades et al., 2011). The concept of 'personal medicine' introduced in the mid 2000s by Patricia Deegan (2005) remains important because it puts the service user at the centre of the recovery journey, and treats medication as one well-being tool among others. This has enabled the move to treating SDM itself as part of an overall well-being strategy within the recovery journey. Personal medicine strategies include a variety of everyday ways of coping with stress, derived largely from experiential knowledge.

The concept of personal medicine makes good sense to most service users, but not necessarily to clinicians, especially those who continue to view medication as the most important intervention, or the only one with sufficient scientific evidence of effectiveness. The fact that this evidence highlights the adverse effects of such medication, often belittled by naming them 'side effects', is known to both service users and providers in the USA and the UK (Whittaker, 2010). Thus it is likely that the dominance of the medical model in psychiatry is one key barrier to the acceptance of SDM between service users and clinicians regarding medication.

Experiential knowledge of medication and of other well-being strategies is highly valued within this relatively new approach to SDM. In fact, all types of SDM are predicated on the assumption that each partner to the process of SDM has unique knowledge they can contribute to the process and the decisions that follow. The concept of Expert in Experience, coined by UK service-user activists in the National Institute of Mental Health England (NIMHE) in the mid 2000s (Wallcraft, 2005), encapsulates the view that mental health service users have relevant knowledge pertaining to their experience of mental ill health and of the mental health service system, which complements the knowledge professionals bring. SDM has been justified in the USA as an effective strategy to enhance collaboration between people who use mental health services and their clinicians, as an ethical practice, and as a right of any citizen to have a say in major decisions related to their lives (Schauer et al., 2007).

The UK, too, has adopted the new meaning of recovery as one of its key policies in mental health (Department of Health, 2001), alongside the accepted bio-psychosocial model of mental illness. Yet the more traditional medical-model approach in which mental illness is perceived as a disease with bio-genetic aetiology, and where medication is treated as the most important intervention, continues to be a dominant feature of UK practice. This contradiction perhaps explains part of the identified paucity in the implementation of the recovery approach (Boardman and Shepherd, 2012; Ramon, 2011). The difficulty of changing professional and organisational cultures has led to current attempts to demonstrate how it can be done more constructively (see the Im-Roc project, Shepherd and Perkins, 2012).

Within the recovery approach there is a focus on personal recovery as against clinical recovery (Slade, 2009) and a growing awareness that without a reasonable degree of social inclusion (Secker, 2010), and reduction in both external and internalised stigma (Thornicroft, 2006), it is not possible to achieve recovery. While not objecting to psychiatric medication as one possible intervention within a range, recovery protagonists and researchers coming from a social-science perspective are concerned with the frequent and lasting negative effects of such medication (Pilgrim et al., 2011; Whittaker, 2010) and are searching for a much wider range of intervention options.

Alternatives to medication include the hearing voices network (Romme et al., 2009), in which service users act as peer supporters by sharing experiences of hearing voices and effective coping strategies for the negative effects of such voices. More emphasis on self-help, dialogical work (Seikkula et al., 2011), the Soteria therapeutic communities (Calton et al., 2008), psychotherapeutic interventions and social inclusion strategies which encourage service users to take up education, vocational training and employment also constitute part of this list of interventions. The introduction of peer support workers, who work alongside professionals mainly in a befriending capacity, to a growing number of mental health trusts in the UK symbolises this change in focus and in the credibility given to the user's experience and abilities (Repper and Carter, 2011).

The co-existence of biomedical and recovery-oriented approaches is problematic in that while the majority of service managers and practitioners would claim to adhere to recovery principles, their everyday practice tells a rather different story. This is one of inherent pessimism towards the likelihood of real improvement in the service users' quality of life and pursuit of wishes and ambitions, together with an ongoing focus on risk avoidance, leading to a preference for compliance with medication without users having a say in the decision-making process. In parallel, we have pockets of exemplary recovery-oriented practice, of people whose lives have indeed changed for the better despite the prevailing pessimism around them (Castillo, 2010; Coleman, 1999; Repper and Perkins, 2003).

More recently, SDM has been mentioned as part of the focus on choice for all people using mental health services and interventions provided by statutory services (Department of Health, 2008, 2011; NICE, 2009b). This emphasis relates on the one hand to the current government agenda aimed at introducing private service providers to the UK health system, where the choice will be between more than one service provider. On the other hand it relates to the growing recognition by policy makers that the effectiveness of clinical and non-clinical interventions is very limited if the patient does not become an active agent in promoting their own health, be it physical or mental. At present, the governmental documentation does not contain guidelines as to the implementation of SDM in everyday health- and social-care practice.

The use and misuse of psychiatric medication in the UK provides a good example of the limitations of the current system in encouraging good collaborative working relationships or SDM between clinicians and service users. Existing evidence suggests that polypharmacy is frequent, and that psychiatric medication prescriptions are not reviewed often enough to ensure effective prescribing in terms of choice of medication, dosage, duration of use, reduction of side effects and use of alternatives to medication. Furthermore, 50 per cent of service users are reported to stop using medication without notifying their clinicians (Nose et al., 2003), a finding illustrating insufficient collaboration and lack of SDM within the mental health system.

There are several UK and non-UK studies on the process of making decisions about and using different types of psychiatric medication by service users (Day et al., 2005; Malpass et al., 2009). Contrary to the assumption heard often from clinicians, service users rarely rush to an impulsive decision to discontinue medication. Instead, the decision may be made within a process of calculating the benefits and adverse effects that taking such medication entails. This process might be better conceptualised as meaning-making or decision making within a *medication career* or a *moral career* (Malpass et al., 2009). Within SDM it is of central importance to understand how service users reach their decisions, and to accept that stopping medication may represent a positive self-management choice if taken as a thought-through decision.

Approaches to risk within the mental health system are central to the possibility of having an SDM policy and practice. Presently, most UK mental health providers focus on risk avoidance interventions, in which the reliance on medication is paramount. However, this approach contradicts common sense and recovery-oriented thinking and practice in which it is necessary to take calculated risks if the person is to begin and remain on the recovery journey (Ramon and Williams, 2005).

At present, it is left to individual psychiatrists to decide if they wish to focus on improving their working relationships with their patients in the context of psychiatric medication management and use SDM in this context. The Royal College of Psychiatrists has recently developed an online training module for its members on this issue (June 2012), which can be accessed only by members of the college. Otherwise, there are no authorised training schemes for SDM or Trusts with a working strategy for how to encourage this in everyday practice.

It can be argued that current training in communication skills for psychiatrists may facilitate SDM, as may training service users to communicate with providers. However, additional communication training needs to be specifically focused on SDM in the sensitive context of medication to achieve this objective.

In summary, while pockets of exemplary recovery-oriented practice and SDM exist in the UK, many organisational and cultural barriers remain. The remainder of this chapter will present findings from the two studies, further shedding light on both the barriers and facilitators of SDM in the UK, by exploring similarities and differences between psychiatrists', care co-ordinators' and service users' perspectives on this issue.

Background to the research

Two research projects are being conducted within Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), by Anglia Ruskin University. Project A (2010–13), a PhD study conducted by Emma Kaminskiy, is concerned with how mental health service users are involved in decisions about their psychiatric medication, exploring both current practice and views of collaborative models of decision making. This study took place in the Intake and Treatment care pathway that provides community-based services for adults with moderate to severe mental health problems. Project B (2011–14), the 'ShIMME' project (Shared Involvement in Psychiatric Medication Management and Education), is a three-year independent research project funded by the National Institute for Health Research.

The project is led by Professor Shula Ramon from Anglia Ruskin University, with Dr Nicola Morant as the qualitative adviser to the project. It is based in the Rehabilitation and Recovery Service of CPFT, which provides longer-term community-based support and interventions for adults with mental health problems. ShIMME aims to develop, deliver and evaluate a training intervention for practitioners and service users focused on the process of shared decision making in psychiatric medication management (see www.shimme.arcusglobal.com for further details).

Both studies have included in-depth explorations of how different stakeholder groups (psychiatrists, care co-ordinators and service users) value and conceptualise service-user involvement in decisions about psychiatric medication.

Uniquely, this chapter presents findings from two research projects that have taken place concurrently in the same mental health trust but in different community-based teams, and in the same university, exploring how shared decision making is perceived, experienced and valued by key stakeholder groups. Very little previous research on this topic has explored both practitioner and service-user perspectives alongside each other, and none of it in the UK.

Data

The data we draw on in this chapter consist of the following. For Project A: 30 individual interviews conducted with psychiatrists (n = 7), community psychiatric nurses (CPNs; n = 8) and service users (n = 15). These interviews covered the following topics: general understanding of how decisions are made about psychiatric medication and different stakeholder groups' roles in the decision-making process; how service users should be involved in decisions, including barriers and facilitators; and an in-depth exploration of critical incidents (both positive and negative) where decisions about psychiatric medication were made. For Project B: eight focus groups conducted with service users (four groups, n = 27), psychiatrists (two groups, n = 4), CPNs (one group, n = 10), and care co-ordinators from a range of professional backgrounds (one group, n = 8), and four individual telephone interviews with psychiatrists, making a total of 53 respondents. Discussions were structured around four broad topics: how decisions about psychiatric medication currently happen; how respondents thought these decisions should be made; factors that might facilitate SDM between professionals and service users; and perceived barriers to shared forms of decision making for psychiatric medication. Thematic analysis using NVivo software was used to analyse data from both research studies. Due to limitations of space, we will focus in this chapter on the principal similarities and differences between stakeholder groups (psychiatrists, service users and CPNs/care co-ordinators) that were detected across the two projects.

Findings

Similarities between stakeholder groups

On the whole, across both projects, there was a genuine desire to involve people / be involved in decision making about psychiatric medication. Service users taking increased ownership in the decision-making process and honest, open dialogue during discussions about medication were seen as important by both practitioners and service users. SDM as an ideal model of practice was valued by all key stakeholder groups.

Service-user involvement varies

However, across both studies, all stakeholder groups emphasise that involving service users in discussion and decision making about psychiatric medication varies according to how well the person is at the time. Limitations in the possibility of exchanging information and expressing preferences during the acute stages of mental health crises are recognised as important barriers to fully participating, with acknowledgement that a more paternalistic approach may often be more appropriate when the person is acutely unwell. Indeed, increased guidance during these more difficult periods is valued by service users.

Service user 3, Project A: *I think when I was particularly ill, I found the meetings very difficult, I didn't know what to say, I really didn't know how to express how I was feeling, and at that point I was very much led by the consultant*

Service user 12, Project A: *I didn't feel in the right place / frame of mind to be able to go away and search on the internet about all these different options and weigh it up.*

Psychiatrist 2, Project B: *I think in more acute situations when maybe the decision making is more difficult and it's sometimes already part of relapse plan, but when people are well and they have a, are able to make decisions and have discussions with their partners or families to make the decision in advance. Ok, so people come unwell, what happens, what treatments would be acceptable to me? Which ones would I continue taking? And (erm) That would be helpful I think for the acute situation when you maybe can't be involved in decision-making decisions and discussions as such.*

Interestingly, in the quote by the psychiatrist above, the acceptance that decisions are more difficult in periods of crisis is directly followed by an acknowledgement that certain tools, such as advance directives and relapse plans, can assist greater involvement during these more difficult periods.

The therapeutic relationship

The beneficial role of a supportive, trusting relationship between the service user and the practitioner is mentioned by the majority of participants in both research studies. A good therapeutic relationship appears to enable broader collaborative decision-making processes, mitigating against the problems of being involved during periods of crisis. Thus during periods of crisis, all participants seem to value increased guidance from practitioners. However, if based on trust, support and mutual understanding, the longer-term goals of service-user ownership and enhancing control and involvement are not necessarily impeded during these more difficult periods, when potentially important decisions about psychiatric medication are made. As such, being supported, feeling cared for, having trust and being honest and open seem to be facilitating factors for meaningful shared dialogue. This greatly assists at times of crisis when equal sharing of knowledge and information becomes more difficult. In the quotes below, the importance of developing a partnership over time and building longer-term goals is explored as assisting shared understanding. The importance of continuation of support from the same person is seen by some as especially important, with familiarity encouraging feelings of safety.

Service user 4, Project B: *I think that the thing that has made the difference between then and now is the relationship. So having constant and continued support from the same person and continuity of care with the same doctor, so that you feel that you're not battling it alone and it's not a battle then of the doctors and the patients, it's that you've got somebody there.*

Service user 1, Project A: *... rather than it just coming from a stranger, like you should take that, that, they don't even know the person and it's just, you know, if you're in such a state that you need to have the decision taken out of your hands. Having some stranger telling you what you should be taking, it's not good; you need familiarity to feel safe.*

Importance is often placed on the concept of walking a shared journey over time in partnership. Crucially, the participants stress the importance of being able to trust someone during the more difficult periods, both in trusting them to take more control of decisions during periods of crisis, and in having an open and honest dialogue and respecting each other's opinions.

CPN 8, Project A: *I think the thing that probably stands out for me about the job I do is how much of it is about standing shoulder to shoulder with the service user, it's not ... it can't be them and us, it has to be about [pause] this journey I walk by your side with, because I can't tell you how to get better.*

Service user, group 4, Project B: *So it's good to have a good relationship with somebody that knows a lot about your history and what you've been through and somebody that you trust to make decisions for you when you are unable to.*

Psychiatrist, group 2, Project B: *I think we mentioned before, trust is important, so is sincerity and honesty (erm) respect for each other's opinions I think.*

Fear of coercion as a barrier

A key barrier to SDM to all stakeholder groups is the acknowledgement of power inherent in the mental health system and the resulting fear of coercion experienced by service users. This is seen as a barrier to being able to achieve an honest and open dialogue where power is truly shared and where a 'meeting between experts' can take place.

Interestingly, both studies were conducted in community settings where, in the most part, contact with mental health services is voluntary. However, there appears to be an underlying awareness by both practitioners and service users in this setting of the legal framework within which mental health services operate and the potentially coercive roles practitioners serve in the modern mental health system. This awareness can sometimes prevent service users from disclosing information about their mental health symptoms or personal use of medication:

Service User 10, Project A: *... so I was quite intimidated about talking to the doctor about that [hearing voices] because I've got children, and I was worried I was going to get sectioned and my children were going to get taken off me because I was completely insane and stuff like that, so that was a difficult conversation for me just for that reason.*

Service user 7, Project B: *Fear, because then you just don't tell the truth. I mean in my case I spent four years just not telling the truth and so then I hadn't got anyone to talk to and when I did tell the truth I was penalised for it. And in other words not wanting to be on medication was a sign of mental illness, and I couldn't say that actually I haven't been on it anyway for years! And so fear prevents shared decision making.*

Differences between stakeholder groups

Valuing different forms of expertise

All stakeholder groups highlight the role of the professional as being an 'expert' in medication management, valuing formal knowledge of medicines and their evidence bases, but also placing importance on expertise in practice.

Service user 12, Project A: *They are the ones who know about the pros and cons. The doctor is the expert to tell about pros and cons and the psychiatrist is the person you talk to about medication. You work on the basis that the psychiatrist has seen loads of other people who have taken pills and they know the pros and cons.*

However, psychiatrists on the whole were less likely to mention service users' expertise, or to suggest that service users' experiential knowledge might form part of the decision-making process. In comparison, CPNs, care co-ordinators and service users acknowledge that in addition to the expertise of professionals in medication management practice, there is also expertise brought to the process by service users. These respondents talk of service users having valuable experiential expertise in taking medication, sometimes over numbers of years, which can make a valuable contribution to discussions and shared decisions. This was linked to the acknowledgement that decision making for psychiatric medication requires greater discussion than other areas of health care and that multiple options are often available. Individuals' responses to medication differ, and medications vary in degrees of risk and side effects. Working to achieve the best type and dosage of medication for an individual over time, through exploration of service-user preferences and experiences is essential.

CPN 1, Project A: *I think that one of the things I've learnt is that patients tend, on the whole, to know themselves pretty well, you know, no matter how unwell they are. They often know each other, they know themselves quite well, and if they say that a particular medication is no good for them, you know, well maybe we have to listen to that, and I think we are getting better at that, I really do, I think everybody's getting better at that.*

Service user 4, Project B: *So it's the respect and being listened to and having expertise about ourselves that's going to help isn't it.*

Differences in descriptions of being ill as a barrier

Lack of insight into mental illness was seen by most practitioners as a barrier to involvement in decision making. The person not understanding they are ill during periods of crisis was seen as the most problematic barrier to a shared dialogue:

Care co-ordinator 5, Project B: *I think it all gets more difficult when people aren't insightful particularly ... I think it all gets much more difficult for everybody when someone maybe doesn't accept their diagnosis but appears very unwell and then it becomes difficult for the team, difficult for them.*

In comparison, while on occasion referring to problems of lacking insight, service users were overall less likely to emphasise this as a key barrier.

Service user 3, Project B: *Some people believe that patients just don't want to take their medication as that being part of the symptoms of their illness. I mean most of the time they're complaining about how unwell they feel on medication.*

More often, service users describe problems in terms of the impact of illness on cognitive abilities such as concentration, memory and motivation, as well as the impact of distress in periods of crisis on being able to fully participate in the decision process. These problems can affect their ability both to communicate and to process information:

Service user 3, Project A: *I think when I was particularly ill, I found the meetings very difficult, I didn't know what to say, I really didn't know how to express how I was feeling.*

Service user 10, Project A: *When I first turned up at the GPs, I wasn't feeling very well at all, so um, it was actually physically hard for me to have a conversation, communicate and understand what was being said to me really.*

When practitioners suspect that a service user 'lacks insight' or does not agree with a diagnosis, they may tailor the way they present information to avoid conflict around the issue of the nature of the person's problems, and to increase the likelihood that they might agree to take medication:

Psychiatrist 6, Project A: *... who often are very distressed about their symptoms but don't necessarily see it as a mental health problem, so a lot of the work is around trying to get some sort of joint understanding. That's really hard because often most of their involvement with mental health services to prove that they are not ... then it becomes quite difficult to involve people um on the same level, because you have to walk a fine line between giving information that is correct and factual um but also if you, you start talking about this is an antipsychotic drug ... People start saying, but I'm not psychotic and so it's often about a fine line. It's not about giving the wrong information but giving information that would lead people to consider perhaps the options more carefully rather than being immediately backed off.*

Of note, however, is that while this theme emerged across both studies, one psychiatrist talks about how insight should not be a barrier to full ownership.

Psychiatrist 5, Project A: *It's not about insight, I think if someone hasn't got an insight and I feel that very strongly he suffers from a mental illness he needs to take medication, again it would be a decision made by him if he doesn't want to take, he doesn't take it.*

Doctor–patient power

Service users often talk about the unequal power base during the psychiatric encounter, feeling inferior and patronised in the conversation:

Service user 2, Project A: *No, I don't work well when I'm obviously not her equal, she has more training but I don't work well when I'm being treated as, you know, an inferior... I'm an intelligent person, if like ... I don't know, I don't really, I can't think what it would be, a parent, child I suppose is what it feels like when ... but they seem to have this; I'm God, you're the patient.*

Service user 13, Project A: *Yeah, I think basically it's like, I don't know how you feel, but the way I feel sometimes, you come to see a doctor and you can feel very uncomfortable. Well, I do, I feel as if I'm thick and mental because I'm so ill sometimes when I come in and I feel sometimes that I get ... I'm being spoken down to and not at that way, that level.*

This power imbalance was also acknowledged among CPNs and care co-ordinators. Psychiatrists, on the other hand, did not generally mention unequal perceptions of the doctor's and patient's roles and status as a potential barrier to SDM. Indeed, one psychiatrist below notes that they find it strange that service users perceive a power imbalance in their relationships with psychiatrists and in decision-making processes:

Psychiatrist 6, Project A: *And you know often people come here and say, oh you're not going to tell me to take or reduce my drugs or take this. And I find that a very interesting view because I wonder where that comes from, this idea that I am going to tell them what to do, with certainty I never tell people what to do. Even when I detain people I tell people that this is the only choice I have now, so I find that very interesting, that because you have a prescription pad you have the power to make them take things, and actually you never can.*

Discussion

On the face of it, we have found broad support for the ideals of collaborative ways of managing psychiatric medication across all key stakeholder groups. A non-specific conceptualisation

of SDM, where individual decisions are part of a longer-term and adaptable process, similar to that proposed by other authors (Entwistle and Watt, 2006; Montori et al., 2006) is widely supported by care co-ordinators, CPNs, psychiatrists and service users in these findings. Service users acknowledge and value more guidance in times of crisis, and strongly believe that SDM can only happen in the context of walking a journey together in a trusting, supportive and honest long-term relationship with a practitioner. As such, opportunities to move towards a more recovery-oriented approach to prescribing and medication management in community mental health services appear to exist. The importance of the therapeutic relationship was also apparent across all participant groups. A long-term process, where trust is gained over time and a partnership is formed, appears to be essential to establishing key principles of an SDM approach to medication management. This fits with the literature exploring what service users see as important to the decision-making process. For example, in a US study by Davidson et al. (2008), who undertook qualitative interviews with mental health service users, the decision-making process was often a protracted process of trial and error in finding both the right doctor or nurse, and then the right medication. The right prescriber was someone who listened to the person, was willing to try different things, and who viewed medication as one of many possible strategies to consider. It takes time to discern the benefits of a medication as change is often incremental and slow. These results also support findings suggesting that service users show a preference for a two-stage process, which first prioritises autonomy, but then, if that is not possible, defers to the clinician's judgement in more challenging or complex decisions.

The current system in which service users are unlikely to have frequent routine appointments with psychiatrists as standard, but rather on an 'as and when' needed basis, is perhaps not conducive to such a partnership being forged, at least between the psychiatrist and service user. It may be, then, that the role of other care co-ordinators, including CPNs, occupational therapists and STR workers (Support Time and Recovery) – many of whom, in our research, view themselves as on a journey with service users – could be usefully oriented towards encouraging SDM for medication management in mental health.

Findings presented in this chapter point to some paternalistic practices in current community-based mental health services, and SDM is at present far from being an integral part of mental health medication management systems. These findings are in line with recent research suggesting that decisions in medication management rarely reflect both parties' contributions and preferences in the outcome. For example, Matthias et al. (2012) show that while 61 per cent of recorded consultations reflected the practitioner perspective, less than 10 per cent reflected both service-user and practitioner perspectives.

The barriers to collaborative practice identified in these findings may go some way to explaining the gap between policy ideals and current practice. Fear of coercion acts as a key deterrent to achieving SDM, instead encouraging greater passivity and 'false compliance' (Chamberlin, 2005). In other areas of health, capacity may be limited by service users' knowledge of medical conditions and treatments, but their ability to reason is not in dispute. In mental health, the capacity to reason and make effective decisions is brought into question, and is often defined by others rather than by the person themselves, thus removing a significant

determinant of choice and control. Part of this is defined in legislation and part through the social construction of professional practice in mental health (Morant, 2006).

Therefore, until risk, accountability and the wider contexts of legislation and organisational culture are acknowledged in a more open manner, system-level change towards a more democratic and risk-taking culture of honest shared dialogue and collaboration between service users and practitioners is unlikely. Perhaps the fact that both practitioners and service users expressed and reflected upon these barriers in these two research projects is, in itself, a step towards recognising these underlying fears and positively embracing a way forward towards the ideals of an honest, open dialogue. However, the lack of value given by psychiatrists to service users' experiential knowledge of medication may indicate that there are strong underlying obstacles to SDM being implemented. Perhaps the consistency of CPNs positioning themselves more alongside service users and less alongside psychiatrists reflects a move of this group away from full adherence to the medical model and a broadening in the types of knowledge they see as valid. A potential alliance of CPNs – now the largest professional group in UK mental health services – with service users may promise a shift in attitudes to SDM.

Differences between what service users conceptualise as important for SDM and what psychiatrists and care co-ordinators think important are also worth consideration. Service users often describe feeling patronised, feeling like a child and being spoken down to. The perception that the doctor knows best is still common in modern-day psychiatric practice, together with an explicit notion that users of services may not have the capacity to decide for themselves, or that their understanding of the situation is not valid. The prevalence of these views in current mental health services is not recognised as much by psychiatrists, and hence alternative positions may be difficult for them to accept, as these challenge what many might see as the psychiatrist's fundamental role within the mental health system.

A second interesting difference between stakeholder groups in our data concerns how illness symptoms are conceptualised. Psychiatrists and care co-ordinators are very clear that lack of insight, perceived as a deficit, is a key barrier to service users engaging in collaborative dialogue. They acknowledge that, when working with a person deemed to lack insight, they may change their communication style, provide less information, and at times use discursive practices that could be understood as subtle forms of deception and persuasion during the psychiatric encounter (Seale et al., 2006). For service users, on the other hand, lack of insight is not seen as so important for full participation in decisions. Instead, they place more emphasis on increased distress and lower levels of concentration and other cognitive functions such as memory and motivation as by far the biggest challenges to both feeling involved and fully participating in a shared and open dialogue. These may either be consequences of the illness itself or side effects of taking medication, although the latter appears not to be recognised as a barrier to SDM by practitioners in our studies.

This discrepancy needs further exploration. Despite practitioners' reservations, insight into illness should not in itself be seen as a prerequisite to engaging in SDM. Indeed, evidence shows that service users are capable of participating in most decision-making situations (Loh et al., 2007). Hamann et al. (2006) have demonstrated that SDM for medication can be successfully understood by inpatients on an admission ward using a simple manual and

support from ward nurses. Decision aids and communication tools, then, may well be important ways of supporting service users to participate in SDM.

The emphasis placed by practitioners on lack of insight as a barrier may also point to the continuing dominance of the medical model in UK psychiatric practice today, moving experiential knowledge into the periphery of the decision-making process, and diagnosis, labelling and *othering* to the forefront. Decisions in mental health are also peculiar in that the acceptance of a mental illness diagnosis can be stigmatising and potentially lead to loss of control. There may be stigma not only from friends, family and society generally, but also self-stigma (Thornicroft et al., 2009; Yanos et al., 2011), and the worry that a diagnosis may interfere with job prospects and life chances more generally. 'Lack of insight', so termed by the practitioners in our respective research projects, while being described as a symptom of the mental health problem in question, could also be seen as a 'symptom' of the wider system and one tool in the existing power structures of a psychiatric system dominated by the medical model.

In summary, a number of obstacles specific to psychiatry appear to hinder the development of fully collaborative relationships between practitioners and service users. At the forefront of these is the central issue of competence or insight, judgement of which remains in the hands of psychiatrists, who, because of their specific training and background, are more likely than other mental health professionals to adopt a medical approach to assessment.

Research suggesting the importance of a respectful culture which recognises service-user expertise and communicates belief in individual potential is supported by these findings (Tee et al., 2007). In addition, while not objecting to psychiatric medication as one possible treatment strategy within a range of interventions, recovery protagonists and researchers from a social-science perspective are concerned with the frequent and lasting adverse effects of such medication (Pilgrim et al., 2011; Whittaker, 2010), and are searching for a much wider range of intervention options. In such a model, SDM sits at the centre of the therapeutic encounter, encouraging dialogue and discussion in an open forum.

Conclusion and looking forward

Numerous diverse aspects of the current UK mental health system suggest potential opportunities for further development of SDM relating to psychiatric medication management. These potential facilitating factors include policy guidelines, the focus on implementing recovery-oriented approaches, the increased autonomy of care co-ordinators within the system, and the existing skills of some practitioners in forming and maintaining strong and enduring therapeutic relationships with clients.

Implementation of SDM could also be facilitated by the increased involvement of service users in service delivery, planning and audit, as well as training and research, and by the desire among many service users and some professionals to see SDM as an integral part of mental health practice.

Government focus on choice has led to the planned introduction of SDM strategies in a few Trusts, but real choice is still a long way from becoming embedded in practice. Barriers

include poor implementation of policy makers' intentions; the need to change attitudes towards the value of service users' experiential knowledge and recovery potential; insufficient lay information about psychiatric medication that service users find easy to access and understand; service organisation and structures that are not conducive to forming therapeutic bonds between professionals and service users; and the lack of research evidence on shared decision-making processes in the context of psychiatric medication management.

The ShIMME project described in this chapter aims to contribute to this evidence base, and presently constitutes the only UK evaluated pilot intervention delivering parallel training programmes for service users, psychiatrists and care co-ordinators focused on SDM in psychiatric medication management (www.shimme.arcusglobal.com). Evaluation findings will be known in late 2013. Encouragingly, several other projects are working on themes central to the implementation of SDM in relation to psychiatric medication management. Devon Mental Health Trust has devised a strategy for recovery-oriented prescription, which includes SDM as a method. Although yet to be implemented, it provides a useful and comprehensive guide (Baker et al., 2013). An RfPB (Research for Patient Benefit) NIHR-funded project conducted in north-east London and led by Dr Joanna Moncrieff focuses on developing a tool for reviewing and recording experiences of taking antipsychotic medication, constructed on the basis of interviews with service users. Jordan and Slade (2012) are carrying out more generic research on SDM in mental health services in five EU countries, entitled CDIS (Clinical Decision-making Involvement and Satisfaction). The tool developed measures the extent to which SDM principles are applied according to both clinicians and service users. Interestingly, preliminary findings highlight differences in ratings of the same situation by clinicians and service users. Thus, a number of small-scale initiatives developing the implementation of SDM are now in existence, illustrating the increasing interest in this issue in the UK. However, a lot more progress is needed if SDM is to become an integral part of our mental health services.

The key challenges in the findings we have presented here suggest over-reliance on an approach that does not value the experiential knowledge of service users and gives preference to the medical model of psychiatry. Fear of coercion is one possible outcome of a clash of perspectives between service users and professionals, in which the latter have a much more powerful position as part of their social mandate. Thus SDM within mental health needs to be explored in terms of its implications for power sharing and ownership of the decision-making process, and not as a narrow model of the procedural actions necessary. SDM should be understood as embedded within long-term therapeutic relationships and the contextual constraints and facilitating factors of the current mental health system. Through making these systemic barriers and facilitators more explicit, developing and evaluating initiatives to promote SDM, and encouraging open dialogue between practitioners and service users about how to achieve shared decision making, it is hoped that change towards increased power sharing and collaboration will emerge.

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4 The Recovery Concept: The Importance of the Recovery Story

By Joanna Fox

Introduction

The care and treatment of people with schizophrenia has been dominated by the biomedical model of mental health, emphasising the importance of medication, treatment compliance and the expertise of the doctor (Bogg, 2010; Campbell and Davidson, 2012). In the last 20 years, the traditional psychiatric model has been challenged and a model of recovery has emerged (Anthony, 2003; Deegan, 1996). This focuses on the service user's abilities to live well with and even beyond the label of schizophrenia by using their own strengths to manage their symptoms and to control their own lives (Spaniol et al., 2002). The recovery concept does not reject the role of medication in care but emphasises the importance of a life that is defined by the service user, rather than a life that is limited by a diagnosis and managed by compliance with treatment.

In this chapter the biomedical model of mental health is introduced. It is suggested that this model is underpinned by a practice that potentially limits the service user's own ability to control and self-manage their mental ill health. The new model of recovery is described and the role that the concept of recovery plays in allowing service users to define the limitations and boundaries of their lives is explored. I differentiate between the traditions of clinical recovery and personal recovery. It is argued in this chapter that clinical recovery reflects some of the difficulties encountered with the biomedical model and removes the expertise from the service user in defining their own recovery.

The concept of personal recovery is introduced, along with the potential it has to enable service users to define their own successes. I illustrate this with a story of personal recovery by describing my own journey to live beyond the disability (Spaniol et al., 2002) and explore what hindered and helped me. It is argued that allowing service users to define their own recovery journey (Brown and Kandirikirira, 2006; Ridgeway, 2001) gives space for them to define their limitations and their strengths; to manage their symptoms by taking responsibility for their lives; and to live well and successfully on their own terms. I describe the difference between the *process of recovery* and the *attainment of recovery*, and how this contributes to an understanding of the recovery concept.