"Work with me": service users' perspectives on shared decision making in mental health

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Abstract:

Purpose

While shared decision making (SDM) in general health has proven effectiveness, it has received far less attention within mental health practice with a disconnection between policy and ideals. The purpose of this paper to review existing developments, contemporary challenges, and evidence regarding SDM in mental health with a particular focus on the perspectives of service users.

Design/methodology/approach

This is a review of international papers analysed using narrative synthesis of relevant data bases.

Findings

The review shows significant barriers to the utilisation of SDM including ethical and legal frameworks, accountability and risk. The medical model of psychiatry and diagnostic stigma also contributes to a lack of professional acknowledgement of service user expertise. Service users experience an imbalance of power and feel they lack choices, being "done to" rather than "worked with".

Practical implications

The paper also presents perspectives about how barriers can be overcome, and service users enabled to take back power and acknowledge their own expertise.

Originality/value

This review is the first with a particular focus on the perspectives of service users and SDM.

Keywords:

[Mental health](), [Shared decision making](), [Barriers to shared decision making](), [Narrative synthesis](), [Service users' perspectives]()

Copyright:

Article

Background

Shared decision making (SDM) aspires to be a collaborative process which allows patients and providers to make health care decisions together ([Charles *et al.*, 1997]()). It aims to take into account best scientific evidence together with service users' values and preferences, combining experiential and scientific expertise. SDM in general health is supported in government policies and guidance in the western world ([Department of Health, 2012](); [Froch *et al.*, 2011]()) and has generated substantial research confirming effectiveness in treatment adherence and patient satisfaction ([Durand *et al.*, 2014]()).

In the field of mental health SDM is a concept which has emerged as an alternative to medical paternalism. It has been hailed as an aspect of health care reform which builds on person-centred developments of previous decades and which enhances recovery-based practice ([Drake *et al.*, 2010](); [Duncan *et al.*, 2010]()). However, [Morant *et al.* (2015)]() suggest that SDM has received far less attention within mental health practice than it has in primary care, and highlight the coercive history of mental health services, which has led to disconnection between policy and ideals.

A key aspect of SDM concerns how it is conceptualised by service users and the degree to which this may be in accord with or differ from professionals' views. This and other challenges, barriers and facilitators to achieving fruitful partnerships may offer insights into best practice concerning SDM within the mental health field. This paper aims to review existing developments and evidence regarding SDM in mental health, with a particular focus on the perspectives of service users. It will also examine implications for others with lived experience of mental health difficulties such as carers and family members.

Method

A narrative synthesis has been employed in order to make sense of material gathered from different study designs and a wide range of approaches, drawing together common themes

about what works and why ([Ryan, 2013](#)). Two groups of materials will be included in the review, a collection of research papers about SDM from peer review journals and a group of additional papers which outline recent approaches to mental health in which service users' decisions are embedded without being focused upon. In addition to the first author, four service users* with long experience of mental health services have reviewed the summaries of the first group of papers and expressed their own views on SDM in mental health.

Search strategy

The electronic search strategy was aimed to identify papers in the English language, written at any time since 2000, focused on service users experience of SDM in any area of mental health. The authors selected eight data bases for the search, *PsychINFO*, *CINAHAL*, *Health Expectations*, *Journal of Psychiatric Rehabilitation*, *British Journal of Psychiatry*, *Advances in Psychiatric Treatment*, *Mind* and *Open Grey* using the words "Shared Decision Making, Mental Health, Service User Experience".

*In the UK and Italy, the term "service users" is applied to note people experiencing mental ill health. We do not use the terms consumers or clients, because most people in this category cannot afford to buy services for themselves, and we do not use the term "mentally ill people" as members of this group have also other, not less important, qualities than experiencing mental ill health.

Refining the search

Papers identified by title and abstract amounted to 1,262. A second groups of 14 papers were also selected for the narrative synthesis. Additional sources for the second group included the first author's clinical contacts and encompass not just SDM regarding psychiatric medication, but also aspirations to wider shared decisions regarding treatment and recovery plans concerning voice hearing, eating distress, personality disorder and suicide interventions. Screening therefore amounted to 1,276 texts. Exclusion criteria included duplicate papers, age group other than adult, and papers concerned with user involvement or recovery which did not encompass SDM in treatment. In all, 42 papers from ten countries remained. Selection was further refined to exclude systematic reviews, literature reviews, comments and guest editorials. In all, 17 papers involving ten countries remained, which clearly addressed issues of definition, application, feedback from people using the service, facilitation and barriers to SDM, which were read and analysed ([Figure 1](#)).

The first nine papers, group A, focus on explicit service users views on SDM.

They include studies encompassing Israel, Norway, UK, USA, Germany, Switzerland, Denmark, Italy and Hungary. The majority of these papers are qualitative in nature (*n*=7; see [Table I](#)), but two quantitative studies are included because they have been judged to be fruitful for the purposes of the review because of the similarity of the themes included (*n*=2; see [Table I](#)). In addition to the nine papers, eight additional documents have been included in group B, most of which are either not yet published in scientific journals or are not systematic research papers but are focused on innovations in mental health in which SDM is embedded, but not explicitly so, one from the USA, six from the UK and one from Australia (*n*=8; see [Table II](#)). All have been incorporated in the review because they are considered to be significant in terms of knowledge and lessons regarding SDM.

Content analysis

Group A

The first nine papers selected for this review are shown in Table I.

Qualitative studies

In the Israeli study by Roe *et al.* (2009), seven participants who had stopped taking medication for one year were interviewed to explore why and how people with serious mental illness (SMI) choose to stop taking prescribed medication. The findings demonstrate that decisions were thought through and were not taken on the spur of the moment. The authors mapped the decision process in all its stages, inclusive of the power of external influences, both lay and professional, and the eventual resolution of conflict in the decision-making process. Limitations were highlighted as not triangulating results with other sources, such as family members and professionals, and the smallness of the sample size. The authors conclude that the study might enrich understanding of clinical trial research. Rather than conceptualising non-adherence as a single, dichotomist phenomenon, this paper gives us an in-depth view of the service user process, showing it as a dynamic, interpersonal journey which occurs over time and changes in relation to circumstances.

In the Norwegian study, Rise *et al.* (2011), 20 service users, 13 public representatives and 44 providers and managers were interviewed to find a common definition for public and patient involvement leading to SDM. This study involved both somatic and mental health care. Core aspects for SDM were identified as respect and dialogue. However, service users and providers assigned different importance to these. Providers considered that respect was inherently implied, whereas service users did not feel it was self-evident. Service users and providers also had different views on dialogue. Service users emphasised respect as a precursor to dialogue which generated a sense of self-worth and equality, while providers saw dialogue as a way to gain better outcomes. SDM engendered concern about the other party wanting to make the sole decision; service users expressed concerns about being overruled; providers saw it as a denigration of provider responsibility for both treatment and management decisions. While useful, the authors do not differentiate between somatic and mental health service users and providers. Also, the public representatives involved in the study included some family members/carers, whose views are not specifically drawn out within the paper.

The UK study, conducted by Farrelly *et al.* (2015), trialled service user treatment, care and management preferences in advance of possible relapse, resulting in a joint crisis plan in order to understand how stakeholders viewed SDM. In all, 50 service users with psychotic disorder and 45 clinicians participated in focus groups and interviews. Mixed focus groups were also held to clarify emerging concepts. Marked similarities arose between points raised by care coordinators and psychiatrists. Clinicians identified four main barriers to engagement and subsequent implementation of the plan, including ambivalence about care planning, a perception that they were "already doing it", concerns about appropriateness of service user choices and limited availability of choices for service user. Service users identified mistrust of clinicians and themselves, and felt they were informed about choices rather than involved in their selection. They considered that the process was ultimately undermined by lack of true engagement.

In the UK study, Kaminskiy *et al.* (2013), two research projects involving 42 service users and 41 clinicians were conducted to ascertain how service users are involved in decisions about their psychiatric medication and their views about the possibility of introducing SDM. Both projects showed that service users considered involvement in decision making to vary according to how well they were at the time. Although the need for increased guidance during periods of mental health crisis was acknowledged by service users, they emphasised above all the importance of the therapeutic relationship with the clinician and building trust, being listened to and having autonomy returned to them over time. Fear of coercion and the power inherent in the mental health system was seen as a barrier to having an open dialogue and a meeting of experts, whereas clinicians considered lack of insight into illness as a major barrier to SDM, especially during periods of crisis. Service users spoke of feeling inferior and being patronised in the doctor-patient relationship. The authors concluded that a key challenge is lack of acknowledgement of the significance of experiential knowledge of service users by the clinicians and giving preference to the traditional psychiatric approach.

The following three studies were conducted in the USA. The Stanhope *et al.*'s (2013) study provides a secondary analysis of survey results from 396 service users with SMI, which explored choice, therapeutic alliance, recovery, quality of life and functioning. The secondary analysis examined whether choice affects outcome and if this is influenced by the therapeutic alliance. Analyses examined choice as a predictor of outcomes encompassing diagnosis and severity of illness. The connections between the therapeutic alliance and patient centeredness, choice and outcomes were explored. The study supported the opinion that more choice predicts better outcomes for SMI and that self-determination leads to motivation and the attainment of goals. The therapeutic alliance was found to play an important role, including in potential conflict situations concerning medication. The complexity of recovery dynamics was emphasised in that people with schizophrenia reported higher rates of recovery than major depression but rated lower on perceived outcomes. Therefore, it was concluded that perception of recovery is related to expectations which may differ according to the course of illness and life prior to diagnosis.

Eliacin *et al.* (2015), involved 54 war veterans, with schizophrenia or mood disorder, in mental health outpatient care. This study investigated service user preferences and appraisals of their involvement in treatment decisions. Some participants wished to be involved in SDM and saw this as an important component of recovery. Of these, some wished to involve friends and family in their decision making but others did not wish for such an involvement, and saw lay supporters as lacking skills. Other participants did not wish to be involved in SDM and preferred to leave decisions to the professionals. For some this was attributed to a trusting patient-provider relationship. For others, this passive role was related to fears about their own decision making abilities. For still others, this concerned the fear of being judged and violating the patient-physician role, resulting in repercussions from providers. Some participants also acknowledged that treatment decisions were fraught with disagreements and noted that poor communication was at the centre of the disagreement. Where disagreements were overcome, a strong patient-provider relationship existed. Conclusions emphasised the importance of a longitudinal patient-provider relationship.

Mahone *et al.* (2011) involved 24 service users, four family members, four psychiatrists and community psychiatric nurses, four other nurses, support staff and managers, and six rural staff. The study aimed to explore SDM between providers and consumers in mental health treatment. This qualitative study collected data in seven focus groups of both service users and clinicians. The barriers identified by providers included the traditional

doctor/diagnosis/medical/disease focused model, legal and other obligations for mental health professionals, the risk of harm to self or others, lack of system support in relation to recovery and the special challenges of crisis situations. Providers also agreed that advance directives could be used more effectively. Family members considered that physicians have legal obligations if they are to act responsibly, but that good dialogue is more likely to have success with service users. Service users considered that the traditional psychiatric approach means that the professionals make all the decisions. They spoke of serious side effects, not learning about alternatives, being condescended to and feeling they needed to keep the peace and please providers. Service users also experienced the system as rigid and spoke of being seen as having a biological illness and receiving a forever-prognosis once within it. They spoke of the challenges of retaining options when in crisis. Service users also expressed concern about their own competence, literacy levels, historical passivity, past trauma and fragile hope. Additionally, service users claimed that SDM was related to achieving basic human dignity and spoke of being considered incompetent when professionals, and indeed they themselves, needed to respect service user expertise.

Quantitative studies

The German study by Hamann *et al.* (2011), undertook a survey of 101 service users with schizophrenia and 102 with multiple sclerosis as a control group, to determine why some service users want to participate in decision making pertaining to medication management, and others do not. Participation preferences were identified using a structural equation model. Service users with Schizophrenia showed lower participation preferences than those with multiple sclerosis. Member of the first group with higher participation preferences were perceived as having more negative attitudes toward drug treatments compared to those with the same diagnosis who were uninterested in making decisions concerning their medication. Other reasons given for greater participation by this sub-group were higher education level, better perceived decision-making skills and poorer treatment satisfaction. The authors acknowledge that the study design limited ability to draw causal inferences, and hence there are no data regarding why patients might feel negatively towards drug treatments or be dissatisfied with treatment decisions made by their clinicians.

The multi-country CEDAR study (Puschner *et al.*, 2016) looked at the connections between preferences, style of decision making and satisfaction of use of style by both staff and service users with outcomes in six European sites. The study included 701 participants, of whom 588 were adults with mental illness and 213 were staff. Two questionnaires were completed, the Decision Making Style Scale and the Clinical Decision Making Satisfaction Scale one on style of clinical decision making, the other the Clinical Decision Making Involvement Satisfaction Style on involvement and satisfaction related to clinical decision making over one year of observation. The majority of service users preferred being active in decisions taken, and having a clinician who shared their preferred decision making style. The unmet needs of service users whose clinicians preferred active and/or shared decisions decreased, while the unmet needs of those whose clinicians did not favour a shared active perspective did not decrease. While this paper focuses on service users' perspectives, it is important to know and understand clinicians' perspectives. This study did not focus specifically on SDM.

Group B

The additional eight papers selected for this review, which focus on service users' active contribution to enabling SDM, are shown in Table II.

In the Common Ground approach (www.patdeegan.com/commonground) which focuses on well-being choices that include personal medicine and medication (Deegan, 2005), SDM has been introduced to service users diagnosed as having Schizophrenia. Personal medicine refers to the repertoire service users develop on the basis of their experiential knowledge. Electronic forms in which service users indicated their priorities and choices were sent to clinicians, to serve as a basis for SDM discussion, alongside a decision support toolkit (Stein et al., 2013) to help people become more knowledgeable about their choices, containing nine short videos, and an on-line library of recovery resources and access to public domain decision aids. Most of the work with the service users is carried out by peer support workers who are with the service user before and after their meetings with clinical staff. Spencer (2013) is a PSW (peer support worker) in one of the SDM centres established by Deegan, Rapp and Drake which follow the Common Ground approach. Writing about her personal experience as a peer support worker in the context of SDM, she highlights the importance of a non-medicalised approach to the issue of hearing voices in her work with a service user who is astonished and grateful when the PSW asked her if her voices give her positive, negative or neutral messages. By doing so the PSW demonstrated awareness and care beyond the clinical model. For Spencer, SDM is a direct outcome of the recovery approach. The move to rely on peer support workers as the main service provider of Common Ground SDM mirrors the innovative work in InnovationInc (now called recovery innovation (RI)), in Phoenix Arizona (Anthony and Ashcraft, 2005) where the invention of peer support workers was initiated and found to have a considerably more empowering effect on those hospitalised within a closed mental health unit than professionals had until then. We have only anecdotal evidence on the contribution of PSWs to Common Ground, but the examples below highlight more systematic evidence of the impact of the involvement of service users in leading training on SDM and other forms of collective and individual user-led interventions which have made a positive difference for service users.

The evaluation of the UK training initiative (Stead et al., 2017) is related to the group A paper above, by Kaminskiy et al. (2013), and was developed as part of the Shared Involvement in Medication Management Education project in an East Anglian mental health trust. The training was designed in multi-stakeholder groups and was always delivered by a service user trainer and a professional to demonstrate the shared aspect of the training. The intervention was evaluated by mixed methods at pre-, immediate post-programme, and follow-up 12 months later; follow-up interviews of service users were carried out by service user researchers. Training was delivered to parallel groups of 47 service users, 35 care-coordinators and 12 psychiatrists, in adult community psychiatric settings. The evaluation showed that the training programme was well received by service users and care coordinators but psychiatrists were less satisfied with certain aspects of it. At the end of 12-month follow-up service users described feeling empowered, able to communicate their preferences to the prescribers, experienced increased understanding of their perspectives by practitioners, and an improved sense of well-being.

The UK evaluation of the "Thinking About Medication Course" (Holmes and Hudson, 2010) involved eleven self-selected members of a walk and talk service user group led by a clinical psychologist and focused on psychiatric medication. Participating members had experienced an average of 7.3 types of psychiatric medication, of all kinds. The professional course facilitators were intentionally uninvolved in participants' care throughout the duration of the group, and group members were left to decide for themselves whether to take up medication and other care matters. Participants generated their own group aims, had open weekly discussions involving shared experiences and mutual support, access to expertise and

speakers, introduction to tools and decision aids, advice if withdrawing from medication, and space to think about alternatives. Evaluation results showed high levels of satisfaction with the support, education and empowerment the group provided. Seven members of the group decided to embark on medication withdrawal and the remainder decided they might wish to do so in the future. A three-year follow-up for four participants showed that one had stopped medication, one had changed anti-psychotics for low-dose minor tranquilisers and two had returned to higher medication doses at stressful times only.

The UK paper by Baker *et al.* (2013) concerns Devon mental health services, where one of the authors was a service user, and is based on a project focused on introducing SDM to service users and professional providers in an NHS trust. The authors note that psychiatrists are required to work within ethical and legal frameworks which contribute to a gap between values and practice. However, they suggest that recovery calls for a shift from medication as a sole focus and a change in the nature of the power relationship between practitioner and service user, with professionals assuming a role of coach rather than one of authority. They highlight ways in which best practice can be maintained during times of crisis when clinicians are required to adhere to their duty to society as well as to the patient and where choices might compromise safety. This paper advocates more time with clinicians and suggests information sources, decision aids, decision support centres, seeing crisis as a possible learning experience, and the use of Wellness Recovery Action Plan (WRAP, constructed by Mary Ellen Copeland, 2001, a service user and clinical psychologist), as an advance statement, followed by post-crisis planning to see how things could be handled differently.

The UK paper by Adlam (2015) highlights the changing nature of the eating disorder inpatient ward which, in a time of limited resources and service erosion, has become a high-dependency medical bay that helps people to survive life threatening conditions. Detention under the Mental Health Act and highly invasive neo-gastric feeding are features of such an environment. In the midst of these challenges, changes to the therapeutic milieu commenced with psychologists on the ward abandoning a hitherto strict boundary and beginning to eat with patients as a group experience. This began a movement along a trajectory from "doing unto" to "living with". Coercion and imbalances of power began to be addressed by the creation of a simple daily community meeting to reflect and negotiate about treatment and daily living on the ward. Although not claiming to have wrought a magical change, this power-based discourse was the beginning of an alliance which prompted ward psychologists to take a leading role, alongside the patient community, in multi-disciplinary team interventions to carry the new culture within the wider team, and enabled genuine SDM to take place.

The UK study by Castillo *et al.* (2013) involved 60 service users and six carers in research about recovery for personality disorder. Historically viewed as a very troublesome client group, including perceptions regarding difficult behaviours, untreatability and a fear of recovering, the study showed that service users could share decisions about the creation and operation of their service, and also demonstrated service user involvement in the methodology of the study at all stages. Here, service user expertise and ownership evidenced that it was possible to work effectively with a relatively large number of people with a personality disorder diagnosis, many of whom had not made progress in other service settings, well in excess of 100 at any one time, at different stages in their journey of recovery. This resulted in significant service and financial savings to health and social care and to the criminal justice system (Castillo, 2016).

Hibbins (2015) provides a first-person account of setting up a suicide prevention service by a person with the lived experience of mental health problems because she found that local services had not provided what she needed. There is little evidence in this narrative of SDM. Medication as an issue is not explicitly addressed other than to mention stockpiling as part of suicide plans, which suggests non-compliance. After more than two years of expressing a choice to have psychological therapy the author was referred for psychotherapy, colloquially known in some service user circles as "the silent treatment". She felt lost in an open space. The therapy was stopped. She asked for trauma therapy and was told by the psychiatrist that she was not ready for therapy. Issues of risk received a dichotomous response, from detention under the Mental Health Act and close observation, to being discharged and told that she had mental capacity and that therefore it was her decision to take her life or not. One psychiatrist proved the exception to the norm, treating her as a person rather than a diagnosis, not speaking to her from a position of power, pointing out her positive qualities and seeing her weekly. She began to engage and felt that someone was committed to doing what they could to help her to survive. She believes that local mental health services are highly sceptical of the creation of her suicide charity and that her expertise is not acknowledged by them, although the service has not yet lost a life. She became determined that she and her staff would create a service that would be the epitome of getting alongside people and that clients would show the way in which the service should be developed.

The Australian blog piece by Daya (2016) is a first-person account of an inpatient stay by a voice-hearer who had been detained under the Mental Health Act after extreme self-harm. During an interview, with what the service user perceived as a well-meaning psychiatrist, she was told which medication she would receive and advised to forget her past traumas. The psychiatrist telephoned her private therapist and explained that psychological therapy would now cease. This left the service user without hope and suicidal. Then a friend from the UK Hearing Voices Network called to say he was in the country and would like to visit. He met her in the same room in which the interview with the psychiatrist had taken place. The room felt different. It became an extraordinary space of compassion and creativity where they sat side by side and she read to him from her diary and showed him drawings of her voices. With his understanding and suggestions, she describes her realisations and plans with such charm and hope in the face of deep suffering. She did not tell those involved in her care about the visit, and placated the psychiatrist saying the treatment was working. Within a week she accepted a "fake" recovery plan and was discharged. Although she felt that the system had failed her utterly, her experience with a peer, who worked with her rather than on her, was to prove a turning point in her recovery. The way of working in the Hearing Voices Network is to leave decision making to the individual. However, the individual's decision is encouraged to be based not only on their experience, but also on verification of their view of voices given by other members in the group (Romme and Morris, 2013).

Results and discussion

Contribution to clarifying emerging themes during the analysis came from four service users, two diagnosed with bi-polar disorder and two with personality disorder, and one family member of someone diagnosed with schizophrenia. At two meetings, they discussed the papers concerned and the initial themes which had emerged, confirming agreement and offering additional perspectives. The involvement of service users and a carer in this study was consultative rather than fully participatory. Their feedback was, nonetheless, valuable and is noted further in this and the limitations section. The results of the analysis of

characteristics and themes for the nine studies, in group A, is shown as the prevalence of characteristics and themes in Table III.

In all, 100 per cent of the studies in group A encompass service users in some way. Two of the studies include family members or carers but in only one of these are their perspectives clearly drawn out (Table III). Whilst service users may hold mixed views regarding the efficacy of lay supporters being involved in decision making, family members and carers express clear anxiety about the process, and concern about whether professionals will carry out their legal duties. The latter point was also emphasised by the family member who commented on emerging themes for this paper.

Of the five papers in group A which include professionals, 60 per cent of them cite legal and professional responsibilities as barriers to SDM. Across all nine papers, 67 per cent highlight issues of perceived risk affecting SDM. This ranges from bias concerning particular diagnoses to SDM diminishing during periods of crisis. In 89 per cent of the primary papers, trust and the therapeutic relationship are explicitly accorded great importance, by both service users and professionals. However, while some practitioners make assumptions about the implicit nature of respect or feel they are "already doing it", in 67 per cent of group A studies service users identify mistrust of clinicians and poor engagement, coupled with a feeling that they are informed rather than involved. This is connected to high incidences of perceived power imbalances; the appropriateness of service user choices being questioned and medication non-compliance being interpreted as illness. Eliacin et al. (2015) stress that the patient-provider relationship should be longitudinal because it can fluctuate over time and may encompass periods of wellness as well as crisis. Therefore, an understanding of this within a longer-term relationship is likely to facilitate better implementation of SDM.

Within the group A papers, 78 per cent have highlighted the need for training in SDM. MacDonald-Wilson et al. (2016) suggest that the training of professionals only in SDM might prove inadequate in the long-term but describe the combination of professional training with the use of decision support aids and resources for service users contributing to improved outcomes. The UK training intervention by Stead et al. (2017) concerns an ongoing multi-stakeholder training initiative for SDM, in which service users, psychiatrists and care coordinators were trained in parallel on the process of SDM and how to use it in the context of psychiatric medication management. The results show that at the 12-month follow-up point, without additional training, service users already felt the benefits of the initiative, reporting a sense of well-being about ensuring they are listened to, and being empowered. The follow-up also highlights that practitioners too became engaged in a process which places them on a journey towards SDM, but less than the service users. Furthermore, the engagement was more noticeable among care coordinators than psychiatrists, an issue which deserves further consideration.

Similarly, the UK evaluation by Holmes and Hudson (2010) evidences clear improvements for service users engaged in a group about medication, even when they were asked to return alone to their service areas to negotiate treatment. The analysis of the group A papers shows 67 per cent of service users doubting their own perspective. However, the additional studies in group B show that changes can be effected by the support and education of service users who can take back power and gain in confidence about their own decision making.

The UK group B paper by Baker et al. (2013) clearly emphasises the reality that clinicians have professional and legal responsibilities to society as well as to their patients. Within this

context, the paper provides a range of solutions encompassing a shift in professional focus to power-sharing and coaching, information sources, decision aids, decision support centres, and ways in which best practice can be maintained at times of crisis with advance directives including an emphasis on the use of the WRAP programme (Copeland, 2001). Even with the most complex and risky of diagnoses, two of the UK group B papers offer pathways to "living with" rather than "doing to" in relation to eating disorders (Adlam, 2015), and involving service users with personality disorder in all stages of service planning, service operation and evaluation (Castillo *et al.*, 2013).

A further difficult challenge for practitioners is suicidality. Hibbins (2015) describes an ineffective response to risk in terms of SDM and the recovery process, ranging from detention under the Mental Health Act and close observation to discharge requiring no further action. This prompted the service user concerned to set up a suicide crisis service which remained unacknowledged by local practitioners in terms of experiential expertise. The Australian piece by Daya (2016) again outlines a service response which is the antithesis of SDM, resulting in a false relationship with clinicians in order to effect discharge and progress. Her description of the meeting with a peer, one which was very healing and prompted a change of direction, highlights the unacknowledged value of lived experience and the substantial untapped resource of service users themselves offering knowledge and support.

Limitations

The heterogeneous nature of the material included in this review may be viewed as a limitation; however, this has been addressed by the narrative nature of the analysis and synthesis. Some of the service users who helped to clarify emerging themes considered that the methodology of a number of studies in group A mitigated against some findings, for example, they considered that fear of coercion was likely to rate higher, dependent on the methodological approach and the way in which service users had been involved in a study. A further limitation is the very low inclusion of the perspectives of family members and carers within the material reviewed, meaning that these perspectives have not been representatively encompassed.

Methodologically most of the studies reviewed above tend to be qualitative, with small samples whose degree of representativeness is either limited or unclear. These features perhaps relate to the fact that researching service users' experiential perspectives on SDM is a relatively new development, one that is not perceived as good enough scientifically for the majority of mental health researchers. The latter tend to be professionals, trained in the traditional psychiatric approach and its perspective about what is good enough knowledge, which largely excludes experiential knowledge. The researchers who wish to include experiential knowledge tend to apply a qualitative approach because it enables people to express themselves in a narrative manner that is more attuned to everyday discursive style.

We have seen an increase in service user researchers, and co-researchers, during the last decade in particular in some English-speaking countries (e.g. Canada, UK, USA and New Zealand). They favour experiential knowledge, and often would like to be in control of researching other service users, without shared perspectives (Russo and Sweeny, 2016). Time will tell if this is merely fleeting, or a new trend here to stay.

Conceptual limitations of the studies

Most service users would prefer to apply SDM; perhaps consequently we know less about those who do not wish to take decisions and their reasons for this preference, though some of the studies reviewed in this paper provide clues to their reasoning (e.g. Hamann *et al.*, 2011; Puschner *et al.*, 2016). Furthermore, the studies do not investigate the wish of some service users to take decisions on their own, an option that raises a number of questions to be further investigated. Perhaps because SDM itself is a new development, service users taking decisions on their own is seen as either unrealistic or as undesirable. Thus, these conceptual and value preference issues need to be included in the conceptual framework of mental health SDM.

Conclusions

Given the centrality of service users to SDM in mental health, it is crucial that their perspectives, based on experiential knowledge, be at the forefront of the SDM process. These preferences include respect and therapeutic alliance as necessary pre-conditions to enable SDM. Professionals may assume that respect is inherent in their approach. However, many service users experience an imbalance of power and feel they are without choices, being "done to" rather than "worked with", sometimes leaving them doubting their own perspective. Training for service users, decision support groups, WRAP, and innovative service interventions and service configuration have all proved successful ways in which service users can gain in knowledge and confidence about their decisions, begin to take back power, and utilise their own expertise.

Professional and legal responsibilities can be a significant barrier to the implementation of SDM; however, situations of crisis and risk can be mitigated by the use of advance directives. The traditional psychiatric approach and stigma seem to have become a hindrance to clinicians' acknowledgement of service user expertise. Training for professionals to appreciate the contribution of experiential knowledge can perhaps begin to move them along a trajectory towards SDM and a change in the power base between clinician and service user.
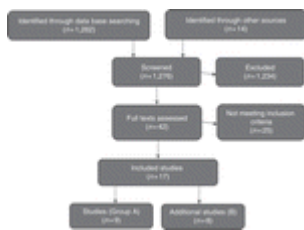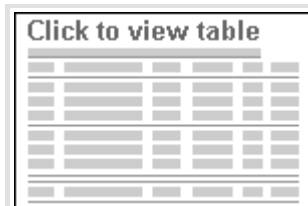

Figure 1 The search

Table I Group A – study characteristics

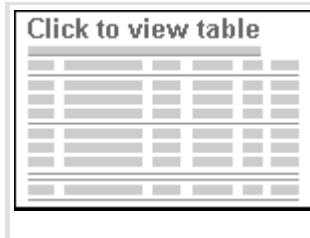| Study	Location/Setting	Method/Design	Population
Roe et al. (2009)	Israel: mental health outpatients in Haifa	Qualitative narrative, thematic analysis: semi-structured interviews about ceasing medication	7 service users with SMI free of medication for at least 1 year
Rise et al. (2011)	Norway: 4 centrally situated somatic and mental health hospital trusts	Qualitative grounded theory: semi-structured interviews to compare definitions of SDM	20 service users 13 public representatives 44 clinicians and managers
Farrelly et al. (2015)	UK: 4 mental health trusts in England	Qualitative grounded theory: 12 focus groups aimed to trial facilitated SDM for joint care plans	50 service users 45 clinicians
Kaminskiy et al. (2013)	UK: 2 studies in 2 areas of the same mental health trust in Cambridgeshire	Qualitative: focus groups and interviews about service user involvement in medication decisions	42 service users 41 clinicians
Stanhope et al. (2013)	USA: 4 community mental health clinics	Qualitative: secondary analysis of survey results to examine choice as a predictor of outcomes	396 service users
Eliacin et al. (2015)	USA: Veterans Mental Health Outpatient Centre, Indianapolis	Qualitative: interviews thematically analysed to understand service user perception of SDM and what affects participation	54 US veterans schizophrenia or mood disorder
Mahone et al. (2011)	USA: local mental health clinic central Virginia	Qualitative participatory action research: 7 focus groups to find SDM intervention for medication use in SMI	24 service users 10 clinical staff and managers 6 rural staff 4 family
Hamann et al. (2011)	Germany: 4 psychiatric and neurological hospitals	Quantitative: survey of two comparison groups to determine reasons for participation in SDM	101 service users schizophrenia 102 service users multiple sclerosis
Puschner et al. (2016)	CEDAR multi-country study: Switzerland, UK, Denmark, Hungary, Italy and Germany	Quantitative: two questionnaires on style and satisfaction regarding SDM	708 participants, 588 adults with mental illness 213 staff

Table I Group A – study characteristics

Table II Group B – study characteristics

Study	Location/Setting	Method/Approach	Population
Spencer (2013)	US: Shared Decision Making Centre, Kansas	An account of the personal experience of a peer support worker using the common ground approach	1st person account
Stead *et al.* (2017)	UK: NHS Mental Health Foundation Trust in East Anglia	Mixed methods evaluation of a UK SDM training programme	47 services users 47 clinicians
Holmes and Hudson (2010)	UK: outpatient psychiatric medication group, Shrewsbury	Evaluation of members of course group for thinking about medication	11 service users
Baker *et al.* (2013)	UK: Devon Partnership NHS Mental Health Trust	Examination of the recovery approach and making SDM a reality	Clinician perspectives in adult mental health
Adlam (2015)	UK: eating disorder inpatient ward, London	Co-production in treatment context arising out of diverse narratives	Inpatients and psychology staff on eating disorders ward
Castillo *et al.* (2013)	UK: personality disorder specialist service, Colchester	Qualitative: SDM in methodology, participatory action research about recovery in PD	60 service users 6 family/carers
Hibbins (2015)	UK: mental health inpatient and outpatient, Cheltenham	Narrative account of inpatient and outpatient experiences	1st person account
Daya (2016)	Australia: psychiatric inpatient ward	Narrative account of decisions during an inpatient admission	1st person account

Table II Group B – study characteristics

Table III Group A – prevalence of characteristics and themes identified

Theme	Roe	Rise	Farrelly	Kaminsky	Stanhope	Eliacin	Mahone	Hamann	Puschner
Service users included in study	*	*	*	*	*	*	*	*	*
Family/carers included in study		*					*		
Professionals included in study		*	*	*			*		*
Service user mistrust of clinicians/poor engagement	*	*	*	*		*	*		
Service user fear of coercion	*			*		*	*		
Service users informed rather than involved	*	*	*	*		*	*		*
Service users feeling patronised/power imbalance	*	*	*	*		*	*		
Medication non-compliance interpreted as illness	*			*			*	*	
Service users doubting their own perspective	*		*	*		*	*	*	
Service users not wanting to share in decisions						*	*	*	
Family/carer fear of risk in SDM	*						*		
Trust and therapeutic relationship highlighted	*	*	*	*	*	*	*		*
Appropriateness of service user choices questioned	*	*	*	*			*		

Theme	Roe	Rise	Farrelly	Kaminsky	Stanhope	Eliacin	Mahone	Hamann	Puschner
Professional and legal accountability barrier		*		*			*		
Diagnosis/wellness/perceived risk affects SDM	*	*		*	*		*	*	
Time or service constraints highlighted		*	*	*		*	*		
Advance directives suggested			*	*			*		
Decisions aids and peer supporters suggested				*			*		
Future training suggested	*	*	*		*	*	*	*	

- **Note:** *Denotes prevalence

Table III Group A – prevalence of characteristics and themes identified

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References

1.

Adlam, J. (2015), "Shared work and existential engagement in the therapeutic milieu: an emergent ethos?", available at: www.researchgate.net (accessed 29 March 2016). [Google Scholar]

2.

Anthony, W. and Ashcraft, L. (2005), "A story of transformation: an agency fully embraces recovery", Behavioural Healthcare Tomorrow, Vol. 14 No. 2, pp. 12, 13, 15-21. [Google Scholar] [Infotrieve]

3.

Baker, E., Fee, J., Bovingdon, L., Campbell, T., Hewis, E., Lewis, D., Mahoney, L. and Roberts, G. (2013), "From taking to using medication: recovery-focused prescribing and medicines management", Advances in Psychiatric Treatment, Vol. 19 No. 1, pp. 2-10. [Google Scholar] [Crossref] [Infotrieve]

4.

Castillo, H. (2016), The Reality of Recovery in Personality Disorder, Jessica Kingsley Publishers, London. [Google Scholar]

5.

Castillo, H., Ramon, S. and Morant, N. (2013), "A recovery journey for people with personality disorder", International Journal of Social Psychiatry, Vol. 59 No. 3, pp. 264-73. [Google Scholar] [Crossref] [Infotrieve]

6.

Charles, C., Gafni, A. and Whelan, T. (1997), "Shared decision-making in the medical encounter: what does it mean? (Or it takes at least two to tango)", Social Science Medicine, Vol. 44 No. 5, pp. 681-92. [Google Scholar] [Crossref] [Infotrieve]

7.

Copeland, M.E. (2001), The Depression Workbook, Barnes and Noble, New York, NY. [Google Scholar]

8.

Daya, I. (2016), "Creating a new voice", The Blog that Shouldn't Be Written, available at: www.indigodaya.com/author/angusmc/ (accessed 13 March 2016). [Google Scholar]

9.

Deegan, P.E. (2005), "The implications of personal medicine: a qualitative study of resilience in people with psychiatric disabilities", Scandinavian Journal of Public Health, Supplement, Vol. 66 No. 33, pp. 29-35. [Google Scholar] [Crossref] [Infotrieve]

10.

Department of Health (2012), "Liberating the NHS: no decision about me without me – further consultation on proposals to secure shared decision-making", Department of Health, London. [Google Scholar]

11.

Drake, R.E., Deegan, P.E. and Rapp, C. (2010), "The promise of shared decision making in mental health", Psychiatric Rehabilitation Journal, Vol. 34 No. 1, pp. 7-13. [Google Scholar] [Crossref] [Infotrieve]

12.

Duncan, E., Best, C. and Hagen, S. (2010), "Shared decision making interventions for people with mental health conditions", Cochrane Consumers and Communication Group, No. 1, p. CD007297, Cochrane Library, 20 January, doi: 10.1002/14651858.CD007297.pub2. [Google Scholar]

13.

Durand, M.A., Carpenter, L., Dolan, H., Bravo, P., Mann, M., Bunn, F. and Elwyn, G. (2014), "Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis", PLoS One, Vol. 9 No. 4, p. e94670, doi: 10.1371/journal.pone.0094670. [Google Scholar] [Crossref] [Infotrieve]

14.

Eliacin, J., Salyers, M.P., Kukla, M. and Matthias, M.S. (2015), "Factors influencing patients' preferences and perceived involvement in shared decision-making in mental health care", Journal of Mental Health, Vol. 24 No. 1, pp. 24-8. [Google Scholar] [Crossref] [Infotrieve]

15.

Farrelly, S., Lester, H., Rose, D., Birchwood, M., Marshall, M., Waheed, W., Henderson, R.C., Szmukler, G. and Thornicroft, G. (2015), "Barriers to shared decision making in mental health care: qualitative study of the joint crisis plan for psychosis", Health Expectations, Vol. 19 No. 2, pp. 448-58, doi: 10.1111/hex.12368. [Google Scholar] [Crossref] [Infotrieve]

16.

Froch, D.L., Moulton, B.W., Wexler, R.M., Holmes-Rovner, M., Volk, R.J. and Levin, C.A. (2011), "Shared decision making in the United States: policy and implementation activity on multiple fronts", US National Library of Medicine, Vol. 105 No. 4, pp. 305-12. [Google Scholar] [Infotrieve]

17.

Hamann, J., Mendel, R., Reiter, S., Cohen, R., Bühner, M., Schebitz, M., Diplich, S., Kissling, W. and Berthele, A. (2011), "Why do some patients with schizophrenia want to be engaged in medical decision making and others do not?", Journal of Clinical Psychiatry, Vol. 72, pp. 1-8. [Google Scholar]

18.

Hibbins, J. (2015), Suicide Crisis: The Story, Suicide Crisis, Cheltenham. [Google Scholar]

19.

Holmes, G. and Hudson, M. (2010), "The 2006 thinking about medication course", in Holmes, M. (Ed.), Psychology in the Real World, PCC Books, Ross-on-Wye, pp. 165-74. [Google Scholar]

20.

Kaminskiy, E., Ramon, S. and Morant, N. (2013), "Exploring shared decision making for psychiatric medication management", in Walker, S. (Ed.), Modern Mental Health: Critical Perspectives on Psychiatric Practice, Critical Publishing, St Albans, pp. 33-48. [Google Scholar]

21.

MacDonald-Wilson, K.L., Hutchinson, S.L., Karpov, I., Wittman, P. and Deegan, P.E. (2016), "A successful implementation strategy to support adoption of decision making in mental health services", Community Mental Health Journal, pp. 1-6, doi: 10.1007/s10597-016-0027-1. [Google Scholar] [Crossref]

22.

Mahone, I.H., Farrell, S., Hinton, I., Johnson, R., Moody, D., Rifkin, K., Moore, K., Becker, M. and Barker, M.R. (2011), "Shared decision making in mental health treatment: qualitative findings from stakeholder focus groups", Archives of Psychiatric Nursing, Vol. 25 No. 6, pp. 27-36. [Google Scholar] [Crossref] [Infotrieve]

23.

Morant, N., Kaminskiy, E. and Ramon, S. (2015), "Shared decision making for psychiatric medication management: beyond the micro-social", Health Expectations, Vol. 19 No. 5, pp. 1002-14, doi: 10.1111/hex.12392. [Google Scholar] [Crossref] [Infotrieve]

24.

Puschner, B., Becker, T., Mayer, B., Jordan, H., Maj, M., Fiorillo, A., Eqerjazi, A., Ivanka, T., Munk-Jorgenson, P. and Slade, M. (2016), "Clinical decision making and outcome in the routine care of people across Europe (CEDAR)", Epidemiological Psychiatric Science, Vol. 25 No. 1, pp. 69-79. [Google Scholar] [Crossref] [Infotrieve]

25.

Rise, M., Solbjør, M., Lara, M.C., Westerlund, H., Grimstad, H. and Steinsbekk, A. (2011), "Same description, different values. How service users and providers define patient and public involvement in health care", Health Expectations, Vol. 16 No. 3, pp. 266-76. [Google Scholar] [Crossref] [Infotrieve]

26.

Roe, D., Goldblatt, H., Baloush-Klienman, V., Swarbrick, M. and Davidson, L. (2009), "Why and how people decide to stop taking prescribed psychiatric medication: exploring the subjective process of choice", Psychiatric Rehabilitation Journal, Vol. 33 No. 1, pp. 38-46. [Google Scholar] [Crossref] [Infotrieve]

27.

Romme, M. and Morris, M. (2013), "The recovery process with hearing voices: accepting as well as exploring their emotional background through a supported process", Psychosis, Vol. 5 No. 3, pp. 259-69. [Google Scholar] [Crossref] [Infotrieve]

28.

Russo, J. and Sweeny, A. (2016), Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies, PCCP Books, Nottingham. [Google Scholar]

29.

Ryan, R. (2013), "Cochrane Consumers and Communication Review Group: data synthesis and analysis", Cochrane Consumers and Communication Review Group, available at: http://cccrg.cochrane.org (accessed 8 March 2016). [Google Scholar]

30.

Spencer, K. (2013), "A look at peer support with common ground sites: a personal perspective", EBP Times Office of Mental Health Research, University of Kansas School of Social Welfare, KS. [Google Scholar]

31.

Stanhope, V., Barrenger, S.L., Salzer, M. and Marcus, S.C. (2013), "Examining the relationship between choice, therapeutic alliance, and outcomes in mental health services", Journal of Personalized Medicine, Vol. 3 No. 3, pp. 191-202, available at:

http://dx.doi.org/10.3390%2Fjpm3030191 (accessed 22 February 2016). [Google Scholar] [Crossref] [Infotrieve]

32.

Stead, U., Morant, N. and Ramon, S. (2017), "Shared decision making in medication management: development of a training intervention", BJPsych Bulletin, 22 January, pp. 1-7, doi: 10.1192/pb.bp.116.053819. [Google Scholar] [Crossref]

33.

Stein, B.D., Kogan, J.N., Nihalyo, M.J., Schster, J., Deegan, P.E., Sorbero, M.J. and Drake, R.E. (2013), "Use of computerised medication shared decision making tool in community mental health settings: impact on psychotropic medication adherence", Community Mental Health Journal, Vol. 49 No. 2, pp. 185-92, doi: 10.1007/s10597-012-9528-8. [Google Scholar] [Crossref] [Infotrieve]

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