RECOMMENDATIONS

Increasing the Uptake of Shared Decision-Making in Integrated Behavioral Health Care

CONTEXT

In the United States, one in four adults will have a diagnosable mental health condition during their lifetime.[1] However, due to discrimination and stereotyping, individuals may be reluctant to seek treatment for these conditions. In order to make patients more comfortable seeking such care as well as to increase trust, equity, and improve mental health outcomes, shared decision-making has been recommended for mental health at the policy level by the federal government and leading policy research organizations.[2,3]

Shared decision-making (SDM) is a process in which patients and their clinicians work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with patients' preferences and values.[4] Shared decision-making requires a two-way relationship between patients and clinicians and takes into account the expertise that comes with lived experiences of mental health conditions.[5] While there are many challenges to incorporating SDM into practice, more researchers and clinicians are realizing the importance of SDM in successfully treating mental health conditions and are seeking ways to tap into patients' motivations, needs, and preferences.

ABOUT THE PRIMARY CARE COLLABORATIVE

The Primary Care Collaborative is a national multi-stakeholder organization dedicated to advancing an effective and efficient health system built on a strong foundation of primary care. Our mission is to engage and unify diverse stakeholders from the public and private sectors in support of high-performing primary care. We convene stakeholders, disseminate evidence and best practices, and connect primary care leaders and advocates. Our work is guided by the Shared Principles of Primary Care that are person-and family-centered; continuous; comprehensive and equitable; team-based and collaborative; coordinated and integrated; accessible; and high-value. We are committed to evidence-based policies and practices.

PCC'S EFFORTS TO FURTHER INTEGRATE CARE AND SDM

The Primary Care Collaborative's (PCC) vision for advanced primary care integrates behavioral health, including shared decision-making. More specifically, the PCC has since 2018 regularly convened a primary care-behavioral health integration workgroup to advance comprehensive, integrated practice as envisioned by the Shared Principles of Primary Care. PCC also has a long history of working on patient engagement, providing educational tools and support to practices to help patients make informed healthcare decisions in collaboration with their care team. From 2015 to 2019, PCC efforts under the Center for Medicare and Medicaid Services' Transforming Clinical Practice Initiative (TCPI) focused on increasing patient and family engagement. Over four years, PCC provided related technical assistance to more than 140,000 clinicians working in ambulatory care practices who were enrolled in the TCPI initiative.

In 2020, a Eugene Washington PCORI Engagement Award for Community Convening[6] provided funding for the PCC to further shared decision-making in integrated practices. PCC began this effort by reviewing the research literature for barriers and enablers of SDM at the intersection of primary care and behavioral health. See the sidebar on page 3 for a summary of this effort, which yielded 80 citations; see pages 7-10 for more details.

PCC then convened a Roundtable of diverse stakeholders with expertise in primary care, behavioral health, and shared decision-making—including patients, researchers, clinicians, payers, employers, and clinical pharmacists—to review the evidence and develop recommendations on how to increase the prevalence of SDM in integrated practice, including for disadvantaged populations. The recommendations that the Roundtable finalized in April 2021 address four main areas related to culture, infrastructure, payment, and the evidence base:

PARTICIPANTS IN THE ROUNDTABLE

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RECOMMENDATIONS

The PCC shares the following recommendations with leaders across the healthcare spectrum—including patient advocates, researchers, clinicians, and policymakers—recognizing the importance of furthering SDM in integrated practice through various levers and across all stakeholder groups in order to achieve systemic change.

RECOMMENDATION 1

Shift toward a healthcare culture that supports shared decision-making in all aspects of care to increase equity and address stigma among patients and members of the care team.

- **Move the cultural needle:** Historic power differentials between patients and care teams will not change overnight. SDM can help balance these differentials and reduce stigma for both patients and clinicians. This movement will take years of collaborative effort across all stakeholder groups.
  - Train the existing and future workforce to use SDM, address implicit bias, and mitigate patients' self-stigma.
  - Fairly reimburse for peer-support services, and integrate peer support as part of the care team.
- **Co-create with patients and families:** Well-intentioned SDM interventions may still fall short of real-world patient needs. Patients and families must be a part of SDM education and training, development of SDM tools, and efforts to measure and improve SDM.
  - Include patients as co-leads in research and development, not only as consultants or reviewers.
- **Foster cultural humility, and ensure diversity and inclusion:** In order for SDM to be effective, the intersectionality of stigma around behavioral health conditions and cultural identity needs to be recognized. Treatment preferences can vary widely across cultures and individual patients, and providers need to be prepared to approach this with cultural humility. SDM interventions need to be flexible and adaptable to meet the needs of individuals in real-world practice.
  - Increase diversity in the workforce, and ensure that care team members reflect the populations they are serving.
  - Include diverse perspectives from across stakeholder groups when developing SDM interventions.

SUMMARY OF EXISTING LITERATURE

Prior to the roundtable that produced these recommendations, PCC produced a summary of evidence of existing literature (80 articles) on SDM in integrated care so roundtable participants could develop a common understanding of the existing evidence base, explore areas for future research, and consider implications for the field. The evidence summary paid particular attention to SDM in an interprofessional context and SDM that considers orienting/training the patient and the clinician. While there is an abundance of research on SDM that suggests benefits to the patient, the method has not been widely implemented in integrated practices. Therefore, there is little concrete evidence that supports the use of SDM to improve clinical outcomes for those seeking behavioral services. The full list of literature that was gathered (available separately here) includes a selection of publications that speak to the potential of SDM from a clinician and patient perspective, almost all recommending that additional research is required to document concrete clinical outcomes. The summary of evidence follows the recommendations in this document.

RECOMMENDATION 2

Build on existing innovations and infrastructure to further shared decision-making implementation; broaden training.

- **Leverage primary care infrastructure:** There is no need to reinvent the wheel. Existing infrastructure and tools should be adapted to integrate SDM into practice. Some individuals are uniquely positioned to shepherd these processes, and their expertise should be leveraged.
  - Learn from the experiences of the patient-centered medical home (PCMH) and other primary care reform efforts.
  - Model interventions after successful SDM tools for other medical conditions when applicable, and adapt as needed.
  - Explore lessons learned from other fields such as advanced directives.
- **Train all team members:** Training in SDM can increase its use and efficacy and is most effective when all members of the care team as well as patients and their families are trained.
  - Include pre- and post-intervention surveys to understand how to effectively train.
  - Ensure trainings are developed by diverse stakeholders and are adaptable to meet different cultural and linguistic needs.
  - Train non-clinical staff such as peer-support specialists, front desk staff, schedulers, billing and other administrative staff to foster a level of trust and comfort with the wider practice, not just the clinician.
  - Develop trainings that are scalable and easily translatable across practices.

RECOMMENDATION 3

Advocate for and implement prospective payment models that incentivize the use of shared decision-making, beginning with a shared definition of SDM and related measures.

- **Create transparent, common definitions:** SDM can mean different things across and within stakeholder groups. To move this forward, there is a need for workable definitions of what SDM entails that are agreed upon across sectors.
  - Consider SDM as a key component of integrated behavioral health.
  - Advocate for a common definition of SDM that is simple and translatable for real-world practice.
  - Ensure diverse patient voices are captured in the process of defining SDM so that the definition meets the needs of diverse populations.
  - Determine what resources and interventions best reflect the chosen definition.
- **Measure, evaluate, and improve:** Performance measures can be used as leverage to catalyze and evolve SDM as it relates to particular behavioral health conditions and processes.
  - Use already defined measures where possible.
  - Incorporate process and outcome measures as well as patient experience and clinical measures into value-based payment arrangements.
  - Capture demographic data in order to measure and adjust for inequities in implementation and outcomes.
  - Include diverse patient perspectives in every step of this process.
- **Leverage payment-model reform, and incentivize SDM:** Payment reforms can provide incentives to keep patients well, quickly restore them to health, and support chronic care management.
  - Comprehensive, prospective payment can be an incentive for practices to implement SDM (among other innovations) and provide necessary time for co-creation of SDM processes and engagement of clinicians in SDM.
  - Consider what incentives encourage both patients and providers to engage in SDM and how those can be implemented.
  - Consider rewarding long-term relationships in primary care/behavioral health by providing incentives when patients stay 13 or more months.

RECOMMENDATION 4

Further develop the evidence base to understand how shared decision-making can improve clinical outcomes, experience of care, and patient and clinician satisfaction.

- **Center diversity and patients' voices:** Include diversity and patients' voices in every step of the research process. Interventions are often tested in narrow populations that do not account for ethnic and cultural differences that impact treatment preferences.
  - Consider patients and families as integral members of the research team.
  - Include diversity in race/ethnicity, age, sex, gender, sexual identity, disability, and socioeconomic status to understand how to best apply SDM in different populations and how to tailor interventions to individual patient needs.
- **Show efficacy of interventions, and disseminate to primary care:** There is limited evidence available to show the impact of SDM interventions on treatment outcomes. More research is needed to demonstrate that SDM can improve outcomes, experience of care, and clinician satisfaction.
  - Explore SDM with psychotherapy and other treatment options outside pharmacotherapy.
  - Develop and test SDM tools and interventions that are customizable to different workflows and adaptable to patients' needs.
  - Study different technologies and how they can make interventions adaptable to practice workflows and patients' needs.
  - Develop channels to disseminate effective interventions and tools to primary care practices.
- **Research payment models:** More research is needed to understand what payment models are most effective at fostering SDM.
  - Explore what types of prospective payments adequately support the time and resources needed to integrate SDM into the culture of a practice.
  - Test different payment models for flexibility and adaptability so that practices can meet patients' needs completely and efficiently.
  - Develop measure(s) that will encourage SDM.
- **Generate real-world evidence:** In order to encourage advocates and decision-makers, pair clinical research with real-world evidence and patient testimony. Quantitative and qualitative data need to be leveraged jointly to understand how clinically tested interventions function in real-world settings.
  - Conduct research in real-world contexts in order to test SDM with different workflows and populations.
  - Collect patient testimony to understand patients' needs, perceptions, and experiences with SDM.
  - Explore how SDM impacts not only experience of care, but also overall patient satisfaction, confidence, quality of life, and sense of wellbeing.

ENDNOTES

[1] Duncan E, Best C, Hagen S. Shared decision making interventions for people with mental health conditions. (2010). Cochrane Database of Systematic Reviews, Issue 1. Art. No.: CD007297. DOI: 10.1002/14651858.CD007297.pub2.

[2] Slade M. Implementing shared decision making in routine mental health care. (2017). World Psychiatry. 16(2): 146-153. DOI: 10.1002/wps.20412

[3] Innovations in Practice: Shared Decision Making in Mental Health. (2010). SAMHSA. https://www.mentalhealth.va.gov/communityproviders/docs/Administrator_Issue_Brief_508.pdf

[4] National Learning Consortium. (December 2013). Shared Decision Making Fact Sheet. https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf#:~:text=Shared%20decision%20making%20is%20a%20key%20component%20of,outcomes%20with%20patient%20preferences%20and%20values%20.%20.

[5] Mental Health America. (2019) Shared Decision-Making. https://www.mhanational.org/shared-decision-making

[6] The recommendations presented in this publication are solely the responsibility of the author and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

SUMMARY OF THE EVIDENCE THAT CONTRIBUTED TO THE RECOMMENDATIONS

This section provides a summary of the existing literature on SDM in integrated care that PCC gathered, reviewed, and provided to roundtable participants to inform the preceding recommendations.

The literature was organized into the categories described below. Please note: This organizational system serves the purpose of a general guide. Several of these articles contain elements that could fall into multiple categories. Publications were categorized by the way the main findings and conclusions were framed.

OVERVIEW/UNCATEGORIZED

General shared decision-making publications as well as publications conceptualizing and translating shared decision-making into a mental and behavioral health context.

IDENTIFICATION OF BARRIERS AND ENABLERS TO IMPLEMENTATION

Publications that explore various barriers and enablers to implementing shared decision-making in behavioral health care.

REPORTED OUTCOMES

Publications that include results for how shared decision-making impacts clinical outcomes and patient satisfaction.

CLINICIAN PERSPECTIVES; INTERPROFESSIONAL COLLABORATION

Publications that focus on clinician perspectives on implementing shared decision-making in mental and behavioral health as well as how interprofessional collaboration can support this implementation.

PATIENT PERSPECTIVES, EXPERIENCES, AND NEEDS

Publications that focus on the perspective of patients, their needs, and wants in shared decision-making and reasons they may feel empowered or disempowered in their care plans.

TRAINING AND EDUCATION

Publications that look at training and educational programs that support the implementation of shared decision-making into behavioral health care.

KEYWORDS

- *Patients* are also referred to as *consumers*, *service users*, and *clients*
- *Clinicians* are also referred to as *providers* and *mental health professionals*
- SDM elements are referred to as *shared decision-making*, *recovery-oriented approach*, *therapeutic alliance*, *patient activation*, and *person-centered planning*

ASSESSMENT OF A DECISION AID

Publications assess the efficacy of specific decision aids or interventions that promote shared decision-making in behavioral health care.

Overview/Uncategorized

Overviewing evidence shows that there is a definite need for more research on shared decision-making (SMD), especially in mental health. More specifically, there is a need for more population- and context-specific research in order to tailor SDM to consumers' varying needs.[10] Available evidence shows one key facet: a strong patient-provider relationship and clear communication are fundamental for making shared decisions.[7] Some preliminary findings showed that SDM is viewed by consumers and clinicians as feasible, acceptable, and useful.[3] Additionally, survey data has shown that both patients and clinicians value client-centered priorities when making decisions about treatment plans.[8] Some "shared decisions" are made with much more pressure than others, and this does not seem to be correlated with patient risk factors.[9] Shared decision-making has the potential to help overcome traditional power imbalances between providers and service users.[5] Structured interventions such as peer instruction, case manager guidance, and condition-specific decision aids can help consumers take initiative in conversations with their providers.[4] Providing training for both consumers and clinicians can help to facilitate mutual understanding and create a space in which consumers can feel comfortable being honest with their clincians.[12] Findings have shown that SDM is most effective and more frequently used when staff members have support, training, and education.[6,11] To inform these interventions, it is important to first effectively translate conceptual descriptions of SDM to guide clinician skill development.[2]

Identification of barriers and enablers to implementation

Studies exploring barriers and enablers to SDM implementation found that, while clinicians find SDM difficult to implement, they still view it as an ethical ideal for motivating a therapeutic alliance.[23] Findings emphasize the need for organized professional development including direct training in SDM communication with clear resources to guide implementation.[15,18,21] There is a strong need for a cultural shift among mental and behavioral health professionals to effectively balance consumer needs for assistance with autonomy.[15,27] One study found that for medication consultations, SDM needs to be contextualized within longer-term patient-provider relationships.[33] According to providers, some of the main barriers to implementation included lack of systematic support, time constraints, cultural challenges, and integration with other recovery-oriented systems.[14,16] For consumers, main barriers included confidence in their own competency, literacy and language barriers, and fear and trauma caused by past experiences in the mental health system.[14] One difficulty found was that clinicians and consumers had very different concerns and perspectives about treatment options, and stakeholder groups had a tendency to blame one another for implementation failure.[17,19] For patients with involuntary hospitalizations, it was found that SDM needs to initiated very early in the care process in order to establish trust in the providers.[29] Overall, the evidence shows that implementation efforts should be flexible and adaptable so that SDM can be individualized for cultural differences among patients.[31,32]

Reported outcomes

Though there are few available studies on clinical outcomes of SDM, preliminary findings are positive. One such study found that even a brief SDM intervention was associated with greater patient initiation and improved adherence to psychotherapy.[35] A similar study showed that SDM intervention with substance use disorder (SUD) patients resulted in significantly better improvements than standard decision-making procedures.[40] A correlational analysis indicated that SDM lowered decisional conflict for patients, which is associated with a higher quality of life.[36] Despite clinician concerns, one study found that involvement in decision-making did not increase visit times and depended mostly on the preferences of individual psychiatrists.[37] It has also been shown that the use of an Electronic Decision Support System (EDSS) resulted in higher patient satisfaction in care

REFERENCES

References in this section are provided in the full list of literature.

planning.[39] While more research is needed, these initial results show that implementation of SDM in mental health can improve patient experiences and outcomes.

Clinician perspectives; interprofessional collaboration

One significant barrier to implementing SDM into practice is the differences in clinician versus patient perspectives and preferences. Several studies have been conducted to assess clinician perspectives and the effects of interprofessional collaboration on implementing SDM into behavioral health. Some major findings in the literature indicate certain hesitations providers have in utilizing SDM with their patients. One prominent barrier was a perceived lack of consumer competence when it came to understanding insights in to their mental disorders.[45,48] Many clinicians also expressed the feeling that SDM should be condition-dependent due to the added complexities of certain conditions.[44] In studies focusing on interprofessional collaboration, limitations included provider preferences, systemic factors, and the need to improve mental health expertise among primary care providers (PCPs).[45] Interprofessional roles need to be better understood and strengthened to increase efficacy of SDM in an integrated primary care-behavioral health space.[44] In a study focusing on PCPs treating mental health concerns of their patients, providers seemed to communicate with patients in a manner falling between a paternalistic and shared approach to decision making.[46] In the same study, it was also found that stigma was a significant barrier to making shared decisions with African American and Latinx patients.[46] The literature finds that clinicians can improve SDM by targeting stigma, demonstrating positive affect, and tailoring communication to specific patients' needs.[49] Another study of clinician perspectives focused on using specific tools to support SDM. It was found that staff found the tools useful and would be receptive to implementing concrete supports that work within organizational contexts.[43]

Consumer perspectives, experiences, and needs

Encouraging consumers to take an active role in conversations with providers about their treatment options is an important way to increase SDM. This can help strengthen the patient-provider relationship, which has been described as the bedrock of SDM.[66] While it is understood that both internal and external factors impact consumer participation in decision making, new findings suggest that mental health consumers may have a different view of decision-making than standard literature on SDM would suggest.[51,56] In mental and behavioral health, it is more common for service users to initially prioritize autonomy but defer to care managers when decisional conflict arises.[56] It is therefore important to engage patients and support their active role in decision-making. One study found that 85 percent of patients preferred being provided options and being asked their opinions about their own mental health treatment.[53] Increasing SDM in mental and behavioral health can improve patients' experiences and treatment outcomes, as shown in one study that found SDM implementation led to more positive attitudes about medication.[62] While more research is needed, one preliminary study of substance-use disorder patients found that matching patient preferences resulted in an overall reduction of substance use.[65] In a study of alcohol-dependent patients, 90 percent preferred an active or shared role in decision-making regarding their care.[67] In studies focused on minority populations, especially with White providers, it was found that patients were more hesitant about taking the initiative to have an active role in decision-making.[52,57] Service users who had experienced healthcare discrimination in the past were found to have more difficulty in forming trusted relationships with their providers and thus in engaging in SDM.[59] Self-stigma and feelings of shame around mental illness led to consumers being less participatory in care decisions.[61] Paternalistic decision-making can reinforce these feeling in patients, so it is critical for providers, particularly White providers dealing with patients of color, to be trained in cultural sensitivity and interventions to reduce self-stigma in order to promote SDM.[52,61]

REFERENCES

References in this section are provided in the full list of literature.

Training and education

External systemic factors and implementation challenges have been found to be the most prevalent barriers to SDM efficacy.[69] Structured clinician training has been shown to significantly increase SDM, and more coaching sessions were associated with more effective SDM and greater patient-reported quality of care.[68] Overall, most of the preliminary literature on this topic shows that SDM is most prevalent and effective when all parties, including service users, care coordinators, psychotherapists, and psychiatrists, receive training or structured support.[70] Training service users and care coordinators specifically was associated with increased confidence to explore medication options.[72] Additionally, patient training was positively correlated with improved self-esteem, problem-solving abilities, and quality of life in a study of patients with schizophrenia.[71] The significant effects that self-esteem and stigma have on patient participation in decision-making warrant further investigation.

Assessment of a decision aid or intervention

Implementing structured tools into decision-making and/or training can greatly improve implementation and efficacy of SDM in mental health. In a study of one eHealth intervention, it was found that when it was applied correctly, patient reported less decisional conflict, which allows for more confidence in decision-making capabilities.[74] When using the CommonGround digital decision support tool, patients were able to access the most up-to-date information about side effects, which has been found to be one of patients' main concerns when making decisions about medication.[75] Use of a web-based safety-planning tool allowed suicidal patients to build their own plan while receiving feedback from clinicians when they needed it.[79] This resulted in significantly lower intensity of suicidal thoughts and an increased ability to cope with suicidal thoughts.[79] For patients with alcohol dependence, the use of a mobile app showed significant reductions in alcohol consumption.[78] Additionally, the use of a web-based SDM tool was shown to increase antipsychotic medication adherence.[73] In one study, focusing on the Right Question Project – Mental Health (RQP-MH) for Latinx patients, findings suggested that there are layers cultural and contextual factors influencing Latinx participation in healthcare interactions.[80] Patients with linguistic differences from their providers were at higher risk of having difficult or negative interactions within the healthcare system, even after they were exposed to training.[80] This study reinforces the need for additional research in this space as well as the need for all providers to receive culturally competent trainings developed with inputs from diverse minority communities.

REFERENCES

References in this section are provided in the full list of literature.

FULL LIST OF LITERATURE

The complete document from which this Summary of Evidence was drawn is available. The full document includes:

- abstracts for the 80 articles that were included in the evidence review
- full citations for the articles