The Place of Shared Decision Making in Mental Health Recovery

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The connection of mental health recovery to shared decision making (SDM)

The concept of recovery in mental health has become a policy direction in many countries. For me, the best definition of recovery is "leading a meaningful life with the mental health issue the person has, and beyond it" , coined by Davidson (2003). Recovery is a journey, in which it is assumed that going back to where the person was prior to their mental health crisis is not the solution. Instead, the focus on a meaningful life allows a high degree of flexibility and choice.

The types of knowledge which contribute to shared decision making (SDM)

Most people wish to be in control of their lives as much as possible, regardless of the fact that we are interdependent on others in most aspects of our lives. Hence making decisions about one's life is an integral part of being in control, even if such decisions are impacted by others, as long as we retain a measure of choice. Most of us accept that at times we need experts' knowledge to be added to our own knowledge, in order to make the right decision. Usually professionals specialising in a particular field or issue are considered to have experts' knowledge. However, their expertise does not come instead of self-knowledge, but needs to be placed alongside such knowledge.

Yet we do recognise that professionals – including in mental health – are trained to believe that they know best, because their knowledge is based on scientific principles. In turn, scientific knowledge is assumed to be the best type of knowledge because it follows proven knowledge that has been accumulated according to an agreed systematic framework. Concerning mental health, more than one scientific discipline is contributing to the knowledge base we have, each coming with its own logic and not necessarily with the same system of evidence accumulation and validation as another discipline. Furthermore, while most of us accept that we are bio-psycho-social beings, these three areas of knowledge do not cohere sufficiently at present in understanding their connections to existing knowledge about mental health and ill health. In addition, all too often self-knowledge is treated as an inferior type of knowledge because it is not based on the same principles as those underlying scientific knowledge. This statement applies particularly to the notion that self-knowledge is subjective, hence biased, and hence invalid. Indeed, such knowledge is biased, but scientific knowledge too is biased, albeit in different directions. Furthermore, subjective knowledge has been impacted by inter-subjective knowledge, namely the affirmation of what we know about ourselves by others who contribute regularly to our self-validation. These others include our family, close friends, teachers and colleagues we respect. Given that the efficacy of different interventions in the field of mental health depends on the readiness of the person to apply them on a regular basis, lack of readiness to do so cannot be overcome either by ignoring it, or by imposing the intervention on the person. People need to be actively motivated to move out of being in a mental ill health state, and no degree of coercion can come instead of such motivation. Coercion and imposition lead to lack of trust and respect, and at times to lying to clinicians, in order to avoid coercion.

Hence the urgent need to enable SDM as a key process of communication, in which both types of knowledge are taken into account rather than ignoring, or rejecting, the existence of one of them. SDM is a form of communication between two experts, or more, in which one is an expert in self-knowledge, the other in scientific knowledge – who have to respect and trust each other in the process of reaching a shared decision (Charles et al, 1999).

The two experts come usually with different social power levels, as the professional is given the social mandate to propose a specific intervention, and at times even to impose it. Alongside infectious diseases, mental ill health is the only other condition where compulsion is legally allowed. SDM is thus about sharing key decisions concerning mental health interventions, based on the assumption that the person with lived experience of mental ill health and the clinician have each a unique contribution to make to the decision. Hence, they can learn from each other and reach better decisions than decisions reached by unshared knowledge. SDM supports the journey of recovery by:

-Enhancing the ability of people with lived experience of mental health difficulties to share their experiential knowledge, thus contributing to providers' knowledge
-Increasing motivation to recover and to being active in doing so
-Increasing collaboration
-Risk sharing
-Saving time by being honest with each other
-Enhancing mutual understanding, trust and respect
-Opting for interventions acceptable to both service users and clinicians.

Implementing SDM in everyday mental health care

However, we are aware that all too often SDM is left unimplemented, a fact we need to understand and to consider how to overcome. Kaminskiy et al (2021) highlight the barriers and enabling factors of implementing SDM in psychiatric medication management as perceived by service users, nurses and psychiatrists in semi-structured individual interview with each group in a UK community mental health service. The findings indicate that the barriers include being too ill at times, the dilemmas of providing information on adverse effects of medication, fears of coercion, stigma, lack of trust, honesty and respect. The facilitators include having a therapeutic alliance of trust and mutual respect, providing clear information, continuity of care, and psychiatrists who act in expert advisory capacity. Schon et al (2018), reporting from a Swedish study on implementing SDM, indicate that professionals do not implement because they see SDM as less important than responses to crisis and emergency situation. Ramon et al (2017) focus on the difficulty of changing professional practice patterns and of accepting the need to change routines as negative critique of a previously not good enough practice, while Zisman-Ilani et al (2021) outline the types of risk professionals come across in attempting to change their role within a highly legalistic system. They suggest a move towards shared risk of professionals and service users as a solution, while Ramon et al propose the application of the Normalisation Process Theory (NPT), which provides a staged format of changing routine practice. MacDonald-Wilson et al (2016), following the CommonGround approach to SDM (Deegan et al, 2010), added the involvement of community teams champions of SDM to that of peer support workers as a crucial element. The structured and focused involvement of family members in a variety of ways has been also found to be helpful in achieving SDM (Weiss et al, 2021, Ramon, 2021, Putnam et al, 2022). Too few studies look at the ease or otherwise of service users' involvement in SDM, perhaps due to its clear endorsement by most service users, unlike the less clear commitment to it by professionals. Grim et al (2016) led three focus groups of experienced mental health service users on the application of Elwyn's scheme (Elwyn et al 2017) concerning SDM in the context of physical ill health to mental health. This scheme includes three phases as the key to the process of SDM: choice talk, options talk and decision talk options (ibid, 2017). The service users interviewed by Grim (herself an EbE (Expert by Experience)) indicated the need to pay attention to issues of trust, genuine interest, respect and equality vs. experiences of being exposed, feeling inferior, being dependent on others, wishing others to be part of the process (e.g. family members, partners, friends).

They also pointed out to the need to have information from providers prior to meetings and after meetings, use of clear language, readiness by providers to be questioned, need to avoid overloading of service users by professionals and discussion of the impact of interventions to personal needs, values, fears, preferences and actions. Strengths of service users – such as self- knowledge and coping competence – were indicated as additional areas requiring inclusion in the process of SDM. Hamman et al (2019) highlighted in a recent study the positive value of SDM plus motivational interviewing in an experimental design for inpatients diagnosed as having Schizophrenia in several dimensions, though not in reducing re-hospitalisation episodes.

Interestingly, the assumed lack of insight by service users which often is cited by professionals as a key obstacle to SDM in mental health, was not raised in the study by Grim et al. Lysaker (2018) has looked at the issue of insight and suggested that this assumed lack is highlighted by professionals when service users have a different interpretation as to what is happening to them from the interpretation proposed by the providers. The underlying assumption is that having another interpretation than the one provided by the professionals indicates denial of having difficulties or of being given a psychiatric diagnosis. Lysaker suggests that providers are too sure of their own interpretation and find it difficult to impossible to question its validity. Refusal to take medication is usually interpreted as having lack of insight, rather than as the outcome of a process of considering the suitability of the medication to the person, especially of its adverse effects on key areas of people's lives. The evidence concerning the outcomes of conscious decision not to take prescribed medication indicates that for a number of people this was the right decision (Katz, 2018). Hamman et al's studies (2006, 2019) of the application of SDM to inpatients in the acute phase of mental illness demonstrated that this phase is often short, and that many inpatients are able to participate in the SDM process.

Alternative SDM models

Several models of the SDM process are practised in addition to Elwyn's 3 questions approach. These include the Open Dialogue, the Family Group Conferences, the Springbank approach, engaging young people as peer supporters and co-researchers in the Oregyn project. The Open Dialogue focuses on family system intervention, in which a network of the person and significant others is created, led by two therapists, aimed at having a dialogue leading to shared decisions. The approach, developed in Lapland initially, is now practised in a large number of countries, following good outcomes evidence concerning improvement of mental state, early resumption of education, employment, and social relationships options, with minimal use of medication (Seikkula, J. et al, 2006). These good results have been questioned more recently by Freeman et al (2019), and a randomised controlled trial is currently being conducted in six UK sites as to the long- term outcomes of applying this project.

The Family Group Conferences (FGC) with adults experiencing mental health issues comes from social work, where it has been applied to child protection cases with mixed outcomes. It focuses on having a family network meeting with the index client aimed at agreeing a specific scenario out of three options proposed by the person's key worker which meet the legal obligations required of a specific case. The initial pre-family meeting is led by an independent co-ordinator who meets individually each invitee to the meeting, followed by the family meeting without the co-ordinator or the key social worker, but which may include the presence of an advocate. The family is asked to agree one of the scenarios, as well as to propose an action plan concerning its implementation. Follow up evaluation research highlights a high level of satisfaction by the participants of the family meeting, with mixed positive and negative results concerning the fulfilment of the expected outcomes. This approach is practised in ten English local authorities, as well as in Australia, Canada, the Netherlands and Norway (De Jong et al, 2018, Malmberg and Johanson, 2014, Manthorpe and Rapaport, 2020, Ramon, 2021).

A third form of SDM is practised in the Springbank ward of Fulbourn hospital in Cambridge, UK, with women diagnosed as having Borderline Personality Disorder since 2016 (Burrin, 2021, Crawford, 2021, and BBC Look East Video). This closed ward admits women ready to follow an agreed shared plan between the person and the staff group for one year, supported by individual and group DBT (Dialectical Behaviour Therapy; see May et al, 2016), regular community ward meetings, medication and an informal welcoming ward atmosphere. Outcomes are very positive in reducing suicide and self- cutting attempts, ability to leave the ward with permission and to come back as agreed, as well as following shared plans for leaving the ward. The emphasis is on accepting responsibility for oneself, which includes key decisions, unlike the regime in most closed wards which denies such responsibility and focuses almost exclusively on medication instead.

Enabling young adults (age 18-25) who experience mental ill health to engage in SDM as clients, but also as co-supporters and co-researchers is practised largely successfully in Orygen, a mental health research setting in Melbourne, Australia, led by Dr. Magenta Simmons (Simmons, et al., 2021).
It focuses on working with the young adults, rather than on working with their parents. The unit has also led to the creation of an international network (Head Start) which follows similar patterns.

Decision Making Aids

Decision making aids can be part of a useful strategy to facilitate the application of SDM (see Garvelink et al (2019), Deegan (2010), Simmons (2017), Thomas (2021). By now more of the aids tend to be digital (Vitger et al, 2021). Auto-ethnography is a recently developed useful method of making sense of one's experience of using mental health services and interventions and for connecting the personal and the political (Fox, 2021). Duo-ethnography enables more than one person to do so jointly, while retaining the value of subjective and inter-subjective perspectives (Fox and Gasper, 2020). In summary, existing evidence demonstrates the usefulness of SDM in the context of mental health recovery. Implementing it in everyday mental health practice is called for if we wish to have a practice in which the knowledge of its key participants is shared and acted upon in intervention decisions. The key barrier to implementation is the need for attitudinal change, especially by professionals and their managers.

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