

Shared Decision Making in Psychiatric Medicines Management

Abstract

It is increasingly recognised that Shared Decision Making (SDM) should be routine in all areas of healthcare. However, although evidence of its effectiveness is emerging, it is not yet standard practice. This article describes one of the first studies in this country to look at promoting SDM for Medicines Management in mental health care. Reactions from participants in the study are described along with recommendations for practice. Facilitators of SDM include providing good quality information about medicines and alternative treatments, implementing structures that enable the service user's preferences to be recorded and valued and acknowledging power differentials in current practice.

The National Institute for Health and Care Excellence (NICE) clinical guideline on medicines adherence tells us that between a third and a half of medicines prescribed for long term conditions are not taken as recommended. The guideline goes on to say that this should not be seen as the patient's problem, but rather as "a fundamental limitation in the delivery of healthcare, often because of a failure to fully agree the prescription in the first place..." NICE suggests that the solution is to start by exploring the patient's perspectives of medicines & recommends that all patients should be offered the opportunity to be involved in decisions about their medicines. The guideline acknowledges that increasing patient involvement may mean that the patient chooses not to take medication; it suggests that as long as the patient has been given enough information to make an informed decision and has the capacity to do so, this should be respected (NICE, 2009, p3-6). Similarly the Department of Health (DOH) now expects that "Shared Decision Making will become the norm" in the NHS (DOH, 2010).

Shared Decision Making (SDM) recognises that each service user has their own goals which are related to their lifestyle and personal identity as well as the impact of symptoms. SDM values choice and self determination and is very much in keeping with the Recovery approach to care (Deegan and Drake 2006). It involves partnership, sharing of information and negotiation (see Box 1). It is not about the professional offering a limited range of options and then making a token gesture of consulting the service user's preferences at the last minute. Nor is it the professional just doing what the service user wants without utilising their own professional expertise.

Box 1: Essential Characteristics of Shared Decision Making:

1. The clinician and patient share all stages of the decision making process simultaneously.
2. There is a two way exchange of information (medical information & the patient's relevant personal information).
3. The clinician creates an environment where the patient is comfortable to express his/her treatment preferences.
4. The clinician and patient try to build a consensus about preferred treatment.

Charles, Whelan and Gafni (1999)

Different types of expertise

A key idea underpinning SDM is that in a consultation, there are two experts in the room (Marshall and Bibby, 2011):

- The prescriber brings an understanding of the benefits and harms of medicines (a combination of clinical experience and theoretical knowledge),
- The service user brings an understanding of their own attitudes to illness and risk, their values, goals and priorities in life plus (in some cases) personal experience of their own response to psychiatric medicines.

SDM explicitly acknowledges that both types of expertise are needed and that a service user's preferences are as valuable as the evidence from medicine research trials.

The results of a large scale randomised control trial (RCT) may tell us that a certain percentage of people benefitted from a medication, but it won't tell us whether the service user sat in front of us will be one of the lucky ones. Additionally, the quality of evidence from

many RCTs is questionable. A review of 114 studies of anti-psychotics revealed that many studies excluded service users with co-morbidities; they rarely reported on side effects such as sedation and restlessness and most did not monitor peoples' response to medication for more than a few months (Hartling et al 2012). Over two thirds of these studies were funded by drug companies which could increase the chance of publication bias. Goldacre (2012 p19-20) describes a review of 74 anti-depressant trials: 51% of these actually showed a positive effect of the anti-depressant. However, most of the studies with negative outcomes were not published, and some were written up to make the results appear more favourable; of the published trials 94% reported positive results.

One obvious reason for valuing the service user's expertise is that their lifestyle and goals will necessarily affect their choice of treatment. For example, a priority for a depressed mother of young children may be to avoid drowsiness in the morning so she can take her children to school.

The Evidence for SDM

A Cochrane review of SDM recognises that patients who are involved in the process of making decisions about their health have better outcomes (Légaré et al 2010)

Although there is not yet a vast range of evidence underpinning SDM in psychiatric medicines management, research done to date (mainly outside the UK) is supportive of SDM. Where mental health staff and service users have received training in SDM, they have reported a positive impact on the service users' quality of life and unmet needs plus increased satisfaction with healthcare. Service users have reported greater involvement in decision making, more agreement about treatment goals and a better ability to decide whether to stop medication through using decision aids. Practitioners have become more confident, developed a better understanding of service users' needs and been more concordant with treatment guidelines. Interestingly, consultation times remained the same; they did not take longer (Loh et al, 2007, Hamman et al 2006, Ludman et al 2003, Holmes 2006, Deegan etl al, 2008, Deegan 2010)

Common Ground

Much of the British research into SDM has been in primary care and has been aimed at developing staff competencies, with little service user involvement. Although there have been initiatives that look at helping service users to assert their views, such as the "Thinking about Medication" groups described in this journal by Allison et al (2012), to date, there have been no initiatives in this country directly aimed at changing what happens in mental health outpatient consultations.

The main established example of SDM in practice for psychiatric medication is Pat Deegan's "Common Ground" model in the USA (Deegan, 2010), where the service user has an 'enhanced medication visit' as described below.

1. Before the Consultation: The service user arrives 30 minutes prior to the consultation time. He/she uses the Common Ground software (with peer worker support if needed) to access information about medication, reflect on their own experience of medication and watch video vignettes of others describing their recovery. During this time the service user completes a questionnaire about their recovery, symptoms, medication concerns and goals for the consultation. This is summarised into a one page "Common Ground Report".
2. The Consultation: The service user and prescriber review the Common Ground Report together. Together they explore options and reach a shared decision about treatment. This is printed off for the service user to take home.
3. After the Consultation: Peer workers are available to support the service user before they leave the clinic with any follow up interventions (eg researching an aspect of self help on the computer).

There are indications that service users are more willing to disclose information via the computer than they would be face-to-face (eg admitting to not taking prescribed medication and embarrassing side effects, Deegan et al, 2008)

The SHIMME Project

Anecdotal evidence tells us that SDM is not yet routinely practised. The SHIMME project (Shared Involvement in Medication Management Education) was set up to investigate

whether routine practice and culture could be changed by training service users and professionals in the process of SDM in psychiatric medicines management. It is a partnership between service users, Anglia Ruskin University researchers and the local mental health trust (Cambridgeshire and Peterborough Foundation Trust, CPFT). There are 2 phases; a research and consultation phase followed by a training and follow up phase.

In the consultation phase, a literature scoping review was performed. 6 focus groups and 4 telephone interviews with were held with 53 staff and service users between July and September 2011. 27 service users, 18 care co-ordinators and 8 psychiatrists (4 via telephone) were consulted.

Each focus group was co-led by a service user trainer and a psychiatrist. The sessions were recorded and anonymised data were collected on the current state of practice regarding SDM, and ideas regarding the proposed format and content of the training programmes. From these focus groups, the consensus was that all parties were in favour of SDM, but felt that it is not currently implemented consistently

In the training phase, programmes were run for participants in the Rehabilitation and Recovery and Assertive Outreach pathways of the mental health trust across 3 localities (see Table 1).

Group sizes ranged from 2 to 11 participants. Although the benefits of training staff and service users together would have been considerable, it was decided that running separate training sessions would provide a safer environment for participants to explore openly some of their fears. For the most part, care coordinators and psychiatrists were trained separately; however one team was trained together in a one day whole team session. The core content of the training sessions was the same for all participants. Care coordinators were encouraged to adopt the role of a SDM coach, which involves coaching service users in the SDM process, ensuring service users have access to good quality information and developing systems to record, communicate and implement service users' preferences (Coulter and Collins 2011).

3 forms (which could be filled out electronically or on paper) were developed to promote SDM:

1. **Service User Preferences Form** This prompts the service user to identify the main symptoms they want help with, summarise the information they have gathered about treatment options and note their preferences about which medication to take and/or what alternatives to medication they would like to use.
2. **Service User Feedback Form** This is a tick box form with space for comments for the service user to complete and bring along to a consultation. The form looks at the service user's experience of their medication (eg adverse effects), alternatives to medication and has space for listing goals, concerns and questions for the consultation.
3. **Prescriber Feedback form** This is a one page form that the prescriber fills out towards the end of a consultation and give to the service user to take away with them. It summarises the main points discussed in the consultation and the decisions made.

A website was developed to support the training which gives information about SDM, research and policy documents as well as the templates for the 3 SDM forms. Most of this information is publicly accessible and can be found at www.shimme.arcusglobal.com/

	Service Users	Psychiatrists	Care coordinators*
Overall number of people trained	47	15	35
Trainers	Service User & Psychiatrist	Service User & Psychiatrist	Service User & Mental Health Nurse
Format of sessions	5 x 2 hours at fortnightly intervals	2 x 2 hours a month apart	3 x 1 ½ hours at monthly intervals
Follow up offered	2 sessions over 6 months	Whole team follow up sessions offered at 2-3 monthly intervals for up to 12 months	
Core Content of training sessions	The concept and process of SDM Facilitators and Barriers to SDM Accessing and evaluating information about medication		

	Alternatives to medication Issues around coming off medication The SHIMME website & 3 SDM forms		
Additional content for specific groups	Wellbeing & assertiveness. IT sessions (in computer suite). Session from Trust pharmacist.	Critical issues in managing psychiatric medicine in collaboration with service users.	Adopting the role of a SDM coach.
*The "Care Coordinators" group included nurses, social workers, occupational therapists, support workers, peer workers and students.			

Pre- and post-training questionnaires were completed by participants and these will be analysed in conjunction with the 12 month follow up questionnaires (which are yet to be completed). The main themes that emerged from the focus groups, training and follow up sessions reflect those found in the wider literature and are listed below.

Service Users should be provided with user friendly information and knowledge of all options, as opposed to leaving the service user to find information, or just relying on the Patient Information Leaflets that are supplied in medication boxes.

"They're given some information but not enough really to make an informed decision..."
 (Community Psychiatric Nurse, CPN)

"One of the things I think works less wellis when psychiatrists ... just sort of say 'Well you know, there's kind of good things and bad things about this.....at the end of the day it's up to you so come back in a month and have a think about it.'" (Care coordinator). In the training sessions emphasis was given to helping service users evaluate the information, eg by looking at comparison charts (available via the CPFT website or Rethink) which compare adverse effects for classes of medication.

Service Users need to feel listened to in an open, trusting and honest relationship.

Service users and care co-ordinators mentioned the importance of valuing the service user's own experience of medication. One service user highlighted the danger when the opposite happens: "[I] didn't get on with my doctor at all and he didn't listen to who I was.....he looked at me as a diagnosis and consequently the relationship went so bad that medication ended up being enforced and it was just awful". Psychiatrists also rated the importance of openness; "If the client feels that you're being open and honest with them then they are going to feel that they can be that way with you." (Psychiatrist)

Interestingly, several service users described themselves as "lucky" if they had a good relationship with professionals.

Processes that support SDM are needed such as time for a good discussion, having time to reflect, and involving carers where appropriate. There were some difficulties in embedding the use of the 3 SDM forms into practice. For example, care coordinators suggested that the vast majority of their service users did not have access to the internet at home and hence had difficulty accessing information. Some service users were apprehensive about attending the computer based training sessions, but those that did attend reported finding them particularly helpful.

The 3 SDM forms were made available in paper form (eg by posting the service user feedback form to service users with outpatient appointment letters). Care coordinators reported lack of time and a reluctance to impose a form-focussed structure on appointments. This was partly addressed by arranging for research assistants to assist service users to complete the forms in the first instance.

Readiness to take a positive risk needs to be shared by all. Some care coordinators feared that initiating an open discussion about medication might set up the expectation in some service users that they could manage without medication; this was a subset of service users who had a history of relapsing whenever they stopped medication (usually against medical advice). This was compounded by a fear that psychiatrists might not support the process. This was countered with the suggestion that by avoiding having these

conversations with service users, staff are perpetuating the status quo with its attendant power differentials and lack of communication. It was agreed that the whole team needed to be signed up to taking positive risks. This was harder to address in the sessions where psychiatrists and care coordinators were trained separately. Where psychiatrists and care coordinators were trained together, these issues were aired more productively. Trainers reiterated that SDM does not have an agenda of 'encouraging people to stop medication'; however, it does mean being willing to initiate a conversation which may lead to a service user choosing to stop medication. Hence, the availability of alternatives to medication (eg psychological approaches to coping with hearing voices) was discussed in the sessions. Some CPNs confidently described how they had supported service users in coming off medication. However, there was a recurring concern that services do not currently have the capacity to provide the social and psychological alternatives to medication.

"I think there is always a kind of worry that 'Well if we change anything, things might go wrong' so it's like if it's not broken then don't fix it. I kind of wish they would be a bit more like 'Well maybe this will make it better' "(Service User).

Power differentials can make it harder for service users to voice their preferences.

Some psychiatrists voiced discomfort that service users sometimes say "you're the doctor, you make the decisions". It was apparent that decisions are shared with some service users more readily than others; "When the prescriber perceives that the service user is intelligent then they are more likely to give more information and there's more likely to be a shared decision" (CPN)

Some psychiatrists felt that in the context of the move towards SDM and service user empowerment they were no longer in a position of relative power. However service users consistently described feeling this power imbalance.

Lack of insight, or capacity or "the illness itself" were identified as potential barriers to SDM. Psychiatrists and service users acknowledged that sometimes when people are acutely unwell, they may be limited to how much shared decision making can take place. It was agreed that crisis plans could be used more widely and effectively.

"I've noticed a big difference between how the SDM happens – whether you're on a section or not." (Service User). Staff were encouraged to apply as many of the principles of SDM as they could to a situation eg someone on a section can still be given information and their preferences should be sought, even if the final decision is made by the psychiatrist. One psychiatrist reported that although she may insist on a sectioned patient having an anti-psychotic, she would always attempt to discuss the range of anti-psychotics and their side effect profiles with the patient and involve them in the choice of which one to use.

Limited knowledge about medication made some staff reluctant to initiate discussions. Several care coordinators (especially the non-nurses) pointed out that they had never had training around medication and side effects and hence felt unprepared to have these discussions with service users. They were encouraged to familiarise themselves with the publicly available information as and when they gave it to their service users and to see themselves in the role of SDM coach rather than as a source of medication knowledge.

Conclusions

This article has highlighted the themes that arose during training and follow up sessions to promote SDM. These sessions have been an opportunity for staff and service users to reflect on their experiences and roles, and to challenge their pre-conceptions. Service users reported finding the training sessions supportive; trainers observed that the support service users gave each other in the sessions was highly valued and constructive. Staff have shown some openness to implementing SDM, albeit with reservations about the risks involved and concerns about the lack of non-pharmacological resources available, including time. Given that research has demonstrated that SDM does not necessarily take extra time, it remains to be seen whether these fears are justified.

Early feedback suggests that where participants have been able to implement a SDM process, consultations have been more satisfying for all parties. Next steps will involve analysing the 12 month follow up questionnaires, embedding the use of the SDM process in

practice and rolling it out to other areas of the Trust. Meanwhile, the principles of SDM are ones that any practitioner can reflect on and apply to their work with service users.

Implications for practice

- Give information about medication and alternatives from a variety of sources, both verbally and in writing
- Support service users to evaluate information and to communicate their preferences
- Be a shared decision making coach; promote SDM to service users and doctors.
- Remember the service user's expertise is as important as the prescriber's.
- Implement systems for recording shared decision making.
- When service users choose to come off medication, encourage them to be open about this, have discussions about responsibility and risks and be prepared to give them information and advice about how to do so safely

Disclaimer

The 'ShiMME' project (Shared Involvement in Psychiatric Medication Management and Education), is a 3 year independent research funded by the National Institute for Health Research, under its Research for Patient Benefit (RfPB) programme (grant reference PB-PG 0909-20054). The views expressed are those of the authors and do not necessarily represent those of the NHS, the NIHR or the Department of Health.

References

Allison R, Flowerdew K, Elsmie A (2012) Promoting a discussion about adherence to psychiatric medication. *Mental Health Practice* 16, 3 18-22

Charles C, Wheelan T, Gafni A (1999) What do we mean by partnership in making decisions about treatment? *British Medical Journal* 319, 7212, 780–782.

Coulter, A. & Collins, A. (2011) *Making shared decision-making a reality*
London: The King's Fund. http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html
(last accessed 08.05.2013)

Deegan P. (2010) A Web application to support recovery and shared decision making in psychiatric medication clinics. *Psychiatric Rehabilitation Journal* 34,1 23-28

Deegan P & Drake R (2006) Shared Decision Making and Medication Management in the Recovery Process *Psychiatric Services* 57, 11, 1636-9

Deegan P, Rapp C, Holter M & Riefer M (2008) Best Practices: A Program to Support Shared Decision Making in an Outpatient Psychiatric Medication Clinic" *Psychiatric Services* 59, 6, 603

Department of Health (2010) *Equity and Excellence: Liberating the NHS*
<http://tinyurl.com/EquityExcellenceliberatingnhs> (last accessed 08.05.2013)

Goldacre B (2012) *Bad Pharma* Harper Collins Publishers, London.

Hamman J, Langer B., Winkler V, et al (2006) Shared decision making for in-patients with schizophrenia *Acta Psychiatrica Scandinavica* 114, 4, 265–273

Hartling L, Abou-Setta A, Dursun S, et al (2012) Antipsychotics in adults with schizophrenia: comparative effectiveness of first-generation versus second-generation

medications. A systematic review and meta-analysis *Annals of Internal Medicine* 157 498-511

Holmes G 2006 Helping people to come off neuroleptics and other psychiatric drugs
Clinical Psychology Forum 163, 21-25

Légaré F, Ratté S, Stacey D, et al (2010) Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews*
<http://www.ncbi.nlm.nih.gov/pubmed/20464744> (last accessed 08.05.2013)

Loh A, Leonhart R, Wills C, et al (2007) The impact of patient participation on adherence and clinical outcome in primary care of depression. *Patient Education & Counseling* 65, 1, 69-78

Ludman E, Katon W, Bush T, et al (2003)
Behavioural factors associated with symptom outcomes in a primary care-based depression prevention intervention trial *Psychological Medicine* 33, 6, 1061-70.

Marshall M, & Bibby J.(2011) Supporting patients to make the best decisions *British Medical Journal* 342:d2117

National Institute for Health and Clinical Excellence (2009) *Medicines adherence. Involving patients in decisions about prescribed medicines and supporting adherence*
<http://guidance.nice.org.uk/CG76/Guidance/pdf/English> (last accessed 08.05.2013)

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