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National Youth Mental Health Foundation

Evidence Summary: Shared decision making (SDM) for mental health – what is the evidence?

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Introduction

Health professionals are increasingly being encouraged to adopt a collaborative approach to making health care decisions. Clinical practice guidelines advocate for clinicians to involve clients in decision-making processes and allow for client preferences (along with evidence) to guide decisions where possible. Shared decision making (SDM) is the most prominent example of this. While this approach has strong face validity, it is a relatively new approach in the area of mental health, and evidence for the effectiveness of collaborative approaches is only just emerging. Decision-making processes for clients diagnosed with mental disorders might also be different to those in general or non-psychiatric health areas. This evidence summary will review available evidence for the effectiveness of SDM for mental disorders and related research about the effectiveness of components of SDM such as allowing clients to choose treatment options.

What is shared decision making?

SDM is an approach to treatment decision making that involves collaboration between a clinician and a client. Multiple health professionals and/or caregivers may also be involved. SDM promotes the selection of a treatment choice that is based on both evidence and client preferences. The stages of SDM include:

1) two-way exchange of information between clinician and client (the clinician communicates information about the suitable treatment options and the potential risks and benefits of these options, while the client communicates information about their values and preferences about these treatment options);

2) deliberation on this information (the clinician and client discuss these possible outcomes and values and preferences); and

3) selection of an option that is consistent with the values and preferences of the client (1, 2).
It is also important to make a time to review this decision (see **Suggested Steps**).

Decision aids

Decision aids are paper based or online tools that facilitate SDM. Decision aids clarify the decision to be made, explain appropriate treatment options, present evidence about the potential risks and benefits of each option, and encourage the client to explore their values and preferences about these possible risks and benefits. The International Patient Decision Aid Standards ***(http://ipdas.ohri.ca/)*** provide guidance about what constitutes a good quality decision aid. A systematic review of decision aids across all health areas found that decision aids increase clients' knowledge of treatment options; give clients more realistic expectations about the potential risks and benefits of these treatment options; help clients to make a decision that is more in line with their personal values; and be more involved in the decision making process (3).

Aren't we already doing this in mental health?

Although clients may receive aspects of SDM (e.g. being involved in making decisions in some way) it is unlikely that a comprehensive SDM approach is used. For example, three studies that have used a standardized measure of SDM found on average clinicians performed poorly on most SDM behaviours (4-6). No studies have measured systematically the extent to which young people diagnosed with mental disorders receive a SDM approach to treatment decision making.

Do clients want to be involved?

Overall, preference for involvement in healthcare decisions appears to have increased in recent years. A recent review (7) of patient preference for involvement in treatment decision making for both mental disorders and non-mental disorders showed that rates of desire for this type of involvement were 50% in studies published before 2000 and 71% in those published between 2000-2007. Although some of this increase may be a result of measurement differences over time, it may also reflect the growing shift towards more client centred care. Generally studies show that individuals who are female, young and more educated are more likely to prefer involvement (7-10).

Looking at mental disorders specifically, there is evidence to suggest that adults diagnosed with mental disorders will want at least some involvement in treatment decision making (8, 11-13), and some studies have shown that in fact those with mental health disorders may be more likely to want involvement than those with general medical conditions (14-16).

Involving young people in their own mental health care

Far less research has been done investigating young peoples' preference for involvement in treatment decision making. However, it is clear that young people have opinions about what sort of interventions they prefer. For example, in a study of 444 depressed young people aged between 13 and 21 years being seen in primary care, counselling was the most preferred option (17). A small, qualitative study explored the experiences and beliefs of young people diagnosed with depressive disorders and found that although most clients wanted some involvement, the desire for involvement varied across participants and also over time for each participant (18). SDM allows for flexibility in the level of involvement, and discussing preferred level of involvement is a step in the SDM process.

Can young people with mental disorders be involved?

It is important to consider the capacity of young people diagnosed with a mental disorder to be involved in treatment decision making given both their age and clinical condition. Laws and policy regarding age of consent will vary according to geographical location.

There is little research investigating the decisional capacity of young people diagnosed with mental disorders specifically, however there have been recent calls for adolescents (particularly those aged 14 years and older) to be deemed competent to provide informed consent for participation in research studies (e.g. (19-22)). Decision making for young people diagnosed with mental disorders is likely to be complex, and the point at which adult input is required needs to be assessed on an individual basis (23-25).

Shared decision making for mental health

Reviews of SDM in mental health describe the small body of work emerging in the area (26, 27). Two additional high quality studies have been conducted since these reviews (28, 29) and, together with the earlier studies (e.g. (30-32)), SDM interventions for depression, schizophrenia, substance use and other serious mental disorders appear to improve client involvement, satisfaction, and in one study, mental health outcomes. All of these studies have been conducted with adult participants.

In addition to these intervention studies, a large study in the United States focused on outcomes for adults diagnosed with depressive disorders (the ***Quality Improvement for Depression study***) showed that higher involvement in depression care resulted in higher participant satisfaction and lower depression scores (33, 34).

Further SDM interventions have also been evaluated and demonstrate the variability in characteristics of SDM interventions in terms of design and delivery. These include an online computer-based program (that clients work through with a peer support worker to generate a report and take into their medical consultation) (35-37); an online hub of tools dedicated to supporting a variety of decisions faced by adults diagnosed with mental disorders (38); an intervention designed to activate and empower clients from ethnic minorities to ask their treating clinician questions that result in a more inclusive decision-making process (39, 40); and decision aid libraries (41, 42).

Shared decision making for youth mental health

While there are no specific studies investigating SDM or decision aids for young people, collaborative care models (CCM) that incorporate patient-centred care, have been tested in young people (45-47).

A small pilot study of a 6-month intervention that included client choice of treatment with input from caregivers was found to be acceptable to young people, their caregivers and physicians, and depression scores improved for the majority of participants (43).

The Youth Partners in Care (YPIC) study (44, 45) tested a 6-month CCM intervention for young people aged 13-21 diagnosed with either a major depressive disorder or sub threshold depression. The intervention involved expert leader teams, case managers who supported primary care clinicians, cognitive behavioural therapy training, and professional development around depression evaluation and management. Additionally, as part of the CCM intervention, participants were informed about, and involved in, making decisions about treatment options. The intervention significantly improved depression severity, quality of life and client satisfaction. The results from these studies offer insight into the effects of CCMs, although it is difficult to tease apart the contribution of the patient-centred elements.

Although the current review highlights a lack of intervention studies in the area of youth mental health, several developing studies have been located (46-50). Results from these studies will help to inform a model of SDM for young people diagnosed with mental disorders.

Conclusion

SDM is an evidence-based approach to treatment decision-making that also allows for client preferences to be accounted for. There is evidence to support the use of SDM and decision aids in adult general medicine and some emerging evidence in adult mental health. SDM offers a framework to promote client involvement and satisfaction. The results of studies currently underway will provide an initial understanding of the effectiveness of SDM for youth mental health. In the mean time, the increasing use of technology within clinical settings offers the possibility for a variety of ways to engage young people in the use of decision aids and other SDM interventions.

Suggested steps for using SDM with young people

1. **Set the scene** Discuss the collaborative approach being taken, for example:
   - 'How do you feel about working together to make a decision?'
   - 'You're the expert on your own experiences'
2. **Define and tailor involvement** Talk about what involvement in treatment decisions means to the client and how they might want to be involved. Ask them about their preferred level of involvement and desire for carer involvement.
3. **Psychoeducation** Initiate discussion about symptoms, aetiology and likely treatment course.
4. **Treatment options** State that there is more than one suitable treatment option, including doing nothing (the potential risks and benefits of this option are discussed in step 6). Describe and briefly explain the rationale for each treatment option.
5. **Information** Discuss how they like to receive additional information (e.g. written, oral, websites etc.).
6. **Treatment outcomes** Discuss the potential risks and benefits of each treatment option, including doing nothing, using evidence-based information. Encourage the client to think about what these outcomes might mean for them personally.
7. **Explore** Talk about ideas, fears and expectations of the problem and possible treatments. Provide the opportunity for the young person to ask questions.
8. **Check in** Check with the client about their understanding of the information and reactions to this, for example:
   - 'What do you see as your treatment options now?'
   - 'Do you remember any of the common side effects of medication we talked about?'
   - 'What is the risk in just seeing what happens without treatment?'
9. **Deciding** Make, discuss or defer the decision/s. Arrange a time to discuss further or follow up.
10. **Review** Once a decision is made, arrange the monitoring of symptoms and make a time to review progress.

Factors to consider:

- SDM must be flexible to the needs of the young person.
- Consider client factors such as cognitive capacity, information processing style, attention and motivation.
- Parental involvement is likely to be higher for younger clients.
- Some young people will choose not to seek help or engage in treatment. By talking about this openly as an option, opportunities to explore reasons for this choice and to provide information to the young person arise. SDM allows this decision to be made with the clinician rather than by the young person outside of the session. Young people can then be encouraged to review this decision and seek treatment in the future if needed. (51, 52)

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