SHARED DECISION MAKING IN MENTAL HEALTH: INTERNATIONAL PERSPECTIVES ON IMPLEMENTATION

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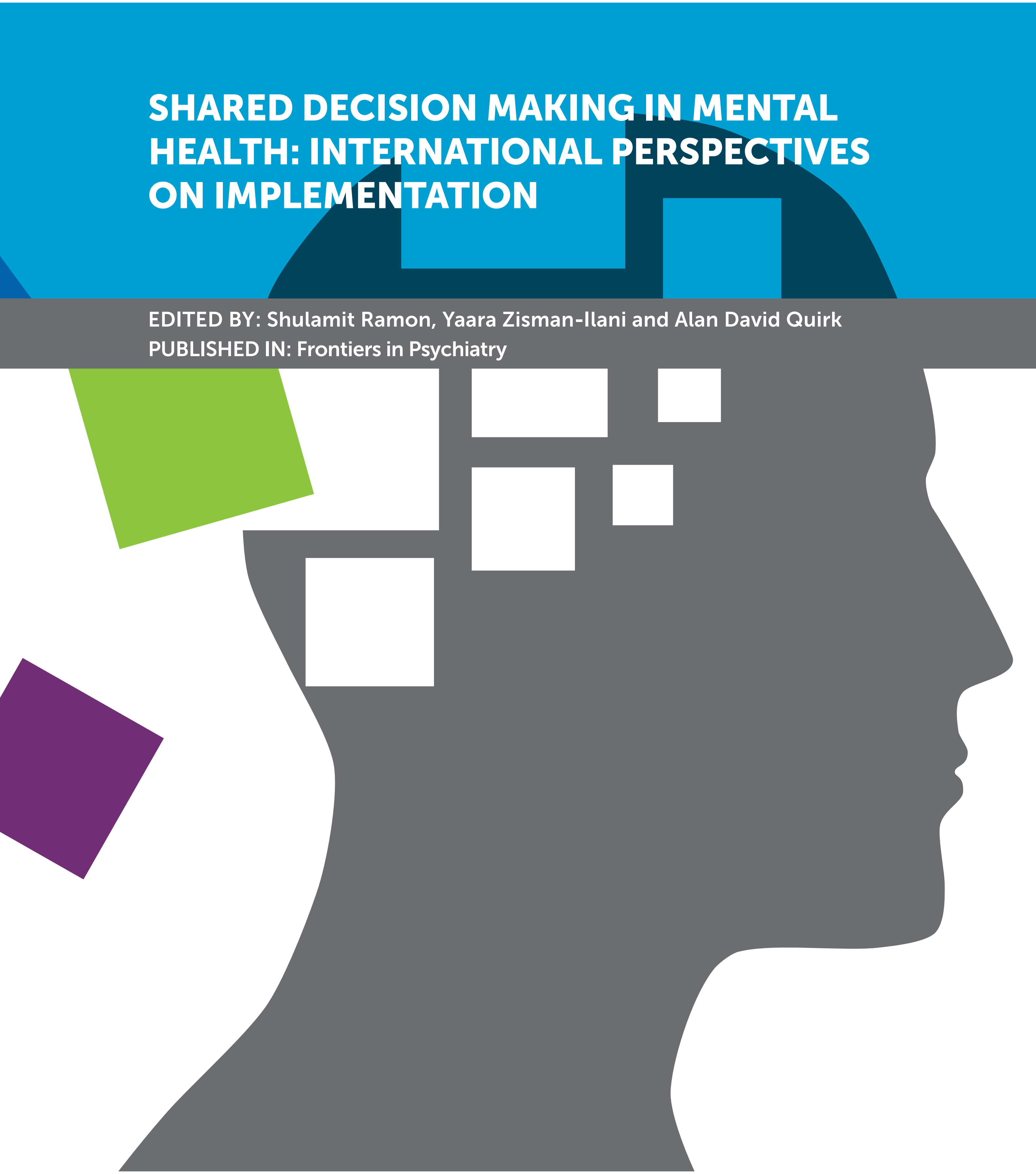

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SHARED DECISION MAKING IN MENTAL HEALTH: INTERNATIONAL PERSPECTIVES ON IMPLEMENTATION

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EDITORIAL
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Editorial: Shared Decision Making in Mental Health: International Perspectives on Implementation

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Keywords: shared decision making, mental health, adults and children, primary care, ethnic minorities

Editorial on the Research Topic

Shared Decision Making in Mental Health: International Perspectives on Implementation

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While there is an increased acceptance of the potential usefulness of applying share decision making (SDM) in everyday mental health practice, its implementation in practice is still lacking. People who use mental health services often do not know what SDM is; clinicians often have reservations concerning the capacity of service users to make decisions, and fear that SDM may lead to harmful risk taking in increased medication non-adherence. Current research of these issues demonstrates the importance of easy access to information concerning mental health interventions, and the relevance of respect and trust by both clinicians and service users to each other in the process of SDM. Existing research highlights the willingness and ability of most people experiencing mental ill health to reach well- informed decisions alongside their clinicians.

The editors of this special issue have therefore invited articles on original research describing SDM projects contributing to advancing the development of SDM and its implementation.

Twelve articles were accepted for publication in this special issue.

Two articles addressed the need to adapt SDM to non-western cultures and underserved racial/ethnic minority populations, emphasizing needed adaptations to make SDM accessible to address cultural aspects. Matthews et al. conducted formative qualitative research in the US, to understand SDM perception among underserved ethnic minority patients with depression in primary care. Results point to stigma and lack of trust in the provider and the system as critical barriers for SDM in depression primary care.

Ismail and Midin describe the first SDM study in Malaysia focusing on SDM preferences of adults with schizophrenia. Based on a cross-sectional design, the authors concluded that although the Malaysian with schizophrenia prefers to be involved in SDM, the practice is limited due to providers' lack of interest in developing SDM.

These articles are in line with a growing critique of the recent NICE SDM guidelines Zisman-Ilani et al. (2021), which exclude variations of SDM practices that have been made to address different policies, cultures and health conditions.

Gutman et al. focus on training health and social care undergraduate and postgraduate Israeli students to learn what SDM is and SDM application in practice placements. The study highlights the complexity of the application to practice due to lack of sufficient knowledge of SDM and of its implementation by their practice teachers, as well as the lack of organizational commitment to SDM.

Stanhope et al. from the US describe the development of a 10-item Person-Centered Care Planning Assessment Measure, a measure of the extent to which mental health services are person-centered.

Vitger et al. from Denmark present a systematic review and meta -analysis of digital SDM intervention in mental health. They concluded that digital interventions to support SDM in mental health is promising, but more evidence is needed.

Three articles focus on parents, children, and young adults. In two articles from the UK, Liverpool et al. and Liverpool et al. looked at the underlying emotional layer experienced by parents taking part in SDM concerning their child who has mental health problems, a layer rarely looked at. Based on qualitative analysis, results show that negative emotional states hindered active participation in the SDM process, while a positive such state encourages an active participation.

The second article by the same groups provides a secondary analysis of a large sample concerning the degree of participation by parents in SDM. The findings highlight that parents of Asian origin and parents of children with learning difficulties had a high level of participation, while the presence of conduct problems among children predicted a lower level of SDM.

Simmons et al. describes a first step of qualitative formative development of an online decision aid to empower young people identified as likely to develop psychosis to become active participants in an SDM process concerning their care using focus groups with both clinicians and clients.

Two articles focused on interventions with family members and service users. Ramon looked at the currently existing evidence concerning the development of the application of Family Group Conferences (FGC) to adults with mental health issues, which has originated in social work. The FGC aims to enhance family involvement in supporting these adults, reigniting the willingness of family members to do so in a meaningful way by devising an action plan and participating in its implementation.

Weiss et al. have developed the Rainbow approach in Israel. They applied a structural cognitive modifiability framework to the practice of enabling family members to improve the relationships they have with an adult member experiencing mental ill health, with considerable success. The article focused on the hitherto hidden aspect of SDM necessary for facilitating communication between parents and their adult son or daughter.

Last, two articles focused on SDM in psychiatric medication management. Kaminskiy et al. describe a formative qualitative analysis of services users, nurse prescribers and psychiatrists on barriers and enablers for SDM around antipsychotic medication. A small group of services users acted as co-interviewers and co-researchers.

Fox provided a first-hand perspective of a service user experiencing two different types of involvement in mental health SDM.

The 12 articles published in this special issues of Frontiers Psychiatry offer the following:

- Explore creatively, yet methodically, at least one key issue of SDM in mental health.
- Apply in an evaluated way SDM across a whole mental health service.
- Identify barriers to implementing SDM and attempt systematically and ethically to devise ways of overcoming the barriers.
- Use facilitators to enhance the implementation of SDM in mental health in a systematic way.
- Pay attention to reducing the power differential between service users and clinicians, while considering ways of increasing more equal collaboration within the research design.
- Address SDM with minority populations.
- Focus attention to the development of SDM with different sub-populations and services (e.g. parents and clinicians of children mental health services, families of adult clients, community mental health services, primary care, families of adult clients, young adults).
- Provide international coverage; articles come from Australia, Denmark, Israel, Malaysia, UK and the US.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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ORIGINAL RESEARCH
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An Affective-Appraisal Approach for Parental Shared Decision Making in Children and Young People's Mental Health Settings: A Qualitative Study

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Background: The majority of existing shared decision making (SDM) models are yet to explicitly account for emotion as an influencing factor to the SDM process. This study aimed to explore the role of parents' and carers' emotional experiences as a concept that has implications for SDM in children and young people's mental health (CYPMH) settings.

Methods: A social constructivist grounded theory approach, analyzing data from focus groups ($n = 4$) and semi-structured interviews ($n = 33$) with parents and healthcare professionals, was undertaken. Participants were identified and selected at CYPMH sites and through social media platforms or in-person advertising as part of a larger feasibility trial. Interviews and focus groups were audio-recorded and transcribed verbatim. Thematic analysis moved from open to focused coding.

Results: The majority of the sample consisted of mothers of adolescent girls. Healthcare professionals had an average of 7.54 (SD = 6.24) years of work experience in CYPMH outpatient capacities. Findings suggested that parents are "expected to, but not always able to" engage in SDM. Themes and subthemes described an affective-appraisal SDM process capturing: (1) views and experiences of SDM, (2) parents' emotional states, (3) the influence of emotions on SDM, and (4) key support systems accessed. The emerging affective-appraisal framework highlighted that negative emotional states hindered parents' active involvement in SDM, and positive emotions encouraged involvement in SDM.

Conclusion: The current findings describe an SDM model specific to CYPMH. This new understanding contributes to addressing a possible theory to practice gap opening new challenges and opportunities for academic enquiry.

Keywords: parent, emotion, shared decision making, child, youth, mental health

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INTRODUCTION

Shared decision making (SDM) has been broadly defined as a cognitive, emotional, and relational process where service providers and service users collaborate to derive care and treatment decisions (1). Service user involvement in healthcare decisions is highly recommended, linked to better health outcomes and promotes satisfaction with services (2–4). In children and young people's mental health (CYPMH), service users include children and young people as primary service users and parents (including non-biological caregivers) as secondary service users (5). However, previous studies have mainly focused on the dyad relationships between service providers and primary service users (6). Therefore, the areas where triad relationships exist have been less understood; further highlighting the need for a consensus definition and unified view of SDM (6, 7).

To date, researchers have proposed several SDM models. The majority of the available models are embedded in adult healthcare, with fewer models specific to pediatric settings and mental health care (6, 8). Although some generic models propose that service users and their families should be a distinct and active part of the SDM team (9), this approach is yet to be taken up extensively in clinical care (10). In pediatric care, researchers highlight that the active participation from all parties (i.e., parent, child, and practitioner) is required for the decision making process to be regarded as SDM (11). However, other researchers accept the inclusion of the child, the caregiver, or both, with the possibility of including other stakeholders (12). These inconsistencies highlight a need to address gaps between theory and practice, suggesting further explorations to ensure appropriate decision-makers are included if implementing SDM in pediatric care (13, 14). Nonetheless, researchers agree that effective SDM requires active participation from service users (15). One such framework for youth SDM proposes (1) setting the stage for youth shared decision making, (2) facilitating youth shared decision making, and (3) supporting youth shared decision making (16).

Despite the efficacy of SDM, several barriers and facilitators have been identified and divided into categories of knowledge, attitudes, agreement, lack of expectancy or hope, and behaviors among service users and service providers (17). Reviews commonly highlight specific barriers such as patient/family characteristics (e.g., demographics and child health status), service constraints (e.g., time taken for consultation and trust in service providers), power imbalances, lack of available evidence-based treatment options, and service providers' limited knowledge of SDM skills (18, 19). In addition, researchers suggest that emotions may impact service users' involvement in SDM (20) and threaten parents' assumed role in the decision making process (21). Interviews with clinicians, parents and young people corroborated those findings, highlighting that strong emotional states affected the SDM process (22–24). The extant literature also highlights the need to increase awareness of emotions as social information influencing SDM (25). However, investigations of conversational interaction patterns in pediatric primary care indicated little opportunities of dialogue about emerging emotions from parents (26). As the Ottawa Decision Support Framework highlights the need for tailored decision support (27), further explorations could deepen our understanding of how emotional states influence the SDM process, with implications for intervention use (28). This approach also aligns with the Triangle of Care model which supports the working collaborations between service users, professionals and carers (29).

Although research investigating emotions and SDM is limited, many studies report heightened emotions in parents of children with mental health problems (30, 31). Previous qualitative studies in the United Kingdom (UK) broadly explored the emotions of parents of children with specific mental health disorders (32–35), belonging to specific minority populations (36), and of specific age groups below age 18 (37–40). The available research mainly focused on clinicians or therapists, and specific family groups. However, researchers also identified that around 20% of young people beyond age 18, especially those transitioning to adult mental health services, are supported by their parents (41). Thus, a research gap exists regarding the views of other healthcare professionals (HCPs) (e.g., nurses, support workers, medical social workers) and parents of children and young people (up to age 24) experiencing any mental health problem and accessing universal CYPMH care and treatment. In order to fully engage parents in SDM, it is important to understand the concept of SDM and how it applies to CYPMH care and treatment.

Aims

This study has four primary aims. First, to provide insight into how HCPs and parents perceive SDM in CYPMH services. This understanding can inform and provide a common language for researchers to use when studying SDM in CYPMH. Second, to describe parents' experiences of SDM from the perspective of HCPs and parents. Third, to qualitatively explore emotion as an influencing factor for involvement in CYPMH decisions. Lastly, to identify parental support systems. This knowledge can inform the development of evidence-based decision support interventions and highlight the additional needs of decision-makers.

METHODS

Research Team and Reflexivity

The interviews and focus groups were mainly conducted by the primary author. However, 2 focus groups were conducted by clinical researchers at the CYPMH site to maintain the privacy of the parents. The primary author has a background in health psychology, psychiatric research and policy development. The primary author was empowered, as a non-UK national, to ask neutral questions as there were no professional affiliations. The remaining authors have a background in CYPMH research and practice, and provided guidance throughout the study. The social constructivist approach accepts the researcher as part of the research process and therefore reflective journaling of thoughts were kept, and responses to data were discussed at regular meetings throughout data collection and analysis.

Study Design

A social constructivist grounded theory approach was adopted (42). According to Charmaz (43), this approach allows the researcher to gain an insider perspective of the meanings of patterns of behavior that can be observed in a particular context. Thus, emerging concepts are socially constructed based on

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Abbreviations: CYPMH, Children and young people's mental health; HCP, Healthcare professional; SDM, Shared decision making; UK, United Kingdom.

descriptions of the participants' experience of SDM. A qualitative study design, analyzing data from semi-structured interviews and focus groups of parents and HCPs was considered suitable to explore their views (i.e., beliefs and attitudes) and experiences of SDM (44).

Study Settings

Participants were given the opportunity to choose between face-to-face interviews, phone interviews or in-person focus groups. Participants also had the opportunity to request the interviews be conducted at the CYPMH site or the university campus. These strategies were adopted to offer convenience and comfort and ensure privacy when conducting focus groups and interviews.

Participant Identification and Selection

Parents were recruited from England in two strands: (1) as part of a feasibility and acceptability trial within the National Health Services (45), and (2) through social media platforms or in-person advertising. Parents were eligible if they (1) had at least one child or young person (0–24 years) with a mental health problem, (2) were over the age of 18, (3) had no known diagnosed mental health problems and (4) had the ability to speak and understand English. The young person's cut-off age at 24 years was selected as it coincides with the United Nations categorization of youth and young people (46).

Exclusion criteria were current involvement in any other research that had the potential to influence this study or if the child or young person was being treated under the Mental Health Act (1983). The Mental Health Act informs and influences how decisions are made for, with and about patients receiving mental health care in England. Parents were recruited through referrals from clinicians or self-referrals. Clinicians at the identified sites who participated in the feasibility trial relayed brief information about the study to the families, and parents who expressed interest were contacted by the site collaborator to be given further details about the study. After informed consent was obtained, the contact details of the parents were securely transferred to the research team. HCPs were also recruited as part of the feasibility trial. Information about the study was provided through presentations by the primary researcher at staff meetings. The site collaborators also identified and recruited HCPs. All staff working with families consisting of a child or young person experiencing mental health problems were eligible to be part of the study. Participants were contacted by email and/or phone call. If no answer was received, a reminder or follow up was sent a further 2 times, 1 week apart. If contact was unable to be made, participants were categorized as "unavailable."

Data Collection

Interview sessions (i.e., focus group discussions or individual interviews) were conducted between October 2018 and October 2019. Before the interview sessions, participants were briefed and informed consent was taken. Semi-structured interviews with open-ended questions were conducted. Probes were designed and utilized to generate further explanation from the participants without "leading" the interviewee. Interview guides were informed by previous research (47) and modified and refined to meet the aims of the current study. Questions focused on participants' views and experiences of SDM and how parents' emotions influenced the process (see **Table 1**). Interview schedules were used as a guide and there was freedom within the interview protocol to further explore some of the answers provided. The data were considered as saturated when the analysis did not produce any new concepts or further inform theory development (48). Interview sessions were audio-recorded and transcribed verbatim.

TABLE 1 | Interview schedule.

Questions (Healthcare professionals)	Questions (Parents)
What does SDM mean to you?	What does SDM mean to you?
How do parents appear (i.e., emotionally) when engaging in SDM?	How do you feel (i.e., emotionally) when attempting to be part of SDM?
Is it important for parents to be part of the SDM process? Why?	Is being part of the SDM process important to you?
Where can parents access decision making support?	Where do you access decision making support?

Sample Characteristics

Overall, data from $N = 55$ participants were included in the study. Four focus groups were conducted, $n = 2$ with parents and $n = 2$ with HCPs. The mean duration of the focus groups was 41.5 min, with an average of five participants. Additionally, 33 interviews with a total of $n = 19$ HCPs and $n = 14$ parents were conducted. The mean duration of the interviews was 26.2 min.

Parents

Fourteen parents were interviewed and 10 participated in the focus groups. Of the total number of parents, there were $n = 22$ mothers and $n = 2$ fathers with a mean age of 44.88 (SD = 6.76) years. The majority of the parents identified as White British (95.83%) mothers, of girls (66.67%). The mean age of their children was 13.88 (SD = 2.8) years and experienced a range of parent-reported mental health problems (see **Table 2**).

Healthcare Professionals

Nineteen HCPs were interviewed and 12 participated in the focus group discussions. HCPs represented a broad range of clinical expertise (e.g., Psychiatrist, Psychologist, Psychotherapist, Nurse, Occupational Therapist), worked with children and young people from ages 0 to 25 years in outpatient capacities and had an average of 7.54 (SD = 6.24) years of working experience (see **Table 3**).

Data Analysis

All transcripts were initially read in its entirety to obtain familiarity and an overall understanding of the contents. Interview transcripts were examined for more detailed descriptions of participants' views, and focus group discussions were examined for consensus or disagreement between participants. Data were analyzed using the thematic coding

TABLE 2 | Characteristics of parents participating in interviews and focus group discussions.

Variable	Interviews ($n = 14$)	FGDs ($n = 2$)	Total sample ($n = 24$)
Parent's age			
Mean (SD)	45.93 (6.12)	43.4 (7.65)	44.88 (6.76)
Range	36–53	31–54	31–54
Relationship to child *n* (%)			
Mother	14 (100)	8 (80)	22 (91.67)
Father	0 (0)	2 (20)	2 (8.33)
Ethnicity *n* (%)			
White	14 (100)	9 (90)	23 (95.83)
Other	0 (0)	1 (10)	1 (4.17)
CYP's age			
Mean (SD)	14.36 (3.61)	13.2 (0.63)	13.88 (2.8)
Range	8–22	13–14	8–22
CYP's gender *n* (%)			
Male	5 (35.71)	2 (20)	7 (29.17)
Female	9 (64.29)	7 (70)	16 (66.67)
Other	0 (0)	1 (10)	1 (4.17)
[a]CYP's clinical characteristics *n* (%)			
[b]ADHD	1 (7.14)	0 (0)	1 (4.17)
Anxiety	0 (0)	4 (40)	4 (16.67)
[c]ASD	1 (7.14)	0 (0)	1 (4.17)
Depression	2 (14.29)	0 (0)	2 (8.33)
[d]PTSD	1 (7.14)	0 (0)	1 (4.17)
Comorbidities*	8 (57.14)	0 (0)	8 (33.33)
Undiagnosed**	1 (7.14)	6 (60)	7 (29.17)

**Comorbidities included a subset of ADHD, Anxiety, ASD, Depression, self-harm, suicide attempt, psychosis, and Asperger's Syndrome.*

***Undiagnosed represented children experiencing psychosocial difficulties but were not yet diagnosed.*

[a]Children or young people; [b]Attention Deficit and Hyperactivity Disorders; [c]Autism Spectrum Disorders; [d]Post-Traumatic Stress Disorders; SD, Standard deviation; FGD, Focus group discussion.

TABLE 3 | Characteristics of healthcare professionals participating in interviews and focus group discussions.

Variable	Interviews ($n = 19$)	[a]FGDs ($n = 2$)	Total sample ($n = 31$)
Occupation *n* (%)			
Consultant Psychiatrist	4 (21.05)	1 (8.33)	6 (19.35)
Psychologist/Psychotherapist	2 (10.53)	5 (41.67)	9 (29.03)
Nurse	2 (10.53)	4 (33.33)	6 (19.35)
Other*	11 (57.89)	2 (16.67)	10 (32.26)
Clinical expertise *n* (%)			
Eating disorders	2 (10.53)	0 (0)	2 (6.45)
General**	17 (89.47)	12 (100)	29 (93.55)
Experience in CYPMHS[b] (years)			
Mean (SD)	6.36 (5.87)	9.40 (6.62)	7.54 (6.24)
Range	0.58–20	2.25–20	0.25–22

**Other—represents Psychiatry/Medical Registrar, Occupational Therapist, Social Worker, Support Worker and Team Manager.*

***General—working in general children and youth MH settings which includes, but not limited to, behavioral, attention deficit and autism spectrum disorders.*

[a]Focus group discussion; [b]Children and young people's mental health services.

process outlined by Charmaz (43). More specifically, an iterative process consisting of open, axial and theoretical coding using inductive and deductive concepts was adopted. The first step generated initial codes from open coding in which units of meanings were derived from line-by-line analysis followed by axial coding to integrate and differentiate among subcategories. An independent investigator reviewed three random transcripts and generated codes. Codes were compared and discussed before inclusion. Theoretical coding was then used to identify relationships among categories. Demographic data and anonymous transcripts were linked and coded in NVivo 11 (49). Memos were written during the coding process to capture impressions and to facilitate interpretations.

Ethical Approval and Trustworthiness

Ethical approvals were obtained from the London Surrey Research Ethics Committee (IRAS 236277) and University College London. The participants received both written and oral information about the study's purpose, confidentiality, voluntary participation and their right to terminate the interview at any point. Participants had access to this information at least 24 h before the interview sessions and were given the opportunity to ask any further questions before the start of the interview sessions. A relationship was established briefly with each interviewee before the interview. Reflective journaling of thoughts was kept, and responses to data were discussed throughout the study. At the point of analysis, weekly discussions occurred to explore emergent themes and achieve consensus. Additionally, member checking was done in the form of clarification probes throughout each interview to ensure the interviewer understood the information as the participant intended. The credibility was also enhanced by triangulation, collecting interview and focus group data from parents and HCPs who may have had different perspectives (50). Findings were reported according to the recommended guidelines for qualitative research (51).

RESULTS

The findings were organized according to the key research questions for this study. Responses were presented as categories of themes and subthemes (see **Table 4**). The following section highlights the themes and subthemes, reported using exemplary quotes with descriptive characteristics as labels.

How Do Parents and HCPs Describe SDM in Current Practice?

A Somewhat Collaborative Process

Generally, participants (when referring to both HCPs and parents) expressed an overall understanding that SDM was the "involvement" of key decision-makers in a process described as

TABLE 4 | Summary of how the qualitative findings address the research questions.

Research question	Categories of themes and subthemes
How do parents and healthcare professionals describe SDM in current practice?	**Views and experiences** A somewhat collaborative process Positive experiences Negative experiences
What are parents' and healthcare professionals' views on the emotional experience of being involved in CYPMH decisions?	**Parents' emotional state** Positive emotions Negative emotions Mixed emotions
How do parents' emotional experiences impact on their involvement in the decision-making?	**Emotional influence** Facilitator or barrier
Where do parents access decision-making support?	**Support systems** Family's support network External agencies Online resources CYPMH site's internal resources

"collaborating," "exchanging information" or "working together" to identify a care or treatment plan that was in the "best interest of the child." Most participants were familiar with the concept and those who were unfamiliar were able to draw from their personal, lived experiences to describe SDM.

> *For me, I suppose shared decision making means some joined up thinking between clinicians, parents and young people if they're of an age where they can contribute and make their wishes known and their voices heard. (HCP, 13 years of experience)*
> *Oh, it means sitting down together, discussing things, listening and then coming up with a plan. (Parent#1 of a 17-year-old)*

Some participants expressed that the extent to which each decision-maker participated in SDM varied. The age and capacity of the child or young person and the nature of the decision were key factors to determine inclusion.

> *Erm.. Well depends on the sensitivity and age of the child because there are some things that I discuss, and I am not ok for my son to be around. (Parent of a 10-year-old)*
> *Her dad would sometimes be part of it as well, but not all the time. So, it would be me alone or two or three of us and the clinician. (Parent of an 11-year-old)*

Some participants also expressed that levels of involvement in SDM influenced who made the "final" decision. This suggested that at least one of the key decision-makers remains with the "final" decision making power. However, participants reported that the "final" decision generally occurred after the exchange of information and ideas. In some instances, it meant that a subset of the decision-makers was involved in the "final decision."

> *Umm. I think it has been a mutual sort of everyone throwing ideas into the pot and then we kinda come up with a plan. The final decision is my daughters. (Parent#2 of a 17-year-old)*
> *But it's not my decision, but I provide information so that they [parent and child] can make a decision. (HCP, 6.5 years of experience)*

Despite the child or young person's age, participants generally expressed that it was important to include parents in the SDM process. Parents and HCPs stressed the importance of parents "being in the loop" and the impact on treatment outcome. However, it appeared that levels of involvement from parents also varied.

> *Not necessarily involved but informed is probably a better way to put it. Just to be informed as to what they were covering. Maybe what they'd advised her to try and do over the week. That kind of thing just to be more informed, I think. (Parent#1 of a 16-year old)*
> *One, it gives the child a sense of they're not doing it alone, they've got somebody to go to who is informed and understands where they're going and what they've been through. If they're [parents] not involved, they [child] often feel very alone and in my experience, there's a lot of worse outcomes when the child is feeling alone. (HCP, 4 years of experience)*

Positive Experiences of SDM

When SDM, as understood by the participants, occurred, it was mainly described as a positive experience. HCPs expressed the usefulness of SDM and how it helped facilitate the care and treatment process. They also valued the child's input and described it as very positive.

> *There are many occasions when a parent will not want a particular intervention. And the child is saying, "Actually, I think I do." And the parent will support that child, even though they don't necessarily agree with it, which is heart-warming in a sense that they're giving the child the opportunity to express their own wishes. (HCP, 6.5 years of experience)*
> *Personally I find it very useful because if you get the young person, the parents and clinicians all get together to target the same goal then I find it more successful, it's more likely the intervention works. (HCP, 1.5 years of experience)*

Parents also found the experience of SDM very helpful. Some parents reported that this "shared" decision making also occurred outside of the medical encounter and was practiced within the family network. Therefore, experiencing SDM at CYPMH clinics was viewed as empowering and supported what one parent described as "interfamilial" decision making.

> *I think it's quite helpful. I think it's something that we generally did as a family anyway before my child became unwell in autumn last year. But I think we had, I don't know, lost the skill of that maybe by what had happened. And, so, it's been quite helpful and quite empowering and helpful that CAMHS have helped us to re-establish that, really. (Parent#2 of a 16-year-old)*

Negative Experiences of SDM

There were more references made to negative experiences of not successfully achieving SDM on many occasions. It was expressed that the lack of available resources limited options and therefore, acted as a barrier to SDM. Shared decision making was viewed as appropriate when more than one choice was available. This was challenging for services, as service users were sometimes aware of additional resources that were not currently being offered by the clinics they attended, resulting in further disagreements. Similarly, disagreements existed between the parent and the child or young person on various topics (e.g., reasons for accessing service). HCPs expressed difficulty to manage these disagreements especially if the parents were not actively engaged. However, some parents felt that they were unable to provide input as they were unaware of the options.

> *Sometimes you just don't have any idea of what all this means, how do I know which would work and which would hurt her even more. I don't even know where to start or what's available (Parent of a 13-year-old)*
> *. . . there may not be much of a lay understanding about mental health within a family. So, when it comes to asking them what they think or what they might want etc., they really have no idea because they've not come across anything like mental health with their child or with any of their family members either. So, they really do then say, "Whatever you think is best, doctor." So, I think that, obviously, makes shared decision making very hard. (HCP, 2.5 years of experience)*

What Are Parents' and HCPs' Views on the Parents' Emotional Experience of Being Involved in CYPMH Decisions?

Parents identified a broad range of positive and negative emotional experiences. Similarly, HCPs described a broad range of emotions observed in the parents they encountered in routine care. These emotions (e.g., anger, stress, frustration, relief) were described on a spectrum.

> *Well, it can be a massive range; some are relieved, some are frustrated, some maybe angry, some are just really grateful that they're being seen. It just goes from one extreme to the other. It depends on the person and from the family of the young person's personal experience of being in the service. (HCP, 20 years of experience)*
> *It always makes me feel quite anxious. Because I know that it makes my daughter then quite anxious and upset. She doesn't like talking about her problems. But it also makes me feel like I'm relieving something. (Parent of a 9-year-old)*

Positive Emotions

Participants described positive emotions arising after a challenging period. Some parents described feeling a sense of relief of finally receiving a diagnosis or finally getting seen at CYPMH clinics. Additionally, after seeing their child "struggle" with mental health difficulties, parents expressed joy in seeing a positive outcome from treatment decisions or being able to share the burden.

> *It is more a sense of relief and being a bit more hopeful by the time they finish the session. (HCP, 10 years of experience)*
> *. . . after I understood what he is going through, or what I can do to help him, it became much, much less stressful. And in general, I am very happy with him and I don't have much stress anymore. (Parent#1 of a 14-year-old)*

Negative Emotions

On the other end of the spectrum, parents experienced emotions such as anxiety, worry, anger, frustration and fear. These feelings were also reported as being observed by HCPs in most cases, and participants reported that these emotions varied among families and situations.

> *I see a lot of frustration. Sometimes a lot of anger from the young people's families about the time that they've had to wait for specific treatments. (HCP, 1 year of experience)*
> *I thought the world had stopped. This came like a bolt out of the blue, and for the first two days I didn't know what had hit me. I was absolutely shell shocked. (Parent#2 of a 14-year-old)*

Mixed Emotions

Parents also described emotions as co-occurring or described having "mixed" feelings. Parents reported having to focus on the outcome of the decision and therefore, despite experiencing negative emotions, they felt a need to be involved. This conflict within themselves resulted in positive and negative feelings co-occurring. To illustrate, one parent stated,

> *Erm. Very mixed emotions. I mean you would rather not be in those decisions at all. But when you are in that situation, I am glad that she wants me there, I am glad that she wants me to support her and I am very glad that I have some idea of what is going on so I can support her more effectively. Umm I mean all of us are highly anxious. The anxiety of worrying about the wellbeing of my child. You got the anxiety at the initial sessions of what are these people thinking of you. There are lots of lots of feelings to be anxious but you manage it because you have to. (Parent#1 of a 17-year-old)*

How Parents' Emotional Experiences Impact Their Involvement in the SDM Process?

Facilitator or Barrier

Participants expressed that emotions generally influenced parents' involvement in care and treatment decisions. In some instances, they described the reverse also occurred where the involvement also affected the parents' emotional state. They expressed that both negative and positive emotions influenced involvement. More expectedly, negative emotional states resulted in parents not being actively involved in SDM and positive emotions encouraged involvement. Participants highlighted that in some instances, the negative emotions appeared to complicate the SDM process as it made it difficult to participate even if they wanted to. However, participants also expressed that negative emotions made some parents more "forceful" suggesting a form of over-involvement. Similarly, some positive emotions, like when parents were comfortable or fully trusting of the HCPs, they decided to be less involved. Other emotions such as relief, content, satisfaction and hope had a more positive impact on the SDM process and appeared to encourage parents to be actively involved.

> *If you're [parents] anxious and distressed, the anxiety may want you to kind of take full control and therefore, you're [parents] going to want to be more involved. But it might make them [parents] back off, so they might not want to be involved. However, if they've got that feeling of hope, because they think that they're in a position where I'm [HCP] talking like I know what I'm on about, then they may think, 'All right, the doctor knows; I don't need to be so involved.' (HCP, 2.5 years of experience)*
> *It was a very difficult and very stressful time. I think I was pretty passive at that time, yes. I wanted other people to tell us what was the right way to go to make life better for my daughter. Yeah. (Parent#1 of a 16-year-old)*

Where Do Parents Access Support?

Participants reported accessing various sources of support during decision making periods. Parents generally appreciated contact with and support from the family's own support network, external agencies, the CYPMH site and online services. Emotional support and knowledge support appeared to almost be used interchangeably. Although, family members and friends offered emotional support, in some instances, parents relied on their decision making input. Strategies that were described as "helpful" or "useful" varied in the participants' responses. The majority of HCPs referred parents to more than one resource, and many parents reported accessing multiple sources of support.

Families' Own Support Network

The support the parents needed and received from others varied between parents, over time and decision type. Many received support from family members, friends, and other parents. In some instances, parents received support from extended family members, e.g., grandmothers. In other instances, they described relying on support only between parent (s) and child.

> *Obviously, my husband. He's always my first port of call really with things like that. And then outside of that, friends and family. (Parent#2 of a 16-year-old)*
> *Just my wife. (Parent of 12-year-old)*

External Agencies

Parents reported accessing charities and other services for support. This was both practical (e.g., financial, information) and instrumental (e.g., seeking advice from persons with similar experiences). HCPs also reported referring parents to known charities and other support services.

> *We often refer them to the Early Help Hub, but they're kind of like a signposting service and they can access family therapy and family support workers. That's something I've done a couple of times recently. (HCP, 4 years of experiences)*

Online Resources

The majority of HCPs reported signposting parents to online resources from "trustworthy" sources. There were some concerns from HCPs about parents using "Dr. Google" and encountering inaccurate or worrying information. However, parents admitted to using a wide variety of online websites and resources to gather information.

> *I use a few websites that are useful. I can always just use the internet and if I put in the right thing to search, I get a bit of information. (Parent of an 11-year-old)*

CYPMH Site's Internal Resources

Generally, the CYPMH site was seen as a vital resource. Although some parents described the help as being solely for the children and young people, parents appreciated this as they felt happy knowing their child was being seen. However, HCPs reported having to spend time responding to parents' concerns outside of appointments. Interventions offered by the CYPMH services were limited but included interventions such as information outlets, signposting, parent groups and family therapy. When reporting family therapy and parent groups as sources of support, parents described shortcomings such as long waiting times and lack of time to attend group sessions.

> *That's probably the one downside is that my husband and my daughter are both on the list for family therapy, but the waiting list is so long I don't know when that's going to happen. (Parent#3 of a 16-year-old)*
> *But on paper, we have family therapy, but it's pretty hard to get because of the waiting list. I think we have maybe one or two teams in our service that I'm aware of. But again, not enough service in my locality. (HCP, 4 years of experience)*

Summary of the Findings and Interviewer's Reflection

An overall concept suggesting that parents are "expected to, but not always able to" engage in SDM encapsulates the findings. Themes and subthemes described: (1) views and experiences of SDM, (2) parents' emotional states, (3) the influence of emotions on SDM and (4) support systems accessed. The overarching themes were organized into a conceptual framework illustrating an evidence-informed affective-appraisal model of SDM (see **Figure 1**) in CYPMH. The figure depicts the key decision making actors and influencing factors. The affective-appraisal approach to SDM recognizes that affect and appraisal interact in shaping the SDM process, influencing each other in a circular way where the decision may elicit the emotional reaction, that in turn influences the SDM process, that again may influence a change in the emotional reaction. The findings suggest that adequately supporting parents can activate them to engage in high quality SDM. In this way, emotional support would allow the identification of parents' values and needs associated with SDM, thus enriching the SDM experience.

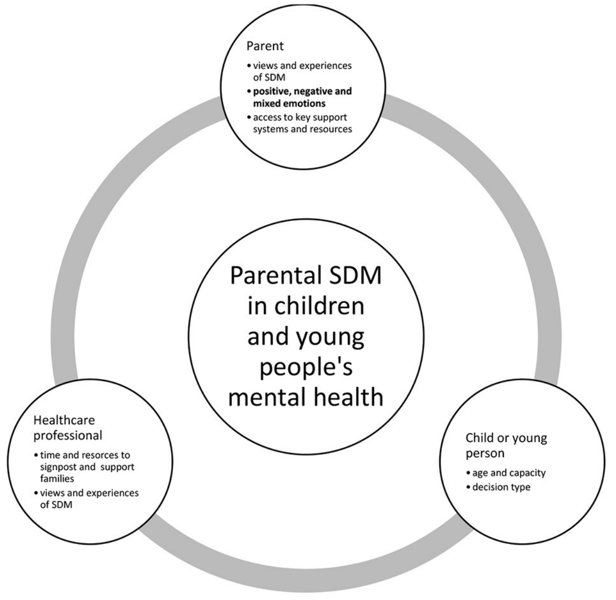

FIGURE 1 | Conceptual framework of an emerging affective-appraisal model of parental involvement in SDM in children and young people's mental health.

DISCUSSION

This study provided insight into the experiences of parents involved in CYPMH care and treatment decisions from the perspective of both HCPs and parents. The overarching concept illuminated the affective-appraisal approach framework to SDM that revolved around an interactive parent, child and HCP SDM process. In line with existing evidence, the appraisal process referred to ongoing value-based judgments linking emotion and cognition occurring before, during and after SDM. The current findings also agree with other researchers highlighting emotions as an influential factor to SDM (25). It was also observed that the circular framework replicated the triangular configuration in previous studies that emphasizes the dual role of parents as both services users and caregivers of their children (26). This study adds that decision maker's views and emotional experiences of SDM and access to key support systems appear to be essential to SDM in CYPMH settings.

The understanding of SDM from parents and HCPs also aligns with the extant literature on definitions of SDM as a collaborative process between service users and service providers (1, 7). However, our findings confirm the uniqueness of the triad in CYPMH decision making and may disagree with other researchers. Although Park and Cho (11) suggested that parents, children and HCPs should be involved for the process to be referred to as SDM, the current findings indicate that not all decisions makers need to be actively involved at all times for SDM to occur. Instead the current findings align with other researchers (12) and further highlights that the levels of participation in SDM may vary in different aspects of the process depending on the legal context, capacity, experience and expertise of the participants and type of decision. Therefore, further investigations are needed to identify if existing SDM measurements are accurately capturing the levels of involvement taking into account the "informed" vs. "involved" approach to SDM in CYPMH settings. This study also confirms there may be a lack of knowledge on SDM involving caregivers, especially when the primary service user is a child or young person (5, 15). Existing models discuss "shared decisions" which were not clear in the current findings as some participants stated that there exists a "final" decision-maker (s) at the end of the SDM process. This understanding suggested that the "final" decision may not be viewed as the end product of the SDM process, but further steps such as agreeing on the final decision (outcome) could be explored and may be unique to the field of child health. Having HCPs and parents explicitly agreeing with a child's or young person's choice of treatment may be empowering. This study also adds to the youth SDM framework (16) by highlighting the importance of identifying parents' and children's preferences for involvement when setting the stage for SDM, and capacity when facilitating SDM. The findings also build on that of Crickard et al. (16) by identifying specific sources of information for supporting youth SDM.

This study also extends on what is already known about the "emotional roller coaster" that parents of children with mental health difficulties experience (30, 31), suggesting implications for an effective SDM process. Although the current findings align with previous research identifying parents' emotions as a possible influencing factor to the SDM process (22, 24); the current findings, build on this knowledge by identifying positive, negative and mixed emotions as barriers or facilitators. Further to this, the current findings suggest a two-way direction that emotions may be influencing parents' involvement in SDM and vice versa. This supports theories in the cognitive literature around decision making and emotions highlighting that health decision making is challenging during emotional periods (52). Similarly, decision making under stressful conditions was proven to be difficult for parents in both quantitative and qualitative studies (53, 54). However, some parents in this study expressed having to "get on with it" despite their own personal feelings. This raises further questions around active and effective involvement. In that light, the current findings support previous research highlighting the expectation that parents are to be involved in the SDM process despite their emotional states (26). As a result, policy-makers, researchers, practitioners and families should work together to develop and promote support mechanisms that are suitable and effective in this population. Nonetheless, it is not yet clear why emotional states vary among different populations and at different times and therefore, future studies could further explore this phenomenon.

This study also highlighted that parents relied on additional support from service providers, and therefore, HCPs had to invest time to offer the necessary support to parents. CYPMH services mainly provide services for children and young people, and limited resources are available within services to support parents (41). Therefore, having interventions that can be used outside of regular appointments can impact both HCPs and parents. Many HCPs reported signposting parents to external agencies and websites, and parents themselves reported accessing charities and online services. The latter is in line with the help-seeking literature that suggests carers are increasingly seeking information from online resources (55, 56) and further highlights the relative importance as expressed by both HCPs and parents. Therefore, policy-makers and practitioners should take note as poor quality information may exist online and some external agencies may not follow appropriate ethical and practice guidelines (57). An exploration and standardization of the role the internet and external agencies play in providing information or added emotional support to parents are warranted so services can harness these resources as tools.

Relevance to Clinical Practice and Policy

An efficient SDM process may help minimize frustrations and anxiety around care and treatment options. Although, HCPs and parents expressed positive experiences when involved in SDM, the perspectives of children and young people are critical before recommendations are made about who should be involved in the SDM process. Therefore, this study also highlighted that the triad should explore each other's preference for the level of involvement considering "informed" vs. "actively involved." This approach can help further minimize the burden and anxieties parents face when being the sole decision-maker (53). If parents are able to share this responsibility in a "trusting" relationship while feeling listened to, this may positively influence the SDM process. Additionally, encouraging a wider partnership with schools and organizations can help support the SDM process by providing families with both information and emotional support.

The findings of this study could further inform the Triangle of Care model by highlighting the lack of or limited support for parents accessing CYPMH services. Although the child is viewed as the primary service user, the importance of parent involvement in the decision making was crucial for successful care and treatment. Therefore, increasing the time spent per client may allow time for HCPs to include and involve parents in the care and treatment plans, depending on the age and capacity of the child. Alternatively, implementing additional programs to support parents throughout crucial decision making time points may help improve experiences of SDM. Whilst this may be useful, HCPs and community services will need to be kept up-to-date with available resources. Lastly, it was noted that parents often access charities and other services outside of CYPMH services to receive the necessary support. Therefore, it would be recommended that policy guidelines are in place to provide a bridge between the community and CYPMH services to ensure consistency, competence and ethics are maintained.

Future Directions

The affective-appraisal approach to SDM model provides a preliminary framework for future works. Therefore, the proposed framework is subject to further revisions and adaptations. First, it is critical to add the voices of children and young people to those of the parents and HCPs obtained in this study to provide an accurate perspective of SDM and the influence of emotions in CYPMH services. Second, a consultation exercise with SDM experts will be beneficial to further enrich our current understanding and interpretations. Third, although it may be challenging, it is important to empirically test the model, specifically controlling for sources of emotions (e.g., receiving a diagnosis).

It is also important to carry out program and intervention evaluations to identify and evaluate currently existing SDM support tools to identify which resources are most beneficial. The theory of "parents being expected to, but not always able to" be involved in CYPMH care and treatment decisions suggests that it would be of great value to continue to develop and implement SDM interventions to promote collaborative decision making. As the theory's transferability is strengthened by this study, the theory can be the basis for intervention development and future research. Therefore, adopting an affective-appraisal approach to SDM may help inform interventions and support families that are in need of additional support. Finally, a quantitative exploration informed by the grounded theory identified in this study may help develop inferences around group differences. This is especially important to ensure traditionally underserved and underrepresented families are targeted.

Strengths and Limitations

This study included a large sample size allowing for the attainment of data saturation. This study also highlighted the views and experiences of parents of children of varying ages and experiencing a range of mental health problems. In addition, HCPs with a variation in clinical backgrounds were involved in this study, allowing for a much broader understanding of the field, as well as increasing prospects for the transferability of the findings. Another strength included the approach to explicitly consider emotion (or affect) and SDM, as well as the specific focus within services for children and young people. However, this study is not devoid of limitations. First, the majority of the sample ($n = 51$) was recruited through referrals from various CYPMH sites as part of a larger feasibility trial and therefore the researcher had limited control over who were invited and recruited into the study. It is possible that parents and HCPs who are more inclined to be involved in SDM may have expressed interest and therefore biased the study sample. However, high levels of involvement with SDM may have increased and maintained active discussion in the interview sessions. Second, the participants' characteristics were not matched to their contributions for the purpose of examining any potential variability among the participants. Similarly no major comparisons were made between participants' views on SDM and their actual experiences of SDM for the purpose of analysis. Therefore, experiences of SDM may be specific to the majority sample (i.e., White British mothers of adolescent girls) and caution should be taken when interpreting and deriving implications from these findings. This could be viewed as a major limitation if attempts are made to generalize the findings to other groups, as the experiences of parents may differ depending on the child's age and gender. Nonetheless, some variety may have existed in terms of child's symptoms, parent's age and HCP's experience that reflected multiple perspectives and a multidisciplinary view on SDM. Although the methods adopted was in line with the social constructivism approach promoting the infusion of understandings through social interaction, the current study acknowledges that the emotional state of HCPs and young service users were not reflected in the analysis. This limits the extent of interpretations as to how much parental emotions could have been influenced by others. In addition, participants were asked to discuss their experiences of SDM in CYPMH services. Due to the slight variations in how the participants defined SDM and the subjective nature of the question, participants may have selected to express their first or most recent recall of SDM, therefore neglecting other instances of SDM or lack thereof. Lastly, the perspectives of children and young people were not captured in this study, and therefore limits the extent which our findings can be readily incorporated.

CONCLUSION

Previous research findings indicate that the involvement of parents in CYPMH is linked to better health outcomes. Although SDM is recognized as a person-centered approach for quality healthcare, this current study suggests that levels of involvement in SDM may vary and parents experience a spectrum of emotions that may influence their participation in SDM. Therefore, the importance of the SDM process in CYPMH cannot be underestimated, and SDM should continue to be assessed and supported. In particular, an affective-appraisal approach to SDM may be needed to adequately support parents. Future studies should continue to investigate this phenomenon.

DATA AVAILABILITY STATEMENT

The datasets generated in this article are not readily available because The data contains confidential information about the participants. Requests to access the datasets should be directed to shaun.liverpool.14@ucl.ac.uk.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethical Approvals were obtained from the London Surrey Research Ethics Committee (IRAS 236277) and University College London. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

Analysis and interpretation of the data was conducted by the SL and supported by the DH and JE-C. SL drafted the manuscript. DH and JE-C contributed to the editing and refinement of the article before submission. All authors contributed to the conception and design of the study.

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Shared Decision-Making: An Autoethnography About Service User Perspectives in Making Choices About Mental Health Care and Treatment

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Shared decision-making (SDM) between mental health medication prescribers and service users is a central pillar in the recovery approach, because it supports people experiencing mental ill-health to explore their care and treatment options to promote their well-being and to enable clinicians to gain knowledge of the choices the service user prefers. SDM is receiving increasing recognition both in the delivery of physical and mental health services; and as such, is of significance to current practice. As an expert-by-experience with over 30 years of receiving mental health treatment, I have made many choices about taking medication and accessing other forms of support. The experiences of SDM have been variable over my career as a service user: both encounters when I have felt utterly disempowered and interactions when I have led decision-making process based on my expertise-by-experience. In this article, I recount two experiences of exploring care and treatment options: firstly, a discharge planning meeting; and secondly, the choice to take medication over the long-term, despite the side effects. The article will explore both opportunities and barriers to effective shared decision-making, as well as skills and processes to facilitate this approach. The need to balance power between service users and professionals in this interaction is highlighted, including the need to respect expertise built on lived experience, alongside that of clinical expertise. This narrative is framed within an autoethnographic approach which allows me to contextualize my personal experiences in the wider environment of mental health care and support.

Keywords: medication choices, autoethnography, service user perspective, prescribers, well-being

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INTRODUCTION

Recovery is an aspirational practice at the center of mental health service delivery in the UK today (1, 2) and underpins the implementation of services for people experiencing complex psychosis (3). Recovery is a process which supports a person with lived experience of mental ill-health to self-manage their condition putting them at the center of decision-making about their lives (4). Using the acronym, CHIME, the essential elements of this approach are conveyed (5): recovery is perceived as a unique journey which requires Connectedness, Hope and optimism about the future, the creation of Identity, Meaning in life and the need for Empowerment. Recovery promotes the development of agency and autonomy in the lives of service users (4); thus, the process of shared decision-making (SDM) in choices about mental health interventions enables people who use services to co-produce recovery in partnership with the practitioner (6). This article will explore my experiences of decision-making processes in two professional encounters as a user of mental health services for over 30 years, enabling me to illuminate this approach from my perspective as both an expert-by-experience and a social work academic. This narrative is framed within an autoethnographic approach (7, 8), which allows me to contextualize my personal experiences in the wider environment of mental health support. Moreover, it provides me with the opportunity to investigate what makes effective SDM in the process of clinical interventions from my hybrid standpoint as both a social care professional and a service user expert.

Shared decision-making (9) is defined as "a process in which decisions are made in a collaborative way, where, trustworthy information is provided in accessible formats about a set of options, typically in situations where the concerns, personal circumstances, and contexts of patients and their families play a major role in decisions." SDM lies along a continuum of forms of decision-making in health and social care settings which range from paternalistic to informed choice approaches (10, 11). The advantages of SDM include increased therapeutic alliance, enhanced shared knowledge and understanding of key intervention issues, saving time in review meetings, and an increased commitment to implementing decisions jointly taken (6). Moreover, in a systematic review and meta-analysis of the evidence, collaborative decision-making around psychiatric treatment (12), in a process that considers patient preferences and values, is likely to help people receiving treatment for psychosis experience greater empowerment and reduced coercion in relation to their care. Moreover, in a study of implementation of SDM in youth early intervention services (13), family caregivers were involved in decision-making and it was posited that involvement should be negotiated on an individual basis; however, all caregivers should be supported with information about mental ill-health and treatment options.

Since 2012, UK guidance has stipulated that processes of SDM should promote choice and the development of agency for people who use mental health services (14). SDM is seen at the forefront of moves toward personalized care which "means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths and needs" [(15): 3]. Moreover, personalized care is at the center of the development and delivery of health and social care in England and Wales (15); and, also, in mental health care (1, 2).

Despite this stipulation, the implementation of SDM in the care of people who use mental health care (15) in mental health policy in England (14, 15) is tempered with the need to manage risk and to ensure the safeguarding of vulnerable people. Thus, the balance between care and control in the delivery of mental health services is located between the duty to protect life under the Human Rights Act, article 2 (16), and a duty to preserve and promote choice, dignity, and freedom (17). These two poles of care provision exist at different ends of a continuum, given that professionals aim at balancing the need for care and control. Thus, SDM is a framework which is controversial for many professionals (18) making its implementation challenging for both professionals and service users (19). Additionally, its emphasis on the importance of acknowledging the value of experiential knowledge in the therapeutic alliance between the service user and the practitioner can also be demanding because it generates a new relationship between these two parties (6). It requires a shift in the behavior and attitudes of both participants in recognizing each other's expertise in this interaction. Moreover, the value of expertise-by-experience is further highlighted in an Australian study, which implemented peer support (individuals with lived experience helping other consumers) in shared decision-making processes in youth early intervention settings (20); this study emphasizes the place of experiential knowledge in SDM.

In the next section, I reflect on my experiences of decision-making in mental health management as I recount two encounters of mental health intervention framed within an autoethnographic approach. These interventions are discussed to enable an understanding of the effectiveness of SDM from my standpoint, as both an expert-by-experience and a social work academic. The reflections thus serve as a *springboard* to highlight the processes of SDM and to enable further exploration of the nature of decision-making in mental health care from the perspective of an expert-by-experience.

Autoethnography: A Process of Reflection to Illuminate My Response to SDM

Autoethnography has been used widely in health and social care research, education, and practice (20, 21). Autoethnography is employed in this article to reflect on my experiences of SDM through a process of writing, and to position them in the wider social and political environment (7). Reflective practice has a long tradition in the helping professions as a method to develop both personal understanding of the lived experiences of service users and carers and of innovation in practice (22), therefore, autoethnography is appropriate to this article. Autoethnographic writing (7) requires the researcher to pay careful attention to both the *epistemic* (claims to knowledge) and the *aesthetic* (practices of imaginative, creative, and artistic craft) characteristics of their texts as they seek to convey the meaning of their individual experiences and communicate their significance to the wider community of practice.

Autoethnography strives for social justice (7) and promotes moral and ethical debate through the process of reflexivity (8). My accounts were analyzed by using thematic data analysis (23) and themes commensurate with the literature were identified and integrated into the discussion. Thematic analysis involves a six-phase process (23); however, it is often flexible, encompassing an approach that can be both "inductive" and "data-driven." Thus, initially, themes were identified inductively as I read and re-read the reflections that *described* the experiences expressed in the accounts; then themes were identified which were commensurate with the published literature. Furthermore, different sources of evidence are used alongside my reports to explicitly link concepts from the literature to my narrations. Thus, both the process of reflexivity (22) as a service user and academic (24) and the narratives in the article facilitated the connection of "the autobiographical and personal to the cultural, social, and political" (25).

Ethical challenges may arise when using such a personally revealing research process as autoethnography and writing about such intimate experiences. This situation is explored by Goldberg et al. (26) who illuminate the experiences of a mental health practitioner who also became a hospital inpatient. Goldberg et al. (26) discuss the need to manage both personal and professional boundaries and to consider these needs carefully in relation to the working and professional environment; an issue highlighted in the context of social work (27).

As an expert-by-experience (24) I choose to use my lived experiences of mental distress to effect positive change in mental health care (28), but, of necessity, I have learnt to separate personal emotions from the professional domain. I communicate my encounters with services by *objectifying* the substance of these experiences to explore them as *empirical data*, rather than as occurrences full of emotional content. This division allows me to disconnect the personal from the professional and maintain a divide between these two domains. However, at times, reliving my past experiences may impact on my sense of mental well-being, and I find it necessary to pause the process of writing to give myself a break (21).

My Experiences of SDM

In this section I recount two experiences of decision-making in clinical care: one at the start of my mental health career and one more recent experience. This illuminates an understanding of this topic from my perspective. I have taken mental health medication for over 30 years and reflect on how my own expertise and relationship with professionals has adapted and changed. I describe, firstly, one memory of early involvement in decision-making following my first stay in hospital, and, secondly, a more recent experience of trying a different mental health medication.

The first situation occurred when I was attending a planning discharge meeting whilst emerging from my first episode of acute psychosis. This was my first experience of being in hospital and of mental distress. On discussing when I would be discharged, I entered a room with more than 15 people and remember nothing more of that meeting than the number of faces staring back at me. This encounter remains in my memories after over 30 years of care, I remember there being no support, no explanation of the meeting, and no discussion of the outcome. It is a single and clear memory, with little embellishment. There was no understanding of the enormity of this experience or of the sense of fear and disempowerment I experienced; this encounter was very far from the ideal of involvement in decision-making and evidenced power being situated completely in the hands of professionals. It may have been helpful if the purpose of the meeting had been discussed in advance; if I had been informed of what to expect from the meeting; and if I could have been accompanied by an advocate or person I had got to know on the ward.

My second account relates to an experience within the last 2 years. I went through a period of excessive weight gain. I met with the psychiatrist who I have known for over 30 years. He has now semi-retired from the NHS and I chose to see him privately; otherwise, I would not be able to access mental health support in a timely way. The medication I take increases my appetite and makes me crave foods; other side effects include: an increased propensity to develop diabetes, global sedation, cloudy thought patterns, reduced libido. I wanted to explore changing medication. This drug supports me to manage anxiety by evening out the extremes of emotion, although, one disadvantage of this medication, is, I believe that it has suppressed my natural emotional responses. This is a side effect which I accept as a pay-off for managing anxiety. The psychiatrist explored my concerns about weight gain and committed to investigate some alternative treatments.

When we next met, the psychiatrist recommended some options, and I chose to take a new medication. I found it to be effective in reducing my appetite, but less effective at containing my anxiety and other feelings of paranoia. I tried the change for 2 months and then, in consultation with my psychiatrist, returned to the medication that I know works best for me; albeit I immediately gained the weight I had lost. I had to decide between taking a medication that enabled me to manage my mental ill-health and increase weight, and to take a less effective medication that did not cause weight gain. This was a decision driven by expediency as I needed to function effectively in both my personal and professional life.

These encounters highlight two specific themes that are central to the practice of SDM in mental health care: the impact that a service user's incapacity, lack of insight and acute distress can have when negotiating clinical interventions in the context of SDM; and the change in decision-making processes when the service user becomes a self- acknowledged expert-by-experience, as well as being recognized as such by practitioners.

DISCUSSION

The first encounter occurred 30 years ago at an inpatient discharge planning meeting following my first episode of acute psychosis. The second was a more recent encounter when I chose to see a psychiatrist as an outpatient to discuss my medication and treatment options, where I subsequently felt this experience was an example of effective SDM. The first encounter occurred at the beginning of my mental health journey, long before there were any guidelines on SDM. I would not have considered myself an expert-by-experience at the time of the first encounter; I had no comprehension of what mental illness symptoms were and had not heard of the terminology of psychosis. In the second encounter, initiated by myself, I had decades of first-hand experience with mental health practice, and was informed about the side effects of the various suitable medications for my condition, hence at that point, considered myself as an expert-by-experience. In the first encounter, the psychiatrist didn't know me, nor was I able to understand my condition or to understand what was happening to me. I remember little being discussed with me about psychosis or little information provided to me. This was a barrier to SDM in its simplest format.

These two accounts demonstrate how decisions are made in mental health care based on different kinds of expertise: the former presents an episode of an uninformed and under-involved patient, subjected to the power of the professionals, having decisions made for her; whilst the latter episode exemplifies an interaction of shared power as decisions are made based on both experiential and clinical wisdom. This second example reflects a process of SDM, because at its core is a shared agreement and shared enterprise between the service user and the professional to share risk (6). This requires the practitioner to give up some of their power and enter a more equal relationship with the service user and be open to the service user perspective (18).

My experiences of recent care have been underpinned by my expertise-by-experience and based on my own expert knowledge of my condition.

To promote SDM, in my experience, effective communication is central to interactions between the service user and the professional (19). Three elements have been identified as key to effective SDM (29): knowing the client; awareness of the practitioner; and the therapeutic relationship. The client needs to want to be involved in SDM and be trained how to engage in it, and the professional should be aware of SDM techniques and should place the therapeutic alliance with the patient at the center of the interaction, offering clear information and actively listening to the client's viewpoints. In support of this, it has been found that establishing effective relationships based on a person-centered and user participation model are more important in decision-making than following an established pathway with little consultation (30). Additionally, the three-talk model of SDM (9) highlights the need for active listening between the parties leading to discussion of possible options for the service user to make when facing a decision.

From my accounts, these elements are essential to effective SDM. Responding to my needs, clarifying information, and respecting my expertise are key to informed decision-making. Although in the first episode of psychosis I was so overwhelmed by the distressing experiences, that I was less able to be involved in making shared choices about my care, but this does not mean that I was too unwell to have care processes explained to me and understood by me. Despite the experiences I had, there are many enablers and barriers which both promote and obstruct the implementation of SDM; these issues are further highlighted in the next part of the discussion.

Clinicians may be more likely to implement SDM in certain circumstances such as when encounters are initiated by the service user (28). Moreover, service users who participate positively in SDM and who do not dispute their diagnosis, do not reject relevant clinical facts about their diagnosis or treatment, and are not experiencing negative emotional symptoms may be more likely to be invited by clinicians to share in decision-making about their care (24, 28). Additionally, when a service user has capacity, a clinician can facilitate current and future SDM by recording the service user's preferences, values, and health experiences (e.g., hospitalisations and treatments) (6). By using SDM, professionals could help service users to clarify their preferred care plan for future care during acute episodes. In parallel, professionals can learn from service users not only what their preferences are, but also the underlying reasons for these choices; learning effectively from their expressed options.

However, a service user's perceived lack of insight into their mental health condition (10) and safe-guarding concerns about their situation may be a barrier to professionals' willingness to implement SDM (18) because risk management is at the center of mental health practice (17). Moreover, challenges to implementing SDM have been identified when clients are in severe mental distress or lack insight (10), as experienced in my first situation of acute distress. Moreover, professionals sometimes believe that lack of capacity negates the process of SDM as a service user is perceived as unable to participate effectively in decision-making processes (18). However, despite this, many service users with psychiatric conditions retain capacity to make all or most decisions about their own care, even though their capacity can fluctuate. Furthermore, even when a service user lacks capacity, their perspective is still worthy of regard and should be considered (4).

Thus, despite these barriers to the implementation of SDM, input from the service user about their care preferences might provide critical information about how a medication makes them feel or how difficult or easy it is to adhere to specific treatment demands. This therefore suggests in the circumstances such as those described in my first encounter with mental health services, information delivered at the right level and respect for my understanding could have been garnered about my preferences for future treatment and care to support my recovery (5).

In cases where service users are perceived by professionals as lacking insight, capacity, or are assessed as engaging in unsafe behaviors, when the professional believes that the "correct" safe-guarding decision is not agreed in a safety concern, then they may believe they have little option but to reject SDM and to revert to former paternalistic strategies (6); a real anti-thesis to the ideal of recovery (4). For example, clinicians may fear that SDM may lead to non-adherence to medication (17). In such circumstances, professionals may not prioritize and value the reasons why service users choose not to comply with medications which may cause them negative and intolerable adverse effects. In such circumstances, professionals may feel that they are accountable for safety decisions; thus, this highlights that professional responsibilities about the medical and legal limitations of professional accountability need to be clarified (18) and emphasizes the need for value to be placed on listening to and respecting the opinions of the service user, as identified above.

This article has explored the process of SDM through the frame of my autoethnographic account of two experiences of intervention; the former episode in which decision-making was based on paternalistic processes and the latter interaction in which decisions were user-led. This discussion has explored the implementation of SDM and discussed the importance of effective person-centered care in this interaction (30) alongside the importance of a therapeutic alliance (6); which are essential ingredients in the promotion of a recovery serviced promoting agency and empowerment (4).

To support the effective implementation of SDM, clinicians should adhere to the necessary conditions for SDM which are mutual respect and trust, and should provide information in a language understood by service users. There must be attitudinal change in the professional domain, as well in the perspective of some service users, about the place of experiential knowledge in building a therapeutic alliance. Practitioners must, for example, be prepared to listen to treatment options suggested by service users which the professionals themselves have not considered previously, acknowledging the value of experiential wisdom, alongside their own practice wisdom. The implementation of SDM thus has real implications for the place of safe-guarding in mental health care and requires a shift in wider policy to a greater focus on the place of experiential wisdom in decision-making in mental health interventions.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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Barriers and Enablers to Shared Decision Making in Psychiatric Medication Management: A Qualitative Investigation of Clinician and Service Users' Views

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Shared decisionmaking (SDM) is a recommended health communication approach in mental health settings. Yet, implementation of SDM in psychiatric consultations discussing medication management is challenging. Insufficient attention has been given to examine the views of both clinicians and service users together about the experiences of SDM in psychiatric medication management. The purpose of this paper is to examine the views of service users, community psychiatric nurses, and psychiatrists about enablers and barriers of SDM. A thematic analysis of 30 semi structured interviews with service users, psychiatrists, and community psychiatric nurses, in a community mental health team in the UK, was conducted. A service user advisory group was involved in all phases of the research cycle, including data collection, analysis, and dissemination. The results offer a detailed contextualized account of how medication decisions are made. For psychiatrists and service user participants SDM is seen as a way of enhancing service users' engagement in and control over treatment decisions. While psychiatrists value the transactional benefits of SDM, service user participants and psychiatric nurses conceptualize SDM as a long-term endeavor embedded within therapeutic partnerships. For service users these partnerships mitigate acknowledged problems of feeling unable to be fully involved during times of crisis. This study identified a range of barriers and facilitators to SDM concerning psychiatric medications from the lived experience of service users and the professional experience of clinicians. Furthermore, it indicates new potential intervention points to support SDM in psychiatric medication decisions.

Keywords: shared decision making, barriers, facilitators, co-production, medication, psychiatry, coercion, stigma

INTRODUCTION

Psychiatric medications are often considered to be the cornerstone of psychiatric care (1, 2). Yet, many mental health service users do not choose to take medication consistently or at all (up to 75%) despite the increased risk of relapse (1, 3–5). Overall, inconsistent use of psychiatric medications may be a reflection of ineffective or lack of communication between psychiatrists and their patients regarding the harms and benefits of the medications, the range of options and varying side effects, and how psychiatric medications can facilitate recovery (6). Inconsistent use of psychiatric medications is associated with mental health services disengagement, frequent emergency department visits, hospitalizations, and more-severe symptoms over time (3, 7).

Shared decision making (SDM) is a recommended healthcare communication practice, with the potential to improve treatment decisions and health outcomes (8, 9). In an SDM process the emphasis is on the patient as a person, taking into account patient's preferences, needs, beliefs, and concerns about etiology and treatment, and incorporating patients' experiential knowledge. SDM can also promote the person's involvement in their care, services engagement and treatment adherence (8, 10). In mental health care, SDM has been also associated with to promotion of self-determination, self-directed care, and the personal recovery approach, dominant across most health care systems in the Europe and Anglophone countries (11, 12). SDM is viewed as an ethical imperative across mental health systems globally (13). In the UK, SDM has been embedded in policy and practice guidelines for the last two decades and forms part of statutory requirements and training among mental health practitioners (14). SDM can lead to reduction in stigma and increased involvement (15) and recovery outcomes, such as improved quality of life and symptom severity (16) and patient autonomy (17).

Although the promise of SDM in mental health has discussed widely the evidence base remains weak and cultural barriers to implementation appear paramount (18–20). Service users often express desire to be involved in decisions and prefer SDM to other models of patient participation (11, 21–23), yet they often report lack of sufficient antipsychotics decision-making involvement and knowledge about antipsychotics risks and benefits (6, 24). Often concerns are expressed about the competence of service users to be involved due to issues of decisional capacity and insight, along with common misconceptions that is it already happening, and that not all patients want SDM (25–27).

Research into how SDM happens in meetings for psychiatric medication management have found that psychiatrist often employ persuasion in encounters with service users, and concerns about adverse effects are often ignored (28, 29). Clinicians, especially psychiatric care providers, often struggle with using SDM in psychiatric medication decisions as SDM is often perceived to involve risk for clinicians, such as liability or making clinical errors (30). Yet, little research exists about cultural and structural enablers and barriers in these settings. In addition, the views of practitioners and service users taken together are rarely reported yet offer important insights into areas of divergence in views (18).

The purpose of the present qualitative study is to address these knowledge gaps and explore cultural and structural barriers and enables of SDM in psychiatric medication management from the point of view of services users and clinicians in a UK community mental health setting.

METHOD

Setting and Recruitment

Participants were recruited from a community mental health team (CMHT) that provided care to people with serious mental illness (SMI) in the Eastern region of England, UK. Recruitment was conducted *via* key workers in the CMHT and leaflets were distributed in the local outpatient clinic.

Ethics

Ethical permission was obtained from an NHS research ethics committee (#10-H0311-58) and all participants gave full informed written consent. A broad inclusion criteria was used to include all psychiatrists, mental health nursing staff, and adult service users receiving services from the CMHT at the time of study. People with a lack of capacity to give informed consent and inadequate knowledge of English language were excluded and diagnosis was not considered in the inclusion criteria. Service user participants received £10 GBP as a token of thanks and to reimburse for any travel expenses accrued. Staff did not receive any reimbursement for participation.

Interviews and Data Collection: A Co-Produced Effort

A project advisory group [consisting of three mental health service users, a community psychiatric nurse (CPN), and one carer] contributed to the development of the interview guide, study design, data collection and analysis. The interview guides for both practitioner and service user interview schedules comprised of three sections: (1) general background questions relevant to the topic (e.g., details of content of recent meetings) (2) participants' views and experiences of involving service users in decision making about psychiatric medication (3) discussion of recent memorable successful and unsuccessful meetings where medication was reviewed (e.g., "what was it about this meeting that particularly stood out for you as being successful/unsuccessful?"). This style of questioning is known to assist accessing more subtle views, less likely to be retrieved along a more general line of questioning. Interviews lasted between 45 and 75 min. Service user interviews were undertaken by the lead researcher (EK), alongside co-researchers (service user members of the advisory group). Clinician interviews were undertaken by a sole interviewer (EK). All interviews were audio recorded and transcribed using standard conventions, and subsequently imported into the qualitative analysis software tool, N Vivo (Version 10).

A Collaborative Data Analysis

We used an inductively oriented thematic analysis aiming for a rich description of the entire data set and focusing on meaning and lived experience of the phenomenon (31). Including co-researchers in analysis supported this goal and offered particular benefits (32). Best practice guidelines were conformed to ensuring a transparent and deliberate process for coproduced knowledge (32, 33).

A collaborative two stage approach was adopted. During stage one the first author coded all interview transcripts and a

TABLE 1 | Service user participant characteristics.

Participant pseudonym	Age	Gender	Class/type of medication currently prescribed	Named medication, if known	Length of time taking psychiatric medication or since medication changed	Discusses medication with
Natasha	31	F	Antidepressant	Unknown	Six months taking current medication	CPN, GP
Holly	36	F	Antidepressant	Trepidone, 200 mg Efexor (or known as Venlafaxine), 300 mg. Also Gabapentin for pain	Taken psychiatric medication on and off since 19 years old. (17 years approx)	Clinical psychologist, GP
			Mood stabilizer (for pain)			
Carrie	38	F	Antidepressant	Fluoxetine, Mirtazapine, tryptophan, Aripiprazole	Taken psychiatric medication on and off for around 10 years. Most recent change 4 months ago	Psychiatrist, GP, social worker
			Antipsychotic			
Carl	28	M	Antidepressant	Unknown	Just over a year	GP, CPN, psychiatrist
Noel	47	M	Antipsychotics	Haloperidol, amitriptyline, resperidone, depixol	On and off for 30 years.	Psychiatrist, CPN, social worker
			Antidepressant			
Ziggy	34	F	Antidepressant	Amitriptyline	2 months since new medication	CPN, psychiatrist, GP
Linda	22	F	Antidepressant	Venlafaxine	2 months since new medication	Psychiatrist, GP, CPN
Terry	31	M	Atypical antipsychotic	Closapine 400 mg	2 years. Reduction in dose 9 months ago	CPN, psychiatrist
David	23	M	Unknown	Unknown	4–5 months	Psychiatrist, CPN
Lara	42	F	Antidepressant	Venlafaxine	2 weeks since new medication	GP, psychiatrist
Peter	50	M	Unknown	Unknown	Unknown	GP
Andrew	49	M	Antidepressant	Unknown	Since 2010	Psychiatrist, GP
Lizzy	54	F	Antidepressant	Venlafaxine, lithium (1,000 mg)	Venlafaxine: unknown. Lithium-6 years since dose changed. Total 10-15 years been taking lithium	CPN, psychiatrist
			Mood stabilizer			
Casey	28	F	Antidepressant	Fluoxetine, (60 milligrams) merotratine (200 milligrams), sleeping tablet	Has been taking psychiatric medication for ∼2 and a half years	GP, psychiatrist, nurse
			Sleeping tablets			
Rosie	24	F	Antidepressant	Venlafaxine, abilify (aripiprazole)	Abilify changed recently but has been prescribed antidepressants for 8 years	Psychiatrist
			Antipsychotic			

sub sample were coded independently by the third author and additional team member, followed by group discussion where themes were continually and iteratively reviewed.

Stage two involved a co-production, collaborative analysis of several transcripts from the service user interview data, undertaken with all members of the project advisory group. During this phase six group analysis meetings took place. These meetings involved group coding of transcripts, discussions of theme structure, and salience and divergence.

RESULTS

Our sample included 30 participants, of which 15 were service users, 7 (out of a total of 8) psychiatrists working in the pathway, and 8 (out of a total of 9) nurses. Background information for participants are shown in **Tables 1**, **2**. Service users aged from 22 to 54 ($M = 36$, SD $= 10.18$) and 60% ($N = 9$) were women. The CMHT served ∼260 service users, with diverse needs and SMI. The maximum length of stay within this service was 18 months. The majority of service user participants in this study were prescribed antidepressants ($n = 14$, 93.3%), followed by antipsychotics ($n = 4$, 26.6%), mood stabilizers ($n = 2$, 13.3%) and sleep medication ($n = 1$, 6.6%). The majority of psychiatrists and all the nurses interviewed had worked in the CMHT for over 6 months.

Three emergent superordinate themes were identified: "Enacting SDM in service users–provider interactions," "The Therapeutic Relationship as an enabler of SDM," and "structural challenges to achieving SDM in practice."

Enacting SDM in Service Users-Provider Interactions

Four subordinate themes comprise the first broad domain which encapsulates perceived key features of SDM for psychiatric medication management comprising: (1) the importance of SU ownership and control, (2) the dilemma of providing information about adverse effects, (3) a meeting of experts—valuing experiential knowledge, and (4) being ill as a barrier.

TABLE 2 | Clinician participant characteristics.

Participant identifier	Gender	Job title and length of time working in the CMHT pathway (at time of interview). Other background information
Psychiatrist 1	M	Consultant Psychiatrist for over 2 years in this pathway. Qualified as a Consultant a number of years ago and has worked in different mental health teams locally.
Psychiatrist 2	M	Consultant Psychiatrist in this pathway for ∼8 months. Previous role was also community based psychiatry. Relatively newly qualified.
Psychiatrist 3	F	Consultant Psychiatrist in this pathway for ∼1 year. Qualified as a consultant a number of years ago and has experience of many parts of MH services locally.
Psychiatrist 4	M	Has acted as a Locum Consultant Psychiatrist in the pathway for ∼2 months. Previously has worked in many different MH teams and contexts (acute/community) across different parts of the UK.
Psychiatrist 5	F	Consultant Psychiatrist on specialist register. Unknown length of time in pathway, but has worked in the NHS for a number of years.
Psychiatrist 6	F	Consultant psychiatrist in this pathway for 2 years. Number of years experience in other parts of MH service.
Psychiatrist 7	F	Consultant psychiatrist in this pathway for ∼3 months. Newly qualified.
CPN 1	F	Worked in pathway for ∼2 years. Extensive previous experience of psychiatric nursing.
CPN 2	F	Worked in pathway for over 2 years. Extensive previous experience of community psychiatric nursing.
CPN 3	F	Team leader and community psychiatric nurse. Worked in pathway for over 2 years and extensive previous experience of psychiatric nursing.
CPN 4	F	Worked in pathway for over 2 years. Extensive previous experience of community psychiatric nursing.
CPN5	M	Worked in pathway for over 2 years. Extensive previous experience of community psychiatric nursing.
CPN 6	F	Worked in pathway for ∼2 years. Extensive previous experience of community psychiatric nursing.
CPN 7	F	Worked in pathway for over 2 years. Extensive previous experience of community psychiatric nursing.
CPN 8	F	Worked in pathway for over 2 years. Extensive previous experience of community psychiatric nursing.

The Importance of Service User Ownership and Control

Service users, psychiatrists, and nurses viewed SDM in terms of encouraging service users to have increased say over decisions concerning medication, and promoting ownership and self-determination in meetings concerning medication. All three groups strived toward the service user achieving greater self-management skills. Receiving a full explanation of options and gaining detailed information about adverse effects was related to feelings of increased control for service users and referred to specifically by clinicians when describing memorable examples of success. For service users, being able to understand the information about the options were associated with feelings of increased control. However, this was tapered by acknowledging that during periods of crisis increased guidance and less ownership over the decision is possible and the "*sad truth you just need someone to treat you*" (Holly*) (see section Being Ill as a barrier). In these more difficult times, having information to take away and revisit was associated with feeling more in control.

> *Casey: But I just think if I'd been given that information and going through it yourself and having time to discuss it, you're going to understand. I just think you'd feel like you had more control and, you know, that might reduce stigma, as well as you feeling you can take control of what's going on.*

[* all names are pseudonyms]

> *CPN 4: I think she gained an understanding about how medication could be useful and, how, you know, it had its place. But she was... but she was taking control appropriately for when she took it. I felt, yeah, she's got it now, and that left me feeling reassured about her coming off it this time.*

For service users not feeling involved in discussion about options in routine, while not in crises, was associated with feelings of helplessness and lack of control.

> *Rosie: The last time that I saw her [the psychiatrist], my medication was increased, and my mood was low but I didn't really know, like I wanted more options and I thought that it would have been better if I had talked it through with her a bit more about increasing the dose and instead she just increased the dose and that' it.*

The Dilemma of Providing Information About Adverse Effects

All stakeholder groups stressed the importance of weighing up information and ensuring service users are provided with information about the potential adverse effects of medication options, advocated in standard models of SDM (9). For most service user participants there was a general concern about associated adverse effects and many had previous negative experiences of medication. Many participants referred to not always receiving adequate information. Likewise, most psychiatrists, while stressing the importance of disclosing possible adverse effects, often referred to not doing so due to time constraints and limiting the conversation about what side effects might be important to them. Instead, psychiatrists preferred referring service users to other sources of information, such as leaflets. In addition, while psychiatrists did not think they would deliberately withhold information on adverse effects, some acknowledged that at times, limiting the discussion about adverse effects and possible benefits of the medication was used as a way (consciously or unconsciously) to encourage concordance and avoid possible conflict (28).

> *Andrew: One thing is that you are never given enough information about the side effects.*

> *Psychiatrist 1: And I'm probably not great about telling people about possible longer term side effects about things and particularly anti psychotics I suppose. I guess there are slightly peculiar circumstances, so if someone's psychotic and has lots of delusions and is fairly wound up in them then a conversation about medication can go a slightly odd way and tend to focus on symptoms that might be otherwise quite secondary.*
> *Psychiatrist 2: I think I'd usually say the commonest side effects that other people have mentioned to me about medication, but I usually tell them to look it up on the leaflet I provide, or the internet, because there's no way I can go through all the side effects and I don't know which of the side effects might be important to them.*

A Meeting of Experts—Valuing Experiential Knowledge

The vast majority of service users and CPN participants mentioned the importance of service user's experiential knowledge for meaningful sharing of expertise in decisions. The importance of both parties having a say, and equally contributing to the conversation, is seen as integral to SDM. This may be particularly important given acknowledged uncertainty of helpfulness of medication options in this context.

> *Linda: Um, I think ideally it should be um, a collaboration between the um, psychiatrist or prescribing doctor and the service user, so there's sort of the knowledge of the different types of medication on the one side and then the SU knows how they are feeling, they know, sort of whether they've got sort of patterns to their moods that sort of certain types of drugs are more able to help with so it's sort of a feedback situation, with both of them contributing.*

Psychiatrists also emphasized the importance of honesty and, at times, disagreement was considered a success (and highlighted this during descriptions of successful meetings). However, CPNs and service users directly expressed the importance of experiential knowledge and a shared dialogue. This aspect was less explicit in the psychiatrists' interviews who instead saw their role as advisors for the evidence base of medication options, which then may subsequently be weighed up by the service user (see also section The importance of service user ownership and control, above).

Being Ill as a Barrier

Challenges surrounding being ill or in crisis for service users involvement in medication related decisions were discussed by practitioners and service users. While research highlights that many inpatients remain capable of participating meaningfully during crisis [e.g., (34)] for service users, reinforcing information and increased guidance become of greater importance during crisis than at other times.

> *Carl: Um, I think if I'd been in a better place mentally at that time I might have pulled up some questions, um but given how I was at the time, um I don't think I could have done much more because I was looking to be informed by her [the psychiatrist] as much as anything and, you know, that didn't really happen at that point in time.*

Lack of insight, or the SU not accepting that they are mentally ill, was mentioned by both CPNs and psychiatrists as a key challenge to SDM and was associated with changing how information is presented and how medication conversations are constructed. Problems when someone was acutely unwell being framed as "lacking insight" by practitioners is an important issue in that a person's competence to participate is directly challenged by this construction. Service users didn't directly refer to problems of lacking insight, but instead referred to functional problems of poor concentration, memory problems, and distress hindering being able to weigh up and process information about medication or be able express oneself clearly.

> *CPN 2: Particularly if someone's very ill and their insight is very poor, and you think, this person really does need to take medication, they're really unwell,… it's important to find out, to support and listen and advise and yet encourage concordance.*
> *Psychiatrist 6: If they don't necessarily see it as part of being ill, and then it becomes quite difficult to involve people um on the same level because you have to walk a fine line.… It's not about giving the wrong information but giving information that would lead people to consider perhaps the options more carefully.*

The Therapeutic Relationship as an Enabler of SDM

Practitioners and service users alike emphasize the importance of achieving a constructive therapeutic alliance and see this as essential. Establishing trust and communicating honestly is seen as an integral aspect of SDM by all participant groups (see section Trust and honesty), yet different conceptualizations about the longer-term, caring, and supportive aspects of relationships emerge between stakeholders (see section Walking the Journey Together and Continuity of Care).

Trust and Honesty

Service user participants were aware of the effort required by both parties to establish a deeper relationship and understood that SDM requires honesty on both sides. Several participants referred to not just establishing a general rapport but rather an ongoing effort in building mutual trust. Experiences that denigrated trust were highlighted by service users as particularly damaging for SDM. One participant referred to having to overcome previous issues with trust and having to make a deliberate effort to trust practitioners in order to embark on their own recovery process,

> *David: I have to do everything I can to allow myself to get better but if it means I have to trust somebody that I don't know, which is very, very difficult for me to do, then so be it.*
> *Carrie: I think the main thing is to be as honest as possible.....the honesty and the trust I think as well, and you know you kind of build up a relationship with somebody and you get to trust them.*

When describing memorable positive meetings, psychiatrists referred to establishing rapport and service users feeling able to speak openly and honestly. Some psychiatrists acknowledge that there are potentially differing agendas in conversations concerning medication [and that conflict may emerge when medication is deemed as the best course of action [see (28)]. In this context, service users feeling able to express their views honestly is seen as a particular success. Conversely, issues of false compliance, or service users withholding information about medication was often described as particularly concerning (but a common reality) for many psychiatrists and CPNs.

> *Psychiatrist 3: I thought it was really good that she was able to talk frankly about the pros and cons of the medication and she felt she could say she needed this stuff. Yeah, good rapport, trust, a sense that she could say what she really wanted.... [Because] I cannot be absolutely sure that people are being absolutely honest with me and would say. "I don't want to take it." I mean some of them are going to say, "I got out of there ... without losing face" and that's the problem, I don't want people to go away and not take the drug because they can't face me, but they will, some of them."*

Walking the Journey Together and Continuity of Care

Establishing a long-term partnership and supporting people with their personal recovery journeys was seen as integral to the process of SDM for CPNs and SU participants. CPNs referred to the importance of a supportive, long term relationship with SUs. Care and empathy is emphasized reinforcing a deeper level of connection as a way of facilitating a collaborative partnership. Both groups saw this as a continued reflective process, of being held accountable, *pushing forward* and having a belief in one's potential during more difficult times, and celebrating, and reflecting on success over time. For SUs, meaningful involvement was not seen as a series of isolated decisions, but instead, a practitioner seeing and commenting on change over time was connected to feelings of being known and cared about (see Natasha, below).

> *CPN 2: So there's a kind of walking the journey together, and sometimes he's pulling back a bit and I'm pushing forward and we were at different paths pulling in different directions. That push - pull stuff, [and] probably the success is about two people building up a mutual respect and real affection for each other [And, for example] thinking "I really care about you."*
> *Natasha: I don't know, I think it's because he [CPN] kept comparing to how I was and how I am. So, you know; look how far you've come, it was all just really positive, rather than "okay, you've taken it, well done." Yeah, it was real...and he was like; "well done, you know, before you would have stopped and that would have been it but I'm glad you have, you know, I' really proud of you, you've done this, you're doing so well."*

Overall, psychiatrists didn't emphasize longer term or caring aspects of the therapeutic relationship. Only one psychiatrist (in an example of a successful meeting) described how knowing the person was an important feature of the meeting, and in general, this was seen as not being central to the psychiatrist's role (see also section The changing role of the Psychiatrist, below).

Structural Challenges to Achieving SDM in Practice

This theme reflects participants' views surrounding the attitudes, structures and cultural challenges of embedding SDM in psychiatric medication management practice. Sub themes include the move toward psychiatrists being seen as performing an expert consultative role (The changing role of the Psychiatrist), construction of distress as a medicalized phenomenon and the associated labeling and stigmas as a barrier to SDM (Medicalization of distress, Labeling, and stigma), and fear of coercion as a barrier (Fear of coercion as a barrier to SDM).

The Changing Role of the Psychiatrist

Psychiatrists often discussed the changing role of the psychiatrist toward that of being an expert advisor and performing a consultative role in the medication management process. Five psychiatrists referred to changing roles in recent years, with family doctors (GPs) providing ongoing continuity of care. This connected to the wider trend that longer term care for people occur in the context of primary care and that psychiatrists often only become involved as experts during crisis periods, or in complex cases.

> *Psychiatrist 5: Compared to the past, where you would see a patient and would continue to see them for a good length of time, you'd build a relationship and you are overseeing the treatment for a long period of time. From there to now it's moving towardz the GP being the center managing the patients and the consultant psychiatrist providing a sort of consultative model... and there are sort of pros and cons with either. But the current model is one of where you don't see the psychiatrist unless it's um, extremely complex, extremely risky.*

Medicalization of Distress, Labeling, and Stigma

Concerns surrounding the dominant discourse of medical understandings of mental health problems and distress emerged as a barrier to collaborative decision making across all three stakeholder groups. Within this, there were differences in conceptualization across participant groups. Service users referred to worries about labeling and stigma associated with a psychiatric diagnosis, and as problematic for SDM. For some participants, diagnosis related to feeling labeled and prejudged impacting feelings of not being valued or listened to in conversations about medication. Ziggy, when describing a memorable negative meeting with his psychiatrist, refers to a pretense of listening by the psychiatrist and feeling ignored: "*And there are some semblances of listening, but it's not really going in because in their mind they've already put a label on me.*" For SUs this theme is also connected to feelings of being spoken down to, of not having a voice, and of a culture of *doctor knows best*. In Natasha's quote below, feelings of being attacked, looked down upon and judged connected to being unable to contribute in a conversation with her psychiatrist.

> *Natasha: I felt like I was being attacked and I don't know, it was like I was coming to them for help, it just felt like I was just being attacked and judged and sort of looked down on and it just made me feel really uncomfortable, upset. The fact that I was too scared to say anything, it was, you know, just horrible, it made me feel even worse.*

Stigma was less directly referred to by psychiatrists and CPNs. Instead, for some psychiatrists and CPNs the trend toward an increased medicalization of distress and pathologization of emotions is seen as an emergent and important problem for adopting a holistic approach and open discussions with service users. This was seen as problematic for some CPNs and psychiatrist participants who referred to feeling an increasing pressure to prescribe connected to feeling that service users expect a biomedical explanation and treatment for their mental health problems. Here, passivity and "*wanting to be led*" was seen as a challenge for SDM in mental health.

> *Psychiatrist 6: And I think there's quite a push for society to see, um, emotions as abnormal and therefore needing treatment. And I think that's certainly increased in the last couple of years, where I see people who are under distress and find it very difficult to deal with emotions that, um, that are probably, um, a combination of social changes and, um, a kind of breakdown of society's normal coping strategies. So that's my sense.*

Fear of Coercion as A Barrier to SDM

The context of mental health services operating within a legal framework and specifically the role of the Mental Health Act (MHA) in removing choice and freedom in the decision making process was acknowledged as a barrier to collaborative decision making by psychiatrist and SU participants. Fear of coercion and the legal context was seen as a particular barrier, hindering honest dialogue, and preventing trust from being established. In one interview a psychiatrist refers to a memorable recent meeting with a service user and reflects that the service user may be withholding information or feeling pressure to take prescribed medication because of his previous experience *"he may be worried that people will cart him off to hospital if he stops taking it*." Often a general fear of coercion was not necessarily based on direct previous experience of being treated under the MHA, but a general awareness of the legal context.

> *Terry: …so I thought to myself; if I get these things going on in my brain, I won't tell a psychiatrist because I don't want to be in hospital.*
> *Interviewer: So that's something you've learnt?*
> *Terry: Try and be as honest as you can but hold back a little bit because you don't want to sort of end up in hospital when you look different to society.*

Interestingly, fear of coercion was not explicitly mentioned by CPNs, perhaps suggestive of the differing role the CPN performs to the psychiatrist in this pathway.

DISCUSSION

The findings of this study support broader conceptions of SDM as a longer term process of trial and error, prioritizing honest open dialogue, valuing experiential knowledge, positive risk taking, and viewing psychiatric medication as only one possible choice in a wider personal tool box approach (8, 30, 35).

These findings support other research exploring service users' views of SDM and highlight the enabling role therapeutic relationships play for SDM in mental health (11). Therapeutic relationships and their connection to shared decision making has been relatively unexplored. Research suggests that positive outcomes of therapeutic relationships may be mediated by impacts on increased involvement and SDM (36, 37).

Considerations of how power is enacted in mental health services is critical (38). Insidious forms of power, and perceived labeling, stigma and self-stigma impact SDM directly *via* professional attitudes toward service users. Many SDM professionals view people with SMI as incapable of participating; and service users may internalize associated stigmatizing attitudes, further hindering a person's confidence to express themselves and portray their preferences and values in encounters with professionals (34).

Other forms of power, such as "aesulpian power" (or a power to heal) suggest it is important to recognize that prescribers perform important symbolic and functional roles (39). Yet, for psychiatric medication management, this may lead to an overly medicalized approach, with subsequent reduced emphasis on personal meanings and wider psychological and social understandings of medicines and threatening the ideal of a meeting of experts and of experiential knowledge holding weight encounters (40, 41). A clearer focus on shared risk taking as a way of conceptualizing SDM for such encounters would allow for a diffusion of power and authority and can lead to a meaningful exploration of issues of accountability within the system along with the context of the person's broader life implications (30).

Implications for Practice

The findings suggest that future interventions to promote SDM in practice need to take a multi-faceted approach, including a focus on changing attitudes amongst mental health practitioners, and empowering service users (12). Recent SDM interventions have advocated for this broader organizational change approach and show early promise, suggesting that attitudes can be effectively changed to support the embedding of SDM in practice (6, 8, 34). However, implementing SDM in mental health settings requires particular attention to the unique defining cultural features of this system. Interventions with a particular emphasis on tackling the insidious effects of labeling and stigma in psychiatry represent an important avenue for future interventions and implementation of SDM in mental health (34). The importance of co-production in the development and implementation of interventions to embed SDM in practice, may be particularly important in this regard (20). In addition, promoting continuity of care and longer term relationships is an important practical implication of the findings. The findings suggest that the role of the CPN for collaborative psychiatric medication management practices may be particularly important. In the UK, an increasing fragmentation of services, and increased emphasis on time-limited focused provision leads to increasing concerns about the impact service design has on health outcomes *via* reduced continuity of care, both within and across different pathways (42, 43).

Strengths and Limitations of This Study

Presentation of themes across three stakeholder groups (CPNs, service users and psychiatrists) allowed for discussion of complexities and areas of convergence and divergence in themes between stakeholder groups. Arguably incorporating multiple stakeholder groups also allows for a more sophisticated construction. The co-produced elements of the research process, and the inclusion of collaborative analysis phases enabled through active involvement from the SU advisory group during the analysis phases strengthened the credibility and quality of the results. However, it may be that by highlighting differences between groups, an artificial portrayal of homogeneity in views within stakeholder groups is presented, portraying a crude distinction that, for example, psychiatrists have one position on this topic, and CPNs or service users another. This was not the explicit intention and hopefully we were able to portray the complexity of the themes and present both inter as well as intra group differences in discourse.

The fact that participants were all recruited from CMHT in one locality, should be considered in relation to relevance of findings to other service users and practitioner populations. It is also possible that selection bias was present in the recruitment of service users participants within the pathway (this issue doesn't apply to interviews with professionals in that all but one participated). It may be that those service users with existing good relationships were approached for participation by gatekeepers (mental health professionals in the CMHT). Also, people with strong views or memorable experiences on the topic may have been more interested in participating. As such, future research should seek to recruit a more inclusive and varied service user sample and involve a larger more representative sample.

Concluding Remarks

This is among the first studies to explore *both* practitioner and service user perceptions of SDM for psychiatric medication management. This study's importance is also reflected in the inclusion of CPN's views (an under researched group) alongside service user and psychiatrist views about SDM for medication management is an important contribution. Currently there is insufficient research examining wider cultural and structural enablers and barriers for successful implementation in everyday psychiatric practice. These results offer a detailed contextualized account of how medication decisions are made and highlight that SDM is a long-term endeavor embedded within therapeutic partnerships. Stakeholder differences in views of SDM reflect a complexity of relations which point to wider system and cultural challenges at different stages of the SDM process. The study provides actionable insights which may help improve SDM practices and improve the quality of psychiatric care.

DATA AVAILABILITY STATEMENT

De-identified data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Hertfordshire Research Ethics Committee, NHS. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

EK was lead researcher for this paper, coordinating the data collection and analysis, and drafting initial findings. SR contributed to the analysis of findings and drafting the paper. YZ-I contributed to the wider discussion of literature and links to other literature in the field. All authors contributed to the article and approved the submitted version.

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Shared Decision Making in Primary Care Based Depression Treatment: Communication and Decision-Making Preferences Among an Underserved Patient Population

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Objectives: Although depression is a significant public health issue, many individuals experiencing depressive symptoms are not effectively linked to treatment by their primary care provider, with underserved populations have disproportionately lower rates of engagement in depression care. Shared decision making (SDM) is an evidence-based health communication framework that can improve collaboration and optimize treatment for patients, but there is much unknown about how to translate SDM into primary care depression treatment among underserved communities. This study seeks to explore patients' experiences of SDM, and articulate communication and decision-making preferences among an underserved patient population receiving depression treatment in an urban, safety net primary care clinic.

Methods: Twenty-seven patients with a depressive disorder completed a brief, quantitative survey and an in-depth semi-structured interview. Surveys measured patient demographics and their subjective experience of SDM. Qualitative interview probed for patients' communication preferences, including ideal decision-making processes around depression care. Interviews were transcribed verbatim and analyzed using thematic analysis. Univariate statistics report quantitative findings.

Results: Overall qualitative and quantitative findings indicate high levels of SDM. Stigma related to depression negatively affected patients' initial attitude toward seeking treatment, and underscored the importance of patient-provider rapport. In terms of communication and decision-making preferences, patients preferred collaboration with doctors during the information sharing process, but desired control over the final, decisional outcome. Trust between patients and providers emerged as a critical precondition to effective SDM. Respondents highlighted several provider behaviors that helped facilitated such an optimal environment for SDM to occur.

Conclusion: Underserved patients with depression preferred taking an active role in their depression care, but looked for providers as partner in this process. Due to the stigma of depression, effective SDM first requires primary care providers to ensure that they have created a safe and trusting environment where patients are able to discuss their depression openly.

Keywords: shared decision making, depression, primary care, patient preference, underserved and unserved populations

BACKGROUND AND RATIONALE

Depression is a major public health issue, and remains a leading cause of disability worldwide (1). In the United States, about 8% of adults aged 20 and over have depression in a given 2-week period, and women are almost twice as likely than men to have had depression (2). Recent findings indicate a 3-fold increase in depression symptom prevalence in the last year due to COVID-19, with amplified effects among individuals disproportionately affected by Social Determinants of Health, such as lower socioeconomic status, those who had acute exposure to psychosocial stressors (e.g., job loss) (3), women with school age children, and individuals belonging to racial/ethnic minority groups (4, 5).

While several depression treatment options exist, including psychiatric medication, therapy, or a combination approach, many individuals experiencing depressive symptoms do not engage in any form of depression care (6). Current estimates indicate that as few as 35% of patients with new depressive episodes initiate treatment (7), and only one in five individuals receive treatment that meets minimum recommended standards care (8), with traditionally underserved populations, specifically Black, Indigenous, and People of Color (BIPOC) and economically disadvantaged groups, accessing treatment at disproportionately lower rates (9). Together, this evidence signals an urgent need to improve both access and continuity in depression treatment, particularly among underserved communities. Broadly, underserved populations are defined as minority populations or communities, or groups that experience disproportionately poorer health outcomes (10). Within this study, we use the term *underserved populations* to refer to individuals experiencing poorer outcomes related to depression specifically, which includes BIPOC individuals and lower socioeconomic backgrounds.

The need to improve depression care for this group is particularly acute within primary care settings, as many individuals experiencing symptoms of depression initially present to primary care physicians, rather than behavioral health providers (11). In addition to being the leading prescribers of antidepressant medication (12), primary care providers therefore also play a critical role in linking individuals to behavioral health care and other social services, and monitoring symptoms over time (13, 14). Consequently, the effectiveness of primary care based interventions for depression may rely on the provider's capacity to engage patients in discussions about various evidence-based treatment options in order to determine an optimal path forward. Many primary care providers report a lack of foundational knowledge and training in the treatment of common mental illnesses, including depression (15, 16), leaving them less equipped to engage in such critical conversations. This suggests that efforts to improve the quality and effectiveness of depression treatment may require increased attention to clinical practice strategies that support providers in initiating discussions about depression treatment options with their patients.

Shared decision making (SDM) is a health communication model designed to optimize treatment of chronic conditions, including depression (17), and is particularly suited for clinical scenarios, such as depression care, where multiple efficacious treatment options exist. The SDM model provides a framework for collaborative information exchange between patients and clinicians, promotes informed decision-making by encouraging discussions about treatment options, and clarifying patients' treatment preferences (18, 19). Developed as a shift away from more paternalistic models of care that privilege the authority of providers, principles underlying SDM include mutual respect, a regard for supporting self-determination, and a recognition of the patient as an expert on their own recovery (20–22). SDM is specifically recommended for use in primary care settings (23), where providers treat a diverse range of conditions.

A small number of studies have tested the impact of SDM interventions and decision aids on depression outcomes in primary care (24–27). Overall, these studies found that SDM tools increased patient involvement in care and knowledge about treatment options, but did not improve depression symptoms depression treatment initiation and adherence. Research examining SDM behaviors (28, 29) and patient-provider interactions (30, 31) during clinical visits have concluded that SDM practices are both poorly implemented and infrequent in depression care (32). In addition, these studies have primarily been conducted in rural areas and with predominantly white samples, leaving much less known about how SDM is being integrated in primary care based depression treatment among the underserved populations that are least likely to access and receive quality depression care, including BIPOC individuals. This gap is notable in light of existing studies in medicine suggesting that doctors are less likely to discuss treatment options or reasons for treatment (33) and elicit patient feedback less often (34) when the individual belongs to a racial or ethnic minority group. Self-rated SDM has also been found to be lower among individuals that are uninsured or underinsured, have lower educational attainment and are have a low socioeconomic status (35). Further, research has also indicated that patients' individual preferences around communication and decision-making vary across demographic, cultural and racial/ethnic characteristics (36, 37). Together, this suggests that current research may not accurately represent the experience of SDM among underserved populations, and that more work examining how to optimize the SDM model for individuals from diverse backgrounds are needed (38).

Alegría et al. (38) have conducted, to our knowledge, one of the few studies that has specifically examined the potential of SDM to improve the quality of behavioral health treatment among a racially and ethnically diverse individuals. This randomized controlled trial found that interventions designed to improve SDM practices increased patient ratings of service quality, but not their self-reported ratings of SDM. This suggests the potential of benefit of SDM, but signals that there is still more to learn about how to improve the experience of collaborative decision-making among this group. Further, this sample was not conducted in primary care and was not limited to those with depression diagnoses; due to the uniquely individualized process of choosing depression treatment, more explicit examination of SDM within the context of depression care is needed.

In sum, existing research has produced mixed findings about the use of SDM to optimize depression treatment, and points to the need to better understand factors that shape the patient experience in depression care, particularly among those from underserved backgrounds, including from racial/ethnic minority groups or low socioeconomic status. One consistent trend across studies is that methods to increase the patients' subjective experience of SDM are not well-understood. Within the context of depression care, little is known about how patients, particularly those from diverse backgrounds, actually prefer choices about their depression to be made. This includes desires relating to patient-provider communication, and decision-making processes, and preferences for autonomy. Efforts to increase the adoption of SDM in depression care without a thorough understanding of how patients define optimal SDM practices within this context may therefore result in the dissemination of clinical strategies that are misaligned with those that will most effectively engage patients in decisions around depression treatment. This gap is particularly problematic for underserved groups, which are among the least likely to receive optimal depression treatment. In order address dearth of information, and to inform efforts to enhance SDM in primary care based depression treatment for underserved patient populations, the purpose of the present exploratory qualitative study was to (1) examine the experiences of SDM among an underserved patient population receiving primary-care based depression treatment, including how often and in what ways they experience SDM in their care, and (2) explore communication and decision-making preferences among this group, including how effective SDM is described.

MATERIALS AND METHODS

Design, Study Setting, and Participants

A mixed-methods study was conducted in the midst of COVID-19 pandemic between June 2020 and February 2021. Participants were recruited from primary care practices within Temple University Hospital, a large, urban safety net hospital serving one of the poorest catchment areas of Philadelphia, PA, USA. Safety net clinics, including those included in this study, refer to practices that predominantly serve patient populations that are uninsured or underinsured, economically disadvantaged, or from racial and ethnic minority backgrounds, reflecting underserved groups that have been historically underrepresented in SDM literature, and are also lease likely to receive care for depression. Consistent with safety net target populations, the patient population of Temple University Hospital is predominantly Black or African American, and more than 70% of the patients receive Medicare or Medicaid.

Eligible patients were identified using chart data abstracted from the electronic health record, and included English speaking adults (18 years or over) with a diagnosis of depressive disorder as defined by ICD-10-CM diagnostic codes F22 and F33. Using a complete list of eligible participants, a consecutive sampling approach was used to recruit patients were recruited over the phone by three bachelors level research assistants (DW, TH & DG), who were not previously known to eligible participants. As required by COVID-19 restrictions, individuals agreeing to enroll in the study participated in an interview conducted over the phone or via video conferencing. Interviews with participants were audio recorded, and lasted an average of 45 min.

A semi-structured interview guide was developed by the first and last authors (EBM & YZI). Following established frameworks (39) this was process was informed by existing knowledge, as derived from extant literature on SDM, and was piloted internally for comprehensiveness and flow. Questions include both *main themes* and *follow up prompts* (39) which are probing questions or responses designed to guide deeper understanding of phenomena of interest. Examples of the interview guide is included in **Table 1**. Interviews were conducted by trained research assistants (DW, TH, DG). Interviews began with a quantitative survey measuring patient's self-rated experience with SDM, and continued with a semi-structured qualitative interview guide targeting SDM preferences. Respondents received a $20 gift card for their participation. Study protocols were reviewed and approved by Temple University Institutional Review Board (protocol # 26820).

Quantitative Methods

All study respondents completed a survey including demographic information (age, gender, race/ethnicity and education level) and clinical characteristics, including whether the respondent was currently prescribed antidepressants and/or enrolled in mental health services (counseling or therapy). The survey also included the SDM-Q-9-Psy, the only validated measure of patient rated SDM for mental health settings (40). The SDM-Q-9-Psy consists of nine statements rating to the respondents' perceived experience of SDM within the context of their care. Sample items include "my doctor wanted to know exactly how I wanted to be involved in making the decision," and "my doctor told me that there are different options for treating my depression." Respondents rate their level of agreement with each statement on a likert scale. Scores are summed and then transformed

TABLE 1 | Sample interview guide.

Main Theme: Could you please describe the last important decision you and your doctor made about your depression?
Follow Up: As you reflect on this decision, in what ways was your doctor involved in this process?
Follow Up: As you reflect on this decision, in what ways were you involved in this process?
Follow Up: Is this the way you prefer decisions about your depression to be made? Why or why not?
Main Theme: If you had to make another decision like this with your doctor about your depression, how would you like them to be involved?
Main Theme: What kind of information do you need in order to make sure you are receiving the right care for your depression?
Follow Up: How do you usually get this information now?

into a range from 0 to 100, with higher scores corresponding with higher levels of perceived SDM. Univariate statistics are presented for descriptive purposes, and summarize the sample's demographic composition and self-reported experiences with SDM.

Qualitative Methods

All interviews were transcribed verbatim and uploaded into Dedoose qualitative analysis software. Coding and analysis were guided by LaRossa's application of grounded theory (41). This process of inductive qualitative analysis begins with *open coding,* or a line-by-line examination of interview designed to identify broad concepts derived from the data. While original conceptualizations of grounded theory discouraged the use of apriori constructs through the coding and analytic process, more recent interpretations incorporate the use of *sensitizing concepts* to guide preliminary coding of the data. Sensitizing concepts are described as "interpretive devices" that provide an organizing framework for making sense of the data (42). Often informed by the investigators' basic research questions, sensitizing concepts guiding this study's initial coding included patients' communication preferences, the roles adopted by both patients and providers, and patients' attitudes toward decisional authority.

Another core component of LaRossa's approach to inductive analysis is the use of a constant comparative method, where similarities and differences between and within codes are examined iteratively throughout the analytic process. To accomplish this, two authors (EBM & DG) first independently coded a sub-sample of interviews, then met to compare codes, identify and refine key, emergent themes, and resolve any discrepancies through consensus building. A third research team member (YZI) not involved in the coding process also joined these meetings in order to triangulate data and enhance the objectivity of the coding process. The initial codebook was iteratively refined as codes were adapted, changed, or distilled into more precise constructs. An audit trail of all team meetings and codebook revisions was kept to promote rigor. A total of 20% of transcripts ($n = 6$) were co-coded in this manner in order to establish reliability in coding and ensure no new themes emerged. Once the research team agreed that saturation had occurred, two research team members (EBM & DG) then independently coded the remaining transcripts.

Inductive, thematic analysis (43) was used in order to address key research questions about how decisions about depressions treatment were made in primary care, and how patients describe their own communication preferences relating to their care. To support this inductive analysis, the authors also used memo writing (44) as a strategy to both clarify and make meaning of emergent themes relating to these processes. Cross-case analysis (45) was also used to examine differences among the diverse sample. Additional strategies to increase the trustworthiness of the themes identified in this data included routine peer debriefing, triangulation, an audit trail, and negative case analysis (46).

RESULTS

Study Sample

Study recruitment continued until the research team achieved a consensus that thematic saturation (47) was reached, meaning that no new or distinct codes or themes were evident from interviews. Of the 314 individuals successfully contacted for enrollment, 226 declined participation (i.e., did not want to enroll), 59 were lost to follow up after an initial contact, and 29 individuals were successfully enrolled. Of those who participated in the study, technical issues compromised the quality of two participants' responses, for a total sample of 27 patient respondents. Of the sample, the majority (70%, $n = 19$) were female. Over half (55%, $n = 15$) identified as Black or African American, while 33% ($n = 3$) identified as non-Hispanic white, 3.7% ($n– = 1$) were non-white Hispanic/Latinx, ($n = 1$) and 3.7% ($n = 1$) identified as "other" or unspecified. In addition, over half of the sample (51.8%, $n = 14$) had a college degree or more, 15% ($n = 4$) reported some college, and a third of the sample ($n = 9$) with a high school education or less. Finally, a most respondents fell into a 18–35 year old age bracket (33%, $n = 9$) or a 46–55 year old age bracket (33%, $n = 9$). Of the remaining sample, about 19% ($n = 5$) were between the ages of 36–45, and 11% ($n = 3$) were over 65 years of age. The vast majority of respondents (82%, $n = 22$) were engaged in some form of depression treatment at the time of interview. Among those receiving some form of care, ∼55% of patients ($n = 15$) were taking antidepressants and 55% ($n = 15$) were in engaged in counseling or therapy, with 25% ($n = 8$) receiving both medication and therapy.

Patient Experiences of Shared Decision-Making

Respondents reported relatively high levels of SDM, with an average score of 68 (SD = 26.2) on a 0–100 point scale. Results from qualitative interviews also suggested that patients within this sample experienced high levels of SDM and were satisfied with their ability to communicate effectively with their provider, as reflected in these responses:

"Um so my doctor [name], can't recommend him like incredible, incredible, incredible, I've never felt that comfortable with a doctor."

"So, it was really, really good, umm like a trusting relationship. I also say umm he helps me solidify the conflict that I had."

"Yeah, I feel like I've been blessed with that (doctor) is open to any questions. And it's never, she never makes me feel like, okay you are taking a little bit too much of my time. She's always, when I began to ask her something that I was like no no. You ask me what you need, she insists that I ask a question."

Preferences for Communication and Decision Making

Building upon these largely positive experiences with their providers, respondents were able to identify several conditions or behaviors that articulated their preferred methods of communication and decision making, including factors that facilitated or inhibited shared decision-making practices.

Stigma Shaping Communication Preferences

Respondents described an acute awareness of the stigma associated with mental illness, particularly when they initially presented for care:

"Well the stigma that people have about people suffering from mental health issues you know it's not easy though. It's not, to put yourself out there."

This perceived stigma appeared to motivate some of the communication and decision-making preferences described by respondents in the following sections. Because of existing, negative associations with depression or mental illness, many respondents described being "anti-medication" when initially presenting for depression treatment. Common concerns included negative side effects from antidepressants, and the stigma associated with being medicated for a mental health condition. When first engaging with providers about their depression, respondents also described an expectation that providers would adopt a paternalistic approach to decision-making, specifically one that would pressure patients to take medication. Together, this meant that many respondents initiated treatment discussions with the expectation that their own preferences (against medication) would be at odds with the preferences of their providers (advocates of medication). As a consequence, they presented to treatment with the perceived need to proactively protect against violations to their autonomy, including being coerced into taking psychiatric medication. Within the context of decision-making preferences, these underlying attitudes seemed to motivate participants' strong desire to maintain decisional authority, as described in the following sections.

Preferences for Decisional Autonomy

Respondents often described decision-making, including SDM, interchangeably in terms of an *outcome* (i.e., who makes a decision) and a *process* (i.e., how information is exchanged during the communication leading up to a decision). When initially asked how decisions about their depression care were made, respondents overwhelming remarked that they controlled decisions about their treatment:

"I did the research, I brought up the concern, I made the final call this is what I wanted."

"it was totally my decision. Yeah, it's totally my decision."

While these responses suggested a consistent preference for patient-led decision making, further examination indicated that this preference primarily applied to the decisional *outcome,* or who made the ultimate choice about depression treatment. Patients' persistent preference appeared related to their concern about being coerced or forced into treatment by their provider. Respondents were clear in their intent to disengage from providers who undermined their control over the decisional outcome:

"I mean I've had those issues with other physicians where I felt like the attitude was like look just take what I told you to don't ask questions. I you know, I've gotten that response from some. And um, I don't want a doctor like that"

In this way, respondents signaled a clear aversion to purely authoritarian, provider-led approaches to shaping treatment, and also underscored patients' tendency to protect against coercive practices by asserting their final right to approval or decline care. One respondent explained the importance of decisional control in this way:

"it puts a lot of control on my hands and I feel like depression is about feeling like you're helpless a lot of the times. So when you see you have control over something it really helps out."

Despite these clear preferences, the *process* of information exchange leading up to the decision-making reflected a different type of expectation from patients. Respondents depended on providers to share their expertise about medication options and medication side effects in a way that was accessible and understandable. In addition, respondents actively sought out their providers' opinions or advice about which medication or treatment option would be optimal, and factored this into their own determinations of appropriateness. Several respondents described such a process in this way:

"just about every decision that I've made with him as my doctor, has felt like I was making the decision he was confirming that it was like a good safe decision and then would sort of we would make like a plan to go from there."

"there is a reason that I go to my healthcare provider. Which is because they have expertise so. You know if I, example let's say that I decided to go back on medication tomorrow. I wouldn't march into my doctor's office and demand a prescription. For specific medication that I wanted, Right I will chat with them about what they thought were my options or the benefits or a drawback of each one."

"So, I feel always involved but I also feel like [doctor] wouldn't let me do something that he didn't think it was a good idea."

Rather than a patient directed process, these discussions were described as a partnership between the doctor and the provider, meaning that both parties shared information, articulated preferences or recommendations, and came to an agreed path forward. As the above quotes suggest, as part of this process respondents actively sought validation from their provider that their chosen treatment option was a good one, and often took heed of their recommendations. This reflects both a simultaneous need to feel control over the decision-outcome, while also desiring providers to offer expert guidance to help them navigate their treatment options. This mutual collaboration contrasts with respondents' firm assertion of their decisional authority described above, suggesting that patients' preferences related to the *process* and *outcome* of a shared decision-making process may be different.

Preference for Person-Centered Care, Rather than Depression-Centered Care

Respondents were attuned to signals that providers viewed them as "more than a diagnosis," and sought an authentic, interpersonal connection with their doctor. As one respondent described it:

"Yeah, it makes me feel like I matter to them. You know, I'm just not a paying customer. But, genuinely care about your health and what these meds do to you, that's always comforting to me."

Respondents experienced this genuine concern through several discrete actions, including providers' updated knowledge on their full medical history, and by their interest and understanding of life outside of depression, including patients' interests, responsibilities, and overall preferences toward their treatment. When providers effectively conveyed their understanding of respondents within the unique context of their unique life early on in treatment, respondents perceived them as better equipped to guide them during subsequent decision-making processes. Specifically, as respondents described, when providers understood the client as a person, they were better able to tailor psychoeducation and information giving to the particular preferences of the patient. The assurance that providers both valued and understood the respondent as a person ultimately seemed to increase the likelihood that they would be receptive to providers' advice or recommendations, as illustrated here:

"She'll say 'you were on this medicine before "and I will say "I don"t know why I went off of it" and she'll say "well-this one conflicted with your other drug" and that 1–10 years ago I was on why did I ever go off of that: "I think because weight gain was the side effect maybe sexual side effects or something like that" so we like we were pretty good together about piecing it out and seeing what the pros and cons of each drug are so that is really helpful... Yea and being really honest you know being really honest with yourself to someone else is kind of hard but she's got my back so.."

Sharing the Role of Expert

Because retaining control of the decisional outcome was important to respondents, they also looked for indications that providers would be willing to share the role of the expert. Within the context of depression care, respondents were particularly sensitive to the experience of being believed when disclosing their experience of symptoms, including when their medication was not working properly, when they felt a particular treatment option was not ideal for them, or when their symptoms were fluctuating. Further, respondents described that the strongest partnerships occurred when providers centered treatment decisions around improving patients' subjective experience and quality of life, rather than symptom reduction alone. Both of these experiences are illustrated here:

"So, he would frequently check in during when I'm still on [medication] and make sure that my dosage was correct. One point I did go up um and every time I went in it wasn't just a discussion of like "everything is good, right?" It would be like, "could this be better?"'

"[the doctor] felt very open to allow me to, you know, see if there is any problems [with medication] or allowed me to see what would be best at this time. And whenever I didn't feel it was right he let me up it or lower it my rate."

As one respondent noted, when providers demonstrated a receptiveness to patients' subjective experience of wellness and well-being, this increased the likelihood that patients would readily disclose issues with medication or changes to their depressive symptoms:

"The [doctor] really tooked his time umm and would just like listen to me when I went, and I feel like. I was a lot more honest about the symptoms I was having the more I started to see him. Just because I feel a lot more comfortable with him."

Trust as a Preceding Condition to SDM

In order to create their preferred type of doctor-patient partnership already described, respondents acknowledged that they needed to be honest and transparent about the symptoms they were experiencing. In order to disclose openly in this way, respondents consistently underscored the need for an established sense of safety and trust with their provider:

"I tried to look for something that really give me um, that I feel safe. That I feel safe cause I don't like to talk about this too much or I don't know sometimes I feel people will don't understand how I feel."

Nearly all respondents in this sample described having a trusting relationship with their current provider. During the decision-making process, respondents described that providers would often offer advice or recommendations about treatment options. Whether such advice was perceived as prescriptive and authoritative or helpful suggestions seemed to depend greatly on the degree trust and safety that existed between patients and providers.

Importance of Continuity of Care

Although conversations were intended to explore the process of decisions about depression were made, respondents consistently described the importance of proactive continuity of care *after* decisions occurred. Many patients in this sample had a long history of depression treatment, and an established relationship with their provider. From this perspective, patients emphasized the importance of accessibility:

"This is why the rates of suicide is, everything happens the way it is because doctors allow their patients to fall through the crack."

Respondents reflected that decisions around depression care are not singular, and many articulated how their treatment needs and preferences change over time. Because of this, patients emphasized the need for providers to be available when they were needed, and for providers to take proactive approach to following up to ensure continuity of care:

"having a doctor that will call and check up on you and that when he sees a form with my name on it. And he sees that I am going in and doing something."

"he would try to you know make sure that I'd schedule meetings with him to check in, you know every few months just to see how everything was going on so he's very involved."

As above, patients described these gestures as genuine investments in in their continued well-being, and also appeared to function as continued reassurance that they would not lose their ability to initiate conversations about changing or terminating their depression treatment if needed.

DISCUSSION

The present study reflects upon the experiences of SDM and decision-making preferences among underserved primary care patients with depression. Overall, respondents described positive experiences of decision-making during depression care, which contrasts with findings from previous literature suggesting that SDM practices are not being readily infused into discussions about depression in primary care (28, 29, 31). These findings offer meaningful and needed insight into how underserved populations define preferred process of SDM in primary-care based depression treatment, and can guide future adaptation of SDM practices to align with the needs of underserved populations.

One notable theme was the prominent influence of stigma associated with depression and its impact on respondents' sensitivity toward being judged or labeled by their providers. The increased sensitivity influenced patients' initial openness toward depression treatment and their attitudes toward discussing symptoms with their provider. This finding is consistent with the wider literature, which has suggested that in the US, individuals from racial and ethnic minority groups are more likely to perceive stigma associated with mental illness than non-Hispanic whites, and, as a consequence, may be less likely to seek treatment for depressive symptoms (48, 49) or have negative attitudes toward depression treatment (50).

Results from this study contribute to this existing work by illustrating how perceived stigma informed respondents' preferences around communication and decision-making. First, although respondents generally described a preferences for collaborative communication during the decision making process, they also indicated a strong preference to retain control over the decisional outcome of depression treatment, specifically the authority to decline or accept services to treat their symptoms. This assurance appeared motivated by a perceived need to guard against coercive practices. Second, respondents emphasized that stigma could prevent effective SDM by inhibiting open and honest communication with providers, or engendering mistrust of providers' recommendations. Consequently, among this sample, successful SDM was dependent upon the development of a safe and non-judgmental environment.

In describing their preferences around communication and decision-making practices, respondents identified several provider behaviors that helped facilitate an environment where effective SDM could occur. Importantly, the behaviors that respondents emphasized most often, namely the development of trust, and consistent, reliable follow-up after making treatment decisions, occurred either *before* or *after* the decision-making process itself. While the importance of developing a strong working alliance is well-established in the mental health literature (51) leading models of SDM tend to approach decision-making as an isolated clinical process. In a critique of such SDM frameworks, Matthias et al. (52) have suggested that decision-making practices are inherently shaped by the overall relationship between the patient and provider, and therefore cannot be divorced from the larger clinical context. Findings from this study underscore this perspective, and point to the need to better account for interpersonal dynamics when implementing SDM in practice, especially with underserved communities, where differences in power and privilege may be particularly acute (53).

While adaptability has been identified as a necessary, albeit complex, component for effective dissemination of best practices (54), research around SDM has been slower to offer refined frameworks, or develop mechanisms that support successful implementation of SDM across diverse contexts (17, 52, 55, 56). To cultivate this environment, providers should first be aware of how the experience of stigma can inhibit patients' disclosure of symptoms, and focus early efforts on signaling their willingness to share the role of the expert with patients and establishing a safe and nonjudgmental space for patients. Respondents in this study suggest that particular components of effective practice include prioritizing and responding to patients' subjective well-being (including negative responses to medication), and maintaining a working knowledge of patients' full range of health and mental health needs.

There are several limitations to this study. First, while these findings provide an in-depth description of patient preferences for SDM, results from this study are not generalizable, and the preferences described by sample population may not be representative of all patients receiving depression treatment in primary care. Second, although the study took place within an urban, safety net ambulatory setting, the respondents in this sample were generally well-educated, and described a substantial history of receiving treatment for their depression. Because of this, this group may not reflect the needs of the most vulnerable population, including those with low health and mental health literacy or those considering depression treatment for the first time. However, respondents' robust historical experiences allowed them to provide rich detail about their challenges discussing treatment and disclosing symptoms, and reflect on the difficulties of negotiating stigma and power imbalances between patients and providers. Further, while about half of this sample had a college education and may therefore reflect those with higher educational attainment, it was quite diverse in terms of age and racial/ethnic background. A majority of literature around SDM reflects a predominantly white sample population, and as such this work fills an important gap in the representation of diverse patient groups in the literature. In addition, because respondents were reflecting on past experiences in care there is a risk for recall bias, and participants may be receiving depression care from multiple providers, including physicians, psychiatrists and therapists. Because all respondents had an active diagnosis of depression and the vast majority (80%) were actively receiving treatment, we believe this risk should be minimal. Additionally, respondents were prompted to speak specifically about their conversations about depression with their primary care provider during the interview process. Finally, this study took place during the COVID-19 pandemic, which required us to do all recruitment and data collection over the phone and via video conferencing. This may have impacted the composition of this sample, as those with greater accessibility to technology were more easily able to participate. Despite this, the success accessing a diverse sample demonstrates that conducting in-depth interviews virtually is feasible.

In sum, this study offers novel, in-depth insight into how patients prefer to approach discussions around depression treatment, highlighting areas where both decisional authority and partnership is desired (57). Through these in-depth interviews, respondents highlighted several strategies that can inform providers' efforts to encourage patient's to actively engage in conversations about depression treatment, and guide flexible and responsive applications of SDM that are most aligned with the needs of individuals seeking depression care.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because data includes protected patient information. Requests to access the datasets should be directed to ematthews13@fordham.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Temple University Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

EM and YZ-I were primarily responsible for the study design and manuscript preparation for this project. MS and AP also informed the study design and assisted with recruitment. DW, TH, and DG assisted with primary data collection. EM, DG, and YZ-I all contributed to the analysis of the data presented. All authors contributed to the article and approved the submitted version.

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REVIEW
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Family Group Conferences as a Shared Decision-Making Strategy in Adults Mental Health Work

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Family Group conferences (FGC) provide a system by which a client and their family reach jointly key intervention decisions, from a number of options proposed by professionals. The system originated in child protection social work.

Conceptually FGC is based on the assumption that the family is potentially a supportive social system for an individual with a variety of difficulties, including mental ill health. Reaching a family network agreement can lead to long term positive outcomes in self-confidence and social relationships. This strategy of shared decision making (SDM) can re-unite the family around the client's needs and wishes. It fits well the strengths based and the recovery-oriented approaches to mental ill health.

Methodologically, this article provides a narrative review of existing empirical research about FGC in the context of adult mental health. In addition, two community case studies consisting of videos of a mother experiencing mental ill health and a daughter are analysed in terms of their **subjective** experience of the FGCs they were involved in, and looks at both the process and the outcomes of FGCs.

The **key findings** demonstrate a high level of satisfaction **from participating** in the FGC meeting, while the evidence pertaining to the outcomes is inconclusive. Only very few systematic review studies, or comparative studies of different approaches to family decision making, exist, and there are no studies which offer cost effectiveness analysis.

Discussion: The observed gap between the satisfaction from the process of FGC by the participants vs. the inconclusive outcomes relates to the implementation phase, in which the decisions made by the family are tested. Evaluating FGC processes and outcomes is complex. A systematic and comprehensive research of the implementation process is missing at this stage.

In conclusion, FGC is a promising strategy of SDM in adult mental health. The research evidence indicates the need for further exploration of its implementation process, evaluative methodology and methods.

Keywords: family decision making strategy, adult mental health, participation process, implementation process, evaluation

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INTRODUCTION

This narrative review is aimed to respond to the following questions:

1. What is FGC and what does it offer to adults facing mental ill health challenges and their families?
2. Is FGC a shared decision making strategy?
3. Key existing empirical research on FGC with this group of adults

3.i. Methodology and methods

3.ii. Key findings concerning processes

3.iii. Key findings concerning outcomes

4. Future challenges for researching FGC with this group.

BACKGROUND

FGC (Family Group Conferences) or FGDM (Family group decision making; its Dutch name) is a system in which key care issues of an individual are sorted out by calling a family meeting to reach jointly relevant decisions and their implementation action plan. The strategy was developed initially in New Zealand, as part of an attempt to reduce the increasing number of Maori children taken into care, roughly based on the Maori's problem solving strategy by a meeting of their elders, to which relevant others are invited too (1). FGC has been practiced in social care, especially in the context of child protection, across English-speaking countries, but also in other countries (such as the Netherlands) and with other issues, such as mental health (2), restorative justice (Restorative Works 2019 Year Review), adults of working age and older people's domestic abuse (3). Edwards and Parkinson's (4) book provides an overview of FGC in different areas. A key aim of this article is to examine the shared decision- making (SDM) component of FGC with adults experiencing mental ill health, its process and outcomes through analysing the existing evidence from empirical studies of FGC with this group.

SDM is by now more widely perceived as a useful component of supporting this group, alongside a greater emphasis on the contribution of family members (some of whom are acting as informal carers). Therefore, we need to ask how productive and satisfactory are the FGC process and outcomes from the perspectives of the index client, family members, and service providers.

The unique features of FGC include:

1. Professionals (often social workers, but not necessarily so) working with the family have a key role in suggesting the FGC, proposing potential solution scenarios that are likely to resolve the difficulties faced by the index client and the family for the family group to consider, and to map the support for the implementation of the agreed plan proposed by the family at the end of the initial FGC meeting.
2. A professional service provider initiates the request to offer an FGC and appoints an independent co-ordinator. The co-ordinator is central to preparing the family meeting, recruiting different family members to participate in the meeting, at times in the context of enduring poor relationships which raise doubts about the option of finding a shared solution. The co-ordinator's withdrawal after the preparatory phase signals to the family the trust in its ability to select a valid solution and an effective implementation plan.
3. Empowering the family and the index client by giving them the opportunity through the FGC to reach key shared decisions concerning the index client's future and the contribution of family members to the implementation plan.
4. The ability of the family to come up with an agreed plan within one meeting, despite past strained relationships, functioning difficulties, and doubts concerning the future.
5. Advocates for people who could not come, or who were reluctant to do so, may join the family meeting at the request of the person they are advocating for.
6. The key role of follow up meetings (usually 1–2 within 3–12 months) to ensure the implementation of the plan.

This model is attractive in terms of its potential to secure positive effect, thus saving efforts, time, funding, reducing and resolving difficulties which significantly affect family members' lives. There are variations between different countries as to whether co-ordinators are independent professionals (e.g., UK) or prominent community members who are not professionals (e.g., the Netherlands), whether the professional who proposed potential solutions scenarios joins the meeting for the phase of explaining the scenarios or just provides a written summary, and proceedings as to what to do when the index client refuses to attend the meeting and/or its evaluation.

CONCEPTUAL FRAMEWORK

The FGC strategy combines more than one conceptual strand. The family is understood to be a social network likely to be supportive of individual members facing difficulties which impede their functioning. The FGC has been constructed to enable families to do so with a specific significant problem. It is expected that family members who do not act as carers would be asked to invest time and energy in supporting the index client. Existing evidence that carers' psychological, physical and economic viability might be negatively impacted by being a carer lands support to this request.

The view of the family as a system, in which each individual depends on the whole family, is an integral part of the underlying assumptions of the approach. Any positive change is significant in contributing to the reduction of tension within the family system, even if the index client does not return to a good level of functioning.

Different cultures vary in the place and power given to families. Hence cultural competence in FGC needs to be secured prior to applying it to each culture. The article by Barn and Das (5) provides a useful contribution concerning this theme. The authors highlight that in order to prevent the othering of the members of a minority group who may also be unsure of an initiative that comes from the majority's culture. Cultural competence requires knowledge of the history and culture of the group the family comes from, their preferences concerning issues such as the place of elders, use of language, and type of food preferred to be served in the family meeting. Barn and Das conducted an empirical research into how 12 managers and 8 co-ordinators of FGC projects in London approached this issue, collecting the evidence from a focus group and profile questionnaires. The findings highlighted that the participants attempt to find out at the referral point what is the cultural background, and then aim to provide ethnic matching, and if possible also matching in terms of language, gender and religion. If necessary, they pare co-ordinators with interpreters, and have bi-lingual co-ordinators.

Attention to Mental Ill Health Challenges Within FGC With Adults

FGC is based on the assumption that in principle the family and its dynamics can be a powerful tool for reaching key decisions concerning its members and in implementing these decisions. It is furthermore assumed that these two components play a part even when one member of the family, or more than one, has experienced difficulties, such as mental ill health challenges. Shame, guilt, blame, bitterness, and unhappiness, typify the experience of many service users and their family members/carers where an identified mental ill health difficulty exists (6).

Contextualising SDM and FGC in the Current Mental Health System

The development of community mental health services, and the considerable reduction in the place of institutionalised care for people experiencing mental ill health that has taken place gradually since the second half of the twentieth century, highlighted the fact that this group does not need to be segregated from society (7). With the success of rehabilitative options, such as being in employment (8), came also a re-evaluation of the abilities of members of this group.

Since the 1960s it is largely accepted that a mental health crisis has the potential to provide an opportunity to develop positive new options, hence need not be perceived only as harmful (9). This perspective relates to the definition of a crisis as an imbalance between arising difficulties and the resources necessary for resolving them (9). The strengths of the person, and of their family members, are part of these resources.

This logic has been taken further in the more recently developed concept of Posttraumatic Growth (10) which has highlighted that Posttraumatic Stress Disorder is not an end point, and that identifying positive lessons in traumatic experiences is both possible and desirable (11). It can also be acquired through a learning process with providers trained specifically to mentor the process of applying PTG, called Expert Companions [(10), p. 141–146].

The Recovery and the Strengths Approaches

The recovery approach to mental ill health came to the fore in the late 1990s and has continued to develop since. It postulates that people can lead a meaningful life with and beyond their mental ill health condition (12). This implies that even if some of their symptoms continue to be present, they still can have a meaningful life with psychosocial support, thus calling for an emphasis on care instead of cure. Existing empirical evidence supports this perspective, which has become a formal policy in many countries (13). The unprecedented element of the recovery approach has been the fact that it was initiated by people with the lived experience of mental ill health who rebelled against the prevailing medical model (14), who were joined later by some professionals from all disciplines.

The strengths approach (15) was developed initially in social work, and is by now accepted as an integral component of mental health recovery by all mental health disciplines. It highlights that having difficulties in mental health functioning does not mean losing all abilities, inclusive that of social interaction. The need for a more nuanced assessment of strengths alongside problem areas, the role of motivation to use abilities that have become hidden, and the need to reduce social stigma are emphasised in this approach. Elements of the strengths approach, such as personal efficacy and social capability, are also referred to as social capital (16, 17) which includes all personally owned resources. The role of informal carers, who are usually family members, has also became more central in the changing mental health system (18).

The lessons learned from these conceptual and practice-oriented developments have highlighted the value of experiential knowledge in understanding mental ill health, the impact of specific interventions in this field, the value of mutual support, and the potential of enhanced self-management, alongside learning from scientifically based knowledge which professional providers bring.

The recognition of the positive contribution of experiential knowledge is also exemplified in the development of peer support work in a number of countries (19–21). Peers are people who are utilising their own mental health experiential knowledge as a key component in providing valuable support to other people/peers who experience mental ill health.

Shared Decision Making (SDM)

SDM entails the contributions of both experiential and scientific knowledge as a method of establishing a process in which key intervention decisions, including medication management as well as psychosocial interventions (8, 22), are reached in mental health practice jointly between experts by experience (i.e. service users) and service providers. Respectful and trusting relationships between service users and providers (23) are necessary conditions for this achievement. SDM calls for attitudinal change by both clinicians and service users, in which sharing experiential knowledge is recognised as a central asset, alongside moving away from the notion that the clinician knows best. Beyond sharing information there is a need for service users to learn to evaluate the information given and to know where to find further information if necessary, as well as to acquire sufficient confidence to present their preferences usefully and convincingly (24). Available decision making aids enable service users and relevant others to understand better the process and to consider their preferred intervention (25).

There are differences in the ways SDM is practiced in the extent to which experts by experience are engaged as co-leading training on SDM and supporting service users in the process of SDM (21, 22, 26, 27) or whether the whole process is led only by clinicians (28).

The stages of SDM in the health system include Choice Talk, Option Talk, and Decision Talk (28, 29), which are practised in both physical and mental health SDM. Decision making sessions are often conducted only between the person/patient and the clinician. However, in care reviews meetings aimed at reviewing the recent past and planning the next phase intervention decisions which take place periodically every 3–6 months, informal carers who are usually family members can be invited too to participate in the decision making process (30).

These stages are reflected also in the FGC process. The choices are part of the initial conversation the co-ordinator has with the people invited to the family meeting as to why such a meeting is necessary, where the key problem areas and the how the FGC process can be of help in resolving them. The options are summarised in the written brief provided by the professional who has initiated the call for an FGC, which every participant at the FGC meeting is given and which are summarised orally by the co-ordinator at the beginning of the meeting. The decision talk is taking place at the FGC meeting in which the participants are asked to opt for a specific option and to follow it up by an action plan as to how it would be implemented.

The main differences between SDM as practised in health systems and the FGC lies in the decision making power given to the key FGC meeting in which clinicians do not participate. But as the options in FGC are prepared by the professional provider, who is also a key figure in the implementation of the decisions made in the FGC, this provider impacts considerably on the option selected by the family. While gaining family support, the individual client has less power in the SDM process as practiced in the FGC than in the one to one meetings between clients and clinicians in the health system SDM process. The one-to-one SDM process is likely to take more than one meeting and hence enables a longer process of establishing trust and respect between clients and professionals.

Currently SDM is not a formally required process in any country, including countries such as the UK where NICE (the National Institute of Excellence) and the DHSC (Department of Health and Social Care) have suggested its use. There is good research evidence that demonstrates the effectiveness of SDM (31, 32), inclusive of cost effectiveness (33, 34). However, the implementation of SDM in mental health is problematic as it requires a considerable attitudinal shift in the views of providers, service users and informal carers (35, 36).

FGC is a strategy in which the family is given the power to exercise shared decision making and an implementation plan within a limited range of options, in collaboration with service providers in the pre-FGC meeting and in the follow up period. Unlike the application of individual SDM, FGC is a legally required practice in all social care agencies which have established it formally as part of their practice.

METHODOLOGICAL FRAMEWORK

A scoping narrative review will be provided below. Its inclusion criteria are: Empirical research of FGC; with adults of working age (18–65 years old) experiencing mental ill health; between 2000 and 2020, only in English; both—or either—qualitative and quantitative methodology. The exclusion criteria are: FGC non-empirical research publications; FGC empirical research on children and older people; FGC empirical research not on adults experiencing mental ill health; publications in other languages than English; publications of empirical research before 2000. Articles focused upon in this narrative review are marked with * in the references list. The literature search included the Scopus database, key social work journals (British Journal of Social Work, European Journal of Social Work, the Family Rights Group[1], J. of Social Work, Social Work and Social Sciences Review), key mental health journals (Journal of Mental Health Social Inclusion and Mental Health, Mental Health Review), key nursing journals (Issues in Mental Health Nursing, J. of Advanced Nursing, International J. of Mental Health Nursing, Nursing Time), the British Medical Journal (BMJ), Child Abuse and Neglect, J. of Family Law, J. of Sociology and Welfare. The choice of journals was based on the likelihood that they will focus on family Involvement with this client group.

A table summarising the articles focused upon in this narrative review appears in **Appendix 1**. Two community case studies videos will be looked at for the purpose of illustrating what FGC looks like from the perspectives of the different key players, the processes of reaching shared decisions, outcomes, and the applied evaluation methods. The use of videos has been chosen because they demonstrate well the process of FGC and the emotional experience of FGC from the perspectives of the index client and other family members. Created by the UK based Family Rights Group[1] (2012), the organisation which promotes FGC practice, the videos are based on real life cases, but do not show specific real people, with participants being depicted through animation. I do not know of any other review of FGC that has used existing videos as part of the research evidence.

A scoping narrative review has been selected because the updated systematic review by Hillebregt et al. (37) highlighted a very small number of studies that fitted the criteria of being conducted with a Randomised control trial (RCT) sampling procedure, which is usually expected to be in place in systematic reviews. The shortage of empirical research on FGC with adults highlights the need to look at how existing research has been conducted, as well as at the gaps in our knowledge of FGC (38, 39). It also raises the question as to whether RCT should be the only criterion for inclusion of research in a systematic review (40). In a recent publication on FGC with adults and the research methods applied to its evaluation in the UK, Manthorpe and Rapaport (41) refer to people experiencing mental ill health, identified as the largest **sub-group** in number within the adult FGC population. They also noted the complexity of evaluating FGC. The only RCT study of adult FGC focusing on people experiencing mental ill health has been carried out in Norway

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[1] https://www.frg.org.uk

(42–45) is described in the research evidence section below. The two community case studies are based on the analysis of a video of a mother experiencing mental ill health and a video of a daughter's point of view. The videos offer two complementary perspectives of FGC index clients of their expectations from the FGC alongside the decisions made at the family only meeting, and their reflections of the meeting.

Research Evidence

Most of the existing FGC research focuses on child protection when the key issue is whether the child should be moved from his/her family, and in which the key worker has clear legal duties to be carried out. The key findings highlight considerable satisfaction from the process by the family members and the index client, yet with inconclusive outcomes (46). Some, but not all, studies have a control group. Follow up time varied from one study to another, and most studies did not apply a randomised controlled sampling.

Existing Systematic Literature Review on FGC With Adults Experiencing Mental Ill Health

Hillebregt et al. (37) have provided the most recent systematic literature review of the key elements and effectiveness of family group decision making interventions in adult health and social care. The three key elements of this review consist of a plan with actions and goals, being family driven, covering three phases which include the follow up of implementation and evaluation [(37), p. 2]. Only studies applying RCT were looked for.

Out of initial 1680 studies, only one met all criteria. Significantly better outcomes in increased social support, mental health and re-employment were demonstrated in the study up to week 23 by the experimental group, but these were not maintained at the end of the follow up year [(37), p. 1]. Conducted by Malmberg-Heimonen et al. (42, 43), it included 149 people with lived experience of mental ill health who have participated in FGC meetings, with the experimental group having an FGC experience, while the control group had treatment as usual. A mixed methods evaluation took place, including filling a questionnaire on social functioning, a mental ill health diagnostic assessment, and the GHQ-12 (General Health Questionnaire) as a measurement of health change at three points in time—prior to the FGC meeting, 3 months later, and 1 year later.

In addition, 15 of the participants were interviewed at the final follow up point (44). The results highlighted a high satisfaction from the FGC process, positive change outcomes at the 3 months follow up, and neutral outcomes at the 12 months follow up in comparison to the outcomes of the control group. The final disappointing results have been explained by the participants as due to lack of reciprocity in social relations within the family and lack of follow up by providers. Attrition in numbers of participants took place too, from 149 to 108, as those who have not completed the FGC full three phases dropped out. The rate of the dropout raises the issue as to whether the RCT sample remained equally randomised at the end as it was at the beginning. Johansen (44) analysed the therapeutic achievements of the 15 interviewees from the experimental group. These included enhancing self disclosure, dialogic communication, and improved family relationships; which are in fact significant achievements for the FGC strategy. It would therefore seem that while not achieving statistical significance, the outcomes for those interviewed have been positive.

Promising Research

a. Research on FGC and its impact on social support, resilience and living conditions of index clients

de Jong and Schout (47), de Jong et al. (48–50), and carried out a large scale follow up research on 41 FGC meetings in terms of their impact on main participants' social support, resilience and living conditions as judged by the index clients, family members, and professionals. Of the total 473 participants (with about 11 participants per each FGC), 312 contributed to the follow up evaluation. A mixed methods evaluation was applied to the multiple case study analysis (51), consisting of interviews and scoring between 1 and 10 of the interview responses. No control group was included in the research design, though there are comments about the index clients who did not complete the evaluation, concerning the likely difficulties that have prevented them from doing so. The FGC meetings were organised by the Public Mental Health Care (PMHC) of Groningen (northern Netherlands) for a client group consisting of people defined as difficult to engage with psychiatric services, experiencing severe mental ill health, addiction, debts, neglected households, and lack of self- care [(50), p. 353]. The FGCs were aimed to enhance the informal support network which could reduce demand for professional care and economic costs, linked to values and conceptual frameworks of creating a more participatory society.

The follow up interviews and scoring of interview thematic content by the researchers took place between 1 and 6 months after the FGC meetings. Participants included index clients (called main participants), family members, the FGC co-ordinators, and professionals. Demographic data is included [(50), Table 2, p. 12].

The results highlighted that the desired change in the three areas of social support, resilience and living conditions, took place in 33 of the 41 cases, reaching statistical significance. The more positive feedback came from the co-ordinators, followed by the clients, with the professionals providing a positive feedback but at a lower level (p. 12). The highest score was given to improvement of social networks, living conditions, and resilience. A small decrease in the wish for further professional care has also been noted.

Unlike other studies, this project demonstrates modest but positive outcomes of the FGC strategy on all three dimensions at the implementation phase, at both the quantitative and the qualitative evaluation facets. It does so with a population experiencing serious difficulties in key living domains, inclusive of mental ill health, many of whom were described as "seemingly hopeless cases" (p. 357). Hence, it indicates that FGC can enable positive impact on key psychosocial dimensions which are critical to success across most living domains. Statistical analysis which included *t*-tests, SPSS 20, and multi-level "nested modelling" analysis demonstrated statistically significant differences between the pre FGC measurements and the post FGC of the key change areas. The study did not aim to cover the degree of change in psychiatric ill health and medical intervention attributed to the FGC intervention.

A number of limitations are noted by the authors, such as having only retrospective reporting, and that not every participant was willing to participate in the evaluation (161 out of the 473 participants). A descriptive design was adopted, rather than an experimental one, the sampling did not follow an RCT model and a control group was not recruited. It is also noted that 30 requests for FGC made by professionals did not lead to an FGC meeting taking place, as the clients invited did not wish to share their problems with their family network, due to feeling ashamed of their situation. It is therefore possible that the finalised sample represents of those who could felt that they could cope with being ashamed about their lives while attending the FGC. It is also possible that the more positive rating by the co-ordinators, as compared with that of the referring professionals, might have been motivated by their greater involvement and motivation to succeed in the FGC.

b. FGC as a tool to reducing compulsory measures in psychiatric admission

Compulsory admissions are known to limit the freedom of mental health service users, as well as to making them feel threatened and demeaned, and to curtail exercising personal agency (52, 53).

Schout et al. (54) looked at the conditions in which the use of FGC in reducing compulsory admission is not warranted, through the analysis of 17 cases of compulsory admission, following the multiple case study analysis (51). They concluded that FGC will not be helpful when the client is in acute danger and has difficulties in communicating and making decision. It will also not be helpful when either the professionals working with the index client do not use FGC, or the client and their network are not open to its application. This issue was followed in their 2017 paper (54), as well as by two additional papers led by Mejier et al. (55, 56) which focuses on the contribution of FGC to reducing the use of compulsory measures in mental health settings through the exploration of new partnerships between clients, social networks and professionals (57). Given that most hospitalised psychiatric patients do not stay at the stage of high risk and mental incapacity for long (58) which justify the use of compulsory measures, this is an important issue for further development.

The proposed measures to reduce compulsory admission follow the logic of indirect social engineering, and include the elimination of nursing stations on wards, creating comfort rooms, family rooms, intensive care units, de-escalation of incidents, the deployment of peer supporters, crisis cards and advanced crisis plans, use of the Open Dialogue approach (59) and the Dutch Resource Group Act (RACT) which facilitates involvement in social networks (60). The added value of FGC within this framework is perceived to be focused on the value of family driven decision-making model and a social network strategy which reflect too the indirect social engineering approach. They have found that a one-off FGC may be insufficient to reduce the use of compulsory measures, and that it was applied as a last resort, likely to reduce its effectiveness. The articles by Mejier et al. (55, 56) focused on innovative experimentation of developing promising practice in this complex and demanding area of the mental health system.

c. FGC effectiveness in reablement in comparison to three other types of family interventions

Tew et al. (61–63) researched the impact and effectiveness of four types of family interventions, including FGC, with adults experiencing mental ill health in terms of reablement through improved use of personal agency and social interaction. Reablement has been defined as aiming to maximise users' independence, choice and quality of life [(64), p. 4].

The reablement dimensions looked at in this study included personal empowerment and social participation. The four family interventions included systemic family therapy (SFT), behavioural family therapy (BFT), FGC, and the integrated systemic and behavioural approach (ISB). Conceptually this research follows the recovery approach, inclusive of the recovery capital concept (17), and Sen's capability perspective (65).

Methodologically a scoping review was conducted, and Yin's multiple embedded case study approach was applied (66). Twenty-two families were involved; the service user, one family member and one professional per each family were interviewed. Participants filled in scorecards, in which rated positive change in each dimension was calculated by each interviewee on a 5-point Likert scale from 0.5 to 2.5, for the categories of negative change, no change, small change, substantial change, and major change [(66), p. 869]. Positive change was found to be higher for service users and family members than the professionals. Change coincided with starting family meetings close to the time of the mental health crisis experienced by the index client.

Although there was no formal control group, this study provides a comparison of the effectiveness of FGC to reablement to three other models of family work. Outcomes for families participating in FGC were very good concerning social participation and good on personal empowerment [(17), Table 4, p. 17]. Substantial work was required in preparing the FGC meeting to secure that the index client and the family will be in control, which often began while the service user was still in hospital or soon afterwards. FGC was particularly effective in sorting out practical issues rather than in reducing entrenched relationships. FGC and the ISB were more consistently focused on developing the family as a flexible supportive resource. Key elements in this process included the index client being in control, with the family network providing a secure base from which to jump off, rather than to be a safe haven. This study highlights the usefulness of the FGC approach to both policy and practice. According to the authors, the study limitations include that it offers a retrospective subjective perspective and that it is not matched demographically. The small number of families per each family intervention (between 5 and 7 families only) and the lack of follow up to check if the changes continue long term or not were additional limitations.

d. FGC effectiveness in reducing economic costs

There is some evidence concerning the economic saving as a result of applying the FGC method, though none is specific to adults experiencing mental ill health challenges. Guthrie (67) mentions a saving of £7,000 per adult FGC in terms of the need to invest less than in a non FGC similar cases, and £77,380 in child FGC, based on a study by Marsh et al (68) published in 1998. Munro et al. (69) in a more updated study outcomes of a Daybreak project show that more of the FGC children stayed at home or with relatives, leading to a considerably lower cost (around £1,598) than children who required a placement outside their family home (around £17,557) [(69), p. 47]. There is no similar evaluation of adult Family Group Conferences.

If cost effectiveness would have been included in FGC evaluation, it would have shed more light on this issue (see further comment on this theme in the Discussion section list of missing issues). However, cost effectiveness analysis, which is taking place in mental health evaluation research (33, 34), does not appear to have been conducted in any of the FGC studies on either children or adults. This analysis would include the calculation of the economic cost, as well as the improvement in quality of life dimensions before and after the FGC meeting and the implementation of its action plan took place. This omission is neither acknowledged, nor explained, in the existing studies.

e. Community case studies: https://www.youtube.com/watch?v=YEDg0FPqGZc

These two case studies (outlined in **Appendix 2**) are aimed to provide a thick description (70) of the ambiguous range of thoughts and emotions concerning the forthcoming FGC meeting and its aftermath the mother and daughter portrayed in the videos had.

DISCUSSION

Attitudes to Working With Adults Experiencing Mental Ill Health Challenges

The paucity of applying FGC to adults in general, noted by Guthrie (67) as well as by Manthorpe and Rapaport (41), and specifically to adults experiencing mental ill health, requires a further exploration. For example, there are only 10 local authorities in the UK practicing FGC with adults, although the size of the adults of working age population is much larger than that of young people below 18 [(41), Table 2, p. 7]. Is it an indirect statement about less readiness to invest in adults? Is the lower level of readiness to do so due to the belief that less can be achieved with them than with children, or that adults deserve less than children do? Perhaps it is also a statement about the fact that there are more adult in need of complex intervention but fewer workers to meet this need. Guthrie (67) proposes that this is due to the wide variety of the adult population group and the challenge of measuring a wide range of outcomes.

It is also possible that while the key decisions in working with children are whether to move the child away from their family or not to do so, as well as to return the child back to the family, key decisions concerning adults experiencing mental ill health are not so clear cut, with neglect and abuse of the latter being infrequently the highlighted key issues. Given the emphasis in Western culture countries on non-institutionalisation, and the recognition of the possibility of leading a meaningful life without the disappearance of all symptoms subsumed under the heading of the recovery approach for people experiencing mental ill health, SDM is likely to be focused on rehabilitative activities and social interaction alongside the use of medication. Family interventions come to the fore when family relationships are recognised as being problematic and impacting negatively on index clients and family members.

Methodological Issues

The value of the taken for granted application of RCT as the golden design in the evaluation of FGC is questioned by de Jong et al. (48), de Jong and Schout (71), and Schout (72). They suggest that the complexity of researching FGC requires a highly nuanced approach, which qualitative research methodology would be more suitable for, while acknowledging that a qualitative methodology depends on the interpretative perspective of the researchers. Thus, the assumed suitability of RCT as the best research design is doubted in favour of a framework which will attend to multiplicity, polyvalence and interference, which they call "interplexity" [(71), p. 164]. The complexity of the evaluation of FGC is indeed considerable, and requires further consideration.

The lack of control groups in most of the studies requires further attention too. On the one hand it could be argued that FGC has a comparative dimension from the outset, namely in looking at changes due to experiencing the FGC processes by the index client vs. their family members. On the other hand a comparison with a control group unexposed to FGC while experiencing similar difficulties is likely to provide a more robust comparison. However, having a control group would require a more demanding research design, financial cost, and time.

Key Findings Concerning the Process of FGC

The research evidence covered above highlights that this group of adult participants in FGC is on the whole satisfied with the process of the strategy and the empowering SDM component it contains, even though the index clients come with a high level of poor self-image, difficult relationships with their families, and of poor social position of long-term duration. This in itself is an indication of the power of the approach to unhook past failures, to lead to at least temporary improvement in these central psychosocial functioning areas, and to enhance the readiness to collaborate better in the future. The indicated potential for economic cost effectiveness—especially in reducing periods of compulsory admissions—is an additional incentive for the systematic use of FGC with this population group.

Key Outcomes Findings

The outcomes focused upon in the research projects were about psychosocial improvements of the index clients and of increasing their family network both quantitatively and qualitatively. These positive changes have taken place soon after the FGC meeting for most index clients. However, the outcomes of FGC at the follow up stages were less satisfactory than the process, an issue explained by the problematic implementation phase in terms of reduced reciprocal relationships and insufficient contact offered by the providers to the index clients. This phase is crucial for the success of the FGC action plan, yet it is not clear from existing research if it does receive the investment it requires in having a skilled workforce for further work with the index client and their family network.

Missing Issues

a. Including shame as an FGC issue

Including shame as an explicit content and methodological issue seems to be a problem area It has clearly emerged in the FGC video cases, and in the de Jong et al. (49) post FGC evaluation. It is likely to be an issue in other strategies of SDM in mental health, such as periodical care management reviews with informal and formal carers alongside the index client. It appears as an indirect issue in stigma reduction, but it has hardly been addressed either in reflection on research or practice.

b. Psychiatric Medication Management Issues

Unlike in individualised shared decision making, where medication management is often discussed, it has not come up in FGC studies of adults experiencing mental ill health challenges. This may be the case due to the lack of involvement of psychiatrists or nurses who are the perceived experts in managing medication, in leading FGC projects with this group. It may be due to the clear preference of FGC researchers to home on psychosocial issues, thus ignoring the significance of psychiatric medication management control for the index client-patient, and for their family members. All too often clients do not wish to take prescribed medication due to the adverse effects of the medication they have been prescribed, to which many carers respond by putting pressure on the clients to take the medication as prescribed, leading to medication compliance becoming a bone of contention in their family relationships. The Israeli based Keshet (Rainbow) training programme offers an example of focusing on providing carers with communication skills that enables the diffusion of the emotional and power struggles between parents and their adult son or daughter who experiences mental illness challenges and leads to more collaborative relationships around this crucial issue (73) which has not reached as yet the agenda of FGC with this client group.

c. Missing cost effectiveness measurements

Cost effectiveness analysis, which is taking place in mental health evaluation research (33, 34), does not appear to have been conducted in any of the FGC studies for either children or adults. If applied, this analysis would have provided the calculation of the economic cost, as well as the improvement in quality of life dimensions before and after the FGC meeting and the implementation of its action plan took place. This would have added two central dimensions to the evaluation. This omission is neither acknowledged, nor explained, in the existing studies. It might be reflecting the pre-occupation at this early stage of applying FGC to adults experiencing mental ill health challenges with key psychosocial themes.

d. Missing a thorough impact analysis of barriers and facilitators to the continuation of the achievements reached in the FGC initial meeting across the implementation stage.

CONCLUSION

The discussion section has highlighted several achievements of existing empirical studies of applying FGC to adults experiencing mental ill health and their family network. While more good quality studies of the impact of FGC are needed, preferably of mixed methods design led by a qualitative methodological framework, the results of existing FGC with adults experiencing mental ill health are similar to the updated research on FGC with children (46). They indicate that the FGC meeting is experienced positively by all participants, though many of the index clients have had a high number of difficulties and past failures, as an empowering method that opens up communication and support options which have been hitherto blocked, as well as enables SDM to take place. The stumbling point to ensuring the continuation of these achievements seems to be located at the implementation stage. The Discussion section has highlighted several missing issues from the current FGCs agenda. Finally, whether an RCT design should be a must or not in FGC research is a mooted point, as already mentioned above. It seems to me that at this initial stage of evaluating FGC with adults experiencing mental ill health there is a place for more than one approach to the issue of sampling design.

AUTHOR CONTRIBUTIONS

SR conceived and wrote the whole article.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2021.663288/full#supplementary-material

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Parent/Carer-Reported Experience of Shared Decision Making at Child and Adolescent Mental Health Services: A Multilevel Modelling Approach

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Background and Objective: Shared decision making (SDM) has been associated with positive outcomes at child and adolescent mental health services (CAMHS). However, implementing SDM is sometimes challenging. Understanding the factors associated with parent/carer experience of SDM could provide empirical evidence to support targeted efforts to promote SDM. This study aimed to explore the frequency of parent/carer-reported experience of SDM and examine possible associations between SDM and clinician's perceptions of the (a) children's and young people's psychosocial difficulties, (b) additional complex problems, and (c) impact of the psychosocial difficulties.

Methods: Secondary analysis was conducted on administrative data collected from CAMHS between 2011 and 2015. The sample was composed of 3,175 cases across 58 sites in England. Frequencies were recorded and associations were explored between clinician-reported measures and parent/carer-reported experiences of SDM using a two-level mixed-effect logistic regression analytic approach.

Results: Almost 70% of parents/carers reported experiencing higher levels of SDM. Individual-level variables in model one revealed statistically significant ($p < 0.05$) associations suggesting Asian parents/carers (OR = 1.95, 95% CI [1.4, 2.73]) and parents/carers having children with learning difficulties (OR = 1.45, 95% CI [1.06, 1.97]) were more likely to report higher levels of SDM. However, having two parents/carers involved in the child's care and treatment decisions (OR = 0.3, 95% CI [0.21, 0.44]) and being a parent/carer of a child or young person experiencing conduct problems (OR = 0.78, 95% CI [0.63, 0.98]) were associated with lower levels of SDM. When adjusting for service level data (model two) the presence of conduct problems was the only variable found to be significant and predicted lower levels of SDM (OR = 0.29, 95% CI [0.52, 0.58]).

Conclusion: Multilevel modelling of CAMHS administrative data may help identify potential influencing factors to SDM. The current findings may inform useful models to better predict and support SDM.

Keywords: multilevel analysis, logistic regression, parents, child mental health, carer

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INTRODUCTION

Shared decision making (SDM) is defined as the involvement of service users in the decision-making process where there are important competing care and treatment options (1, 2). This approach to health decisions has been widely advocated across various health settings and patient populations (3, 4). However, in child and adolescent mental health services (CAMHS), the SDM process is unique as it involves a sometimes-complex triad relationship between clinicians, parents/carers and children or young people (5, 6). Yet, previous studies have mainly focused on the dyad relationships between clinicians and adult patients (7). SDM in chronic care settings, like CAMHS, may require service users to make and revisit decisions, with fewer decisions occurring during the clinical encounter and several ongoing lifestyle decisions, compared to acute physical care (8). Therefore, the areas where triad relationships exist in chronic care settings have been less understood, with implication for a universally accepted definition (9). Consequently, it is vital to monitor SDM to ensure elements of SDM are still being met. Makoul and Clayman (10) described an SDM model with nine essential elements. These include identifying or discussing: the problem; treatment options; benefits/risks; service user values/preferences; service provider recommendations; service user understanding; service user abilities/self-efficacy; decisions; and arranging a follow-up. Nonetheless, some researchers indicate that passive involvement in SDM is quite common in pediatric care. A previous study evaluating videotapes of 101 child care visits to 1 of 15 physicians observed that around 65% of cases resulted in decision making efforts mainly from the physician and fewer cases with child or parent involvement (11).

Frequency of Service-User-Reported SDM

Despite researcher observations, studies conducted in the USA suggest that many parents/carers (55–68%) generally report experiencing SDM in CAMHS, reporting mean scores of 3.37 to 3.6 out of a possible four on SDM outcome measures (12–15). These studies analyzed data from national surveys that explored physical health (e.g., asthma) and common mental health and behavioral conditions (e.g., attention deficit/ hyperactivity disorder, anxiety, depression, conduct problems and autism spectrum disorder) in children up to the age of 17 years. Based on the available datasets the authors used composite measures of SDM including questions such as "If there were a choice between treatments, how often would your medical provider ask you to help make the decision?" (14) or "How often did they [clinicians] make it easy for you to ask questions or raise concerns?" (12, 13). All previous authors acknowledged the absence of a validated parent/carer reported SDM measure as a key limitation. It was also noted that the inability to capture the views of the child or young person could have potentially influenced their findings (15).

Similar findings have been reported in youth physical health (16) and adult mental health settings (17). In Europe, a study including over 8,000 participants in the general population found that over half (51%) of the sample reported experiencing aspects of SDM (18). Around 71% of the English respondents reported being satisfied with their level of involvement and being involved as much as they wanted to (18). National surveys in England have also shown an upward trend (52–59%), with more patients reporting experiencing SDM in the last decade (19).

Nonetheless, a scoping review of parent-targeted SDM interventions in CAMHS reported that existing interventions met an average of 4.57 SDM elements (20). To achieve this, the authors conducted a mapping exercise using the Makoul and Clayman (10) SDM model of nine essential SDM elements to evaluate the identified decision support tools. That finding suggests there is still room to improve when providing support to parents/carers to promote SDM. There is also evidence suggesting that only about 50–55% of parents/carers report discussing child psychosocial difficulties with health professionals (21). Further, previous studies reported lower SDM among families with children experiencing mental health conditions compared to physical health conditions (15). Taken together, researchers may agree that our understanding of the extent to which parents/carers of children with psychosocial difficulties experience SDM when accessing care is still limited. Similarly, the existing evidence indicates that SDM may be influenced by several factors, including demographics and clinical characteristics.

Potential Factors Influencing SDM

Studies in general healthcare report that younger patients and those with higher educational levels preferred involvement in SDM (22). Similarly, other population-based studies in the USA and Canada reported that younger persons and women experienced more involvement in SDM (23, 24). Researchers in physical health have also observed lower involvement in SDM opportunities from ethnic minority groups (25). In CAMHS, research suggests that higher levels of SDM are associated with children and young people (CYP) and parents/carers experiencing improvement in psychosocial difficulties (26). Similarly, higher SDM was associated with CYP experiencing mild mental health difficulties vs. those experiencing moderate to higher levels of difficulties or decreasing impairment scores (13, 14, 27). However, an in-depth understanding of parents/carers' involvement in SDM in CAMHS is still limited, as qualitative findings and observation reports suggest that parents/carers of children with psychosocial difficulties *struggle* to be involved in SDM (11, 28, 29). To support this group of parents, researchers are beginning to explore an affective appraisal approach for SDM in CAMHS. This model incorporates the emotional states of parents, by exploring a two-way direction that emotions may be influencing parents' involvement in SDM and vice versa (30).

Rationale for the Current Study

The above evidence suggests that families of CYP with psychosocial difficulties may be at risk of experiencing varying levels of SDM. Studies thus far generally examined the association

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Abbreviations: CAMHS, Child and Adolescent Mental Health Services; CVT, Current View Tool; CYP, Children and young people; ESQ, Experience of service questionnaire; SDM, Shared decision making.

between SDM and parental perceptions of child mental health status highlighting limitations such as self-report bias. This can have implications for how findings are interpreted, as previous research shows a higher proportion of parents (41.6%) may recognize externalizing problems compared to internalizing symptoms (28.1 %) (31). In the same vein, parent/carer perceptions of psychosocial difficulties may differ from CYP's perceptions (32). Therefore, further studies representing an objective view of CYP's psychosocial difficulties (e.g., clinicians' perspective) can support the existing literature. In addition, previous studies focused mainly on specific psychosocial problems (e.g., severity or impairment) among children up to age 18 and failed to account for comorbidities (e.g., learning difficulties) and further complex problems, such as the parent's own health. Also, due to the complex nature of SDM, the growing interest in the field and the potential service user and service provider influencing factors, it is of great importance to identify target areas for improvement. Lastly, given that CYP generally appreciate the involvement of their parent/carer in treatment decisions (33–35), an examination of associations as potential barriers to parent/carer experience of SDM could also be beneficial.

Aims

This study has three overarching aims. First, to explore the frequency of higher *quality* parent/carer-reported experience of SDM at CAMHS. Second, to examine associations between parent/carer-reported experience of SDM and clinicians' perceptions of the (a) presence of CYP's psychosocial difficulties, (b) presence of additional complex problems, and (c) impact of the psychosocial difficulties. Third, to investigate the potential influence of service level variables on parent/carer-reported experience of SDM.

METHODS

Participants

A secondary analysis was conducted on administrative data routinely collected from clinicians and parents/carers accessing CAMHS; more specifically those accessing the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) between 2011 and 2015 (36). The sample included in the current study was composed of $N = 3{,}175$ cases of CYP accessing care from 58 CAMHS offered by the National Health Services in England. The CYP were between the ages of 0 and 23 years with a mean age of 11.08 (SD = 3.93) years at the point of data collection. The sample was predominantly White (68%), with approximately half the sample being parents/carers of girls (52%), and the majority of the sample being mothers (66%). Further details of the sample is included in **Table 1**.

Measures

Covariates

Demographic Characteristics

We included the CYP's gender, age and ethnicity as covariates. Gender was categorized as male, female or other. Age was measured on a continuous scale. Ethnicity was recorded using

TABLE 1 | Characteristics of the sample.

Characteristic	***n* (%)**
Demographics	
Relationship to child	
Mother	2,084 (66)
Father	192 (6)
Both parents	790 (25)
Other	109 (3)
Age of child	
0 to 10	1,304 (41)
11 to <25	1,871 (59)
Ethnicity	
White	2,167 (68)
Mixed race	182 (6)
Asian	232 (7)
Black	150 (5)
Other	444 (14)
Gender of child	
Male	1,539 (48)
Female	1,636 (52)
Psychosocial difficulties	
Separation Anxiety	706 (22.24)
Social Anxiety	782 (24.63)
General Anxiety	845 (26.61)
[a]OCD	403 (12.69)
Panic disorder	511 (16.09)
Agoraphobia	358 (11.28)
Depression	796 (25.07)
Self-harm	448 (14.11)
[b]ADHD	440 (13.86)
Conduct disorders	507 (15.97)
Difficult to manage	588 (18.52)
Family problems	777 (24.47)
Attachment problems	496 (15.62)
Peer problems	757 (23.84)
Other	1,824 (57.45)
Additional problems	
Learning disabilities	283 (8.91)
Autism	375 (11.81)
Child in need	218 (6.87)
Experience of abuse	395 (12.44)
Parental health issues	704 (22.17)
Financial difficulties	238 (7.50)
Other	614 (19.34)
Impact on CYP	
Home	833 (26.24)
School/work	796 (25.07)
Community	488 (15.37)
Service engagement	261 (8.22)

[a]Attention-deficit and hyperactivity disorders; [b]Obsessive compulsivity disorders; M, Mean; SD, Standard deviation; CYP, Children and young people.
N = 3,175 (n refers to the count for each condition). Percentages representing psychosocial difficulties, additional problems and impact may not total 100 due multiple responses for each case.

the 2001 Census classification (37), and based on self-report by the young person or their parent/carer. For the purpose of analysis, ethnicity was collapsed into five broad categories: White, Mixed, Asian, Black and Other ethnic groups. The relationship to the child or young person was categorized as father, mother, both parents, and other to reflect the person (s) completing the SDM measure. The anonymised site identifier was used to denote the different CAMHS site the families attended.

Criterion Variables

The Current View Tool (CVT) is a clinician-reported measure that routinely captures information about a child or young person and their family. The clinician utilizes information from meetings with the CYP and their families, pre-meeting liaison (e.g., referrals, teachers and other health professional notes), patient-reported outcomes measures and clinician-rated measures (38).

The CVT records 30 presenting problems, 14 additional complex problems, as well as six contextual problems (e.g., impact on the school or home) and issues in education, employment or training. Generally, the ratings of the CVT do not imply a diagnosis (38, 39). However, routinely collected data have several strengths including comprehensiveness, cost-effectiveness and the ability to capture the same data throughout the National Health Services (NHS) allowing for comparison (40). The items on the CVT were used to assess the presence of psychosocial difficulties and complex problems as well as the impact of these problems.

Presence of CYP Psychosocial Difficulties

To assess the presence of psychosocial difficulties, 30 items of the CVT were used. Items included responses to statements such as "Anxious away from home," "Depression/low mood" and "Eating issues." Responses to the psychosocial items on the CVT were rated on a five-point scale with the responses categorized as "None," "Mild," "Moderate," "Severe," and "Not known." To capture the presence/absence of psychosocial difficulties, the responses "None" and "Not known" were coded as 0 and labeled as condition "absent or unknown." The decision to group these together was based on the assumption that the clinician had insufficient information to even identify mild symptoms. It was also observed that the unknown category represented <10% of the total sample. All other responses were coded as one and labeled as condition present.

Items with low frequencies (i.e., those representing <10% of the sample) were grouped together in a single category and labeled "Other" to avoid including under-powered groups in the main analysis. This group included items such as Gender Identity Disorder, Selective mutism and Substance abuse which clinicians reported on fewer occasions. As a result, 14 distinct problem types were represented in addition to "Other" totalling to 15 categories.

Presence of Complex Problems

To assess the presence of complex problems, 14 items of the CVT were used, capturing the presence of different factors, such as "Looked after child," "Parental issues" and "Deemed child in need of social services input." Responses were categorized as "Yes," "No" and "Not known." To capture the presence/absence of additional complex problems; the responses "No" and "Not known" were coded as 0 and labeled as condition "absent or unknown," and "Yes" to any of the items was coded as 1 and labeled as present. Similar to psychosocial difficulties, the additional complex problems with low frequency (e.g., having current protection plan and contact with the justice system) were grouped into a category called "Other" resulting in seven possible categories of additional complex problems.

Impact of Psychosocial Difficulties

To capture the impact of the psychosocial difficulties, items describing four contextual problems were used (i.e., difficulties at home; school, work or training; community and service engagement). Responses to the impact items were also rated on a five-point scale with the response categorized as "None," "Mild," "Moderate," "Severe," and "Not known." To capture the impact, responses "None" and "Not known" were coded as zero and labeled as "absent or unknown" and all other responses were coded as one and labeled as present.

Outcome Variable

Parent/Carer-Reported Experience of SDM

To measure parent/carer-reported experience of SDM using the available measures collected in the dataset, the following four items of the Experience of Service Questionnaire [ESQ, (41)] were used: (1) I feel that the people who have seen my child listened to me; (2) It was easy to talk to the people who have seen my child; (4) My views and worries were taken seriously and (6) I have been given enough explanation about the help available here. Previous studies have also utilized these items as a composite score for SDM (26). Responses to these questions were dichotomized and coded as Yes = 1 and No = 0. For the purpose of this research, an overall composite score of the four items were tallied and a parent/carer with a total score of 4 was classed as experiencing higher levels (i.e., quality) of SDM and any value <4 was classed as experiencing lower levels of SDM. Previous researchers have also utilized similar approaches to discriminate between levels of SDM (15). The four-item SDM measure displayed high internal consistency (Cronbach's alpha 0.9) with the current sample.

Design and Statistical Analysis

Preliminary Tests

To ascertain whether Logistic Regression models could be used for our analysis and to ensure the validity of the data, all assumptions were tested. The sample size of 3,175 was deemed adequate given the number of predictor variables (42). The assumption of no multicollinearity was also met. All Variance Inflation Factor (VIF) scores were <5 with a mean VIF of 1.57 implying that none of the independent variables correlated highly with each other (43). All potential outliers were removed prior to analysis (44).

Main Analysis

First, descriptive data including frequencies of SDM was calculated. Then we investigated the associations between the criterion variables and parent/carer-reported experience of SDM controlling for demographics and using conventional (i.e., standard/simple single-level) logistic regression analysis (model one). This unadjusted model included only individual/family level variables and did not consider the service level influence. Due to the nested nature of the dataset, a null model was fitted using the CAMHS Service ID and revealed an intraclass correlation coefficient (ICC) of almost 48% (ICC = 0.479) of the variance of SDM being explained at the service-level. As a result, families attending the same CAMHS site may share similar experiences biassing estimates of standard errors when examining the effect of services. Consequently, we investigated the associations between the criterion variables and parent/carer-reported experience of SDM using a multilevel mixed-effect logistic regression analysis (model two). The results of associations are shown as odds ratios (ORs) with a 95% confidence intervals (CIs). A two-sided p-value of <0.05 was considered significant (45).

To address the aims of the study, model one was compared to model two. Researchers argue that estimates of specific effects (e.g., OR) provide insufficient information if they are not accompanied by measures of general contextual effects (i.e., area under the receiver operating characteristic curve, AUC) (46). In line with Merlo et al. (46) recommendations for multilevel logistic regression of discriminatory accuracy, the AUC was estimated and compared. Therefore, the higher the AUC, the better the model was at distinguishing between lower and higher quality experiences of SDM (47). Additionally, the Akaike information criteria (AIC) was used as a measure of goodness of fit of the models (48). STATA (v 11) was used to conduct the analyses (49).

Ethical Considerations

The primary author obtained the necessary permission to conduct secondary analysis on routinely collected administrative data from CAMHS. Data was received in an anonymous format and only accessible via a password-protected server. As a result, this study did not require any formal institutional ethical approvals (50, 51), and we received permission to proceed with our analysis from the University research ethics committee.

RESULTS

The sample included in the analysis was composed of $N = 3{,}175$ cases of CYP accessing care from 58 CAMHS offered by the National Health Services in England (see **Table 1**).

Frequency of Parent/Carer Experience of SDM at CAMHS

Overall, 69.23% (2,198/3,175) of the parents/carers reported experiencing higher levels of SDM. For each of the four items on the SDM measure, over 90% of parents/carers reported that it was "true" the healthcare provider related to them in ways consistent with SDM.

Model 1: Factors Associated With Parent/Carer Experience of SDM (Unadjusted)

Model one was statistically significant, $\chi^2\ (32) = 220.48, p < 0.05$, suggesting associations between ethnicity, relationship to the child, presence of conduct problems or learning difficulties and parent/carer experience of SDM were observed. The regression model explained almost 6% of the individual level variance in SDM ($R^2 = 0.056$). More specifically, Asian parents/carers (OR = 1.95, 95% CI [1.4, 2.73]) and parents/carers having children with learning difficulties (OR = 1.45, 95% CI [1.06, 1.97]) were more likely to report higher levels of SDM. However, having both parents/carers involved in the child's care and treatment decisions (OR = 0.3, 95% CI [0.21, 0.44]) and being a parent/carer of a child or young person experiencing conduct problems (OR = 0.78, 95% CI [0.63, 0.98]) were associated with lower levels of SDM. No other significant associations were identified. Results of the model are presented in **Table 2**.

Model 2: Factors Associated With Parent/Carer Experience of SDM (Adjusted)

When adjusting for service level factors, $\chi^2\ (35) = 45.60$, $p < 0.05$, only the presence of conduct problems was found to be statistically significant and predicted lower levels of SDM (OR = 0.29, 95% CI = [0.52, 0.58]). No other significant associations were identified.

Model Diagnostics

It was observed that the adjusted model (model two) accounted for higher discriminatory accuracy in parents/carers experience of SDM than the unadjusted model (AUC change of 0.0088). This indicated that the added value of potential service level data introduced a higher chance of that model being able to distinguish between parent/carer experience of higher or lower levels of SDM. Model two also had the lowest AIC and as such was selected as the model that best fitted the current dataset. AUC and AIC scores are reported in **Table 2**.

DISCUSSION

The current study first aimed to statistically describe parents/carers experience of SDM at CAMHS. In addition we examined associations between parent/carer reported experience of SDM and clinician's perceptions of CYP psychosocial difficulties, additional complex problems and the impact of the psychosocial difficulties.

The results of this study indicated that almost 70% of parents/carers reported experiencing higher levels of SDM (4 out of 4) at CAMHS which aligns with the high proportion of self-report SDM in the previous literature (12–18). Although parents/carers in the current study reported high levels of SDM, it may not be sufficient to represent the complex nature of SDM in a triad (9), since researchers generally report several barriers to successful SDM in CAMHS (34, 52). Therefore, this raises further questions of whether we are accurately capturing

TABLE 2 | Regression coefficients, variation and fit indices across fitted models.

Parameters	Simple logistic regression analysis (unadjusted)		Multilevel logistic regression analysis (adjusted)	
	Model 1[a]		Model 2[b]	
	OR (SE)	95% CI	OR (SE)	95% CI
Demographics				
Age of child	1.02 (0.09)	0.86–1.21	0.96 (0.09)	0.79–1.16
Gender of child				
male vs. female	1.03 (0.88)	0.87–1.22	1.06 (0.1)	0.85–1.27
Ethnicity of child				
Mix vs. white	0.94 (0.16)	0.67–1.32	1.02 (2)	0.7–1.49
Asian vs. white	1.95 (0.33)**	1.4–2.73	1.43 (0.28)	0.97–2.11
Black vs. white	1 (0.19)	0.69–1.46	0.81 (0.16)	0.55–1.2
Other vs. white	1.19 (0.14)	0.94–1.51	1.07 (0.15)	0.81–1.41
Relationship to child				
Father vs. mother	1.1 (0.19)	0.78–1.55	1.05 (0.19)	0.73–1.5
Both parents vs. mother	0.3 (0.56)**	0.21–0.44	0.75 (0.18)	0.47–1.2
Other vs. mother	1 (0.292)	0.57–1.77	1.16 (0.35)	0.64–2.1
Psychosocial difficulties				
Separation anxiety	1.12 (0.11)	0.91–1.36	1.21 (0.14)	0.97–1.51
Social anxiety	0.99 (0.1)	0.81–1.21	0.97 (0.11)	0.78–1.21
General anxiety	0.85 (0.08)	0.7–1.02	0.84 (0.09)	0.69–1.03
OCD	0.94 (0.12)	0.74–1.2	0.1 (0.14)	0.77–1.3
Panic disorder	1.06 (0.12)	0.85–1.33	0.1 (0.12)	0.78–1.3
Agoraphobia	0.98 (0.13)	0.76–1.28	1.02 (0.15)	0.77–1.35
Depression	0.96 (0.09)	0.79–1.16	0.96 (0.1)	0.78–1.17
Self-harm	0.94 (0.11)	0.75–1.19	0.87 (0.11)	0.68–1.12
ADHD	0.88 (0.1)	0.7–1.11	0.91 (0.12)	0.71–1.16
Conduct disorders	0.78 (0.09)**	0.63–0.98	0.75 (0.09)**	0.59–0.94
Difficult to manage	1.09 (0.12)	0.88–1.34	1.14 (0.14)	0.9–1.44
Family problems	0.99 (0.11)	0.8–1.23	0.98 (0.12)	0.78–1.24
Attachment problems	1.07 (0.12)	0.85–1.34	1.16 (0.15)	0.91–1.5
Peer problems	0.89 (0.09)	0.73–1.07	0.88 (0.09)	0.72–1.9
Other	0.87 (0.09)	0.72–1.06	0.82 (0.09)	0.66–1.02
Additional problems				
Learning difficulties	1.45 (0.23)**	1.06–1.98	1.16 (0.19)	0.84–1.6
Autism	0.91 (0.12)	0.7–1.18	0.9 (0.13)	0.68–1.19
Child in need	0.74 (0.12)	0.84–1.03	0.71 (0.13)	0.5–1
Experience of abuse	0.87 (0.12)	0.67–1.14	0.88 (0.13)	0.66–1.18
Parental health issues	1.04 (0.11)	0.85–1.27	1.12 (0.13)	0.89–1.4
Financial difficulties	1.12 (0.18)	0.81–1.52	1.01 (0.17)	0.72–1.42
Other	1.18 (0.13)	0.95–1.47	1.2 (0.14)	0.95–1.52
Impact				
Home	1.09 (0.1)	0.9–1.31	1.04 (0.11)	0.85–1.28
School/work	0.9 (0.09)	0.75–1.09	0.84 (0.09)	0.68–1.03
Community	1.01 (0.12)	0.8–1.26	1.09 (0.14)	0.85–1.4
Service engagement	1.14 (0.17)	0.85–1.54	1.05 (0.17)	0.76–1.44
Amount of variance				
Pseudo R_sq (%)	0.06 (6)			
ICC (%)			0.45 (45)	
AUC	0.6511		0.7391	
AUC change*			0.0088	

(Continued)

TABLE 2 | Continued

Parameters	Simple logistic regression analysis (unadjusted)		Multilevel logistic regression analysis (adjusted)	
	Model 1^a		Model 2^b	
	OR (SE)	95% CI	OR (SE)	95% CI
Goodness of fit				
AIC	3756.85		3433.82	
AIC change*			322.18	

AIC, Akaike information criteria; AUC, Area under the receiving curve; ICC, Intraclass correlation coefficient; OR, Odds ratio; CI, Confidence intervals; OCD, Obsessive compulsive disorder; ADHD, Attention deficit hyperactivity disorder.
N = 3,175.
***p > 0.05.*
**change in relation to the previous model.*
[a]Model 1: SDM + demographics, MH difficulties, additional problems and impact (unadjusted).
[b]Model 2: SDM + demographics, MH difficulties additional complex problems and impact (adjusted).

SDM with existing self-report measures in CAMHS. One possible explanation may be that not all service users want to be involved in healthcare decision-making (53). However, it must be noted that studies usually represent specific decisions, for example, parents facing challenges during medicinal decision-making (29). Also, with the increasing promotion for CYP to be actively involved in their care and treatment decisions (54), future studies can further explore how decision type and number of decision-makers affect parent/carer levels of SDM in CAMHS. Nonetheless, the current findings add to the existing knowledge base by reporting frequency of parental SDM in CAMHS in England, and represents a sample experiencing a wider range of clinical characteristics and age range beyond those commonly reported in the previous studies. The current findings also advance the observed SDM trend reported in the UK (19), by providing the most recent statistics in a specific CYP population.

To address the second aim of this study, only individual-level data was used in model one. We identified significant associations between ethnicity, relationship to the child, presence of conduct problems and learning difficulties and SDM. This aligns with previous research which demonstrated that higher levels of psychosocial difficulties were associated with lower experiences of SDM among parents (26). More specifically, the more severe the behavioral difficulties the lower the level of parent/carer SDM was reported (15). However, due to the cross-sectional nature of the study it was not feasible to determine the direction of the relationship. Although previous studies found associations between other psychosocial difficulties (e.g., anxiety) and level of impact and parents/carers SDM (13, 26), these findings were not replicated in the current sample. One possible explanation for this might be that previous samples used continuous variables for the clinical characteristics and therefore captured severity, whereas the current study explored the mere presence of the problem as measured on a dichotomous scale which limits the capacity to explain variability (55). Nonetheless the current study builds on previous research by highlighting the importance of taking into account the additional complex factors such as learning difficulties. The positive relationship could be as a result of the existing policy guidelines for SDM among people with learning difficulties which recommend the involvement of family members to support the patient (56).

For the third aim of the study, model two was selected as the model that best fitted the current dataset and included a combination of clinical and demographic characteristics. This is consistent with the general SDM literature indicating the influence of both clinical and demographic characteristics on SDM among service users. For example, systematic reviews have consistently reported demographic and health status as influencing factors (33, 35). Further investigations confirmed that when accounting for service-level data the model had a better chance of distinguishing between parents/carers experience of SDM. This also aligns with the existing literature confirming the importance of higher-level factors such as time constraints at the clinics, motivation and skills of the clinician, and available resources (21, 33–35, 52). For the most part, these findings suggest that targeting factors at individual and larger ecological levels will remain important. However, failing to acknowledge the service user characteristics and efficacy downplays the important role that individuals may play in contributing to their own care and treatment. At the same time, relying too heavily on only individual-level change neglects the role that environments and context have in influencing individuals' decisions and behaviors.

Although model one revealed that the involvement of both parents/carers in the CYP's care and treatment resulted in lower levels of SDM, the area of triad relationships in SDM in CAMHS is yet to shed light on this phenomenon. However, this finding is not surprising as researchers in adult healthcare suggest that the involvement of an additional family member increases the complexity of the interactional dynamics (1). Similarly, parents identifying as Asian in the current sample were associated with higher levels of experiencing SDM. This is surprising because research shows that minority ethnic groups (e.g., Blacks and Hispanics) report lower experiences of SDM than White Caucasians families (27). Therefore, further investigations using qualitative designs and purposive samples are needed.

Future Directions

The findings of this study suggest that policies and interventions to improve SDM in CAMHS should target both services and individuals. However, to give further insight into identifying target groups (e.g., parents/carers of CYP with conduct problems), more information is needed. Therefore, as recommended by other researchers, future research including specific service level variables, such as population size of the service or number of clinicians will further enhance our understanding. Additionally, it may be just as important to identify clinician-level variables such as years of experience or area of expertise that may further explain variation in experiences of SDM. Hence, a three-level analysis will help to inform our knowledge of this phenomenon. As confirmed by this study, more qualitative research is needed to help inform the SDM predictor variables (for example, presence of problem vs. severity of the problem vs. impact) in order to capture critical thresholds that may influence parent/carer experience of SDM. Another recommendation for future research would be to repeat this study using a longitudinal sample to capture the directional nature of the variables and infer causality. Lastly, similar to Edbrooke-Childs et al. (26), it is recommended that future studies include child- and clinician- reported SDM to fully capture the triad relationship. These are important factors that can possibly influence parent/carer level of involvement (9).

Strengths and Limitations

First, this study incorporates a variety of observer-reported predictor variables beyond psychosocial difficulties while the majority of previous studies focused mainly on the self-report severity of the CYP mental health. Additionally, using a broad range of psychosocial difficulties added to the potential to target specific disorders such as types of anxieties and mood problems that could influence SDM, as opposed to categorizing difficulties into broader groups of anxiety and depression. Second, considering the nested nature of the data and utilizing an innovative multilevel analytic approach highlighted the important potential influence of service level factors on an individual level experience of SDM. This is crucial to the study of SDM as without this knowledge, interventions and policies may be developed and implemented without taking this contextual level variation into account. This can result in the inefficient allocation of government funds and unproductive use of both the clinician's and service user's time.

In spite of these strengths, the findings of this study should be considered as exploratory and interpreted with caution due to several design and measurement limitations. The current data represents only a cross-section of the population. The items used to calculate the composite SDM score were taken from the self-report ESQ and therefore may be prone to bias. Although this measure has been used in previous studies as a measure of SDM (26), a high percentage of the sample scored 4 out of 4 suggesting ceiling effects which are common in these types of measures (57). Considering this as an exploratory study, by dichotomizing the composite measure we were better able to address the aim of our study to identify the frequency of "higher quality" SDM experiences. In addition, dichotomising the measure was based on the decision to be consistent with previous research (15), and therefore aid with comparisons. The decision was also based on the limitations of previous studies reporting challenges with the low to high spectrum and its inability to determine parents/carers' "full" experience of SDM (14).

Another limitation is the low representativeness of fathers and ethnic minorities in the sample due to the constraints of conducting secondary analysis of routinely collected data. This in itself is a limitation as the data was not collected under controlled conditions and there may be variations among sites on instruments used and how data was collected. Another limitation of the dataset, with implications for the analysis and interpretation, was the pooled categorisation of clinical characteristics (e.g., selective mutism and Gender Identity Disorder) which represented <10% of the sample. Together these low frequency problems accounted for over 50% of the total sample. This may influence the study's findings raising assumptions that these characteristics influence parent/carer experience of SDM in the same way. Despite the study's limitations it remains one of the few quantitative studies to examine parent/carer SDM in CAMHS in England and the knowledge gained can be used as a basis for future research.

CONCLUSION

In summary, this study has highlighted the need for using a multilevel approach to promoting and implementing SDM interventions in CAMHS, as suggested by the high service level variation (ICC = 0.48) in parent/carer-reported SDM. This identifies CAMHS sites to be a potential target for effective intervention. However, the findings of this study suggest that more research is needed if data is to be modeled in this way. Ethnicity, learning difficulties, relationship to the child and conduct disorders were the only potential service user level factors that were associated with SDM in the simple logistic regression and the presence of conduct disorders remained the only significant predictor variable when accounting for service level factors. Future analyses of SDM could aim to utilize more detailed measures of SDM and include clinician level factors, such as the clinician's years of experience, and service level factors, such as population size, to help explain the variability in SDM. Future research could also include clinician and young people experience of SDM to further understand the triad relationship. Nonetheless, this exploratory study highlights the evident influence of service-level factors on parent/carer experience of SDM and suggests that families with children experiencing conduct problems could be targeted for additional support if they are to be involved in the SDM process.

DATA AVAILABILITY STATEMENT

The data analysed in this study is subject to the following licences/restrictions: Restrictions apply to the availability of these data, which were used under licence for this study. Data are available https://www.corc.uk.net/media/1883/request-for-use-of-corc-dataset-27-09-2018.doc with the permission of the Child Outcomes Research Consortium. Requests to access these datasets should be directed to https://www.corc.uk.net/media/1883/request-for-use-of-corc-dataset-27-09-2018.doc with the permission of the Child Outcomes Research Consortium.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent from the participants' legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

All authors contributed to the conception and design of the study. Analysis and interpretation of the data were conducted by the primary author and supported by the other authors. The primary author drafted the manuscript and the other authors contributed to the editing and refinement of the article before submission. All authors contributed to the article and approved the submitted version.

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CONCEPTUAL ANALYSIS
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Aspects of Shared Decision Making in a Cognitive-Educational Intervention for Family Members of Persons Coping With Severe Mental Illness

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Background: Partnerships and family inclusion are embedded in mental health policies. Shared Decision Making (SDM) is as an effective health communication model designed to facilitate service users and providers engagement in reaching jointly decisions concerning interventions. Keshet is a 15 bi-weekly academic course for family members of people with mental illnesses that enhances positive family cognitive communication skills.

Purpose: To exhibit how SDM is inherently expressed in Keshet.

Method: We conducted a secondary analysis of previous Keshet evaluation studies and course protocols that focused on revealing SDM use.

Results: SDM was found to be a prominent feature in Keshet interventions in both the structure of the course as well as the process and procedures. Following participation in the program, making decisions jointly was found to be a prominent feature.

Conclusions: Interventions such as Keshet that include an SDM approach can contribute to the integration of academic, professional and "lived experience" within a shared perspective, thus promoting an enhanced equality- based SDM model that benefits individuals as well as mental health systems.

Keywords: family caregivers, dynamic cognitive intervention, shared decision making, mental health, Keshet

INTRODUCTION

Family caregiving serves as the bedrock upon which health care systems tend to depend. However, caregivers face physical as well as emotional repercussions, due to the challenges they experience in the caregiver role, particularly in the mental health field (1).

The length of active caregiving by parents who have a daughter or son with mental illness often extends for many years (2, 3). During this long-time span, parents have to cope with a variety of challenges, including those of caregiving as well as from the additional accumulation of other life stressors that potentially all lead to experiencing psychological distress, due to their own health problems and psycho-social situations (1, 4). These caregiving and other life stressors may affect family caregivers in multiple ways, including increasing their experience of caregiving burden, elevating the risk of depression, and diminishing feelings of closeness to their family member who is coping with mental illness (5).

Maintaining family caregiver's health and well-being has been identified as a preventive public health promotion objective (6, 7). As families play a central role within the caregiving context, it is important to create and sustain equal and balanced partnerships with family members so they can provide specialized care while maintaining their own health, well-being, and resilience (1).

Since 2001, the Israel Ministry of Health is engaged in an accelerated process to develop community based psychiatric rehabilitation and recovery services as part of its implementation of the "Rehabilitation in the Community of Persons with a Psychiatric Disability law" (2000) (8). As part of this development, families of people coping with severe mental illness (SMI), are identified as a population that require specific and targeted needs. They are also perceived as a means to achieve effective recovery goals and outcomes. The Keshet program, described below, was developed as part of this process.

KESHET (RAINBOW IN HEBREW)

Keshet is a didactic program held in academic settings intended primarily for family members of people coping with mental illnesses. The course provides tools for communication based on awareness and a meta-cognitive analysis of cognitive components within dialogues that take place within and outside the family. Keshet focuses on teaching parents/family members about cognition and thinking processes, as well as mediation. During the course human interactions are turned into a source of learning. It is based on a number of theoretical entities which include:

Theory of Structural Cognitive Modifiability (SCM) which means that cognitive structural changes are possible at any age and in any health status (9). This is based on the concept of brain plasticity and modifiability. This theory further explains that these structural cognitive changes occur by using Mediated Learning Experiences (MLE) an interventional approach that addresses communication, by which the mediator adjusts, filters, and enables processes and changes in a way that the learner will understand and achieve higher cognitive abilities (9–11). Employing MLE principles into the health field in general and particularly for family members of mental illnesses, is based on Dynamic Cognitive Intervention (DCI) developed by Hadas Lidor (12). Being taught these principles provide family members with more choice and control over various situations (12, 13).

The DCI within the mental health Recovery process, is an approach that emphasizes and supports an individual's ability to live with the illness and beyond it (14).

Choice and control over management decisions are important elements during the recovery process. Given the uncertainties involved, these elements are often associated with inherent tensions between the person, the family and professionals. Decisional conflict is also a central element in SDM process (15). The family member or the clinicians would identify communicative elements of SDM such as describing pros and cons of various options. In the Keshet course, choice and control are related to, not just as a part of Recovery, but as cognitive elements, that can be addressed as such in the discourse, as well as in the understanding, of a particular situation. Using DCI methods, family members can achieve joint control over a situation by opening various possibilities to choose from while respecting the choices of the family member as well (16). These conflicts about choice and control are central to SDM approaches and thus there are areas of overlap between Keshet and SDM. One of the purposes of Keshet is the transfer of DCI principles beyond the course into everyday life.

Feuerstein's SCM is based on the belief that every person has the potential to achieve cognitive development if he/she is exposed to supporting elements, such as Mediated Learning Experiences (MLE) within an environment that provides opportunities for active growth. The DCI approach, derived from the SCM theory, is specifically intended to enhance the therapeutic-based relationships in health-related fields with a direct emphasis on emotional issues and the way they affect cognitive development (12, 13).

DCI views the client as an equal partner in the therapeutic process. In this approach, not only do therapists work together with clients to select methods and goals, but they also convey to clients the central concepts of cognition, the steps involved in cognitive development and processes, and the clinical reasoning behind intervention techniques. Clients are exposed to the ways the cognitive communication skills based on mediation can enhance learning, adaptability, and recovery. This attitude leads to the partnership of everyone involved in the therapeutic process (16). Thus, in Keshet, parents are introduced to concepts and strategies usually used solely by clinicians.

This sharing of professional tools during Keshet, can be viewed as a strategy directed to promote SDM. Shared Decision Making is defined as an effective health communication model designed to facilitate patient engagement in treatment decision making. Engagement in decision making fosters communication skills by encouraging open dialogue with focus on empathy, trust and partnership (17–19). In its essence, after ensuring that the client is informed about his/her rights and options, SDM provides a space for trust, reciprocity, and mutual respect of relevant knowledge in decision making. Participating in SDM increases active participation and involvement of users in their care by eliciting an interactive and collaborative process between them and others (20, 21). Shared Decision Making (SDM) focuses on the centrality of experiential knowledge, alongside scientific knowledge (19, 22). SDM is aimed at reaching an agreed solution but agreeing to disagree is acceptable. A collaborative approach not only benefit user's treatment but also encourages them to become equal partners with professionals (23). SDM has been recognized as an effective health communication model designed to facilitate patient engagement primarily in mental health treatment decision making (24). Keshet and SDM both provide evidence to effectively contribute to personal recovery and decision making in psychiatric rehabilitation settings (1, 23, 24).

PURPOSE

This paper describes a secondary analysis of Keshet components from inception to program evaluation post participation, with the purpose of highlighting elements related to SDM.

METHODS

Using secondary analysis is an integral part of research development, which provides a different set of skills to bear on the data. A secondary analysis of previous Keshet evaluation studies was used, in order to generate valuable practical insights and derive new additional interpretations and conclusions.

Keshet is a course designed as an intervention to fill the void concerning parents of adult children with mental illness- whom in this role spend much more time than professionals with family members coping with mental health illnesses, but are equipped with less tools than professionals for effective coping with everyday life challenges. The course is led a jointly by a professional and a family member who had participated previously in Keshet (25, 26). Central themes that Keshet addresses promote transfer of knowledge from professionals to families by exposure of participants to the way cognitive communication skills, based on mediation, can enhance learning, adaptability, and recovery in a way that promotes active involvement.

The central components taught together by a family member and a professional in Keshet, and which are included in meaningful mediated cognitive based communication according to both the SCM theory, MLE, and the DCI approach are:

1. *Intentionality and reciprocity*. The mediator's responsibility in any purposeful interaction is to ensure intent is clear to the recipient. Reciprocity is making sure that the idea, thought, or request was understood precisely, by the recipient, even though it is possible that the recipient did not necessarily agree with the expressed ideas. The structuring of communication based on these elements promotes feelings of trust and engagement.
2. *Transcendence.* An interaction that provides mediated learning must be also directed toward transcending the immediate needs or concerns of the recipient by venturing beyond the here and now, in space and time. Transcendence is the ability to make generalizations. Participants learn to use new communication strategies that include SDM approach and this is also transferred to their own personal relationships and interactions.
3. *Mediation of meaning*. This deals mainly with the energetic dimensions (increasing motivation) of the interaction (i.e., with why things happen or are done). It raises the individual's awareness and understanding and makes explicit the implicit reasons and motivations for doing things. Mediation of meaning focuses on the interaction of the individual with other people and aims to increase his or her ability to make choices (27, 28). Raising awareness of participants to the importance of relating to meaning (i.e., what/because I understand what matters to you, it matters to me) helps to create a trust building relationship directed at empathy and mutuality.
4. *Mediation of competence*. This parameter deals with the way the mediator helps the individual feel a sense of competence and ability, in relation to him- or herself and to the task s/he undertakes. Learning how to direct an exact sense of competence is an enabling experience which leads to a more profound emotional sense of belief in oneself and in others, which in turn develops into a basis for the sharing of ideas and thoughts.
5. *Sharing*. Sharing behavior implies the need of the individual to share his/her feelings, thoughts and experiences with another person. Loneliness and social exclusion are characteristic of many populations with disabilities. Sharing, which is a way to overcome this setback, has two aspects: sharing one's world, difficulties, and successes with someone else; as well as doing and experiencing things together such as brainstorming, decision making, playing, and traveling.

A central method used in Keshet, are MILEs (Meaningful Interactional Life Episode), which are authentic verbal interactions that are experienced between at least two people, who then write up and submit the dialogue. The purpose of the MILEs is to use authentic personal experiences in creating connections to theoretical concepts taught. Documenting episodes and their analyses serve a number of purposes. They support and connect theoretical concepts and terminology with authentic personal experiences. As theoretical terms unfold, participants are encouraged to return to the written episodes and explore how the new parameters of mediation are expressed or missed within the MILEs. The MILEs are read jointly by Keshet moderators who together determine the key components to address in each particular MILE. Family member moderators input is invaluable as their lived experiences add an empathetic perspective to the understanding of the MILE and lead to a more sensitive response to the participant who handed it in. All MILEs are returned to participants who wrote them with commentary written jointly by instructors, linking between the personal dialogue and the theoretical and practical structures being taught.

Institutional Review Board (IRB) approval was obtained for each of the original studies performed. As the current paper utilized a secondary analysis of previous data, ethical board approval was not required. The primary research assessed various aspects of intervention evaluation, such as changes in attitudes, problem solving, and communication abilities using quantitative and qualitative measures both prior to and following the course. In the present paper, we re-examined the studies with a focus on SDM criteria.

RESULTS

The Results section describes the way SDM is reflected within Keshet at all stages of course evolvement- inception, content, and process. Furthermore, previous studies that were readdressed from an SDM perspective during the secondary analysis, are presented.

Course Inception

Hadas-Lidor and Weiss (25) outlined the major principles used in inception stage that reflect a SDM approach:

a. Before initiating the course, focus groups that included family members of mental health service users and professionals (occupational therapists) with expertise in mental health rehabilitation were held, aimed at partnering jointly to define course purpose, need, content, and structure. Family members' personal lived experiences were the basis that helped establish which components were to be included in Keshet.
b. The theoretical base for Keshet was based on partnership and collaboration, including lived experiences of both carers and service users as integral components, creating partnerships based on a non-judgmental stance (Recovery) and the mediation of Sharing.
c. Two versions of the course manual were developed; one for the professionals and users leading the course, and a parallel one for family caregiver participants which includes home assignments, thus reflecting SDM features of involvement, interactivity and collaboration (16).
d. Partnering with parents and other family members in the course leadership and mentoring, enabling an authentic and relevant learning process for all. Joint professional and family member mentors bi-weekly meeting was established, both before and during the intervention, in order to contribute and facilitate their full partnership.

Creating partnership and collaboration within Keshet were special changes and adaptations that were made in the course. Weiss et al. (29) describe the changes that were made to ensure compatibility for a specific population which required cultural adaptation, namely the ultra-orthodox Jewish community in Israel (26). This community is characterized by being secluded and viewing of modernity as a threat to religious beliefs. In order to create the same type of partnering as with other Keshet participants, this particular population required special adaptations to ensure the same comfort zone, level of involvement, and ability to transfer learning from course into their natural surroundings. Rabbis were consulted and changes were made in course material accordingly. For example, wording of material was changed, more references to religious belief, and foreign language expressions not commonly used within religious communities were removed from course Power Point presentations. This sharing of perspectives and changes formed better partnerships within the groups later on (30). This is based on the concept of Knowledge Translation (KT), a term that represents relating valued research findings to the clinical field. This concept was applied to the importance of promoting transference of knowledge used by professionals to families - conveying to participants' knowledge of central concepts of cognition, cognitive development and processes and the understanding of the clinical reasoning behind intervention techniques. That in turn enables sharing and can be viewed as a benchmark that later on promotes SDM, as family members gain a better and more holistic understanding of knowledge and strategies relevant to them and their service user family member. This became one of the central aspects of the program.

Course Structure

The Keshet course involves teaching methodology that promotes SDM.

1. Joint teaching by two course leaders- The interaction between the leaders becomes a role model of communication techniques being taught. This demonstration of an interactive relationship based on MLE and Recovery concepts is used and mirrored through the course as an example of sharing, empathy and partnership (28). Joint reading and writing of responses to MILES as well as analysis of MILES within the course meetings together with participants include teaching of strategies and tools that relate to SDM (see example below in **Table 1**: MILE analysis).
3. Follow up- in order to encourage continued participation, connection, and involvement between group meeting, both professional and family member group leaders maintain contact- by phone or online. These interactions promote feelings of caring, trust, openness, and empathy among participants.

Course Content

Often, although not all family members participate in the courses, participants share with us (31) that they share with their family (spouse/children/service users) the course manual and material, thus creating a joint family learning experience, that in turn considerably improves family communication and decision making.

All five aspects of MLE described above, are achieved in Keshet by involvement, collaboration and partnership which are the essence of the SDM approach. These aspects, enhance active involvement, hope and resilience of family members who in turn aid the development of these communication strategies in relationships with meaningful others, whether with service users, professionals, or other family members (1, 32).

An Example to Understand Key Programmatic Elements

These MLE components can be viewed in the SDM approach as described below:

1. Two people conversing in room each have meaningful knowledge that is equal in value and relevant to discussion- **Reciprocity, Sharing, Meaning**
2. Within the conversation there is certainty that the client is informed about their rights, ideas, and options- **Intention, Transference**
3. Ensure that the person I am conversing with has the ability to negotiate with me- **Intention and reciprocity**
4. Ability to converse- **Competence**
5. The outcome may go in either direction, is created within the conversation and is not known in advance- **Reciprocity, Sharing**

Decisional conflict is defined as personal uncertainty about which option to choose.

As mentioned above, instruction in Keshet is enhanced by the use of MILEs. Here is an example of a MILE handed in by a mother toward the end of a KESHET course.

"During the Keshet course, our daughter who copes with an anxiety disorder was to start school again. She refused to return to the previous school and we searched for a new educational framework together. In order to decide, we sat together and thought about what was important to her in school- we made a list.

We, as parents, emphasized that it is important to find a school that provides full matriculation exams. Then, we thought about how we would get the information about whether what is important to her and what is important to us as parents takes place in various schools. She only wanted to attend a school that provides everything that is important to her, particularly music. We decided we would do an initial evaluation according to the criteria, and then we would think together again. It turned out that not every school has all the things, and there are differences between the schools. We presented them to her and thought together what was most important to her among the criteria. I remembered it was very important to her that there be a music track there. As mentioned, it was very important for us to have the possibility of full graduation. And it was this combination that brought her to the school she eventually attended."

Originally this MILE was analyzed according to MLE/ DCI principles. However, this MILE can be also viewed as an SDM process the parents had developed following Keshet.

If we look carefully at the above MILE, one can identify active listening and respect, mutual trust, invitation to an open communication and information.

The MILE analysis in **Table 1** highlights the MLE and SDM components/attributes, that make for effective communication, within a Recovery based approach.

A third aspect that can be viewed as an SDM within Keshet components is embedded in another exercises given to Keshet participants, where they are requested to think about things they want to change in their lives. More often than not, family caregivers provide answers relating to what they would change in their **childrens**' lives. This is done, without consulting or involving the children themselves in the process. Parents are always amazed while acknowledging that something is lacking in the way they determine goals they want to change. Keshet moderators (a professional and a family member) assist participants in understanding that changes can be brought about only if the change is accomplished within a partnership in which the feeling, thoughts, desires, and dreams of the family member experiencing mental ill health are taken into consideration and treated with respect and encouragement. Following this, participants are requested to once again do this exercise, but this time together with the service users. Following this process, the goals they want to change are transformed. For example, parents want a change in that their son/daughter should keep his/her room tidy and to maintain good personal hygiene. But when asking their children what they would like to change, the latter have altogether much grander ambitions, such as getting married, be able to play a musical instrument or be able to leave their parents' home and live on their own. The goals are jointly redefined, taking both intents into a common, joint one.

The changes participants in Keshet achieves, are nonetheless of the stance of the consumer regarding the degree of involvement the consumer expects of the family member. For example, A son of a family member in one course had not spoken with her for 6 years prior to the course. During the sessions of the course, with the skills she developed during Keshet, they started making joint written decisions that eventually led to face to face meetings and conversation.

Studies on Keshet Evaluation

A previously published qualitative study about KESHET (31) analyzed 14 course protocols from three stages of two different Keshet groups, namely beginning, middle, and end of courses. The study focused on participants' attitude changes regarding faith in ability to change, empowerment, acceptance and empathy, and the ability to apply problem solving skills to everyday conflictual interactions. The study found a shift, from not believing change is possible and feelings of pity and self-helplessness, to trust building relationships, mutual respect, and value of each participants' knowledge as meaningful and equal. One father, who experienced helplessness since his son did nothing all day … following Keshet, started passively joining him while watching basketball games … went on to discuss the games with him, and afterwards gradually with the improved communication with his son, went on to engage with him in carpentry- planning and building a bench together. The

TABLE 1 | MILE analysis.

Text	MLE/DCI	SDM	Recovery
We sat together and thought. Then we made a list together	Intention and reciprocity	Developing trust Collaborative task	Peer support, Respect
We focused on "…what is important to us … [and] what is most important to her…"	Meaning	Invitation for open communication and shared information	Person-centered, Strength-based
"We decided we would do an initial evaluation [of schools] according to the criteria (she decided about), and then we would think together again."	Competency	Following her preferences Increases autonomy and involvement of service users in their care	Hope, Responsibility, Non-linear
Her and our preferences were mutually respected (a music track for her and full graduation for us)	Intention and reciprocity	Mutual respect Reaching a shared decision based on mutual respect and trust	Respect

study also explored the change from a passive to an active stance. One of the changes participants experienced was in their ability to understand that a index family member's choices must be honored. Changes participants experienced throughout the course- led to enabling increased freedom to make choices, even identification with index family members' choice. This move enables them to become less defensive, with improved acceptance of family member, by the end of the course.

Mental illness creates uncertainty as well as helplessness for all involved, namely for both family members and service users. Often, parents join the course with the purpose of achieving more control over their children's lives, a tendency which in itself leads to unbearable tension. Keshet strengthened the parents by helping them through improved communication and awareness to change the focus of control to a more joint effort. In turn, this move which creates sharing and honoring of their family members opinions ends up by enhancing their sense of control (25, 26).

The parents learned to include the index family member in the decision making during the process as an alternative to being controlling (32). Elazari et al. (31) also points to the actual verbal/use of language by parents that affect the partnering with their family members from general wording that does not bring about change (like "it is hard to connect" at the beginning), to specific wording that can be used as practical stepping stones for creating change (e.g., "My sharing with her" toward the end of the course).

In a study that addressed attitudes of parents regarding knowledge, beliefs, and action changes following participation in Keshet, participants attitude regarding inclusion of service users in decision making improved significantly following Keshet (33).

In another study based on both quantitative and qualitative methodology, participants found to be significantly more confident in their mastery of tools for coping with MILEs following the course in comparison with beginning of course (34). Three themes were under covered which are essential to the SDM process. (1) Keshet is an attempt to go beyond the despair and frustration to improved relationships with self, child, and the health system; (2) Keshet is a means to improve communication empowerment and feelings of competency and (3) The group leaders have a meaningful role and effect on learning and promoting recovery and change (35).

In a recent meeting of Keshet moderators and graduates, a follow up discussion targeting SDM was conducted. This was done, in order to directly inspect SDM use by Keshet participants prior to and post participation. Participants and professionals reported a change in SDM use within their family following their exposure to Keshet.

DISCUSSION

The purpose of this paper was to examine the place of SDM approach within the Keshet intervention, while initially acknowledging that SDM was not a theoretical entity introduced purposefully into the intervention. Furthermore, this secondary analysis serves the purpose of suggesting that the Keshet intervention can be used as a base for teaching and learning SDM communication strategies.

SDM is an approach that has previously been perceived as a pathway to aid effective and collaborative shared medical decision making, by service users together with professionals (21) and family members (36, 37). It is our belief that SDM can be regarded as a broader, therapeutic, as well as an interactional, effective communication approach. To validate this belief, the present study demonstrates ways SDM is inherently expressed in a cognitive communication intervention for family caregivers. With time, it became apparent that this cognitive communication intervention includes elements of SDM at all stages of the course development and throughout the course itself. As hopefully we head toward an era of personalized medicine that differs from the "one size fits all" approach, it is important to advance interventions that reflect partnerships and collaborations between professionals and users in a way that individuals have a voice that is heard, seen and related to. Keshet is unique in the way it manages to bring about changes (i.e., more sharing behaviors, giving more of a voice to the family service user) in the individual, although it can be defined as a psychoeducational group intervention, which is done primarily via the use of MILEs.

This paper applied a secondary analysis approach to broaden and deepen knowledge. SDM in Keshet can be seen in course inception process, course content, and process as well as in outcomes.

In recent years SDM has been proved beneficiary for service users, family members, and professionals, in terms of improved relationships and outcomes, primarily regarding health related decisions. Research findings highlight that SDM has a positive impact on reducing the length of hospitalizations, increased compliance and satisfaction with medical treatment (21, 25).

Keshet is an intervention based on a number of theories and approaches that promote improved communication and relationships. These are:

1. Feuerstein's SCM that postulates the belief in a person's ability to change and develop regardless of his/her diagnosis, etiology, and age.
2. MLE and environment- both provide the settings in which change can be set into motion.
3. Recovery- Concepts such as honor, respect, and making choices taken from the mental health recovery perspective are inherent in Keshet and have added value within a SDM based relationship.
4. Knowledge Translation (KT), defined as a dynamic and iterative process which includes synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve health, provide more effective health services and products while strengthening the health care system (38, 39). In Keshet, principles of mediated communication lead to translated knowledge, intended to be used by family members in order to achieve SDM through enabling equality and equity in any meaningful relationship (40). The clinician or family

member is responsible to ensure the client has all necessary information s/he needs to make informed choices in any life matter and in all interpersonal relationships.

In order for this to happen, the course developers had to reach the realization that the partnership between professionals and family members is the key pathway to improved communication, potential cognitive development and participation, and well-being. While the therapist comes and goes, family members are a stable entity in the service users lives and as such must have the tools to enable growth and development for all involved.

In terms of practical implications, it is apparent that Keshet can be used as an intervention that has the potential to support the development of the SDM capacity of course participants leading to improved interactions within healthcare institutions, as well as familial improved communication, participation, and well-being.

Hence, it is important to stress, that there are reciprocal ties between Keshet and SDM that provide added value and benefits, as the learning of the mediation language helps participants undercover and develop a more structured "language" based SDM set of skills.

Integrated descriptions of shared decision making exist, but many focus only on medical decision making. There is much to benefit from a broader approach, which takes SDM into everyday life situations.

CONCEPTUAL OR METHODOLOGICAL CONSTRAINTS

As this study is primarily a secondary analysis, it is primarily descriptive with some qualitative components. Additionally, the sample size of the original study section was small. Therefore, it may have limited generalization capacity. It is important to provide evidence to the presence of SDM in Keshet via larger quantitative and controlled trials to attest the usefulness of Keshet as a tool to develop SDM strategies among participants.

FUTURE DIRECTIONS

Future evidence-based research should be conducted with the purpose of addressing the use of SDM methodologically both prior to, and following participation, in Keshet. Likewise, it is equally important to continue evidence-based research to further establish Keshet as an SDM based intervention. To the best of our knowledge, this is the first time an intervention that was not originally developed from focusing on the SDM process, was analyzed according to SDM principles. Further studies might look at other interventions through an SDM scope to add an in-depth dimension to client centered care and well-being.

In the mental health, it may be important to expose service users and family members to the elements taught in the Keshet intervention. Holding courses for all members of the family can create a setting where DCI theory can be put into practice jointly by service users together with their family members.

AUTHOR CONTRIBUTIONS

PW, DR-A, and NH-L contributed to conception and design of the study, performed the secondary analysis, and wrote sections of the manuscript. SD-I organized the references and styling. All authors contributed to manuscript revision, read, and approved the submitted version.

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Shared Decision-Making and Role Preference Among Patients With Schizophrenia in Malaysia: A Cross-Sectional Study

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Introduction: Shared decision-making (SDM) is recognized as a promising strategy for improving collaboration between clinicians and their patients in achieving recovery. In Malaysia, SDM among people with schizophrenia is still lacking both in practice and in research. This study aimed to determine the level of SDM and role preference and their associated factors among patients with schizophrenia in Malaysia.

Methods: A cross-sectional study was conducted on 86 outpatient attendees with schizophrenia at a teaching hospital in Kuala Lumpur, Malaysia. The nine-item Shared Decision Making Questionnaire and Control Preference Scale were used to assess perceived SDM experience and role preference, respectively. Linear and logistic regression models were used to analyze the factors associated with SDM and role preference, respectively. Factors with a $p < 0.25$ from the simple regression analyses were controlled as the covariates in the multiple regression analyses.

Results: The study respondents were predominantly female, single, and unemployed, with a mean age of 44 years. Only 35% of the participants reported having high SDM experiences, even though the majority (56%) preferred autonomous role preference. Among the participants who preferred autonomous roles, only 40% experienced high SDM. High SDM was found to be significantly associated with being younger ($B = -0.33$, 95% CI = −0.67 to −0.003) and being non-clozapine users ($B = 19.90$, 95% CI = 9.39–30.41), while autonomous role preference was significantly associated with a lower level of insight [adjusted odds ratio (AOR) = 0.84, 95% CI = 0.72–0.99] and being on oral antipsychotic drugs only (AOR = 2.94, 95% CI = 1.10–7.82).

Conclusion: The practice of SDM is still lacking in the treatment of patients with schizophrenia in Malaysia, even though many of them preferred to be involved in the decision-making pertaining to their treatment. This study indicates the need for clinicians to improve their patients' involvement in the treatment process. More research is needed on how SDM can be implemented in patients with schizophrenia, especially in Asian population settings.

Keywords: shared decision making, role preference, schizophrenia, associated factors, Malaysia

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INTRODUCTION

Shared decision-making (SDM) is recognized as a promising strategy for improving collaboration between clinicians and patients in achieving recovery. SDM is a process in which clinicians and patients work together to select tests, treatments, and management or support packages based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes, and uncertainties, together with decision support counseling and a system for recording and implementing patients' informed preferences (1). It was developed in the mental health field in response to the reality that psychiatric medications come in a package with varying degrees of benefits and risks. Therefore, there is a need for a process that ensures concordance between clinicians and their patients (2). SDM has been shown to improve functional outcomes (3) and quality of life (4) and enhance satisfaction and adherence with medication among all patients, in general patient population (5). Similar outcomes were observed in patients with mental illnesses, with the added benefits of reduced anxiety and depression following SDM interventions (6). Furthermore, SDM has been shown to improve personal recovery among patients, and its application has been suggested in the broader context of decision-making related to rehabilitation (7). One recent cost–benefit analysis study on pharmaceutical care among patients with schizophrenia revealed a net benefit of more than USD 2,000 within 3 months when SDM intervention was practiced (8).

SDM largely reflects the values in medical practices in western countries in Europe and North America (9). In Malaysia, research on SDM was initiated in 2010–2011 (10) and considered a pioneering work in Asia (11). Existing local studies showed low levels of patient and public involvement in SDM. A study showed that doctors were aware of informed consent, but few practiced SDM (12). Another study revealed a lower rate of preference for SDM among rural as compared to urban population (28 and 51%, respectively) (13). There has been an increasing recognition and effort from the academia and the Health Ministry to follow the first steps in SDM with patient involvement (14). Additionally, SDM has become more widely discussed in recent years in Malaysia and other non-Western countries including China, Taiwan, and Iran (14). In China, it was reported that information about SDM is still limited with very sparse evidence—qualitative or quantitative—about the feasibility, cultural and structural fit, processes, and outcomes of SDM (11). A study indicated that doctor–patient relationships are poor, consultations are brief, and levels of trust are low (14). It was concluded that implementing SDM that involves a shift in doctor–patient power balance may be challenging in Asian countries like China and Malaysia (11, 14).

SDM in mental health has started to gain mileage in Malaysia only in very recent years. A locally developed intervention to promote SDM was created in 2017 involving the use of antidepressants among patients with major depressive disorder (MDD) (15). Research to determine its effectiveness is currently undergoing. Particularly among patients with schizophrenia, SDM approach is still lacking both in practice and in research in Malaysia. Available studies in other countries generally revealed inconsistent and inadequate SDM involvement of patients with schizophrenia in their treatment and care (16, 17). One study was a randomized controlled trial in Japan (18), which was prematurely terminated due to slow enrollment. A recent qualitative study in China revealed main themes of patients having a positive attitude and self-motivation in decision-making but feeling excluded from the process (19). SDM experience is generally lower among patients with schizophrenia than those with milder conditions. A study done in Spain reported lower rates of SDM experience among patients with schizophrenia as compared to others with bipolar disorder, depressive disorder, and anxiety disorder (10, 15, 17, and 18%, respectively) (20). Among all patients with different psychiatric diagnoses, a study reported 60% SDM experience at some point in their care (21).

An important concept related to SDM is role preference, as not all patients may desire or are prepared to participate in the treatment decision-making process with their physicians (22). Some patients want active or shared responsibility, while others may be passive decision makers who prefer their providers to make treatment choices and decisions on their behalf. There is a wide variation of reported role preference among patients with psychiatric illness. A study in Spain revealed that only 36% of patients with bipolar disorder and schizophrenia preferred autonomous roles (23). Other studies reported higher levels of role preference among patients with mental illness (24). For example, a review on published surveys showed that a majority of patients wanted a shared responsibility on their healthcare decisions with their doctors (25). A very recent study revealed 82% of mental health service users preferred autonomous roles (26). SDM experiences and role preference may be associated with multiple factors, such as demographic variables, clinical characteristics, and types of clinical decisions (25, 27). Among the sociodemographic factors, being younger (20) and having a higher educational level and economic status (28) were known to be associated with autonomous role preference in decision-making. The level of insight among patients with schizophrenia was shown in a study to have the strongest link to a poor decision-making capacity among all clinical characteristics (29). Patients may prefer active roles in types of decisions relating to behavioral changes, less serious illnesses, and lifelong decisions while preferring passive roles in decisions concerning severe exacerbations of a condition (27).

While there is ample evidence indicating its benefits, SDM implementation for patients with serious mental illness has been relatively less successful than for other groups of patients (30). Individuals with schizophrenia, among all the patients with mental illnesses, experience the lowest SDM (20). This could be due to many possible barriers in implementing SDM in this group of patients. Clinicians may have the assumption that individuals with schizophrenia lack the capacity for decision-making in their treatment (18). Schizophrenia, by nature, is a chronic and disabling illness, with the majority of patients experiencing multiple relapses during the course of the illness (31). Common symptoms like delusions, apathy, and social withdrawal, which can affect relationships and desire to take part in decision-making, may present as significant therapeutic barriers to SDM (32). To the best of our knowledge, there was no published study on SDM and role preference among patients with schizophrenia in Malaysia at the moment this study was conducted. The findings from this study would add to the scientific data in countries that are less represented in the SDM research and practice to facilitate its implementation, measurements, and interventions. In this study, we aimed to determine the level of SDM and role preference and their associated factors among patients with schizophrenia in Malaysia.

MATERIALS AND METHODS

Study Setting and Design

This study was conducted among patients with schizophrenia at the Universiti Kebangsaan Malaysia Medical Center (UKMMC). The UKMMC is an academic medical center that was created by the merger of the Faculty of Medicine and the teaching hospital of Universiti Kebangsaan Malaysia (UKM) and is located in Kuala Lumpur, Malaysia. This cross-sectional study was conducted from July 2020 to January 2021 at the outpatient psychiatric clinic of the UKMMC during patients' follow-up visits.

Population and Sample

The inclusion criteria were individuals attending the psychiatry clinic during the study period who (1) were diagnosed as having schizophrenia by an experienced psychiatrist based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5); (2) were aged 18 years and above; (3) had a sufficient command of both English and Bahasa Malaysia (the national language); (4) were clinically stable, as judged by their treating psychiatrist, i.e., they were treated as outpatients, had no modified treatment regimen, and had had no essential change in symptomatology for at least the previous 6 months (33). The exclusion criteria were those who (1) were exhibiting aggressive behavior, (2) had concomitant intellectual disability, (3) had severe cognitive impairment, (4) refused informed consent, (5) were not clinically stable (33).

Study Instruments

Four instruments were used in this study.

Sociodemographic and Clinical Characteristics Questionnaire

This is a researcher-generated questionnaire that captures sociodemographic information: age, gender, ethnicity, religion, marital status, level of education, and employment status. The clinical characteristic variables were as follows: the age of onset, the duration of untreated psychosis (DUP) as within or more than a year (34), the duration of illness, the number of psychiatric hospitalizations, and antipsychotic treatment. Antipsychotic treatments were assessed for the route of administration [only oral or with long-acting injectable (LAI) antipsychotics] and types of antipsychotics. In this study setting, second-generation antipsychotics (SGAs) are the most prescribed type of antipsychotics (35). Clozapine is used in this center for treatment-resistant schizophrenia (TRS).

The Nine-Item Shared Decision Making Questionnaire

Measurements for SDM can be categorized by decision antecedents (role preference), the decision process (observed or perceived behavior of the clinician), or decision outcomes (decisional conflict or satisfaction) (11). Few scales are available that assess SDM from both the patient's and the physician's points of view. This includes the nine-item Shared Decision Making Questionnaire (SDM-Q-9), which was published in 2010 (32) and is commonly used to assess interventions aiming to improve SDM. The SDM-Q-9 has good psychometric testing and acceptance and is relatively easy to administer with only nine items (34). Internal consistency yielded a Cronbach's alpha of 0.938 (36). It is a patient-reported measure that focuses on the decisional process by rating physicians' and patients' behavior in medical encounters. It was developed as a revision of the original Shared Decision-Making Questionnaire in 2006 (32). Response options were provided in the form of a 6-point Likert scale ranging from "completely disagree" (0) to "completely agree" (5) for each item. Summing up all of the nine items leads to a raw total score between 0 and 45. Multiplying the raw score by 20/9 provides a score forced (transformed) to range from 0 to 100, where 0 indicates the lowest possible level of SDM and 100 indicates the highest extent of SDM. Various studies have used different cutoffs, as there were no predefined cutoffs. One study transformed into three categories using tertiles of the theoretical score range: (1) low SDM, with SDM-Q-9 sum scores up to 33; (2) intermediate SDM, with SDM-Q-9 sum scores between 34 and 66; and (3) high SDM, with SDM-Q-9 sum scores of at least 67 (37). SDM dichotomous variables were computed as total scores of percentile 25 or lower representing a low perception of SDM and percentile 75 and above as having a high perception of SDM in another study (20). Due to pragmatic considerations (the variation of cutoffs), percentile 75 and above was analyzed as high SDM in this study. Meanwhile, total scores 0–100 were used as a continuous variable for the inferential analyses. SDM-Q-9 is available and validated in a range of different languages, including the English and Malay versions. It is accessible to be downloaded from www.sdmq9.org as public domain software. Written permission was granted to use SDM-Q-9 in this research. The SDM-Q-9-Psy (Hebrew) scale for evaluating SDM from the perspective of psychiatric inpatients was also developed with good reliability and validity (38, 39).

Control Preference Scale

This scale determines the degree of control a patient wants to assume when decisions are being made about medical treatment (40). It consists of one question: "How do you prefer to make a decision during consultation?" and has five options in terms of answers to choose from: option 1 = "I prefer to make the final treatment selection about which treatment I receive"; option 2 = "I prefer to make the final selection of my treatment after seriously considering my doctor's opinion"; option 3 = "I prefer that my doctor and I share responsibility for deciding which treatment is best for me"; option 4 = "I prefer that my doctor makes the final decision about which treatment will be used but after seriously considering my opinion"; option 5 = "I prefer to leave all the decisions regarding my treatment to my doctor." Autonomous and passive role preferences were determined by regrouping the chosen options, i.e., option 1 or 2 or 3 became an autonomous roles preference, while option 4 or 5 became a passive role preference. A Cronbach's alpha of 0.72 was attained, pointing out a moderate internal consistency level (41). Permission to use this scale was granted for this study. The validated Malay version (13) of the scale was used with permission.

Schedule for the Assessment of Insight

The Schedule for the Assessment of Insight (SAI) is an interviewer-rated, three-item rating scale used to evaluate insight into psychotic illness (42). The SAI assesses insight in three domains: Awareness that one has a mental illness [0–6], Ability to relabel psychotic phenomena as symptoms of mental illness (0–4), and Awareness of the need for treatment (0–4). Respondents are scored on a 0–2 scale (0 = never, 2 = often). The total score is 14, with higher scores indicating a higher level of insight. The SAI has the advantage of brevity and ease of administration. This questionnaire has been widely used among patients with psychoses (43). A comparative study of various insight scales demonstrated a high correlation between the SAI and the other insight measurement scales (44). This suggests that the SAI has good concurrent validity. Written permission to use this scale was granted by the original author.

Study Procedure and Data Collection

Eligible participants were identified at the clinic triage counter from the daily registration book and patients' medical records. Patients attending the psychiatry clinic of the UKMMC during the data collection period were approached in the waiting area while they were waiting to be seen. A total of 112 respondents were approached. A total of 26 participants were excluded from the study for several reasons: 11 had difficulty comprehending English or Malay, eight were rushing to leave the clinic, five refused to participate without giving any reason, and two had prominent psychotic symptoms with persistent irrelevant speech. The response rate was 76.8%, producing a final sample of 86.

Each participant received a full written explanation of the study, after which they signed an informed consent form. Each patient was given all four questionnaires. These were self-administered with the assistance of the researcher or caregiver except for the SAI questionnaire, as it was interviewer-rated. To rate the SDM-Q-9, participants were instructed to think about their last consultation and to use this event as a reference point for the rating. Patients received no financial compensation for their participation.

Statistical Analysis

Data were entered and analyzed using IBM SPSS Statistics 26. For the categorical variable, descriptive data were presented by absolute number and percentage. For the continuous variable, descriptive data were expressed as mean ± standard deviation (SD) or median ± interquartile range (IQR) depending on the normality of the data. The normality of the distribution of the continuous variables was evaluated using a histogram and the Shapiro–Wilk normality test. Simple linear regression (SLR) analysis was done to determine the important independent variables for the SDM total scores as a continuous dependent variable. Meanwhile, simple logistic regression (SLogR) analysis was done for the Control Preference Scale (CPS) level as a dichotomous dependent variable. The variables with a $p < 0.25$, or any clinically important factors, were selected for multiple linear and multiple logistic regression (backward method). Those with a $p < 0.05$ were considered statistically significant. Multicollinearity, interaction, and model fit analyses were also performed on the model.

Ethical Considerations

This study was approved by the UKM research ethics committee (JEP-2019-530). Informed consent was obtained from each patient before the study was conducted and after an explanation of the purpose of the study and assurance of the confidentiality of individual data collected. All clinical data were kept in a secure, password-protected electronic database system.

RESULTS

Descriptive Analysis

A total of 86 patients participated in the study. The mean age for the respondents was 44.86 (SD = 13.86) years. The majority of them were female (60.5%). Regarding ethnicity, Malay was the highest number of participants [(38), 44.2%], slightly higher than Chinese [(35), 40.7%]. The majority were single [(45), 61.6%], which included those never married, divorced, and widowed. Most [(46), 53.5%] had up to secondary education. At least 29 (33.7%) of them had at least tertiary education of certificate/diploma and above. The majority were unemployed [(47), 70.9%]. Among 25 participants who were employed included an intensive care unit (ICU) nurse, lecturer, teacher, and real estate negotiator. Details of the sociodemographic aspects of the study sample are provided in **Table 1**.

The clinical characteristics of the respondents, SDM scores, role preference level, and SAI are summarized in **Table 2**. A total of seven respondents could not recall their age of onset of symptoms. Thus, only 79 respondents completed the questions related to the age of onset, duration of untreated psychosis, and the duration of the illness. The median age of onset was 25 years. Only 30.8% of respondents had DUP within a year. The median duration of illness was 18 years. A total of 33.7% of respondents had no history of psychiatric hospitalization, while 11.7% had been hospitalized more than five times. In addition, 65.1% of respondents had only oral antipsychotics as the route of administration, while 25.6% had clozapine as one of the antipsychotic treatments. The SAI median scores were 10 out of 14 as the overall total scores for the level of insight.

The mean SDM total score was 62.09 (SD = 22.76). Only 34.9% of respondents scored high SDM. A total of 65.1% of respondents scored below 75 for SDM. A total of 55.8% of respondents had autonomous role preference, while 44.2% preferred to be passive. Among these 48 respondents who preferred autonomous role preference, 29 (60.4%) had not scored high SDM. Meanwhile, only 19 respondents matched their

TABLE 1 | Sociodemographic characteristics of respondents ($N = 86$).

Variables	Mean (SD)	*N*	%
Age	44.86 (13.86)		
Gender			
Male		34	39.5
Female		52	60.5
Race			
Malay		38	44.2
Chinese		35	40.7
Indian		13	15.1
Religion			
Islam		38	44.2
Buddhist		25	29.1
Christian		13	15.1
Hindu		10	11.6
Marital status			
Single		53	61.6
In marriage		33	38.4
Occupation			
Employed		25	29.1
Unemployed		61	70.9
Educational level			
No/Primary education		11	12.8
Secondary education		46	53.5
Certificate/Diploma		19	22.1
Undergraduate/Postgraduate		10	11.6

SD, standard deviation.

TABLE 2 | Clinical characteristics, SDM scores, CPS level, and SAI scores.

Variables	Mean (SD)	Median (IQR)	*N*	%
Age of onset		25.00 (15)		
Before 18 years old			16	20.3
18–30 years old			42	53.2
31–40 years old			9	11.4
After 40 years old			12	15.2
DUP				
Within a year			30	38.0
More than a year			49	62.0
Duration of illness (years)		18.00 (15)		
Number of Psychiatric Hospitalization				
Never			29	33.7
1–5 times			47	54.7
6–10 times			6	7.0
More than 10 times			4	4.7
Antipsychotics treatments				
Route of administration				
Oral only			56	65.1
With LAI			30	34.9
Type of antipsychotic				
No clozapine			64	74.4
With clozapine			22	25.6
SDM total scores	62.09 (22.76)			
High SDM (75 and more)			30	34.9
>75			56	65.1
CPS level				
Autonomous			48	55.8
Passive			38	44.2
SAI total scores		10.00 (5)		

CPS, Control Preference Scale; DUP, duration of untreated psychosis; IQR, interquartile range; LAI, long-acting injectable; SAI, Schedule for the Assessment of Insight; SDM, shared decision-making.

autonomous role preferences with a high SDM total score, which represented only 22.1% of the total of 86 participants.

Inferential Analysis

Simple Linear and Multiple Linear Regression Analyses to Determine the Factors Associated With the Shared Decision-Making Total Score

Simple linear regression analyses were used to determine the factors associated with the SDM total scores. Significant associations observed were between the SDM with the SAI total scores ($p = 0.029$) and no clozapine usage ($p = 0.001$).

Multiple linear regression analysis was conducted, with variables showing $p < 0.25$ or any clinically important factor from the simple linear regression analysis. The independent variables selected were age, religion, education level, duration of illness, number of psychiatric hospitalizations, antipsychotic treatments (LAIs or oral only and with or without clozapine), the SAI total scores, and CPS level. These covariates were controlled in the multiple linear regression.

During Step 1, all selected independent variables were entered and explained 24.2% of the variation in the SDM total scores as the initial r-square. In Steps 2, 3, and 4, duration of illness, Hindu religion, and LAI antipsychotics were removed with no r-square changes. In Steps 5 and 6, psychiatric hospitalizations of 6–10 times and educational level were removed with both explained 24.1% of r-square. In Steps 7, 8, 9, 10, and 11, psychiatric hospitalizations of 1–5 times, SAI total scores, Buddhist religion, psychiatric hospitalizations of more than 10, and CPS level were removed, respectively. R-square changes were from 23.5, 23.0 22.3, 21.3 to 19.7% respectively. In Step 12, the Christian religion was removed and left with age and clozapine usage as the significant predictors with an overall r-square of 18.2%, which means that there are other factors relating to SDM total scores that have not been included in this study.

Two significant factors associated with SDM total scores were identified while other factors were being controlled. It was observed that age ($B = -0.334$, 95% CI $= -0.666$ to -0.003) was found to have a significant negative correlation, while "being a non-clozapine user" ($B = 19.899$, 95% CI $=$ 9.392–30.406) was found to have a significant positive correlation with the SDM total scores. **Table 3** shows the results of factors associated with SDM using simple linear regression and multiple linear regression.

TABLE 3 | Factors associated with SDM using SLR and multiple linear regression.

Variables	**SLR**		**Multiple Linear Regression**		
	***b*[a] (95% CI)**	***p*-value**	**Adj. b (95% CI)**	***t*-stat**	***p*-value**
Age	−0.281 (−0.640, 0.77)	0.122	−0.334 (−0.666, −0.003)	−2.010	**0.048**
Gender					
Male	Ref				
Female	1.301 (−8.739, 11.341)	0.797			
Race					
Malay	Ref				
Chinese	−5.709 (−15.756, 5.599)	0.347			
Indian	−1.881 (−16.525, 12.762)	0.799			
Religion					
Islam	Ref				
Buddhist	−8.533 (−20.215, 3.150)	0.150	−4.395 (−15.332, 6.543)	−0.801	0.426
Christian	1.881 (−12.695, 16.457)	0.798	7.653 (−5.323, 20.629)	1.175	0.244
Hindu	−1.335 (−17.458, 14.788)	0.870	0.670 (−16.955, 18.294)	0.076	0.940
Marital status					
In marriage	Ref				
Single	−0.210 (−10.308, 9.889)	0.967			
Occupation					
Employed	Ref				
Unemployed	4.706 (−6.061, 15.472)	0.387			
Educational level					
Up to secondary education	Ref				
College/university	8.750 (−1.463, 18.962)	0.092	1.396 (−10.368, 13.160)	0.237	0.814
Age onset	−0.110 (−0.523, 0.303)	0.596			
DUP					
Within a year	Ref				
More than a year	−5.346 (−15.728, 5.036)	0.308			
Duration of illness	−0.345 (−0.792, 0.103)	0.129	0.002 (−0.585, 0.589)	0.006	0.995
No. of psychiatric hospitalization					
Never	Ref				
1–5 times	−0.405 (−11.035, 10.225)	0.940	3.490 (−13.714, 6.336)	−0.694	0.490
6–10 times	−1.676 (−21.866, 18.513)	0.869	1.851 (−18.977, 22.679)	0.177	0.860
More than 10 times	−23.526 (−47.536, 0.485)	0.055	−11.396 (−34.60, 11.807)	−0.979	0.331
Antipsychotics treatments					
Route of administration					
With LAI	Ref				
Oral only	−6.795 (−16.993, 3.403)	0.189	−0.794 (−11.974, 10.385)	−0.142	0.888
Type of antipsychotic					
With clozapine	Ref				
No clozapine	18.422 (7.901, 28.944)	**0.001**	19.899 (9.392, 30.406)	3.772	**0.000**
SAI total scores	1.789 (0.184, 3.394)	**0.029**	0.630 (-1.149, 2.409)	0.706	0.483
CPS level					
Autonomous	Ref				
Passive	−5.740 (−15.550, 4.069)	0.248	−5.750 (−15.100, 3.600)	−1.225	0.224

Bold values indicate Significant $p < 0.05$, [a]crude regression coefficient. Multivariate linear regression ($R^2 = 0.182$; the model reasonably fits well; model assumptions are met; there is no interaction between independent variable and no multicollinearity problem).

CPS, Control Preference Scale; DUP, duration of untreated psychosis; LAI, long-acting injectable; SAI, Schedule for the Assessment of Insight; SDM, shared decision-making; SLR, simple linear regression.

Simple Logistic and Multiple Logistic Regression Analyses to Determine the Factors Associated With the Autonomous Role Preference Level

Simple logistic regression analyses were used to determine the factors associated with autonomous role preference. No significant association was observed with autonomous role preference from simple logistic regression. However, five variables had a p <0.25.

Multiple logistic regression analysis was conducted with these five variables. The independent variables selected were age, number of psychiatric hospitalizations, antipsychotic treatments (LAI or oral only), the SAI, and SDM total scores. These covariates were controlled in the multiple logistic regression. The model fit the sample as a Hosmer and Lemeshow test showed a p = 0.634. During Step 1, all selected independent variables were entered and explained 17.6% of the variation in the CPS level as the initial Nagelkerke r-square. In Step 2, psychiatric hospitalization of 6–10 times was removed with no r-square changes. In Steps 3, 4, and 5, SDM total scores, age, and psychiatric hospitalizations of more than 10 were removed respectively. Nagelkerke r-square changes were from 16.9, 14.9, to 12.9% respectively. In Step 6, psychiatric hospitalization of 1–5 times was removed and left with SAI total scores and LAI usage as the significant predictors with an overall r-square of 11.3%, meaning there are other factors for role preference level that have not been included in this study.

Two significant factors associated with autonomous role preference were identified while other factors were being controlled. Every one increment of the SAI total scores decreases by 0.84 times the probability of having autonomous role preference [adjusted odds ratio (AOR) = 0.844, 95% CI = 0.719–0.989]. Those using the oral route only in the administration of antipsychotics had 2.94 times the probability of having autonomous role preference compared to those who had LAI antipsychotics (AOR = 2.939, CI = 1.104–7.823). **Table 4** shows the results of factors associated with role preference using simple logistic regression and multiple logistic regression.

DISCUSSION

This study aimed to determine the level of SDM and role preference and their associated factors among patients with schizophrenia. To our knowledge, this is the first study that examined SDM among patients with schizophrenia in Malaysia. Overall, this study yielded four main findings. First, 35% of the study participants experienced high SDM, and 56% preferred autonomous roles. Second, role preference did not correlate well with SDM experiences; the majority of participants who preferred autonomous roles perceived a lack of SDM. Third, being younger and a non-clozapine user were factors significantly associated with SDM experiences. Fourth, a lower level of insight and being on oral antipsychotics only were significantly associated with autonomous role preference.

Level of Shared Decision-Making and Role Preference

Level of Shared Decision-Making

The majority (65%) of the study participants perceived a lack of SDM experiences, whereas only 35% experienced a good level of SDM with a mean score of 62. Studies of SDM among patients with schizophrenia remain lacking. The majority of the research on SDM in the mental health field has focused on mental illness in the population in general and has been done mainly in the United States and European countries (48). The only study to which we can compare our findings is a study done in Spain (20) that focused on patients with schizophrenia and used the same measurement tool and cutoff point. This study revealed an even lower percentage of participants experiencing a good level of SDM (10%), with a mean score of 39. Otherwise, the study on patients with all psychiatric conditions revealed a much higher percentage (60%) of participants experiencing a good level of SDM at some point in their care (21). A recent national survey in Hungary that studied the general adult population using the same measurement tool revealed a higher mean score of 67 (46).

Other studies on SDM among people with schizophrenia are qualitative in nature, which focused on an exploration of the elements of SDM. One qualitative observational study on psychiatric illness, with patients with schizophrenia as the majority of the participants, revealed most clinicians and patients shared opinions or concerns and frequently arrived at an agreed-upon decision, but most observed decisions still fell short of the criteria that constitute SDM (16). In a recent qualitative study among patients with schizophrenia spectrum disorders, including schizoaffective, schizophreniform, schizotypal personality, and delusional disorder, participants reported that healthcare professionals inconsistently involved them in treatment decisions (17). Meanwhile, in a qualitative study of patients' experiences with antipsychotic drugs in Norway, only one-third of the participants reported receiving sufficient information, while the rest received little to no information (49).

The degree to which SDM is relevant and sensitive to the Asian culture and practice is still not well-known. SDM is expected to be less common in Asian culture than in the Western system, which supports individualism, empowerment, and independence (50, 51), whereas health providers in Asian countries are assumed to be more paternalistic in their treatment approaches (52). In Asian clinical settings, mental health professionals are expected to be respected as authority figures, which might make it more difficult for patients to express preferences and discuss treatment options (53). A recent study among people with schizophrenia in China using a qualitative interview explored participants' attitudes, experiences, and factors related to SDM (19). All the participants described situations in which the psychiatrist made the decision, and the family gave informed consent to decision-making. Some participants felt that the psychiatrist dominated the decision-making process without discussing preferences for treatment. Participants felt excluded and that they had no influence over decision-making when the psychiatrist and the family made a

TABLE 4 | Factors associated with role preference using SLogR and multiple logistic regression.

Variables	SLogR		Multiple Logistic Regression		
	Crude OR (95% CI)	***p*-value**	**Adj. OR (95% CI)**	**Wald**	***p*-value**
Age	1.022 (0.989, 1.055)	0.189	1.017 (0.983, 1.051)	0.945	0.331
Gender					
Male	1				
Female	0.669 (0.277, 1.61)	0.370			
Race					
Malay	1				
Chinese	1.440 (0.398, 5.211)	0.578			
Indian	1.200 (0.326, 4.414)	0.784			
Religion					
Islam	1				
Buddhist	2.100 (0.471, 9.364)	0.331			
Christian	1.833 (0.383, 8.778)	0.448			
Hindu	2.000 (0.352, 11.364)	0.434			
Marital status					
In marriage	1				
Single	1.087 (0.453, 2.606)	0.852			
Occupation					
Employed	1				
Unemployed	0.621 (0.238, 1.619)	0.330			
Educational level					
Up to secondary education	1				
College/university	1.188 (0.481, 2.935)	0.709			
Age onset	1.014 (0.978, 1.052)	0.437			
DUP					
Within a year	1				
More than a year	0.864 (0.346, 2.157)	0.755			
Duration of illness	1.014 (0.974, 1.055)	0.498			
No. of Psychiatric Hospitalization					
Never	1				
1–5 times	0.175 (0.016, 1.913)	0.153	0.192 (0.015, 2.496)	1.590	0.207
6–10 times	0.319 (0.031, 3.297)	0.338	0.396 (0.031, 5.021)	0.511	0.475
More than 10 times	0.167 (0.010, 2.821)	0.214	0.212 (0.011, 4.181)	1.041	0.308
Antipsychotics treatments					
Route of administration					
With LAI	1				
Oral only	2.179 (0.884, 5.373)	0.091	2.939 (1.104, 7.823)	4.658	**0.031**
Type of antipsychotic					
With clozapine	1				
No clozapine	0.836 (0.313, 2.231)	0.720			
SAI total scores	0.886 (0.764, 1.027)	0.107	0.844 (0.719, 0.989)	4.375	**0.036**
SDM total scores	0.989 (0.970, 1.008)	0.246	0.992 (0.971, 1.014)	0.476	0.490

Bold values indicate Significant p <0.05, 1, reference. Multiple Logistic Regression: Cox & Snell R Square 8.4%, Nagelkerke R Square 11.3%; the model reasonably fits well; model assumptions are met; there is no interaction between independent variable and no multicollinearity problem.

DUP, duration of untreated psychosis; LAI, long-acting injectable; OR, odds ratio; SAI, Schedule for the Assessment of Insight; SDM, shared decision-making; SLogR, simple logistic regression.

joint decision without them. A very recent review recommended family-centered decision-making (FCDM) as a more adaptive approach for use among Asian service users than the usual SDM. FCDM may be seen as allocating a greater degree of priority to patients challenged by more disabling illnesses, such as among patients with schizophrenia (54).

The level of SDM in our study of an Asian population is still comparable to, and relatively higher than, those findings in

Western countries, despite the expectation that SDM experiences would be fewer. This can be explained by a few potential reasons. Firstly, about 20% of the participants were excluded from this study for various reasons, such as language barriers and their refusal to participate for unknown reasons. It is possible that among these excluded participants are people who possibly could not comprehend the questionnaires and had a lower capacity for SDM. The results could have been lower if they had been included. Secondly, this hospital caters to a population that is socioeconomically more privileged compared to the general population. The economic backgrounds of the outpatient attendees might be different, since this teaching hospital is semiprivate, unlike government hospitals run by the Ministry of Health where medical services are charged at a minimal rate. Additionally, this hospital is located in an urban area that may cater to people with a higher capacity for SDM. The urban population preferred SDM much more than the rural population, according to one local study (13). Urban dwellers are often younger, more literate, and more highly educated (45). Of our participants, 34% had at least a tertiary education level compared to one local study in a less urbanized population that showed a much smaller tertiary education percentage (6%) (55). Our participants' education level is also higher when it is compared to those in a population-based study using nationwide registers, which occurred in one European country and in which only 12% had a tertiary educational level (56). Our patients' educational backgrounds are similar to those investigated in a study done at the same center on common medical illnesses, which revealed a slightly higher tertiary education level percentage (36%) (57). Patients with higher levels of education and income were shown to prefer autonomous roles in a previous study of the general public (28). Thus, these factors may affect the findings for both the level of SDM and role preference in this current study.

Role Preference

Slightly more than half (56%) of the participants in the current study preferred autonomous roles. Role preference measures individual preference in decision-making in terms of whether they prefer autonomous or passive roles. In a systematic review paper, there were emerging trends and perspectives that SDM is generally highly accepted and desirable in the treatment of patients with schizophrenia and related disorders (58). People with schizophrenia were shown to prefer SDM with varying degrees of role preferences, based on a recent qualitative study in China (19). An earlier study in Spain of people with bipolar disorder and schizophrenia revealed a lower percentage (36%) with autonomous role preference (23). Non-psychiatric patients treated in primary care settings were shown to have a much higher autonomous role preference compared to patients with bipolar disorder and schizophrenia, according to a previous study. Non-psychiatric primary care patients were 18 times more likely to prefer to be given options about their treatment and twice as likely to prefer making medical decisions on their own (59). This contrasts with a previous study among inpatients with schizophrenia using Autonomy Preference Index scores, in which patients with schizophrenia had slightly higher mean scores than those reported for the primary care patients (60). Role preference among mental health service users, in general, was reported to be high (82%) in a very recent study whereby the majority of them preferred active and shared decision-making regarding their medication (26). Generally, patients with psychiatric illnesses appeared to prefer autonomous roles.

Correlation Between Role Preference and Shared Decision-Making Experiences

Another finding from the current study worth discussing is that role preference did not correlate with SDM experiences. Autonomous role preference was considered to be correlated with SDM when the participants who preferred autonomous roles also perceived high SDM experiences. In our study, the majority (60%) of participants who preferred autonomous roles perceived a lack of SDM experiences. Among the total respondents, only 22% of participants matched their autonomous role preference with high SDM experiences. The Hungarian national survey revealed that the preferred and perceived roles matched for 52% of the population, whereas 32% preferred more participation and 16% opted for less (46). Another study revealed a mean of congruence between the preference for and perceived participation in decision-making of 60% (28). However, both studies were conducted on the general population in medical decision-making. A study reviewing major psychiatric illnesses showed that SDM occurs less often in mental health treatment than is desired by patients (58). Another study involving patients with schizophrenia spectrum disorders revealed that almost all participants identified a desire for SDM but nearly all also described experiences in which they felt insufficiently included in treatment-related decisions (17). People diagnosed with schizophrenia perceived they were not involved in the SDM although they may have had a preference for SDM, according to a recent study in China (19).

Barriers to this SDM practice being followed against patients' role preferences should be investigated, and intervention should occur. One recent review summarized that the barriers to SDM for psychiatric medication management were due to patients' lack of confidence and awareness of their rights, limited access to information, poor communication by all parties or either party, and misperceptions about patients' decision-making abilities (61). The most commonly identified barriers were the assumption of hierarchical doctor–patient relationships and the paternalistic views of decision-making in the culture. Particularly among patients with schizophrenia, there is a high societal expectation that psychiatrists should hold statutory powers in the treatment of the condition (47). Barriers to implementing SDM also varied based on place of origin; physicians in the United States mentioned limited time, physicians in Jordan reported that a lack of patient education limits SDM practices, and physicians in Israel reported a lack of communication training (62). Meanwhile, in Malaysia, the barriers were noted to be limited teaching of SDM in undergraduate and postgraduate curricula and a lack of accurate and accessible health information for patients (12). The importance of this study is to understand both the role preference and SDM experiences particularly among patients with schizophrenia. Interestingly, there have not been many quantitative studies on the topic in this population. Understanding the level of SDM and role preference will contribute to guiding future research and the development of clinical practice for this population.

Associated Factors of Shared Decision-Making

Association Between Being Younger and Higher Levels of Shared Decision-Making

Our study revealed that being younger was significantly associated with better SDM experiences after being adjusted for other factors. This finding was similar to a study by De las Cuevas et al. that showed an association between being younger and having better SDM experiences (20). Other studies looked into the association between age and role preference, but without including SDM experience in their studies. In these studies, younger patients were shown to prefer autonomous roles compared to older patients (23, 55). Interestingly, our study revealed the association between age and SDM experiences but not role preference. This might mean that clinicians are giving more opportunities to younger patients to get involved in decision-making regardless of their role preference. The brain changes that happen among patients with schizophrenia are another possible explanation of why the older age-group does not experience SDM as much. White and gray matter deteriorations have been observed in the brains of patients with schizophrenia during late adulthood, with a vulnerability in the prefrontal and cingulate cortices (63). This assumption may prevent clinicians from practicing better SDM with their older patients. However, aging can affect executive functioning differently (64). Thus, clinicians should not underestimate the capacity for SDM among their older patients.

Association Between Being a Clozapine User and Lower Shared Decision-Making

Our study also revealed a significant association between being a clozapine user and SDM. The non-clozapine user group had a strong positive correlation with SDM experiences, even after adjustments were made for other factors, as the $p = 0.000$. Twenty-six percent of our participants were clozapine users, a percentage almost similar to earlier local studies in Malaysia that revealed clozapine user frequency to be 20% (55, 65). All the patients in our study who were prescribed clozapine were being treated as treatment-resistant schizophrenia (TRS) patients, consistent with most guidelines that support the use of clozapine in the management of TRS (66). This association between clozapine users having lower SDM is most probably TRS-related rather than being due to the effect of clozapine. Clozapine has generally been proven to improve cognitive functions and, presumably, the capacity for SDM (67).

TRS reflects a more severe stage of the illness and is associated with more negative symptoms, a longer duration of illness, frequent relapses and hospitalization, more social or occupational dysfunction, a lack of family support, and poor therapeutic alliance (68). All these factors may affect the patients' capacity for SDM. A lack of social support for TRS patients may reduce such an individual's capacity to live more independently in the community environment and have meaningful relationships (69). Poor cognitive impairment is reflective of poor cognitive reserve, which may affect an individual's capacity for interpersonal functioning (70), which happens more so in patients with TRS (71). Self-esteem is another factor that may affect the capacity for SDM with patients with schizophrenia, especially among those with TRS; it impairs psychological well-being and the capacity to express a preference for SDM (72). Therefore, it may be understandable that the TRS patient group has a lower capacity for SDM.

Associated Factors of Autonomous Role Preference

Association Between Lower Levels of Insight and Autonomous Role Preference

Our study revealed a negative correlation between levels of insight and patient role preferences. Patients with lower levels of insight, surprisingly, chose autonomous role preference more than those with better insight. A similar negative correlation was observed between levels of insight and SDM experiences in the simple regression model, but this correlation became insignificant in the multiple regression model when adjusted with other confounders. This finding is similar to that of an earlier study that used a seven-item questionnaire to measure insight and the autonomy preference index to measure role preference (60). However, in this earlier study, the negative correlation between insight and role preference was not significant, with a $p = 0.09$. Other previous studies seem to prove the contrary and show that a lack of insight had the strongest link to a lack of decision-making capacity relating to treatment (29). Poor insight is seen as the most common and absolute barrier to SDM among patients with schizophrenia (32, 47) and has been linked to a poorer perceived therapeutic alliance (73). This can be explained by the description of insight as the ability of people with schizophrenia to recognize that they have an illness and their ability to understand how their experiences relate to the illness (74).

One possible explanation for our finding, which differs from most previous studies, as they were conducted in western countries, is related to Asian cultural values. The paternalistic approach is still very much being practiced and generally accepted by patients and the public. As the patients gain insight, they will fall back on these Asian values in leaving decision-making to the doctors, a process that is socially desirable (60). However, this value is disrupted when their capacity for insight is impaired, and their preference for an autonomous role during this stage may reflect an act of distrust when they are still under the influence of the symptoms of the illness (32). Previous studies looking into the association between the domain-specific insight of patients with schizophrenia and symptomatology, multiple neurocognitive functions, and personality-related traits found that poor insight was shown to be associated with self-certainty, increased novelty-seeking behavior, better self-esteem and self-efficacy, higher education (75), and overconfidence (76). These factors can predispose such people to be more active in SDM despite having poor insight.

Thus, they preferred to be more active in decision-making with their clinician.

Nevertheless, helping patients gain insight into their illness is an important process. Insight has been proven to enhance medication adherence and long-term clinical outcomes and offer a better quality of life (77). A recent review in a journal of ethics suggests that a patient's lack of insight should not be a reason for healthcare providers to abandon decision-sharing with a patient (78). It would be ethical for clinicians to improve their patients' insight about the proven benefits and assist autonomous role preference and SDM at the same time in order to facilitate recovery.

Association Between Being on Oral Antipsychotics Only and Autonomous Role Preference

In this current study, those on oral antipsychotics only were more likely to have an autonomous role preference compared to those on LAI antipsychotics. In this study setting, patients who are on oral antipsychotics only (65%) may have been in a situation where good responses had already been achieved with oral medication or they had not been keen on LAI for various reasons. One common reason for patients' reluctance to be treated with LAI is the stigma associated with it. A study revealed that patients tend to prefer the route of administration that is commonly used, and that LAIs generate greater feelings of shame or stigma (79). However, the reasons for using the different formulations of medication among the patients were not explored in this study.

The association found in this study between being on oral antipsychotics only and autonomous role preference may be explained by the fact that, in this study setting, LAI is still not commonly used in the early stages of illness. Being on oral antipsychotics only reflects a lower illness severity. It is acknowledged that SGA LAIs are increasingly chosen for use in the early stages of illness due to the advantages they offer in preserving white matter brain volume, which provide a greater degree of neuroprotection and better cognitive performance. A very recent article from Hong Kong provided consensus statements promoting the use of SGA LAIs with all patients with schizophrenia as an SDM process due to the extensive volume of evidence supporting the benefits for treatment outcomes regardless of the illness stage (80). The practice of using SGA LAIs as a preferred option in the early stages of illness is new in Malaysia. Generally, LAIs are still reserved for patients having difficulties in controlling the symptoms of illness. One recent review revealed that patients admit to preferring a more directive/paternalistic practitioner style during a crisis, but they feel pressured or persuaded into accepting pharmacological treatments like LAIs if they fail to take their prescribed oral medication (81). These factors, which can signify more chronic and cognitive impairment, may affect their role preference and subsequently the SDM process. This may explain our findings.

Strengths, Limitations, and Recommendations

Our study findings confirm previous reports, albeit not many in number, on the lack of SDM practices, despite it being a widely accepted standard of patient-centered care and promoted by the authoritative guidelines. The implementation of SDM among patients with schizophrenia has remained relatively less successful despite the increasing development of SDM interventions (48). This study addresses this gap and highlights some important complexities.

The limitations of our study were related to bias, including selection and response biases. Additionally, this study, being cross-sectional in design, could not establish cause-and-effect relationships between variables. The relatively small sample size of this study also limited the reliability of the study. Clinician perspectives, which may have complemented the findings, were not assessed in this study, as it was limited to the patients' perspectives. The study was conducted in only one center, i.e., a teaching hospital, which may limit the generalizability of the findings. In addition, there were limited factors contributing to SDM that be analyzed in this current study.

Other factors contributing to SDM should be explored in future studies. More research is needed regarding how SDM can be implemented in regular mental health care. A randomized controlled trial with complementary SDM interventions is recommended to yield the maximum effect on patients as active participants (82). Adapting SDM concepts and tools to public mental healthcare settings poses numerous challenges, as reported from the field tests of one of the patient decision aids (PDAs) for consumers, which considered the use of antipsychotic medication (83). Newer PDA tools for aiding antipsychotic medication decision-making were developed by a research team in a study by Zisman-Ilani et. al. (84). This tool was used with patients and by clinicians as part of the psychiatric consultation and was shown to be valuable and acceptable for people with first-episode and long-term psychosis.

Due to cultural differences, locally validated tools should be available. In Malaysia, there has been an ongoing initiative to improve SDM for patients with MDD but none yet directed toward patients with schizophrenia. At the moment of writing, one local trial had just been completed on the strategic alliance between patients and healthcare professionals in recovery (SAPHIR). The intervention groups were given a booklet of scripts for doctors and the Antidepressant PDA Booklet to facilitate SDM during patient–physician consultations. A similar initiative may be applicable for patients with schizophrenia. A recent open forum suggested a new conceptualization, shared risk-taking, to facilitate the implementation of SDM (30). The clinician and patient should explicitly conduct a risk assessment of a decision, its safety implications, and the patient's capacity to be involved in the decision-making process. Most decision support tools, however, are not designed to capture risk-taking in the context of complex decisions with broader life implications.

CONCLUSION

The present study showed that the practice of SDM is still lacking in the treatment of patients with schizophrenia in Malaysia, even though many of them preferred to be involved in the decision-making pertaining to their treatment. Contrary to the understanding that the paternalistic approach of decision-making being socially desirable in Asian cultural values, this study illustrated that active involvement in decision-making is preferred by many patients with schizophrenia. This study indicates the need for clinicians to improve the way they involve patients in their treatment process. More research is needed regarding how SDM can be implemented with patients with schizophrenia, especially in Asian population settings. Additionally, the chronicity among patients with schizophrenia, as reflected by being in the TRS group and older in age, may contribute to a lack of SDM. The coincidental finding connecting a lower insight level and being on oral antipsychotics only with more autonomous role preference warrants further study and a better explanation.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

This study was approved by the Universiti Kebangsaan Malaysia (UKM) research ethics committee (JEP-2019-530). The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

MI contributed to the original design of the study, management of the study, data collection, data analysis, interpretation of results, preparation, and editing of the manuscript. MM contributed to the conceptualization of the study, interpretation of results, and review of the manuscript. Both authors read and approved the final manuscript.

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Developing a Tool to Measure Person-Centered Care in Service Planning

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Background: Delivering person-centered care is a key component of health care reform. Despite widespread endorsement, medical and behavioral health settings struggle to specify and measure person-centered care objectively. This study presents the validity and reliability of the Person-Centered Care Planning Assessment Measure (PCCP-AM), an objective measure of the extent to which service planning is person-centered.

Methods: Based upon the recovery-oriented practice of person-centered care planning, the 10-item PCCP-AM tool rates service plans on the inclusion of service user strengths, personal life goals, natural supports, self-directed actions and the promotion of community integration. As part of a large randomized controlled trial of person-centered care planning, service plans completed by community mental health clinic providers were rated using the PCCP-AM. Reliability was tested by calculating inter-rater reliability across 168 plans and internal consistency across 798 plans. To test concurrent validity, PCCP-AM scores for 84 plans were compared to expert rater scores on a separate instrument.

Results: Interrater reliability for each of the 10 PCCP-AM items as measured by Kendall's W ranged from $W = 0.77$ to $W = 0.89$ and percent of scores within ± 1 point of each other ranged from 85.7 to 100%. Overall internal consistency as measured by Cronbach's alpha across 798 plans was $\alpha = 0.72$. Concurrent validity as measured by Kendall's W ranged from $W = 0.55$ to $W = 0.74$ and percent of item scores within ± 1 point of expert rater scores ranged from 73.8 to 86.8%.

Conclusions: Findings demonstrated that the 10-item PCCP-AM was a valid and reliable objective measure of person-centered care. Using the service plan as an indicator of multiple domains of person-centered care, the measure provides a valuable tool to inform clinical supervision and quality improvement across programs. More psychometric testing is needed to strengthen the measure for research purposes.

Keywords: person-centered care, person-centered care planning, community mental health, mental health services, measurement, service planning

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INTRODUCTION

There has been a growing recognition that patient-centered care is integral to health care reform efforts. The Institute of Medicine (1) has defined patient-centered care as "providing care that is respectful of and responsive to individual patient preferences, needs and values" (p.3). Also referred to as "person-centered" care in behavioral health settings to convey a more active role for the individual receiving care, the approach embraces a holistic understanding of wellness rather than reducing care to treating isolated symptoms (2). While receiving widespread endorsement both in medical and behavioral health care settings, how this individualized and contextual approach to health care translates to specific clinical practices has been less clear. As health care systems are faced with increasing demands to demonstrate and document person-centered care, there is a need to specify and objectively measure this approach (3). This article describes the development and validation of the Person-Centered Care Assessment Measure, an objective measure of person-centered care based upon documentation within mental health settings.

Person-centered care (PCC) is one of the key aims for health care reform (1). Essentially a values-based approach, person-centered care challenges the disease-centered approach of the medical model and empowers individuals to make decisions about their treatment. In the United States, the Affordable Care Act has provided incentives for new health care models to deliver person-centered care and globally, the World Health Organization has articulated a vision for integrated people centered health services (4). Initiatives in the United Kingdom include the Health and Social Care Act 2012, which requires NHS England to involve people in their care and similar policies exist in Scotland, Northern Ireland and Wales (5). In Australia, patient-centered approaches are supported by the Australian Charter of Healthcare Rights and the National Quality and Safety Health Services Standards (6).

There is a growing evidence base demonstrating that person-centered approaches can improve an individual's self-management and treatment engagement, as well as their overall satisfaction and the perceived quality of care (7–9). Within mental health settings, empowering people to make decisions about their care has been shown to increase engagement in therapeutic (10) and psychiatric treatment (11), reduce symptom severity (12), increase medication adherence (13) and increase client reports of well-being (14). However, as some systematic reviews have concluded, positive outcomes are not consistent across studies, despite efforts to conceptualize and operationalize person-centeredness in mental health (15).

Part of the challenge lies with how intuitive and self-evident the idea of person-centeredness can be for healthcare providers. Many providers feel that they are "already doing it" and so are resistant to efforts to make their practice more person-centered (16). In turn, when providers are asked to self-report their person-centeredness, they tend to endorse high levels of PCC even when objective indicators suggest otherwise (17) undermining efforts to accurately evaluate PCC. Currently, the large majority of person-centered care measures rely on self-report creating a need for objective measures.

Person-centered care has been conceptualized as one aspect of service quality (18). When considering how to capture the implementation of an evidence-based practice, some researchers have conceptualized service quality as a service outcome, which is predicted by implementation outcomes such as adoption, penetration, fidelity and sustainability (19). Whereas others have posited that service quality is an aspect of fidelity, referring to the extent to which a provider adheres to techniques and the theoretical ideal of an intervention (20, 21). A common critique of fidelity measures is that they have focused more on structure than process, despite the fact that the less tangible elements of a program maybe their most essential aspects (22). While our understanding of how service quality fits into implementation frameworks are unresolved, there remains an urgent need for effective measures of the more nuanced but highly valued process aspects of service delivery such as person-centered care.

While PCC is more emphasized in certain practices than others, it is increasingly an aspiration for service delivery generally and therefore, needs to be measured across all programs. In mental health, some programs articulate PCC as a core aspect (23) and other more specified programs, such as assertive community treatment, have person-centered care as an explicit part of fidelity measurement (24). Given variety in the purpose, structure and intensity of mental health programs, the challenge is to find a shared practice across programs that reflects person-centered care. One such practice is service planning which produces a service plan, a form of documentation, that all programs utilize to map the course of care for service users. Evaluating service plans, while not a direct measure of the person-centered process, can provide a common indicator.

In mental health settings, the shift toward person-centered care has been driven by the recovery movement. Emerging in the 1980's from the voices of people with lived experience of mental illnesses, the recovery movement has challenged the prevailing paradigm of authoritative and paternalistic approaches to mental health care (25). More recently, recovery has shaped system transformation efforts after being endorsed by the U.S. policymakers. Person-centeredness is one of the fundamental components of recovery, which calls for care that acknowledges the unique recovery journey of each individual and is self-determined (26).

One recovery-oriented practice that has operationalized the delivery of person-centered care within mental health settings is Person-Centered Care Planning (PCCP) (27). This manualized intervention is anchored in service planning, which maps out a person's care and shapes his or her care experience. The aim of the planning process is to develop and implement an action plan to assist the person in achieving his or her unique, personal goals on the recovery journey. PCCP combines both the values of recovery and a well-specified collaborative approach to service planning. PCCP has explicitly been identified as a requirement by key funders of community mental health services (28) and a core standard of certified community behavioral health clinics established by the Excellence in Mental Health Act (29).

Recent efforts have identified five primary competency domains which support a fully person-centered planning process: 1) strengths-based, culturally informed, whole person-focused; 2) cultivating connections inside the system and out; 3) rights, choice, and control; 4) partnership, teamwork, communication, and facilitation; and 5) documentation, implementation, and monitoring (28). While the person-centered plan itself is directly related to the documentation domain, it is also an overall indicator and reflection of the other competency domains. A person-centered plan is rooted in a person-centered process which includes the therapeutic encounter and decision making.

When implementing PCCP at the provider level, the first step is to elicit and empathize with an individual's subjective experiences as a whole person and help them identify and articulate their interests, preferences, and personal recovery goals. Providers then translate conversations into the documentation of the person-centered plan itself. This includes reframing symptoms and impairments as barriers to goal attainment; reframing the use of medications as tools for overcoming these barriers and moving ahead in one‘s life; instilling hope and encouraging the person‘s incremental efforts in the face of fear, uncertainly, and demoralization; identifying short-term, realistic, and measurable objectives that can be achieved within the plan period of 3 to 6 months, while keeping these objectives explicitly connected to longer term aspirations that might span years; and expanding the action network to include natural supporters as well as professional providers. Providers address requirements for "medical necessity" criteria by offering methods of documentation that simultaneously honor what is most important to the individual while still incorporating elements from a health and safety perspective (27).

This study presents the development and validation of the Person-Centered Care Planning Assessment Measure, an objective measure of person-centered care that can be utilized as a clinical tool for quality improvement purposes. Based upon a randomized controlled trial of PCCP, the study tests the reliability and validity of the measure using a sample of service plans from community mental health clinics.

MATERIALS AND METHODS

The first phase of the study was the development of the scale and the second phase was psychometric testing of the scale. The parent study (ClinicalTrials.gov ID: NCT02299492) was approved by the New York University Institutional Review Board and was conducted 2013–2018.

Development of the Measure

The PCCP-AM was created by the practice developers as a competency-based measure to evaluate the extent to which practitioners incorporate person-centered content within their required service plan documentation. It is organized around the following key plan components: goals, strengths and barriers, short-term objectives, supports, professional/ billable services, and natural support and self-directed actions. Each item is scored according to a four-point Likert scale: One (1) equals "needs improvement"; two (2) equals "approaches standard"; three (3) equals "meets standard"; four (4) equals "exceeds standard." An initial 13-item measure of PCCP was developed based on a review of the literature including a white paper on person-centered planning commissioned by the Substance Abuse Mental Health Services Administration (30). The developers generated items that captured the most common domains of person-centered practice identified in the literature and informed by reviews of recovery plans and documentation requirements from over 25 states (31, 32). The initial draft measure was piloted in trainings and consultation efforts throughout the United States, including an initiative with the Texas Department of Mental Health to develop a standard recovery plan auditing tool for statewide quality monitoring efforts (33). Within this partnership, the measure was reviewed by a wide range of stakeholders including clinical practitioners, agency administrators, state office quality monitoring representatives and people with lived experience. This stakeholder review process was then followed by a 2-day, on-site auditing pilot where the draft PCCP-AM was applied to recovery plans with a diverse team of stakeholders carrying out side-by-side ratings, which led to further refinement of the items.

In the interests of parsimony and to develop a measure that would be feasible as a clinical tool, the PCCP-AM was further reduced to a 10-item measure by discarding three items. Specifically, an item on strengths in the assessment was discarded as it was deemed to be duplicative of another question evaluating the integration of strengths throughout the plan. A second item on Specific Measurable Attainable Relevant and Time-based criteria for short term objectives was discarded as it was duplicative of another item, which evaluates the specificity of the plan. Finally, a third item on person-first language was discarded as it was found to be less sensitive to variation than another similar item which asks about evidence of person's input into the plan. The final version of the PCCP-AM was a 10-item measure (see **Table 1**).

Collectively, these items capture the main domains of person-centered documentation which discriminate traditional service planning from recovery-oriented person-centered planning including: utilization of strengths throughout the plan; presenting problems as barriers to personal goals; having goal statements that focus on having a meaningful life; demonstrating direct input from the person; integrating cultural factors; ensuring community integration and use of informal supports; and specifying measurable individualized action steps by both provider and the person. These domains of person-centered documentation are consistent with practitioner core competency areas in person-centered planning (31) as well as federal regulations and guidelines which outline requirements for person-centered care in community mental health (28, 29).

Psychometric Field Testing

Psychometric testing was conducted as part of a multi-site randomized controlled trial of PCCP (34). Reliability was tested using data collected from a chart review and validity was tested

TABLE 1 | Comparison of PCCP-AM items and expert rating instrument items.

PCCP-AM item(s)	Expert rater item(s)
(1) Presenting problem/barriers	Barriers and functional impairment clearly stated
(2) Narrative/interpretive summary	Cultural factors Stage of change Hypothesis Medical necessity
(3) Direct service user input	Client and family driven
(4) Goal statements	Goal statements
(5) Actively incorporates strengths	Strengths actively used
(6) Objectives go beyond service participation	Objectives linked to goals and barriers
(7) Target dates on short-term objectives	No corresponding item
(8) Natural supports and community engagement	Natural supports identified
(9) Interventions—who, what, when, why?	Interventions
(10) Self-directed action steps	Self-directed and Natural Support Action Steps

using data collected during the technical assistance phase of the PCCP training.

The parent study was set within community mental health clinics with seven sites randomized to the PCCP condition and seven to the control condition. These clinics were from two states with ∼8,000 service users and provided a range of services including outpatient therapy, crisis intervention, medication management, case management, residential programs, community support programs, and rehabilitation services. Site eligibility criteria included serving people diagnosed with severe mental illnesses and no prior PCCP training. The provider sample consisted of 60 provider teams who retained the same supervisor throughout the study (out of a possible 81 teams trained in PCCP). Teams included one supervisor and two direct care staff nominated by the supervisor for their leadership capacity defined as being a role model and having potential to be a supervisor. The experimental sites received a 2-day in-person training session followed by monthly technical assistance over a 12-month period.

Internal Consistency

To evaluate the effectiveness of the training, chart reviews of service plans were conducted at experimental and control sites by researchers not blind to the intervention. Agency medical records staff, who were not members of the research team, were instructed to randomly select service plans from a list of study participants. Each service plan selected was from a unique service user. Based on power calculations for the RCT, 20 plans were selected from each of the 14 sites at three time points: 1 month prior to intervention baseline, 1 month prior to 12 months, and 1 month prior to 18 months. Due to low service user enrollment at one site, only 18 service plans (six from each timepoint) were selected. In total, 798 charts were randomly sampled. Three raters, two at each site, assessed the 798 service plans using the PCCP-AM. Two of the raters had master's level social work degrees and one had a bachelor's level degree. The raters were trained by PCCP experts on using the measure. They developed coding rules to guide scoring and met regularly to review their coding process.

Internal consistency was calculated using Cronbach's alpha for each of the three collection time points ($N = 266$), and for all three combined ($N = 798$). Cronbach's alpha was used as a conservative statistic for determining internal consistency as it calculated the lower bound of the internal consistency of the PCCP-AM (35).

Interrater Reliability

Interrater reliability was established by comparing PCCP-AM scores of a subsample of the 798 service plans. At each of the 14 clinic sites, 12 service plans were randomly selected to be coded by two raters yielding a total of 168 service plans, sufficient to test reliability while also being feasible for the raters.

Kendall's W was used to assess concordance among raters while correcting for ties, due to the non-parametric, ordinal nature of the data (36). In addition, agreement between raters of the 168 service plans was assessed by determining the percent of agreement between raters that was within ± one point. This analytic method was utilized because the PCCP-AM is designed for use as a quality improvement measure in routine care. The tool is designed for providers with different disciplines, education levels, licensing levels, and clinical or administrative experience and different types of agencies. Recognizing the possible wide variation in agency context and rater characteristics, we chose to determine the percent of scores ± one point in our analysis to better reflect interrater agreement in agency practice.

Concurrent Validity

Concurrent validity was established by comparing the assessment summaries of PCCP expert raters on service plans with the PCCP-AM scores. The sample size was determined by the technical assistance phase of the RCT study. Provider teams in the experimental condition submitted de-identified service plans for feedback during monthly technical assistance calls. A team from each of the seven experimental sites provided one service plan for each monthly call over a year, yielding a total of 84 care plans. Expert raters provided feedback to providers using a 14-item assessment instrument which included narrative feedback and a quantitative rating. Seven of these plans were excluded from the analysis as the primary diagnosis was not a mental health disorder and nine were excluded as the expert raters did not provide a numeric rating, resulting in a total sample of 68 service plans. Raters from the research team also rated these 68 service plans utilizing the PCCP-AM.

For construct validity, we hypothesized that the ratings of the PCCP-AM would be in concordance with expert ratings of the same service plans. To conduct a comparison between the expert rater instrument and the PCCP-AM, the 14 plan components of the expert rater instrument were mapped to the

10-item PCCP-AM (see **Table 1**). Two of the PCCP-AM items did not correspond one-to-one with expert rater instrument items. Four categories in the expert rating instrument corresponded to the narrative/interpretive summary in the PCCP-AM: cultural factors, stage of change, hypothesis/clinical interpretation, and medical necessity. The mean of these four ratings was calculated with equal weights. PCCP-AM Item 7, target date on short term objectives was not mapped onto any expert rater instrument item. PCCP-AM Scores were compared with expert rater scores by calculating the percent agreement within one point (±) for each item, in addition to using Kendall's W to assess concordance (36). The final sample resulted in 68 plans compared between expert consultants and PCCP-AM. Individual items had a range of 61 to 68 due to missing data, which was managed with pairwise deletion.

TABLE 2 | Percentage differences and coefficients of concordance between two raters on PCCP-AM items.

	% difference of ≤1	Mean of differences (SD)	Coefficient of concordance*
Item 1	94.0	0.05 (0.69)	0.84
Item 2	98.8	0.07 (0.50)	0.89
Item 3	95.2	0.18 (0.73)	0.78
Item 4	98.8	−0.02 (0.64)	0.81
Item 5	96.4	0.11 (0.62)	0.81
Item 6	85.7	0.07 (0.86)	0.77
Item 7	100.0	0.12 (0.45)	0.85
Item 8	94.0	0.20 (0.76)	0.79
Item 9	97.6	0.01 (0.66)	0.83
Item 10	94.6	0.09 (0.76)	0.78

**as calculated by Kendall's W.*

TABLE 3 | Percentage differences and coefficients of concordance between PCCP-AM items and expert rating instrument items.

	% difference of ≤1	% < −1	% > 1	Mean of differences (SD)	Coefficent of concordance*
Item 1	80.9	1.5	17.6	0.47 (1.15)	0.60
Item 2	86.8	0.0	13.2	0.94 (.70)	0.69
Item 3	72.1	19.7	6.6	−0.46 (1.21)	0.55
Item 4	85.3	1.5	13.2	0.49 (1.00)	0.74
Item 5	85.1	7.5	7.5	0.13 (1.17)	0.61
Item 6	83.8	7.4	7.4	0.43 (1.12)	0.63
Item 7	na	na	na	na	na
Item 8	81.8	18.2	0.0	−0.68 (1.07)	0.61
Item 9	84.8	4.5	10.6	0.12 (1.05)	0.65
Item 10	80.3	3.0	16.7	0.39 (1.07)	0.74

**as calculated by Kendall's W.*
na, not applicable.

RESULTS

Reliability

The overall internal consistency as measured by Cronbach's Alpha was $\alpha = 0.72$ for 798 service plans. For 266 service plans collected at baseline, the internal consistency was $\alpha = 0.64$. For 266 service plans collected at 12-months, the internal consistency was $\alpha = 0.74$ and for 266 service plans collected at 18-months, the internal consistency was $\alpha = 0.73$.

Interrater Reliability for each of the 10 PCCP-AM items as measured by coefficients of concordance ranged from $W = 0.77$ to $W = 0.89$, with four items being > 0.80 (see **Table 2**). The percent of scores within ± 1 point of each other ranged from 85.7 to 100% (see **Table 2**). All items with the exception of item 6 had 94% agreement or above. Item 7 had 100% agreement and items 2 and 4 had 98.8% agreement. Compared to the other nine items, Item 6 had much lower agreement between raters, with only 86.7% of scores being within ± 1 point of each other. Item 6 was also the only item to have <50% of scores in perfect agreement between raters. Items 1 and 8 had the second lowest percentage of scores within ± 1 point, at 94.0%. The mean percentage of scores between ± 1 was 95.5% and the median percentage was 95.8%. Only one item, Item 6 was more than two standard deviations from the mean, being 2.4 standard deviations less than the mean. Item 7 was the only item greater than one standard deviation above the mean. Neither Items 2 nor 7 had any differences in scores of ± 3, while Items 6, 8, and 9 each had differences of scores of both +3 and −3. Item 9 had the highest percentage of scores in perfect agreement, with 43.9% of scores having no difference between raters.

Validity

Coefficients of concordance ranged from $W = 0.55$ to $W = 0.74$. One item fell below $W = 0.60$ and two were above $W = 0.70$ (see **Table 3**). The percent of PCCP-AM item scores within ± 1 point of expert rater scores ranged from 73.8% (Item 3) to 86.8% (Item 2), with all scores except for Item 3 being equal to or higher than 80% (see **Table 3**). For seven items, the raters more often scored lower than the experts and for two items the raters more often scored higher than the experts. Item 2 was 1.02 standard deviations above the mean, while Item 3 was 2.21 standard deviations below the mean. All other percentages were within 1 standard deviation of the mean percentage by item. Item 2 had the strongest relationship between scores on the PCCP-AM and expert rater scores, despite measuring multiple aspects of assessments. Item 9 was the only item to have more than 40% perfect agreement with a difference in scores of 0. All items had at least 20% perfect agreement. Item 2 had over 60% of scores with a difference of 1 between the PCCP-AM and expert raters and no scores where expert raters scored the charts 2 or 3 points higher than PCCP-AM raters. Item 8 had 40% of scores with a difference of −1 between PCCP-AM and expert raters, with no differences being +2 or +3 between the two. Only two items, Item 3 and Item 8 had any difference of −3 between PCCP-AM and expert raters, while seven items had some number of score differences of +3. Item 10 was the only item for all PCCP-AM and expert rater scores to reside within ± 2 of each other.

DISCUSSION

The PCCP-AM demonstrated acceptable reliability and validity as a clinical tool to measure person-centered care. The measure, which was developed by PCCP experts who had authored the PCCP intervention, uses the service plan as an indicator of multiple dimensions of PCCP. When compared to the gold standard ratings by PCCP experts, the tool performed well overall with all but one item showing good concordance and falling within one point of the expert rating for more than 80% of the scores. The items 2 and 5 had the highest levels of validity showing that the measure was strongest in capturing competency in developing a plan that is strengths-based, culturally informed and whole person-focused. Item 9 also performed well, which measured competency in creating a plan that specifies the details of the intervention, in terms of what is done and by whom. These competencies are both key indicators of person-centered care and part of creating a plan that functions as a meaningful tool of accountability. These plans not only meet requirements for reimbursable services but also map out how an individual and their team work to support recovery. The weakest item in terms of validity was the item capturing direct service user input which may be the difficulty of operationalizing exactly how that is indicated in a service plan, whether it is inferred or should be stated explicitly.

The measure showed acceptable reliability, with an overall internal consistency of 0.72 across all service plans. Results revealed there was lower reliability in the sample of baseline service plans, perhaps indicating that the measure is more consistent when providers have been trained in the PCCP intervention. In terms of interrater reliability, all but one of the items was reliable within one point for 94% of the item scores. Raters disagreed to a greater extent about the item pertaining to whether the objectives go beyond service participation. There may have been ambiguity for the raters in terms of what constitutes activities beyond service participation or in determining the extent to which the objectives go beyond service participation.

By assessing person-centered care as indicated by the service plan, the PCCP-AM meets the need for an objective measure of PCC. While PCC encompasses the whole process of care inclusive of but not limited to documentation, the plan covers each of the core competency domains (e.g., strengths-based, culturally informed, whole person-focused, cultivating connections inside the system and out; rights, choice, and control; partnership, teamwork, communication, and facilitation; and documentation, implementation, and monitoring). While the plan itself is directly tied to the documentation domain, it is a strong indicator of other domains. However, measures of PCC should not be limited to a review of the service plan, as it is still possible that a plan can indicate a high level of person-centered care "on paper" but care in actuality could still be pathologizing and professionally driven. This need to capture process directly in quality measures still prevails, particularly through observational measures and integrating service user perspectives.

As a clinical tool, the PCCP-AM can be an important implementation strategy by facilitating ongoing monitoring and feedback to providers on their person-centered care practice. A recent synthesis of implementation frameworks lists ongoing implementation support strategies as: technical assistance, supervision and coaching and supportive feedback mechanisms (37). Similarly, Powell et al. (38) include developing and implementing tools for quality monitoring as a key implementation strategy. The PCCP-AM is an accessible tool for supervisors, coaches and technical assistance providers to monitor the delivery of person-centered care and provide feedback to clinicians. The measure can also be embedded in the electronic health record for documentation and quality improvement purposes by aggregating PCCP-AM scores across providers and programs.

There are several limitations to this study. The reduction of items in the interests of parsimony and feasibility may have restricted the breadth of the instrument. The psychometric analysis of the PCCP-AM focused on establishing validity for clinical utility and therefore, neither the interrater reliability nor concurrent validity were established using the most robust tests. This trade off had the positive effect of establishing how the PCCP-AM may be useable by clinicians and administrators with a variety of education levels and practice experience. The measure should undergo more robust psychometric testing to establish it as a research instrument. Lastly, the study is limited in its use of a single comparison measure for establishing validity which relied on expert rating. Future refinement should consider more sources of data to establish both concurrent and predictive validity.

Conclusion

Based on a large study across multiple agencies, the PCCP-AM proved to be a reliable and valid measure of person-centered care as indicated by the service plan. The strength of the measure is that it is objective and can be applied across programs, making it a valuable tool to meet the increasing demands for documentation of person-centered care (39). The tool also can be utilized for clinical purposes by supervisors and coaches to monitor care and provide ongoing feedback. The PCCP-AM should be refined more to strengthen its validity and reliability by comparing it to independent assessments of care processes and by improving the calibration of the response set. In the meantime, the PCCP-AM provides an important step toward developing a clinically useful measure that captures person-centered care, a vital but often elusive aspect of service quality.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by New York University Institutional Review Board. The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

VS designed the study and drafted the manuscript. DB, JT, LJ, AR, and SM drafted the manuscript. DB and SM developed the analytic strategy and conducted the data analyses. All authors reviewed and approved the manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2021.681597/full#supplementary-material

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SYSTEMATIC REVIEW
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Digital Shared Decision-Making Interventions in Mental Healthcare: A Systematic Review and Meta-Analysis

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Background: Shared decision-making (SDM) in mental healthcare has received increased attention as a process to reinforce person-centered care. With the rapid development of digital health technology, researchers investigate how digital interventions may be utilized to support SDM. Despite the promise of digital interventions to support SDM, the effect of these in mental healthcare has not been evaluated before. Thus, this paper aims to assess the effect of SDM interventions complimented by digital technology in mental healthcare.

Objective: The objective of this review was to systematically examine the effectiveness of digital SDM interventions on patient outcomes as investigated in randomized trials.

Methods: We performed a systematic review and meta-analysis of randomized controlled trials on digital SDM interventions for people with a mental health condition. We searched for relevant studies in MEDLINE, PsycINFO, EMBASE, CINAHL, and the Cochrane Central Register of Controlled Trials. The search strategy included terms relating to SDM, digital systems, mental health conditions, and study type. The primary outcome was patient activation or indices of the same (e.g., empowerment and self-efficacy), adherence to treatment, hospital admissions, severity of symptoms, and level of functioning. Secondary outcomes were satisfaction, decisional conflict, working alliance, usage, and adherence of medicine; and adverse events were defined as harms or side effects.

Results: Sixteen studies met the inclusion criteria with outcome data from 2,400 participants. Digital SDM interventions had a moderate positive effect as compared with a control condition on patient activation [standardized mean difference (SMD) = 0.56, CI: 0.10, 1.01, $p = 0.02$], a small effect on general symptoms (SMD = −0.17, CI: −0.31, −0.03, $p = 0.02$), and working alliance (SMD = 0.21, CI: 0.02, 0.41, $p = 0.03$) and for improving decisional conflict (SMD = −0.37, CI: −0.70, −0.05, $p = 0.02$). No effect was found on self-efficacy, other types of mental health symptoms, adverse events, or patient satisfaction. A total of 39 outcomes were narratively synthesized with results either favoring the intervention group or showing no significant differences between groups.

Studies were generally assessed to have unclear or high risk of bias, and outcomes had a Grading of Recommendations Assessment, Development and Evaluation (GRADE) rating of low- or very low-quality evidence.

Conclusions: Digital interventions to support SDM may be a promising tool in mental healthcare; but with the limited quality of research, we have little confidence in the estimates of effect. More quality research is needed to further assess the effectiveness of digital means to support SDM but also to determine which digital intervention features are most effective to support SDM.

Systematic Review Registration: PROSPERO, identifier CRD42020148132.

Keywords: shared decision-making, systematic review and meta-analysis, mental health, digital health (eHealth), patient activation

INTRODUCTION

Digital health technology has become an integrated part of the global healthcare system and is continuously developing and growing. Within mental healthcare, traditional means of care are being complemented by health technology such as smartphone decision aids, web-based self-management systems, or online support groups. As technology develops, new possibilities arise; and the World Health Organization advocated through the global strategy on digital health for 2020–2024 to use digital technology for more person-centered healthcare (1). Person-centered care focuses on placing people at the center of their healthcare, and technology may complement this in various ways such as supporting people to become more aware of their health and needs.

Researchers within mental healthcare have increasingly turned their attention to shared decision-making (SDM) as a process to reinforce person-centered care (2). SDM can be defined as a process involving at least two people (e.g., patient and provider) who share information, discuss options, and collaborate to reach a mutual decision (3). SDM aims to ensure that both patient and provider are actively involved in decision-making processes and that their unique competences are utilized. Providers have an expertise in information on symptoms management, treatment options, and potential benefits or side effects; while patients are experts on their needs, preferences, goals, and values. SDM may be affected by mechanics surrounding the patient and provider such as their individual engagement, working alliance, and mutual understanding of one another but also the risk associated with the decision. If done successfully, SDM may increase autonomy, self-management, working alliance, satisfaction, and quality of care (4). For SDM to be successful, both the patient and provider must be engaged in the patients' care. Patients have indicated that being an active partner and embracing the same qualities as one would expect from their provider is necessary for the success of SDM (e.g., honesty, responsibility, and trust) (3). Patients in mental healthcare have also indicated that they want to be active participants when making health decisions (5). Still, SDM has not been widely implemented in clinical practice with barriers such as time constraints at consultations, providers believing they can guess how the patients wish to be involved, or uncertainty of how to fit SDM into the workflow (2, 6). In addition, recent research notes that SDM may be easier to incorporate when making a decision has a low personal risk and may be more difficult to incorporate when decisions have a higher risk such as adjusting one's medication (7). A systematic review—covering 33 studies on including patients in decision-making—reported that a minority of healthcare providers consistently attempted to facilitate patient involvement, and even fewer adjust care to patient preferences (6). The review highlights SDM interventions as a means to promote patient-involving behaviors but that the responsibility of facilitating SDM cannot lie solely with the provider—decision aids and communication tools may serve as part of the solution (6). Therefore, to facilitate the process of SDM, research has begun to investigate how digital interventions may be utilized to support SDM and potentially address some of its barriers. Using technology as the tool and SDM as the process, randomized controlled trials (RCTs) are investigating whether digital SDM interventions are effective at promoting person-centered care.

Previous systematic reviews and meta-analyses have found that SDM interventions have a small effect on empowerment for people with psychosis and that SDM may increase provider facilitation of patient involvement (8, 9), while meta-analyses on the effect of digital interventions for mental health have found an effect at improving symptoms (10). However, a systematic assessment of the effect of digital interventions to support SDM in mental healthcare has not been conducted before. Thus, this paper aims to assess the effect of SDM interventions complimented by digital technology in mental healthcare for promoting person-centered care. Using subgroup analyses, we explored whether the effect was dependent on the type of digital intervention, age, or mental health condition. The results of these meta-analyses may guide future research and stakeholders in how digital technology may complement SDM in mental healthcare.

METHODS

This systematic review and meta-analysis followed the PRISMA statement and adhered to the registered online protocol at PROSPERO (CRD42020148132) (11).

Definitions

We defined SDM in this review as a process with three main components: (1) sharing information; (2) discussing treatment options; and (3) reaching a mutual decision that both parties can agree upon. Around these three components lie several surrounding mechanisms affecting this process such as learning about the patient, supporting the patient to initiate discussions with the provider, or evaluating the decision. The process of SDM and its surrounding mechanisms is illustrated in **Supplementary Material 1**. This definition is based on previous research investigating patients' understanding of SDM and also a systematic review on the most common components of SDM models (3, 12). In this review, an SDM intervention is an intervention that supports at least one of the three main components of the SDM process.

Digital interventions were defined as information and/or communication technology delivered via phones, computers, personal digital assistants, or other similar devices. Interventions did not have to be internet-based.

Mental health conditions were defined in concordance to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and *International Classification of Diseases* (ICD).

Search Strategy

We conducted a systematic literature search of the following databases up to March 2021: MEDLINE, CINAHL, EMBASE, PsycINFO, and the Cochrane Central Register of Controlled Trials. The PICO framework was used to develop the search strategy. Our search terms focused on SDM, digital health technology, mental health, and RCTs. The complete search strategy is listed in the **Supplementary Materials**. Our search terms on SDM were developed based on existing Cochrane reviews on SDM (9, 13). Due to the complexity of SDM, our search terms focused on person-centered terms (e.g., patient involvement), technique style (e.g., decision aids), and relationship components (e.g., working alliance). Search terms on digital health technology focused on components such as e-Health, m-Health, and information technology. Search terms on mental health were broad and attempted to reach all mental health conditions. The reference lists of retrieved studies were checked to identify further eligible studies.

Study Selection Criteria

Only RCTs presenting original data were included in the review. For a study to be included in the review, 50% of the participants needed to have a mental health condition as defined by the DSM and ICD. Besides having a mental health condition, there were no restrictions regarding clinical or demographic characteristics of the participants. Exclusion criteria were studies focusing on relatives rather than the patient or provider. For an intervention to be included, it had to cover one of the three main components of SDM and use a digital tool for people with a mental health condition (as defined above).

The search strategy was developed by the author TV and approved by CH and LK (see **Supplementary Material 2** for the search string). All identified studies were extracted and exported into Zotero reference manager software by TV. All identified studies were title screened by TV against inclusion/exclusion criteria to determine eligibility for selection. The abstract screen and full-text assessments were independently performed by CH and TV with a 74% agreement. In case of disagreements, a third reviewer (LK) was included in the discussion.

Data Extraction

For included studies, the following data were extracted by TV into predefined tables: year of publication, sample size, mental health condition, type of intervention, duration of intervention, type of outcome, results (number of events, means, and SD), control condition, type of setting, and baseline demographics (age, gender, and the highest educational level). The authors of the retrieved papers were contacted if clarification was needed or if data were not accessible from the article.

Statistical Analyses

All analyses were conducted by Review Manager 5.3.5, using random-effects model to account for heterogeneity. The total difference in changes on measurements for patient activation or indices of the same between digital interventions and controls were pooled to compute the overall effect size of the digital interventions with 95% confidence intervals. TV and CH assessed the risk of bias in the included studies using Cochrane Collaboration's Risk of Bias tool. This tool assesses studies six areas, ranking each area as high, low, or unknown for risk of bias. The areas are sequence generation, allocation sequence concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, and selective outcome reporting. In addition, TV and CH used the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system to assess the quality of evidence of each outcome by downgrading from high by one level for each serious issue identified in the domains: risk of bias, inconsistency, indirectness, imprecision, and publication bias (14). In case of a disagreement on the assessment of the studies' risk of bias and the outcomes' GRADE score, a third reviewer was included in the discussion. As stated in our protocol, subgroup analysis was performed for type of intervention (web-based, PC software, or smartphone/tablet application) and diagnosis (11). However, due to discrepancies in the length of the interventions, subgroup analysis on the duration of intervention was also included and was divided into short-term (<3 months) and long-term interventions (>3 months). The cutoff at 3 months was chosen to ensure that trials would be divided somewhat equally and that subgroup analysis on duration would be feasible. For outcomes only occurring in one trial or outcome data not appropriate for a meta-analysis (and where the corresponding author was unable to assist), we did a narrative synthesis. The synthesis was done by counting the numbers of trials reporting a significant positive effect, no effect, and a negative effect for each outcome.

Changes From Protocol

Decisional conflict was not originally planned as an outcome for our meta-analysis according to our protocol; however, after discovering several of the studies measuring this area and considering its relation to SDM, it was included (15–18).

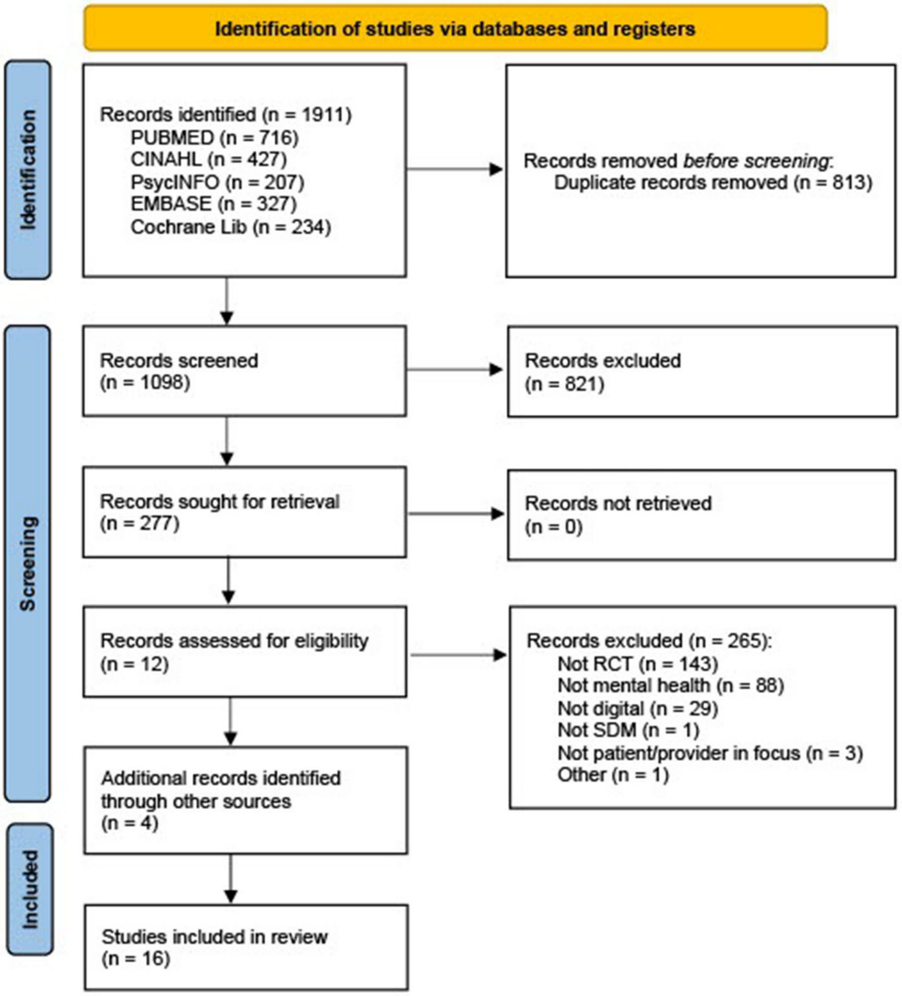


FIGURE 1 | PRISMA flow diagram (19).

RESULTS

The search resulted in 1,911 references, 1,098 after duplicates were removed and 277 after title screening. After abstract screen and full-text assessment, 12 articles were assessed as eligible. Four additional articles were included after reading protocols from the initial search where authors of unpublished results were contacted. Thus, 16 RCTs investigating digital SDM interventions within mental health were included in the meta-analysis. The progress of including and excluding articles is shown in the PRISMA flow diagram **Figure 1**.

Study Characteristics

Characteristics of the 16 study populations, aim, duration, comparison treatment, and outcome measures are presented in **Table 1**.

Overall, 2,400 participated in the 16 trials with a mean sample size of 150 ranging from 50 to 507 participants. Mean age for the participants was 40 years (SD = 8.5) ranging from 15 to 51 years. The proportion of females was 49% across all studies ranging from 14 to 100%. The mean duration of the interventions was approximately 3.4 months ranging from 1 day to 12 months. Because of this variation, studies were divided into either short-term intervention (3 months or less) or long-term intervention (more than 3 months): 11 trials were categorized as short-term interventions (15–18, 20–22, 24, 25, 27, 29) and five trials as long-term interventions (23, 26, 28, 30, 31). Seven studies investigated a system accessible through a website (15–18, 20–22), six studies investigated a computer software program (23–26, 29, 31), one study investigated a smartphone application (27), and two studies investigated a tablet application (28, 30). Half of the 16 studies reported using some form of clinician training and that the intervention was used in conjunction with the provider or a peer worker (16, 22–24, 26, 28, 30, 31). Studies that did not actively involve the clinicians mentioned, however, that patients were encouraged to talk with their provider about the intervention. Eleven studies mentioned an inclusion criterion of mental health condition, four

TABLE 1 | Characteristics of the 16 trials.

References, Location	*N*	Mental health condition	Duration	Aim	Comparison treatment	Outcome measure
Steinwach et al. (20), USA	50	Schizophrenia	1 day	A web-based intervention to support patients navigate areas of care supplemented by video clips of actors simulating a patient discussing treatment concerns. Goal was to increase the likelihood that patients will initiate discussion with their therapist	An educational video about schizophrenia treatment	Visit duration; Patient contribution; Reduce amount of clinician talk; Amount of questions asked
Van der Krieke et al. (21), The Netherlands	73	Psychosis	6 weeks	A web-based information and a decision tool aimed to support patients in acquiring an overview of their needs and appropriate treatment options	Treatment as usual	Patient perceived involvement (two subscales): Satisfaction with communication (COMRADE); Confidence in decision (COMRADE); Client Satisfaction Questionnaire (CSQ-8); Satisfaction With the Web-Based Decision Aid
Perestelo et al. (17), Spain	147	Major depressive disorder	1 day	A web-based decision aid aimed to improve users knowledge and promote their active participation in health-care decisions	Treatment as usual	Knowledge about treatment options (authors scale); Decisional conflict (DCS), Treatment intention; Preference for participation in decision making (Control Preference Scale)
Metz et al. (16), The Netherlands	200	Personality, Anxiety or Mood disorder	2 months	A website aimed to support patients in preparing themselves and be more able to actively participate in the dialogue with their clinicians about choices in treatment	Treatment as usual	Decisional Conflict (DCS); Patient participation (PPQ); SDM process (SDM-Q-9); Working alliance (PRDRQ-9); Symptom severity (SQ-48); No-show and Drop out
Moncrieff et al. (22), UK	60	Psychosis, schizophrenia, schizoaffective disorder, delusional disorder or a mood disorder with psychotic symptoms and currently taking antipsychotic medication	3 months	A web-based medication review tool to gain information about psychotic conditions, medication and support people to consider when to discuss and make decisions about medication with professionals	Treatment as usual	Decision Self-Efficacy Scale (DSES); Client Satisfaction Questionnaire (CSQ-8); Drug Attitude Inventory 10 (DAI-10); Liverpool University Neuroleptic Side Effect Rating Scale (LUNSERS); Brief Positive and Negative Syndrome Scale (Brief PANSS); Medication Adherence Questionnaire
Priebe et al. (23), Spain, The Netherlands, Sweden, UK, Germany, Switzerland	507	Schizophrenia or related disorders	12 months	A computer-mediated procedure, DIALOG, to ensure that a range of life domains and treatment aspects were consistently addressed and patients' perspectives always elicited	Treatment as usual	Quality of life (MANSA); Unmet needs (CANSAS); Satisfaction (CSQ-8); Symptoms (PANSS)
Woltmann et al. (24), USA	80	Schizophrenia, schizoaffective, bipolar disoder, major depressive disorder, posttraumatic stress disorder	4 days	An electronic decision support system to support client involvement in goal setting and to assist clients and case managers in engaging in shared decision-making	Treatment as usual	Satisfaction with the care planning process; Knowledge of the care plan; Case manager satisfaction with the care planning process
Manthey (25), USA	110	Schizophrenia, bipolar, or major depression	3 months	An electronic decision support aid to conduct self-assessments of their strengths, identify personal recovery goals, link their strengths to their goals, and identify initial tasks toward goal completion	Treatment as usual	Empowerment (Empowerment scale); Self-Determination Scale (subscales: Awareness of self and perceived choice); Stage of Recovery (SIS-R)

(Continued)

TABLE 1 | Continued

References, Location	*N*	Mental health condition	Duration	Aim	Comparison treatment	Outcome measure
Campbell et al. (26), USA	84	Schizophrenia, bipolar, or major depression	5 months	A computer program, CommonGround, that included videos of consumers who talk about their recovery, answers questions concerning medication usage and decisional uncertainty etc. A report is generated that the patient can bring to his/her consultation to help set the agenda by focusing on the consumer's values and decisional uncertainty	Treatment as usual	Measure of Patient-Centered Communication (MPPC); The Patient Perception of Patient-Centeredness Questionnaire (PPPC) for patient and provider
Edbrooke-Childs et al. (27), UK	62	Unclear – Children and young people from 8 Child mental health services	3 months	A smartphone app, Power up, with the aim to promote patient activation. Used to record questions, plans, decisions, and diary entries and supports young people to identify individuals in their support network	Treatment as usual	The Patient Activation Measure (PAM-MH); (2) CollaboRATE; Shared decision-making Questionnaire (SDM-Q-9); Youth Empowerment Scale—Mental Health; The Strengths and Difficulties Questionnaire; The Experience of Service Questionnaire
Vigod et al. (18), Canada	96	Major depressive episode, Generalized anxiety disorder, Panic disorder, Social anxiety disorder, Obsesssive compulsive disorder, Posttraumatic stress disorder	1 month	A web-based tool aimed to increase knowledge, provide evidence based information on medication, help patient consider how relationships with family, partners, providers etc. may impact their decisions	Online information sheet comprising publicly available information	Decisional Conflict Scale (DCS); Symptoms (depression and anxiety); Knowledge
MacInnes et al. (28), UK	112	Schizophrenia and Schizoaffective disorders and other mental health disorders	6 month	A tablet app to assess and record their satisfaction with life and treatment domains–patient and nurse would together go over relevant domains	Providers were encouraged to meet control patients with the same frequency as intervention and discuss difficulties but without the structured communication approach as in the intervention group	Quality of Life (MANSA); Engagement with Services (HAS); Ward Climate; Patient Satisfaction [Forensic Satisfaction Scale (FSS)]; Recovery [Process of Recovery Questionnaire (QPR)]; Nurse Stress; Disturbed behavior; Satisfaction with intervention; service user perspectives, and experiences of the study
Kravitz (29), USA	391	Depression	3 months	A tailored interactive multimedia computer program providing patients with feedback tailored to symptoms, visit agenda, depression causal attributions, treatment preferences, self-efficacy for communicating with healthcare providers, and depression stigma	A sleep hygiene video	Receiving an antidepressant recommendation or a mental health referral; Patient-physician communication self-efficacy; Whether the patient reported asking the provider for information about depression; Scores on the PHQ-8; SF-12 Version 2.0 Mental Health Component (MCS-12); Physical Health Component Summary Scores (PCS-12)

(Continued)

TABLE 1 | Continued

References, Location	*N*	Mental health condition	Duration	Aim	Comparison treatment	Outcome measure
Priebe (30), UK	179	Psychosis	6 months	A tablet app aimed to provide a way to deal with concerns raised by the patient and equip the clinician and patient with a method to explore and deal with problems	The same app as the intervention, however, it was used at the end of the consultation and used independently rather than collaboratively and without further discussion	Quality of life (MANSA); Unmet needs (CANSAS); Satisfaction (CSQ-8); Self-efficacy (GSE); Mental well-being [Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)]; Symptoms (PANSS); Therapeutic relationship [Scale for Assessing Therapeutic Relationships in Community Mental Health Care (STAR-P And STAR-C)]; Social functioning
Fisher et al. (15), Australia	196	Bipolar II disorder	3 months	A web-based decision-aid to improve treatment decision-making regarding options for relapse prevention in Bipolar disorders	Access to publicly available, evidence-based information on treatment options for bipolar disorder	Symptoms (Bipolar and/or anxiety symptoms); Decisional conflict; Knowledge of treatment options; Feeling prepared for decision making; Decisional regret
Yamaguchi et al. (31), Japan	53	Schizophrenia (70%) and other psychiatric diagnoses	6 months	A computer program with peer support to support shared decision-making. A report is generated that the patient can bring to his/her consultation to help set the agenda by focusing on the consumer's values and decisional uncertainty	Treatment as usual	Shared decision-making (SDM-18); cale To Assess Therapeutic Relationships in Community Mental Health Care (STAR-C and STAR-P); Level of communication with doctor (IPC); Patient activation (PAM); (5) Satisfaction (CSQ); Symptoms (BPRS–Brief Psychiatric Rating Scale); Level of functioning (GAF); Medication side effects (Drug Induced Extra-Pyramidal Symptoms Scale); Adherence to medication (MMAS–Morisky Medication Adherence Scale); Quality of Life–WHO-QOL; Recovery (SISR–Self-Identified Stage of Recovery)

Risk of bias

Study	D1	D2	D3	D4	D5	D6	D7	D8
Steinwach, 2011	-	-	-	X	○	+	+	X
Van der Krieke, 2013	+	+	X	X	X	-	X	+
Perestelo, 2017	+	+	-	X	X	○	-	X
Metz, 2018	+	+	+	X	X	+	+	X
Moncrieff, 2016	+	+	-	X	X	X	-	X
Priebe, 2007	+	+	X	X	X	X	+	X
Woltmann, 2011	-	-	-	X	X	○	X	X
Manthey, 2014	+	-	-	X	X	○	X	X
Campbell, 2014	-	-	+	X	X	-	X	+
Edbrooke-Childs, 2019	+	-	+	X	X	+	X	X
Vigod, 2019	+	+	X	X	X	X	+	+
MacInnes, 2016	+	+	X	X	X	+	X	+
Kravitz, 2015	+	+	+	X	X	+	X	X
Priebe, 2015	+	-	X	X	X	X	X	-
Fisher,2020	+	-	X	X	X	○	X	X
Yamaguchi, 2017	+	+	+	X	X	X	+	X

D1: Random sequence generation
D2: Allocation concealment
D3: Selective reporting
D4: Blinding of participants and personnel
D5: Blinding of outcome assessment (subjective outcome
D6: Blinding of outcome assessment (objective outcomes
D7: Attrition bias
D8: Other sources of bias

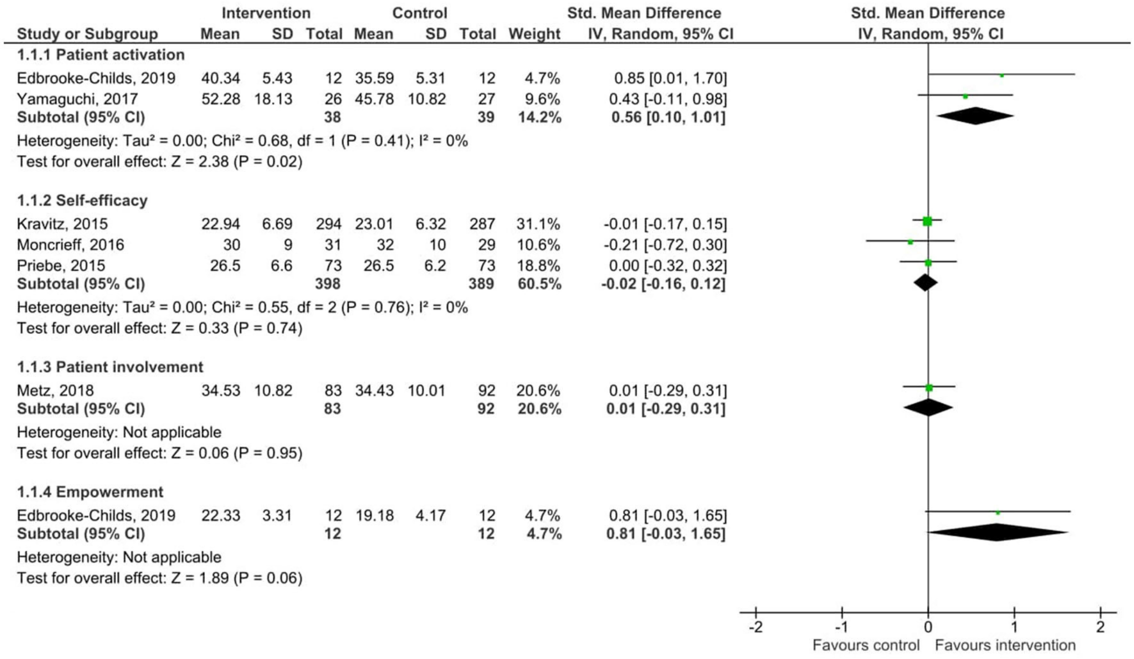
Judgement
X High
- Unclear
+ Low
○ Not applicable

FIGURE 2 | Risk of bias of the 16 trials.

studies mentioned recruiting from mental health services (15, 18, 24, 26), and one study mentioned recruiting from primary care; and a majority of their participants were assessed as depressed by the research team (29). Ten studies recruited exclusively or primarily participants with psychosis, schizophrenia, or related disorder (20–26, 28, 30, 31). Three studies recruited primarily participants with depression or depressive symptoms (17, 18, 29), one study recruited participants with a personality disorder (16), one study focused entirely on bipolar disorder (15), and one study only mentioned that participants were recruited from a mental health setting without specifying the type of mental health condition (27).

Risk of Bias

All included studies were assessed for risk of bias using the Cochrane Collaboration's Risk of Bias tool on the following domains: random sequence generation, allocation concealment, selective reporting, blinding of participants and personnel, blinding of outcome assessments (objective and subjective), attrition bias, and other bias. The risk of bias for each study is presented in **Figure 2** showing that the most frequent risk factor for bias was blinding of participants and blinding of subjective outcome assessment. Furthermore, more than half of the studies were at high risk of bias in terms of attrition bias and other bias.



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
1.1.1 Patient activation								
Edbrooke-Childs, 2019	40.34	5.43	12	35.59	5.31	12	4.7%	0.85 [0.01, 1.70]
Yamaguchi, 2017	52.28	18.13	26	45.78	10.82	27	9.6%	0.43 [-0.11, 0.98]
Subtotal (95% CI)			**38**			**39**	**14.2%**	**0.56 [0.10, 1.01]**
Heterogeneity: Tau² = 0.00; Chi² = 0.68, df = 1 (P = 0.41); I² = 0%								
Test for overall effect: Z = 2.38 (P = 0.02)								
1.1.2 Self-efficacy								
Kravitz, 2015	22.94	6.69	294	23.01	6.32	287	31.1%	-0.01 [-0.17, 0.15]
Moncrieff, 2016	30	9	31	32	10	29	10.6%	-0.21 [-0.72, 0.30]
Priebe, 2015	26.5	6.6	73	26.5	6.2	73	18.8%	0.00 [-0.32, 0.32]
Subtotal (95% CI)			**398**			**389**	**60.5%**	**-0.02 [-0.16, 0.12]**
Heterogeneity: Tau² = 0.00; Chi² = 0.55, df = 2 (P = 0.76); I² = 0%								
Test for overall effect: Z = 0.33 (P = 0.74)								
1.1.3 Patient involvement								
Metz, 2018	34.53	10.82	83	34.43	10.01	92	20.6%	0.01 [-0.29, 0.31]
Subtotal (95% CI)			**83**			**92**	**20.6%**	**0.01 [-0.29, 0.31]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 0.06 (P = 0.95)								
1.1.4 Empowerment								
Edbrooke-Childs, 2019	22.33	3.31	12	19.18	4.17	12	4.7%	0.81 [-0.03, 1.65]
Subtotal (95% CI)			**12**			**12**	**4.7%**	**0.81 [-0.03, 1.65]**
Heterogeneity: Not applicable								
Test for overall effect: Z = 1.89 (P = 0.06)								

FIGURE 3 | Forest plot for patient activation and indices of the same.

Meta-Analysis on the Effects of the Primary Outcomes

Patient Activation or Indices of the Same

Results of the pooled effect size from digital SDM interventions on patient activation, self-efficacy, empowerment, and patient involvement with the individual effect of each intervention are presented in **Figure 3**. The random-effects meta-analysis revealed a moderate significant effect of digital SDM interventions to promote patient activation in comparison with a control group (two studies, $N = 77$, standardized mean difference (SMD) = 0.56, CI: 0.10, 1.01, $p = 0.02$) (27, 31). Variation across trials due to heterogeneity was not present ($\text{Chi}^2 = 0.68$, $p = 0.41$, $I^2 = 0\%$). There was no significant effect on self-efficacy (three studies, $N = 787$, SMD = −0.02 CI: −0.16, 0.12, $p = 0.74$) (22, 29, 30). Variation across trials due to heterogeneity was not present ($\text{Chi}^2 = 0.55$, $p = 0.76$, $I^2 = 0\%$). Meta-analysis on empowerment and patient involvement was not applicable due to only one study respectively reported data on these areas. Still, the results of these single studies are included in **Figure 3**, indicating no significant effect of digital SDM interventions on empowerment (SMD = 0.81, CI: −0.03, 1.65, $p = 0.06$) (27) or patient involvement (SMD = 0.01, CI: −0.29, 0.31, $p = 0.95$) (16). Due to differences between these aspects and the fact that one study measured both activation and empowerment, the total score in **Figure 3** was removed to avoid study participants being counted twice.

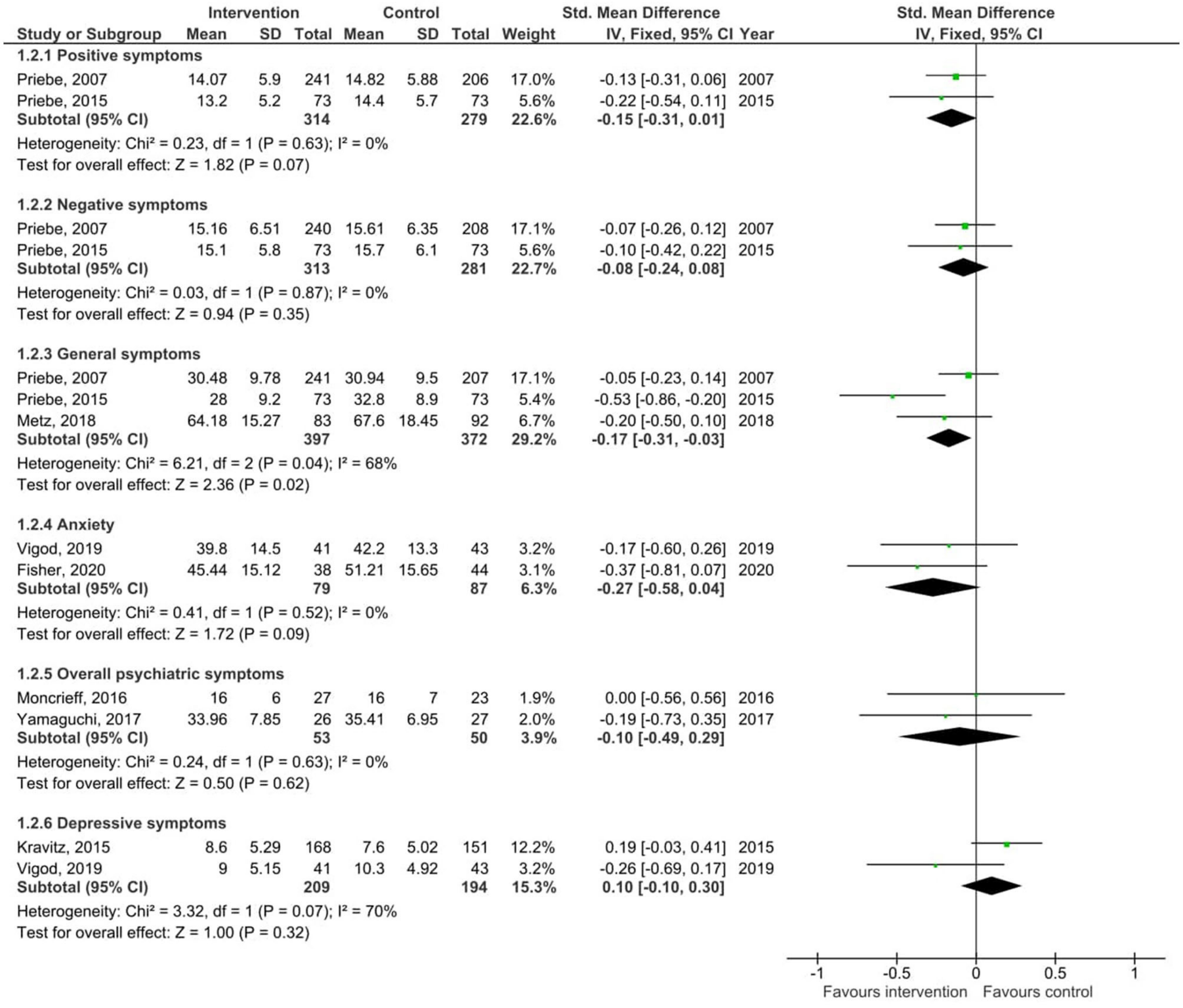
Symptoms

Results of the pooled effect size from digital SDM interventions on symptoms together with the individual effect of each intervention are presented in **Figure 4**. The random-effects meta-analysis revealed a small significant effect of digital SDM interventions to improve general symptoms (three studies, $N = 769$, −0.17, CI: −0.31, −0.03, $p = 0.02$) (16, 23, 30) but revealed no effect on positive (two studies (same research group), N = 593, SMD = −0.15, CI: −0.31, 0.01, $p = 0.07$) (23, 30), negative symptoms [two studies (same research group), $N = 594$, SMD = −0.08, CI: −0.24, 0.08, $p = 0.35$] (23, 30), overall psychiatric symptoms (two studies, $N = 103$, SMD = −0.10, CI: −0.49, 0.29, $p = 0.62$) (22, 31), depressive symptoms (two studies, $N = 403$, SMD = 0.10, CI: −0.10, 0.30, $p = 0.32$) (18, 29), or anxiety (two studies, $N = 166$, SMD = −0.27, CI: −0.58, 0.04, $p = 0.09$) (15, 18). Due to differences between the types of symptoms and that studies appeared more than once, the total score in **Figure 4** was removed to avoid study participants being counted twice.

Variation across trials due to heterogeneity was not present for positive symptoms ($\text{Chi}^2 = 0.23$, $p = 0.63$, $I^2 = 0\%$), negative symptoms ($\text{Chi}^2 = 0.03$, $p = 0.87$, $I^2 = 0\%$), overall psychiatric symptoms ($\text{Chi}^2 = 0.24, p = 0.63, I^2 = 0\%$), or anxiety ($\text{Chi}^2 = 0.41$, $p = 0.52$, $I^2 = 0\%$) but was present for general symptoms ($\text{Chi}^2 = 6.21$, $p = 0.04$, $I^2 = 68\%$) and depressive symptoms ($\text{Chi}^2 = 3.32$, $p = 0.07$, $I^2 = 70\%$). Egger's test was not performed due to the small sample of studies.

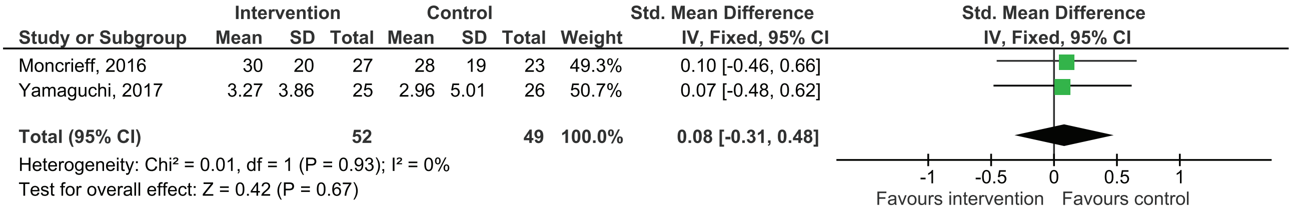
Adverse Events

Results of the pooled effect size from digital SDM interventions on adverse events defined as harms or side effects together with the individual effect of each intervention are presented in **Figure 5**. Only measurements of side effects of medication were



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Fixed, 95% CI	Year
1.2.1 Positive symptoms									
Priebe, 2007	14.07	5.9	241	14.82	5.88	206	17.0%	-0.13 [-0.31, 0.06]	2007
Priebe, 2015	13.2	5.2	73	14.4	5.7	73	5.6%	-0.22 [-0.54, 0.11]	2015
Subtotal (95% CI)			**314**			**279**	**22.6%**	**-0.15 [-0.31, 0.01]**	
Heterogeneity: Chi² = 0.23, df = 1 (P = 0.63); I² = 0%									
Test for overall effect: Z = 1.82 (P = 0.07)									
1.2.2 Negative symptoms									
Priebe, 2007	15.16	6.51	240	15.61	6.35	208	17.1%	-0.07 [-0.26, 0.12]	2007
Priebe, 2015	15.1	5.8	73	15.7	6.1	73	5.6%	-0.10 [-0.42, 0.22]	2015
Subtotal (95% CI)			**313**			**281**	**22.7%**	**-0.08 [-0.24, 0.08]**	
Heterogeneity: Chi² = 0.03, df = 1 (P = 0.87); I² = 0%									
Test for overall effect: Z = 0.94 (P = 0.35)									
1.2.3 General symptoms									
Priebe, 2007	30.48	9.78	241	30.94	9.5	207	17.1%	-0.05 [-0.23, 0.14]	2007
Priebe, 2015	28	9.2	73	32.8	8.9	73	5.4%	-0.53 [-0.86, -0.20]	2015
Metz, 2018	64.18	15.27	83	67.6	18.45	92	6.7%	-0.20 [-0.50, 0.10]	2018
Subtotal (95% CI)			**397**			**372**	**29.2%**	**-0.17 [-0.31, -0.03]**	
Heterogeneity: Chi² = 6.21, df = 2 (P = 0.04); I² = 68%									
Test for overall effect: Z = 2.36 (P = 0.02)									
1.2.4 Anxiety									
Vigod, 2019	39.8	14.5	41	42.2	13.3	43	3.2%	-0.17 [-0.60, 0.26]	2019
Fisher, 2020	45.44	15.12	38	51.21	15.65	44	3.1%	-0.37 [-0.81, 0.07]	2020
Subtotal (95% CI)			**79**			**87**	**6.3%**	**-0.27 [-0.58, 0.04]**	
Heterogeneity: Chi² = 0.41, df = 1 (P = 0.52); I² = 0%									
Test for overall effect: Z = 1.72 (P = 0.09)									
1.2.5 Overall psychiatric symptoms									
Moncrieff, 2016	16	6	27	16	7	23	1.9%	0.00 [-0.56, 0.56]	2016
Yamaguchi, 2017	33.96	7.85	26	35.41	6.95	27	2.0%	-0.19 [-0.73, 0.35]	2017
Subtotal (95% CI)			**53**			**50**	**3.9%**	**-0.10 [-0.49, 0.29]**	
Heterogeneity: Chi² = 0.24, df = 1 (P = 0.63); I² = 0%									
Test for overall effect: Z = 0.50 (P = 0.62)									
1.2.6 Depressive symptoms									
Kravitz, 2015	8.6	5.29	168	7.6	5.02	151	12.2%	0.19 [-0.03, 0.41]	2015
Vigod, 2019	9	5.15	41	10.3	4.92	43	3.2%	-0.26 [-0.69, 0.17]	2019
Subtotal (95% CI)			**209**			**194**	**15.3%**	**0.10 [-0.10, 0.30]**	
Heterogeneity: Chi² = 3.32, df = 1 (P = 0.07); I² = 70%									
Test for overall effect: Z = 1.00 (P = 0.32)									

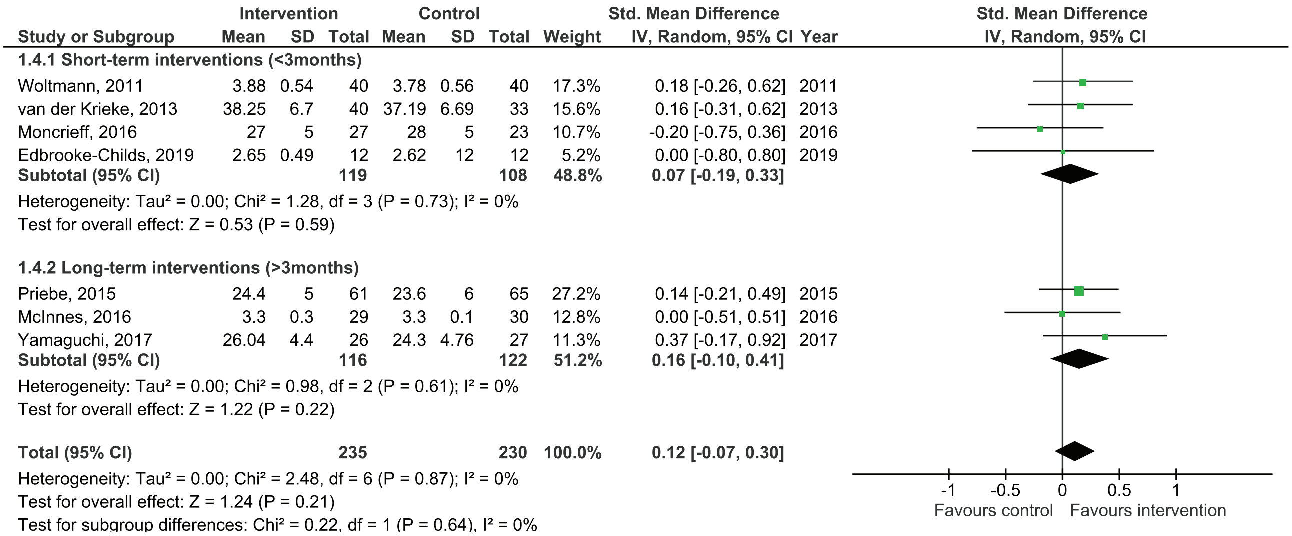
FIGURE 4 | Forest plots for symptoms.



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Moncrieff, 2016	30	20	27	28	19	23	49.3%	0.10 [-0.46, 0.66]
Yamaguchi, 2017	3.27	3.86	25	2.96	5.01	26	50.7%	0.07 [-0.48, 0.62]
Total (95% CI)			**52**			**49**	**100.0%**	**0.08 [-0.31, 0.48]**
Heterogeneity: Chi² = 0.01, df = 1 (P = 0.93); I² = 0%								
Test for overall effect: Z = 0.42 (P = 0.67)								

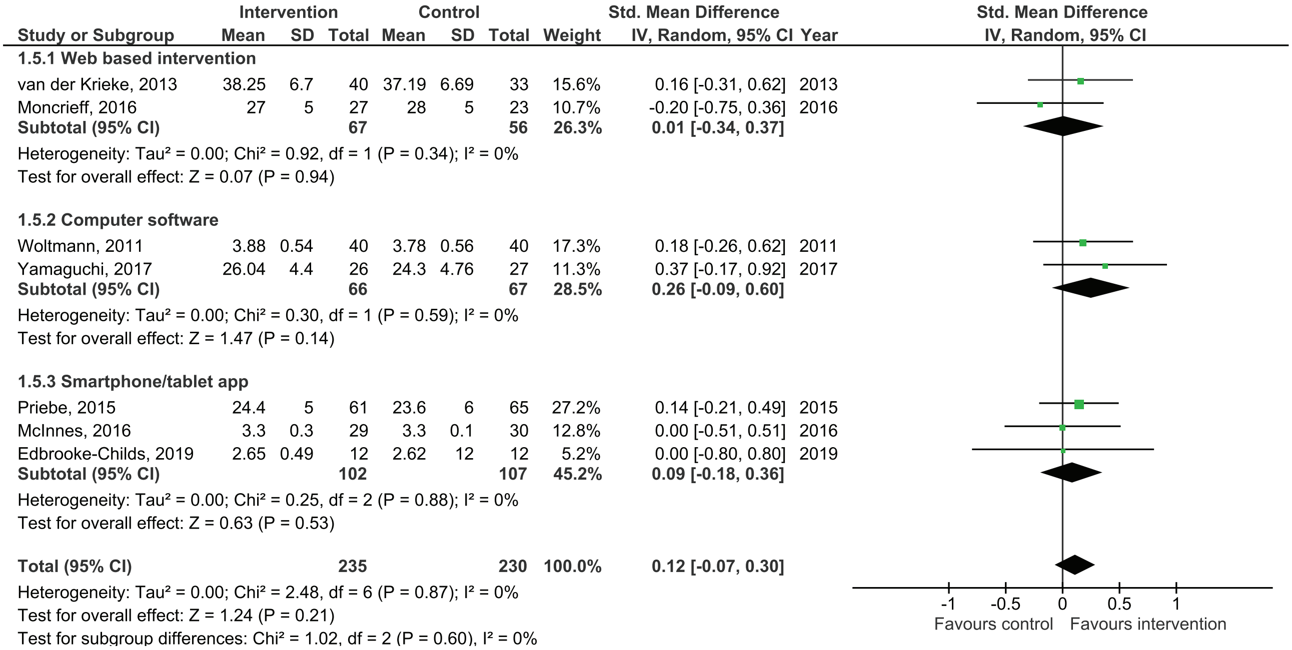
FIGURE 5 | Forest plot for adverse events defined as harms or side effects.

identified from the studies. The random-effects meta-analysis revealed no significant effect of digital SDM interventions to improve side effects induced by medication (two studies, $N = 102$, SMD = 0.08, CI: −0.31, 0.48, $p = 0.67$) (22, 31). Variation across trials due to heterogeneity was not present ($\text{Chi}^2 = 0.01$, $p = 0.93$, $I^2 = 0\%$). Subgroup analysis for the primary outcomes showed no significant differences, which are included in the **Supplementary Materials 3–8).**



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI	Year
1.4.1 Short-term interventions (<3months)									
Woltmann, 2011	3.88	0.54	40	3.78	0.56	40	17.3%	0.18 [-0.26, 0.62]	2011
van der Krieke, 2013	38.25	6.7	40	37.19	6.69	33	15.6%	0.16 [-0.31, 0.62]	2013
Moncrieff, 2016	27	5	27	28	5	23	10.7%	-0.20 [-0.75, 0.36]	2016
Edbrooke-Childs, 2019	2.65	0.49	12	2.62	12	12	5.2%	0.00 [-0.80, 0.80]	2019
Subtotal (95% CI)			**119**			**108**	**48.8%**	**0.07 [-0.19, 0.33]**	
Heterogeneity: Tau² = 0.00; Chi² = 1.28, df = 3 (P = 0.73); I² = 0%									
Test for overall effect: Z = 0.53 (P = 0.59)									
1.4.2 Long-term interventions (>3months)									
Priebe, 2015	24.4	5	61	23.6	6	65	27.2%	0.14 [-0.21, 0.49]	2015
McInnes, 2016	3.3	0.3	29	3.3	0.1	30	12.8%	0.00 [-0.51, 0.51]	2016
Yamaguchi, 2017	26.04	4.4	26	24.3	4.76	27	11.3%	0.37 [-0.17, 0.92]	2017
Subtotal (95% CI)			**116**			**122**	**51.2%**	**0.16 [-0.10, 0.41]**	
Heterogeneity: Tau² = 0.00; Chi² = 0.98, df = 2 (P = 0.61); I² = 0%									
Test for overall effect: Z = 1.22 (P = 0.22)									
Total (95% CI)			**235**			**230**	**100.0%**	**0.12 [-0.07, 0.30]**	
Heterogeneity: Tau² = 0.00; Chi² = 2.48, df = 6 (P = 0.87); I² = 0%									
Test for overall effect: Z = 1.24 (P = 0.21)									
Test for subgroup differences: Chi² = 0.22, df = 1 (P = 0.64), I² = 0%									

FIGURE 6 | Forest plot for patient satisfaction by duration.



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI	Year
1.5.1 Web based intervention									
van der Krieke, 2013	38.25	6.7	40	37.19	6.69	33	15.6%	0.16 [-0.31, 0.62]	2013
Moncrieff, 2016	27	5	27	28	5	23	10.7%	-0.20 [-0.75, 0.36]	2016
Subtotal (95% CI)			**67**			**56**	**26.3%**	**0.01 [-0.34, 0.37]**	
Heterogeneity: Tau² = 0.00; Chi² = 0.92, df = 1 (P = 0.34); I² = 0%									
Test for overall effect: Z = 0.07 (P = 0.94)									
1.5.2 Computer software									
Woltmann, 2011	3.88	0.54	40	3.78	0.56	40	17.3%	0.18 [-0.26, 0.62]	2011
Yamaguchi, 2017	26.04	4.4	26	24.3	4.76	27	11.3%	0.37 [-0.17, 0.92]	2017
Subtotal (95% CI)			**66**			**67**	**28.5%**	**0.26 [-0.09, 0.60]**	
Heterogeneity: Tau² = 0.00; Chi² = 0.30, df = 1 (P = 0.59); I² = 0%									
Test for overall effect: Z = 1.47 (P = 0.14)									
1.5.3 Smartphone/tablet app									
Priebe, 2015	24.4	5	61	23.6	6	65	27.2%	0.14 [-0.21, 0.49]	2015
McInnes, 2016	3.3	0.3	29	3.3	0.1	30	12.8%	0.00 [-0.51, 0.51]	2016
Edbrooke-Childs, 2019	2.65	0.49	12	2.62	12	12	5.2%	0.00 [-0.80, 0.80]	2019
Subtotal (95% CI)			**102**			**107**	**45.2%**	**0.09 [-0.18, 0.36]**	
Heterogeneity: Tau² = 0.00; Chi² = 0.25, df = 2 (P = 0.88); I² = 0%									
Test for overall effect: Z = 0.63 (P = 0.53)									
Total (95% CI)			**235**			**230**	**100.0%**	**0.12 [-0.07, 0.30]**	
Heterogeneity: Tau² = 0.00; Chi² = 2.48, df = 6 (P = 0.87); I² = 0%									
Test for overall effect: Z = 1.24 (P = 0.21)									
Test for subgroup differences: Chi² = 1.02, df = 2 (P = 0.60), I² = 0%									

FIGURE 7 | Forest plot for patient satisfaction by type of intervention.

Meta-Analysis on the Effects of the Secondary Outcomes

Results of the pooled effect size from digital SDM interventions on the secondary outcomes are presented in **Figures 6–12**. The random-effects meta-analysis revealed a small positive effect of digital SDM interventions for improving working alliance (four studies, $N = 423$, SMD = 0.21, CI: 0.02, 0.41, $p = 0.03$) (16, 28, 30, 31), a small-to-moderate positive effect for improving decisional conflict (four studies, $N = 550$, SMD = −0.37, CI: −0.70, −0.05, $p = 0.02$) (15–18), and no significant effect on patient satisfaction (seven studies, $N = 465$, SMD = 0.12, CI: −0.07, 0.30, $p = 0.21$) (21, 22, 24, 27, 28, 30, 31). Variation across trials due to heterogeneity was present for decisional conflict ($\text{Chi}^2 = 10.69$, $p = 0.01$, $I^2 = 72\%$) but not for satisfaction ($\text{Chi}^2 = 2.48$, $p = 0.87$, $I^2 = 0\%$) and working alliance ($\text{Chi}^2 = 2.96$, $p = 0.04$, $I^2 = 0\%$). Assessment of publication bias was only performed for

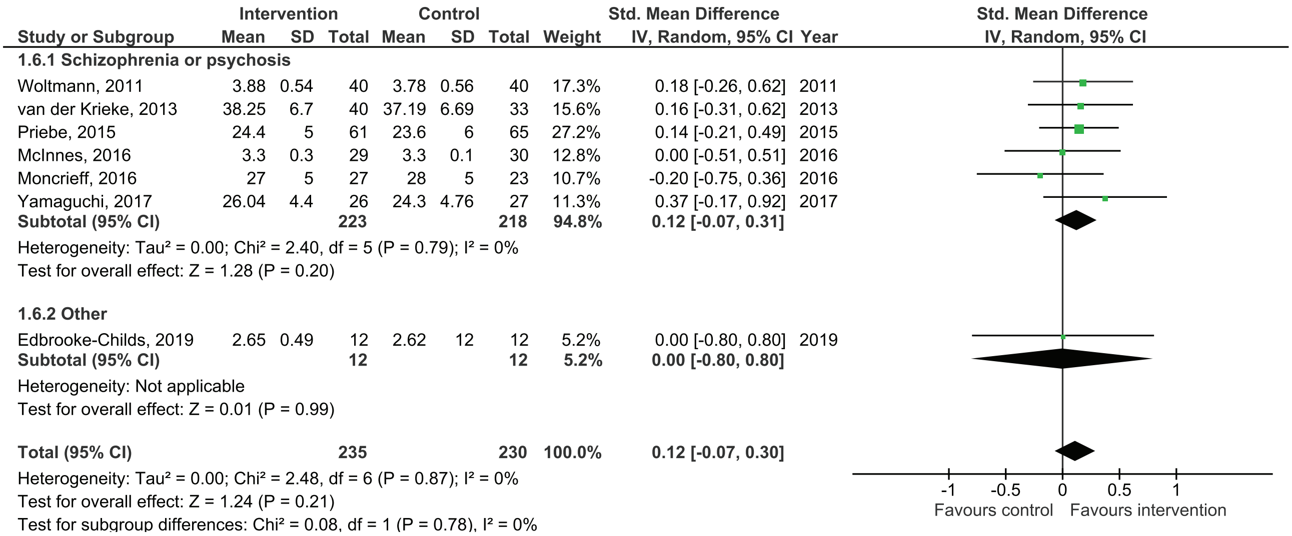


FIGURE 8 | Forest plot for patient satisfaction by diagnosis.

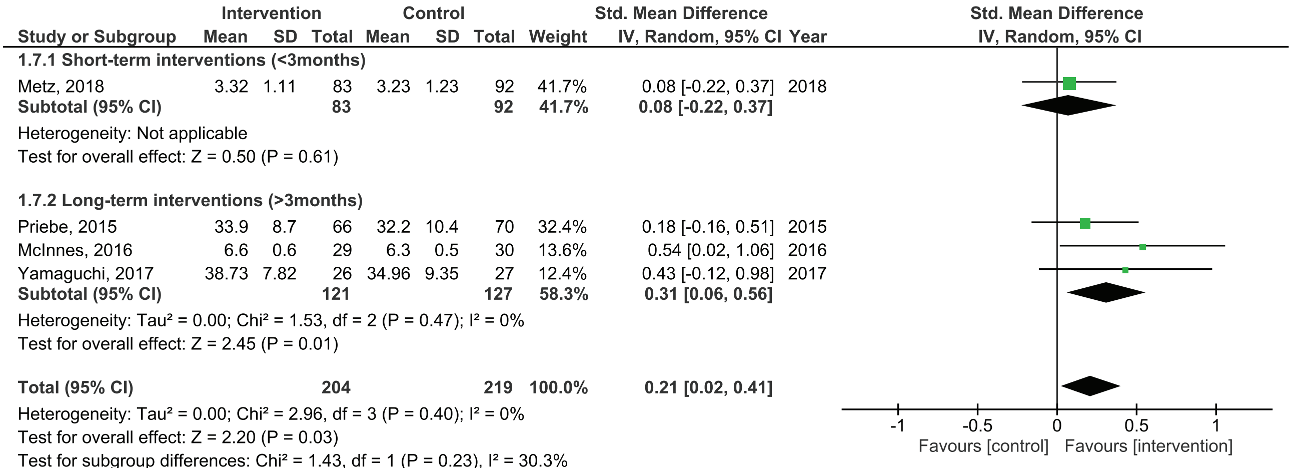


FIGURE 9 | Forest plot for working alliance by duration perceived by the patient.

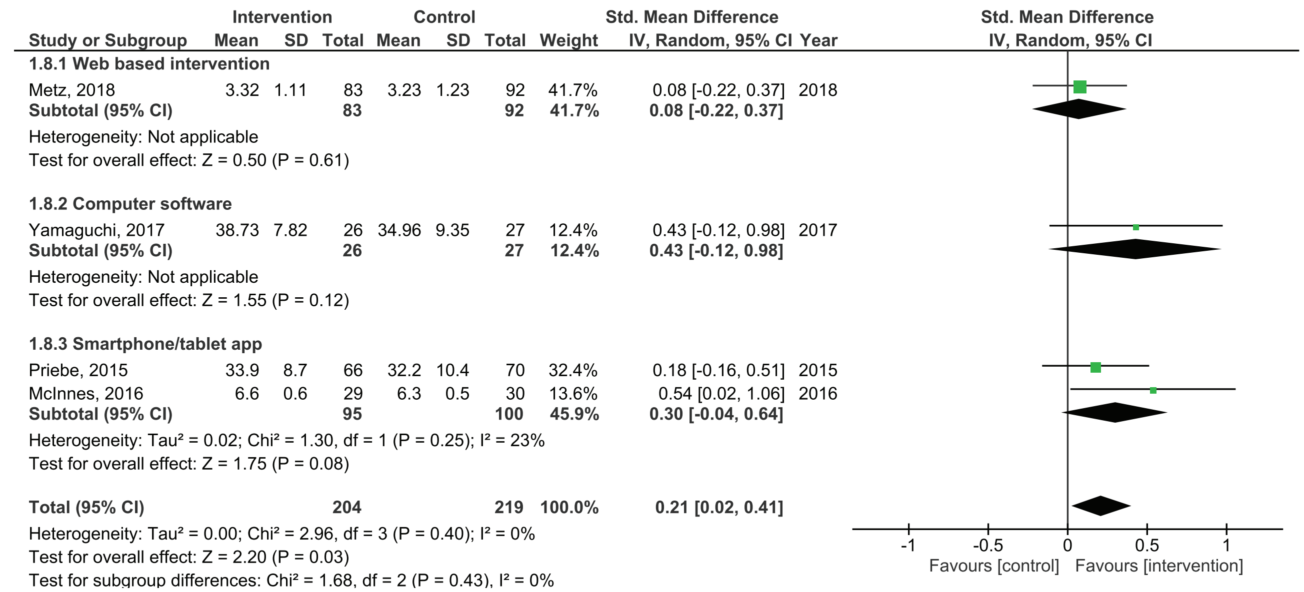
patient satisfaction due to the limited amount of studies for each pooled outcome. Via visual inspection of funnel plots, we did not assess any publication bias for patient satisfaction. Subgroup analysis on satisfaction by duration, type of intervention, and diagnosis showed no statistical significant differences between groups (**Figures 6–8**). Subgroup analysis on working alliance by duration, type of intervention, and diagnosis showed no statistical significant differences between groups (**Figures 9–11**). Subgroup analysis on decisional conflict by diagnosis showed a tendency for a greater effect for populations with symptoms of depression than other types of symptoms (two studies, $N = 232$, SMD $= -0.61$ CI: -0.94, -0.28, $p = 0.0003$; **Figure 12**). Subgroup analysis on decisional conflict by duration and type of intervention was not performed due to all studies being in the same subgroup.

Assessment of Quality

The outcomes had a GRADE rating of very low quality for patient activation and low quality for self-efficacy, adverse events, symptoms, working alliance, decisional conflict, and patient satisfaction. This implies that we have little confidence in the estimates of effect for these outcomes.

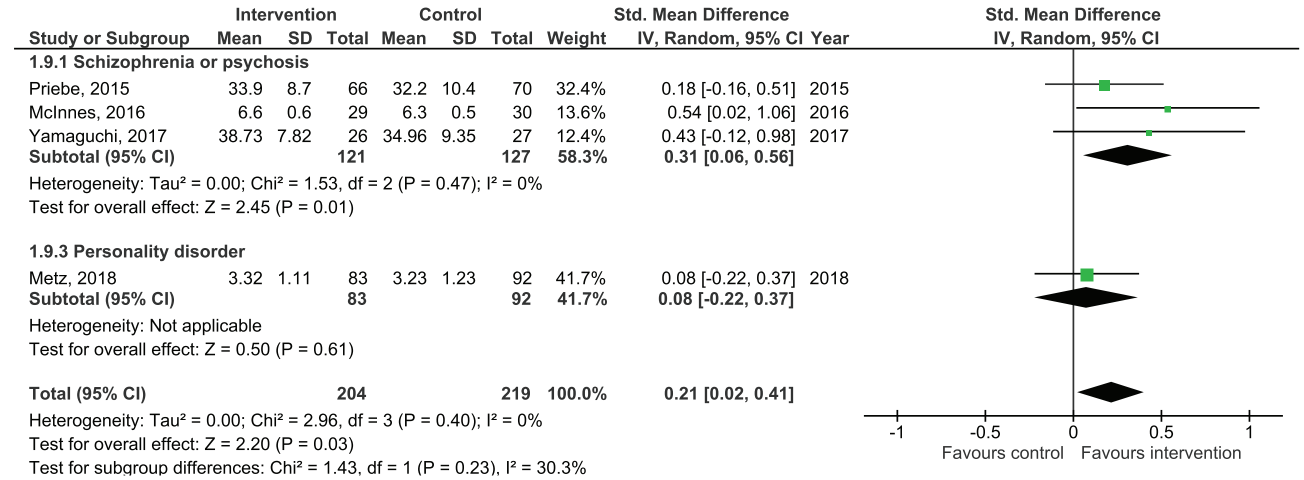
Narrative Synthesis of Intervention Effects

Table 2 presents the results of the narrative synthesis of 39 outcomes. The results on these outcomes were mixed between showing no difference between the groups and favoring the intervention group. None of the studies found effects favoring the control group.



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI	Year
1.8.1 Web based intervention									
Metz, 2018	3.32	1.11	83	3.23	1.23	92	41.7%	0.08 [-0.22, 0.37]	2018
Subtotal (95% CI)			**83**			**92**	**41.7%**	**0.08 [-0.22, 0.37]**	
Heterogeneity: Not applicable									
Test for overall effect: Z = 0.50 (P = 0.61)									
1.8.2 Computer software									
Yamaguchi, 2017	38.73	7.82	26	34.96	9.35	27	12.4%	0.43 [-0.12, 0.98]	2017
Subtotal (95% CI)			**26**			**27**	**12.4%**	**0.43 [-0.12, 0.98]**	
Heterogeneity: Not applicable									
Test for overall effect: Z = 1.55 (P = 0.12)									
1.8.3 Smartphone/tablet app									
Priebe, 2015	33.9	8.7	66	32.2	10.4	70	32.4%	0.18 [-0.16, 0.51]	2015
McInnes, 2016	6.6	0.6	29	6.3	0.5	30	13.6%	0.54 [0.02, 1.06]	2016
Subtotal (95% CI)			**95**			**100**	**45.9%**	**0.30 [-0.04, 0.64]**	
Heterogeneity: Tau² = 0.02; Chi² = 1.30, df = 1 (P = 0.25); I² = 23%									
Test for overall effect: Z = 1.75 (P = 0.08)									
Total (95% CI)			**204**			**219**	**100.0%**	**0.21 [0.02, 0.41]**	
Heterogeneity: Tau² = 0.00; Chi² = 2.96, df = 3 (P = 0.40); I² = 0%									
Test for overall effect: Z = 2.20 (P = 0.03)									
Test for subgroup differences: Chi² = 1.68, df = 2 (P = 0.43), I² = 0%									

FIGURE 10 | Forest plot for working alliance by type of intervention perceived by the patient.



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI	Year
1.9.1 Schizophrenia or psychosis									
Priebe, 2015	33.9	8.7	66	32.2	10.4	70	32.4%	0.18 [-0.16, 0.51]	2015
McInnes, 2016	6.6	0.6	29	6.3	0.5	30	13.6%	0.54 [0.02, 1.06]	2016
Yamaguchi, 2017	38.73	7.82	26	34.96	9.35	27	12.4%	0.43 [-0.12, 0.98]	2017
Subtotal (95% CI)			**121**			**127**	**58.3%**	**0.31 [0.06, 0.56]**	
Heterogeneity: Tau² = 0.00; Chi² = 1.53, df = 2 (P = 0.47); I² = 0%									
Test for overall effect: Z = 2.45 (P = 0.01)									
1.9.3 Personality disorder									
Metz, 2018	3.32	1.11	83	3.23	1.23	92	41.7%	0.08 [-0.22, 0.37]	2018
Subtotal (95% CI)			**83**			**92**	**41.7%**	**0.08 [-0.22, 0.37]**	
Heterogeneity: Not applicable									
Test for overall effect: Z = 0.50 (P = 0.61)									
Total (95% CI)			**204**			**219**	**100.0%**	**0.21 [0.02, 0.41]**	
Heterogeneity: Tau² = 0.00; Chi² = 2.96, df = 3 (P = 0.40); I² = 0%									
Test for overall effect: Z = 2.20 (P = 0.03)									
Test for subgroup differences: Chi² = 1.43, df = 1 (P = 0.23), I² = 30.3%									

FIGURE 11 | Forest plot for working alliance by diagnosis perceived by the patient.

DISCUSSION

Our review on the effectiveness of digital SDM interventions in mental healthcare included 2,400 participants across 16 RCTs examining digital interventions to support SDM with the majority conducted on psychosis, schizophrenia, or similar disorders.

The main analysis found that digital SDM interventions led to a moderate significant effect on improving patient activation in mental healthcare but not on self-efficacy, empowerment, or subjective level of patient involvement. Such result could be that digital SDM tools are more effective at addressing the concepts of patient activation. However, only two small sampled studies investigated the effectiveness on patient activation, three studies on self-efficacy, and one study each on empowerment and patient-involvement. Therefore, more quality research on the effectiveness of SDM interventions on patient activation or indices of the same are greatly needed to investigate this further.

As for symptoms, the use of a digital SDM intervention had a significant effect on general symptoms but not on positive, negative, anxiety, depressive, or overall psychiatric symptoms. Still, subgroup analysis showed no differences between types of symptoms, and with the GRADE level of the symptom outcomes, more research is needed to assess the effects of digital SDM tools on severity of symptoms.

We identified two trials that included an outcome of adverse events showing no significant differences between groups. In addition, none of the studies investigated potential negative

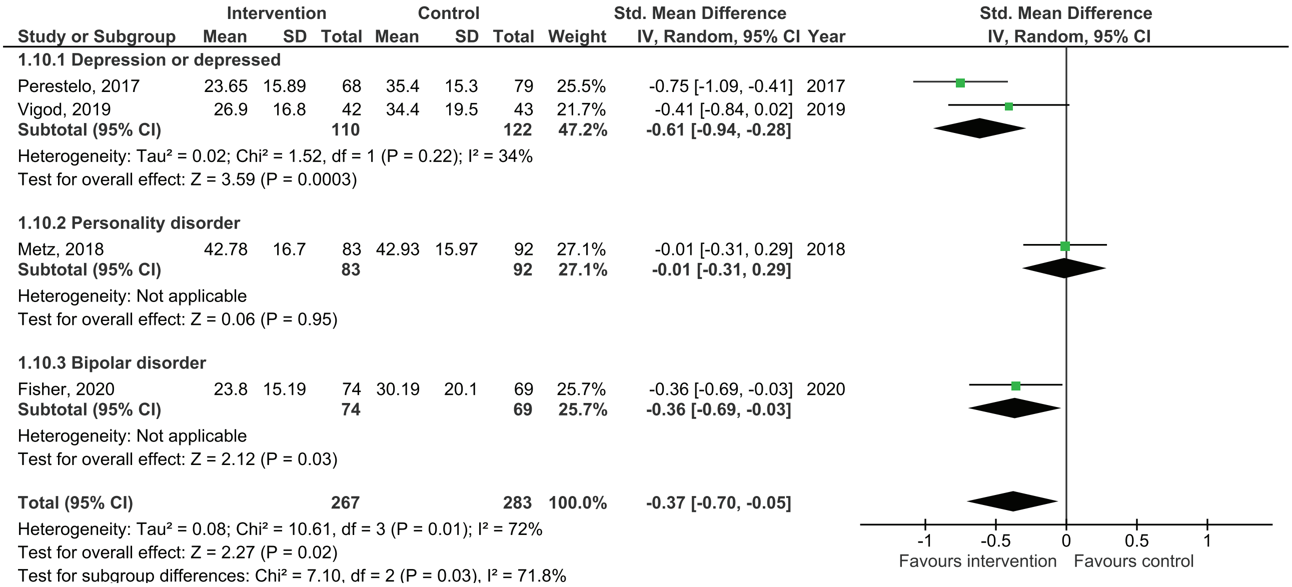


FIGURE 12 | Forest plot for decisional conflict by diagnosis.

effects of using the digital intervention. The current evidence on the effectiveness of digital interventions on adverse events is scarce, which also has been highlighted by other systematic reviews (32). While there are many positive possibilities with digital health technology, it is essential to also examine the potential negative effects of these tools especially with the continuous and rapid development of IT.

For the secondary outcomes, a small significant effect was found for working alliance and decisional conflict. The most frequent outcome measured by the 16 trials, patient satisfaction, revealed no significant effect; but authors of the included trials indicates that "instruments focusing on satisfaction might suffer from ceiling effects" (21). As previous reviews have reported mixed results on patient satisfaction (9, 33) with it being advocated as an argument for implementing SDM (4), future trials may wish to consider their choice of measurement for patient satisfaction and pilot test to identify a potential ceiling effect. Lastly, the narrative synthesis indicates a broad range of outcomes that digital SDM interventions may have an effect on, such as knowledge, unmet needs, and the level of SDM.

The significant effect on patient activation, working alliance, and decisional conflict may indicate that SDM benefits the collaboration between patient and provider. Future research may wish to investigate whether SDM is directly associated with an effect on health outcomes or if the collaboration serves as a mediator for health outcomes (e.g., severity of symptoms).

The fact that the most frequent outcome measures in this review were assessed by half of the trials and that only two trials measured our planned primary outcome, patient activation, highlights the vast differences in how trials evaluate their SDM interventions. Furthermore, although all included interventions support SDM, only three studies directly measured the level of SDM (16, 27, 31). According to our protocol, we had also planned to conduct meta-analyses on other outcomes (i.e., adherence to treatment, hospital admissions, level of functioning, and adherence/usage of medicine) (11). These analyses were, however, not possible due to either lack of studies assessing the outcome or outcomes not being compatible for meta-analysis. These outcomes were instead included in the narrative synthesis. The vast differences in how studies evaluate their SDM intervention create a limitation for reviews and meta-analysis since the combined data for each specific outcome are scarce.

Although all included studies investigated an intervention to support SDM, none of the included studies addressed all aspects of SDM, and only three studies included a measurement to assess the overall level of SDM. This may highlight a challenge in how to measure and evaluate the effect on SDM. The included trials in this review could be divided into two groups of systems: (1) a system developed to be used independently of the involvement of a provider or (2) a system developed to be incorporated into the collaboration with the provider. A system to support the patient could be a tool aimed at improving the patient's knowledge on needs, values, options, and the feeling of being prepared for the consultation. A system to support the consultation could be a tool aimed to ensure that a range of life domains and treatment aspects were consistently and structurally addressed and that patients' perspectives were always elicited at the consultation. For interventions not actively including the provider, patients were still encouraged to use the tool in collaboration with their provider (e.g., sharing one's self-assessments or showing one's notes). However, a challenge occurs when either the patient or provider is not actively included: the responsibility of incorporating and using the tool in the consultation is no longer shared and is instead solely placed on either the patient or provider—a responsibility that may be overwhelming for some. Also, as reported by one of the studies "A one-off intervention

TABLE 2 | Results of the narrative synthesis of 39 outcomes.

Outcomes	Number of trials favoring intervention group	Number of trials showing no difference between groups	Number of trials favoring control group
Objectively reported			
Visit duration	1 (14)		
Patient contribution	1 (14)		
Reduce amount of clinician talk	1 (14)		
Amount of questions asked	1 (14)		
Patient-Centered Communication		1 (29)	
Receiving an antidepressant recommendation or mental health referral	1 (25)		
Did patient ask provider for information	1 (25)		
Social functioning		1 (28)	
Weight		1 (26)	
Level of functioning		1 (26)	
Subjectively reported			
Patient perceived involvement		1 (18)	
Knowledge	1 (15, 16, 27)	1 (17)	
Preference for participation in decision making		1 (15)	
Attitude toward medication	1 (24)		
Unmet needs	2 (28, 30)		
Provider satisfaction	1 (16)		
Empowerment (not compatible with review manager)		1 (21)	
Self-Determination		1 (21)	
Recovery	1 (21)	2 (26, 31)	
Patient-Centered communication perceived by patient		1 (29)	
Patient-Centered communication perceived by provider		1 (29)	
Level of shared decision-making	2 (20, 26)	1 (22)	
Strengths and difficulties		1 (22)	
Quality of life	1 (30)	3 (26, 28, 31)	
Level of burnout (provider)		1 (31)	
Institution's social atmosphere		1 (31)	
Overall mental well-being		2 (25, 28)	
Overall physical well-being		1 (25)	
Working alliance (provider perspective)	1 (26)	1 (28)	
Understanding of treatment options	1 (27)		
Feeling prepared for decision making	1 (27)		
Decisional regret	1 (27)		
Quality of communication with provider	1 (26)		
Medication adherence	1 (24)	1 (26)	
Treatment intention	1 (15)		
Treatment adherence (no-show, drop-out)		1 (20)	
Satisfaction (not compatible with review manager)	1 (30)	1 (16)	
Disturbed behavior	1 (31)		
Anxiety (Trait)		1 (17)	

While we planned to perform meta-analyses on adherence to treatment and hospital admissions, these analyses were not applicable since <2 trials reported data on these aspects. Analysis on level of functioning was not performed due to the scales not being comparable. Analysis on adherence/usage of medicine was not performed due to only two studies reporting this area with one of the studies reporting data not compatible with review manager. The outcomes were therefore included in the narrative synthesis.

[…] may be insufficient to improve patient involvement in decision-making" (22), indicating that tools to support patients may be helpful but insufficient on their own. Similarly, SDM on its own has shown to be difficult to incorporate into clinical practice due to its complexity and vagueness on how to translate its theoretical model into practice. Therefore, research has called for diverse ways in which SDM principles can be translated into practice such as decision aids (33).

With the vast differences in how researchers are developing tools to support SDM, quality guidance to develop and to assess these tools are needed. Such assessment is possible for, e.g., patient decision aids where International Patient Decision

Aid Standards (IPDAS) may be used to assess the quality of the tool (18). In this review, five studies defined their intervention as a decision aid, but only one study mentioned having developed their intervention based on IPDAS guidelines. Since decision aids are not the only mean to support SDM, similar assessment tools could assist in providing clarity on the similarities between tools to support SDM and their level of quality. In addition, future trials investigating the effect of a digital SDM intervention are encouraged to consider including a measurement of adherence/usage of the tool and have their participants evaluate the tool. Reporting an observed effect of a tool in combination with data on how the tool was used will assist future trials and stakeholders to determine whether an effect is dependent on a certain level of usage or acceptance or if the participants found the tool meaningful. While digital interventions may be able to address some of the barriers associated with SDM, it is also important to consider what barriers are introduced with a digital intervention. Traditional barriers for digital interventions may be privacy and data security concerns, but there is also a need for more evidence on how digital interventions may be influenced by variables such as user engagement, data-driven feedback, or individual expectations and characteristics (34).

A majority of the included trials investigated either a web-based intervention or a computer software, while only three studies investigated a smartphone or tablet application. This limited the possibilities to assess the effectiveness of a digital intervention depending on its features or system category (e.g., web-based, computer software, and smartphone app). To determine what digital features are the most effective at supporting SDM, more research investigating different types of features is needed.

Strengths and Limitations

Our review has several strengths. Firstly, it provides evidence regarding the effectiveness of digital SDM interventions, which has not been conducted before. Secondly, this meta-analysis strictly follows the registered protocol describing our search strategy, types of studies to be included, data extraction, and targeted outcome measures (11). The only change was the inclusion of one extra secondary outcome, which was done due to several studies assessing this outcome (decisional conflict). A limitation to the study was our inclusion criteria on SDM. The complexness of SDM creates several ways to support SDM, which may cause high heterogeneity between studies. Because of the broad definition of SDM, many of the included trials share similarities while also differing from one another. Subgroup analysis on what components of SDM were used could be highly relevant to identify what aspect of SDM is providing the largest effectiveness. However, such subgroup analysis may be difficult without a clear definition of the SDM process and necessitates that studies clearly describe how their intervention supports SDM. Our study was also limited by not acquiring unpublished literature and assessing publication bias for only one outcome due to the limited amount of studies reporting the same outcomes.

CONCLUSIONS

Digital interventions to support SDM may be a promising tool in mental healthcare. The complexness of SDM and possibilities with digital tools create many possibilities for researchers as showcased in this review. It is still unclear which features of digital tools are most effective at supporting the SDM process. More quality research is needed to further assess the effectiveness of digital means to support SDM but also to determine which intervention features are most effective in supporting SDM.

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses/restrictions: Most data from the included trials can be found online. For some trials, we had to contact the corresponding author to receive the data for analysis. Requests to access these datasets should be directed to tobias.vitger@regionh.dk (I am happy to put you in contact with those authors who delivered raw data).

AUTHOR CONTRIBUTIONS

TV, CH, and LK designed the search strategy and the study protocol. TV and CH screened the identified studies against inclusion/exclusion criteria to determine eligibility for selection. TV performed the data analysis under supervision of CH and wrote the first draft of the manuscript. CH, LK, MN, SA, and LP all critically revised the manuscript. All authors approved the final version of the manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2021.691251/full#supplementary-material

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Shared Decision Making With Young People at Ultra High Risk of Psychotic Disorder

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Introduction: While the majority of young people who meet the criteria for being considered at increased risk of psychosis do not go on to develop a psychotic disorder, young people are currently being identified and treated in early intervention services. Ethical concerns have been raised concerning the decision about whether or not to provide treatment, and if so, what type of treatment. This study sought to support young people themselves to make these decisions with support from their clinician through a shared decision-making approach, facilitated by an online decision aid.

Methods: This project used the International Patient Decision Aid Standards (IPDAS) to guide the development and piloting of an online decision aid across two phases: (1) qualitative, semi-structured focus groups with young people who were past clients and clinicians from an early psychosis service; and (2) pilot testing of the decision aid with clinicians and young people who were current clients to finalize the development.

Results: Issues discussed by clinicians in the focus group were grouped into three main areas: (1) engagement phase; (2) assessment and priorities for treatment; and (3) initial and ongoing decision making. Clients focused on the context in which the decisions were made, including as they experienced initial feelings of resistance, and then acceptance of efforts made to describe and treat their mental health challenges. Clients highlighted the need for collaboration between themselves and their clinician, and the need to be equipped with the knowledge and tools to take care of themselves. These focus group data were used to refine the online decision aid. Pilot testing revealed that while it was overall useful and relevant, important limitations were noted by both clients and clinicians.

Discussion: The use of a decision aid to facilitate shared decision making (SDM) in this area is feasible and has utility for both clients and clinicians. Use of such a tool can help to address the need to uphold the rights of young people as decision makers about their own care. Future efforts should embed decision aids within complex SDM interventions, and research to understand issues relating to implementation of these interventions.

Keywords: shared decision making, ultra high risk, clinical high risk, at risk mental states, youth, early intervention, psychosis

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INTRODUCTION

Approximately three in every 1,000 Australians will experience a first episode of psychosis (FEP) in any given year (1). Despite this relative low incidence, psychotic disorders can be highly debilitating, with a recent systematic review and meta-analysis suggesting those with a diagnosis of schizophrenia experience an average of 14.5 years of potential life lost (2). Psychotic disorders are also associated with an increased risk of homelessness (3), decreased social functioning (4), and higher rates of suicide (5) and unemployment (6, 7). Given the potential impact of psychosis, efforts have been made to identify individuals most at risk in order to intervene early in the hope of delaying, ameliorating, or even preventing the onset of a disorder (8).

The main way in which risk has been operationalized is through the development of the Ultra High Risk (UHR) criteria (9). To meet the UHR criteria, a young person must have experienced either (1) a 30% or greater drop in functioning sustained for 1 month within the past 12 months, or (2) chronically low functioning for the past 12 months or longer, and also fall into one of the following risk groups: (1) Vulnerability Group (those with either a family history of psychosis or a diagnosis of Schizotypal Personality Disorder); (2) Attenuated Psychosis Group [sub-threshold positive psychotic symptoms in the past year as assessed using the Comprehensive Assessment of At-Risk Mental States (10)]; and (3) Brief Limited Intermittent Psychosis Syndrome (BLIPS) Group (experienced episodes of psychotic symptoms within the past year that have not lasted longer than a week and have resolved without treatment).

For young people meeting the UHR criteria, the cumulative risk of transitioning to a psychotic disorder is estimated to be approximately 19% at 2 year follow-up, and 36.5% at 10–11 year follow-up (11). Other longitudinal research indicates that individuals who met UHR criteria but did not go on to develop psychosis still experienced significant, persistent negative symptoms, mood and anxiety concerns, low rates of employment, and high suicide rates in comparison to those with first episode psychosis and their peers who do not meet UHR criteria (12). Together, these findings highlight that young people who meet the UHR criteria require early intervention for mental health challenges, regardless of whether they experience a psychotic episode.

Randomized controlled trials have investigated cognitive behavior therapy (CBT), anti-psychotic medications, and Omega-3 fatty acids as interventions for those who meet UHR criteria aiming to reduce the risk of transition to psychosis (13). Recent systematic reviews and meta-analyses have demonstrated CBT as the most effective intervention in comparison to controls at reducing transition to psychosis, however, a network meta-analysis comparing multiple interventions (CBT, integrated psychological therapy, omega-3, family therapy, ziprasidone, needs-based interventions, risperidone plus CBT, and olanzapine), showed no intervention was more effective than another (14–16). However, systematic review evidence indicates that interventions in this population are cost-effective, and can lead to cost-savings (17), however the results were limited by the heterogeneity of services and a lack of consensus on the best practice for intervention in the UHR population.

Current Australian clinical guidelines (18) recommend CBT as the preferred intervention for young people meeting UHR criteria, but note antipsychotic medications may be provided if a person is considered to have experienced a psychotic episode (i.e., more than 1 week of frank positive psychotic symptoms have been sustained) or if milder positive symptoms associated with risk of self-harm or aggression are present. Psychoeducation about psychosis, their risk of developing psychosis, and what evidence-based treatment options are available, with consideration of client preference, is also recommended (19). The guidelines also indicate Omega-3 fatty acids may delay or prevent transition to psychosis, however the finding underpinning this recommendation has not been replicated in a larger trial (20). It should be noted, there has been considerable debate in the field over the last decade on the ethics of labeling and intervening on young people at UHR (21–25). A major focus of the debate is on whether treatment should involve a focus on the clients presenting problems or their psychosis-risk symptoms (24, 25). One approach which has been argued for as imperative to ensuring that treatment decisions are evidence-based and preference-sensitive for young people at UHR is shared decision making (SDM) (19).

Shared decision making is a collaborative approach to treatment decision making with roots in both evidence-based medicine and client-centered care (26). Decision aids are the most common way to facilitate SDM; decision aids describe the different treatment options relevant to the decision and present evidence-based information about the potential harms and benefits of each option, and the likelihood of these outcomes. They also elicit personal preferences and values so that the person faced with the decision can work together with their treating clinician or team and any caregivers involved in their care. Decision aids have demonstrated effectiveness in increasing client knowledge, reducing decisional conflict (both in terms of feeling uninformed or feeling unclear about personal values), reducing the proportion of clients who are passive in the decision-making process, and reducing the proportion of clients who remain undecided about what treatment option to choose (27).

Systematic reviews within the mental health field have led to recommendations for decision aids, along with other approaches to facilitate SDM, to be used within mental health treatment settings, although most of the research to date has focused on adult populations (28–30). A systematic review of SDM specifically with psychiatric patients found that SDM interventions were associated with a small overall increase in indices of empowerment such as patients' subjective sense of involvement in treatment, self-efficacy, and autonomy (31), with a trend toward reducing the likelihood of compulsory inpatient treatment over 15–18 months. However, authors acknowledge the data were heterogeneous and imprecise, highlighting a need for high quality studies in this area (31). A more recent clinical review found SDM to be particularly important when considering drug treatments for patients with schizophrenia, although research to date lacks data on the stability and maintenance of positive effects over time (32). Despite the increasing focus in this area, there is still a paucity of research focused on youth populations.

Incorporating SDM in youth mental health settings, with young people aged 15–24 years, may be beneficial in managing complexities arising from agreeing treatment plans between young people, caregivers, and clinicians, especially considering the ethical and legal issues associated with treatment consent (33). Service providers are already beginning to introduce SDM practices with young people (34) however, the effectiveness of these approaches have limited empirical evidence. One study found that an intervention that combined peer work led to an increased sense of involvement in their assessment and lower decisional conflict, both of which are important components of client satisfaction (35). Another study in young people with depression trialed a collaborative care intervention which included aspects of SDM, and demonstrated greater improvements in depressive symptoms 12 months later (36). One study developed an Encounter Decision Aid and piloted it with patients with first-episode psychosis and long-term psychosis, family members, and clinicians (37). The decision aid was found to be valuable and acceptable, however the research did not exclusively focus on young people and excluded any patients under the age of 18. Of interest, a recent protocol has been published that aims to evaluate the feasibility of a decision aid to promote SDM among young adults with first-episode psychosis, but results are yet to be published (38). To date, there have been no studies specifically focused on SDM approaches with young people, inclusive of those under the age of 18, who are accessing UHR services, despite the clinical guidelines recommending clinicians utilize SDM (18).

The current study focuses on empowering young people meeting UHR criteria to become active participants in their own care by involving them in the treatment decision-making process. We describe the development of an online decision aid that presents the evidence for treatment options according to the Australian Clinical Guidelines for Early Psychosis and is designed to be used with young people and their treating clinician. This study reports on the development and piloting of this decision aid. We sought to answer the following research question: do clients and clinicians find the decision aid relevant and useful, and does it result in clients feeling satisfied with the decision and have low decisional conflict?

METHODS

This study used the International Patient Decision Aid Standards (IPDAS) (39) to guide the development of the decision aid across two phases. Phase one involved using the IPDAS to generate a prototype decision aid, which was then used as a prompt in qualitative focus groups both with young people who had previously accessed early psychosis services and clinicians working at such a service. The results of these data then informed phase two, which involved refining the content and design of the online decision aid and piloting it with a small number of clinicians and clients to finalize the development process (example screen shot of the final version presented in **Supplementary Material 1** and study timeline presented in **Supplementary Material 2**). This study was approved by the Melbourne Health Human Research Ethics Committee (reference 2014.155).

Setting

This study was conducted at the Early Psychosis Prevention and Intervention Center (EPPIC) and the Personal Assessment and Crisis Evaluation (PACE) Clinic, both of which are part of Orygen Specialist Program (OSP). Orygen Specialist Program is a tertiary mental health service that provides mental health care to young people aged 15–24 in the north-western metropolitan area of Melbourne in the state of Victoria, Australia. It runs a range of clinics for young people with emerging and established mental disorders (including EPPIC and PACE) and provides both outpatient and inpatient care. Orygen Specialist Program has a consumer reference group called Platform; Platform members are young people who have been discharged from OSP and engage in activities to contribute to the ongoing improvement of the service, improve mental health literacy and help seeking in young people, and reduce stigma around mental illness (40, 41).

Phase One: Qualitative Focus Groups With Stakeholders to Refine the Decision Aid

The development of the content and design of the initial version of the decision aid was conducted in accordance with the International Patient Decision Aids Standards (IPDAS) (39). The IPDAS are a set of theory-driven and empirically-informed standards that provide guidance on how to develop decision aids to maximize the chances of providing effective decision-making support and reduce the risk of introducing biases to the process. Two key decisions were identified to be supported by the decision aid, namely whether or not to seek help for meeting the UHR criteria and choice of intervention for those deciding to engage in treatment. The treatment options were based on the clinical practice guidelines (42), which at the time recommended omega-3 fatty acids (fish oil), cognitive behavioral therapy, supporting counseling, and support for mental health challenges in general. This early prototype was used as a prompt in two focus groups: the first with members from a consumer reference group (Platform), and the second with healthcare professionals working in the PACE Clinic. The focus groups lasted 67 and 55 min, respectively, and were co-facilitated by MS and AM using a semi-structured focus group schedule (see **Supplementary Material 3** for example probes). Focus groups were audio recorded and transcribed verbatim. Data were analyzed using inductive thematic analysis (43), whereby thematic interpretations of the transcripts were derived directly from the text (44). Both AM and MS initially analyzed the data separately and then collaboratively, addressing any discrepancies through revisiting the data and discussion with the broader team, to support the validity of the analysis. Coding continued until no new themes were identified in the data (data saturation), and all responses could be explained in terms of the thematic structure.

Phase Two: Pilot Testing

In order to complete the development process, pilot testing of the decision aid was conducted at the PACE Clinic with both clinicians and clients as participants. The clinician focus group in phase one was conducted with current clinicians, making it possible for clinician participants to participate in both phase one and two (which was the case for three clinicians), but not for clients, as phase one involved past clients and phase two involved current clients. Clinicians were recruited using convenience sampling through staff meetings and invited to nominate new clients of the service who were facing a decision about treatment options at the time. Clinicians were able to refer more than one client, and once a referral was made the research assistant contacted the client to provide more information and obtain informed consent if the client was willing to participate. Once this occurred, the decision aid was made available on a tablet device for use in the clinical appointment where treatment options were due to be discussed. After using the decision aid, both client and clinician were asked what decision was reached and why, and were invited to provide open-ended feedback about the usefulness, relevance, and appearance of each decision aid section and were asked for suggested changes.

Clients also completed the following measures to identify any extreme scores that could indicate the lack of utility of the decision aid:

1) Decisional conflict was measured with the Decisional Conflict Scale (DCS) (45). The DCS is a 16-item measure that uses a 0–4 Likert scale. It has a total score range of 0–100, where higher scores indicate higher decisional conflict (undesired outcome).
2) How satisfied participants were with the decision was measured with the Satisfaction With Decision (SWD) scale (46), a six-item 1–5 Likert scale self-report questionnaire with a maximum score of 30 where higher scores indicate higher satisfaction with the decision.

RESULTS

Phase One: Qualitative Focus Groups With Stakeholders

In total, eight clinicians participated in the focus group, including allied health professionals ($n = 6$) and psychiatrists ($n = 2$). There were three males and five females, and age was not recorded. The Platform group ($n = 6$) included two young people who had been clients of PACE only (i.e., met the UHR criteria but not experienced a FEP); two young people who had been PACE clients and then transitioned to FEP and subsequently became EPPIC clients; and two young people who had been clients at EPPIC but who had not received treatment from PACE before experiencing FEP. There were two males and four females, with ages ranging from 18 to 29 years (mean = 25.5; SD = 3.94).

Clinicians' Experiences and Beliefs About Treatment Decision Making

When describing their experiences and beliefs about treatment decision making for young people meeting the UHR criteria, clinicians spoke about issues common to treatment decision making in youth mental health in general (e.g., tenuous clinical engagement). However, clinicians reported that these issues were heightened in this clinical population due to the lack of a formal diagnostic framework. Issues discussed by clinicians fell into three main areas: (1) engagement phase; (2) assessment and priorities for treatment; and (3) initial and ongoing decision making (see **Figure 1**).

Engagement Phase

Clinicians felt that deciding whether or not to engage in the service at all was the first decision faced by clients. Having information about the service was seen as a necessity at this stage, including what was "on offer" in terms of ways in which the client could be helped. The PACE Clinic was perceived differently to other youth mental health clinics, in that clients were referred with a "somewhat more subtle and ambiguous" rationale for treatment. This was seen as a factor that increased ambivalence of clients deciding whether or not to engage in treatment. Related to this was the concern that clients did not remember what was described about the service, psychoeducation about mental health, and information about treatment options.

> *"Often, it's interesting, after you have your first one session, maybe two sessions, (and then you ask) 'So why are you here? What do you know about PACE?' Despite having done a spiel and them seeming to engage, they very rarely retain any of that information."*

Perceived reasons for this included clients facing "information overload"; having been through multiple services in their referral pathway to the PACE Clinic ("they have often bounced around a bit"); and the complexities and "subtleties" in understanding the concepts of being at risk for a mental disorder rather than being diagnosed with one. Clinicians also suggested that clients might focus more on the clinician-client "fit" rather than on retaining information.

> *"And they are sussing you out and getting a feeling for whether I want to talk to this person, getting a sense of the process, the atmosphere, rather than the content. You could be talking about anything, it's just a matter of 'What's the rapport like? What's engagement like?'"*

To facilitate this engagement process, clinicians felt it was important to be "on the same page" as clients in terms of what clients wanted help with and what the service could offer. Addressing the concept of risk within this context was seen as something that could impair engagement and that timing was an important consideration to minimize this. There was general agreement, however, that providing information about risk was ethically correct.

Psychiatrist participants drew analogies between PACE clients and risk assessments for physical health conditions, for example saying that they would not consider withholding information about the reasons for, and potential outcomes resulting from a pap smear. There was a concern that withholding information was therefore potentially stigmatizing. Psychologists agreed that in order to make an informed decision, information about risk

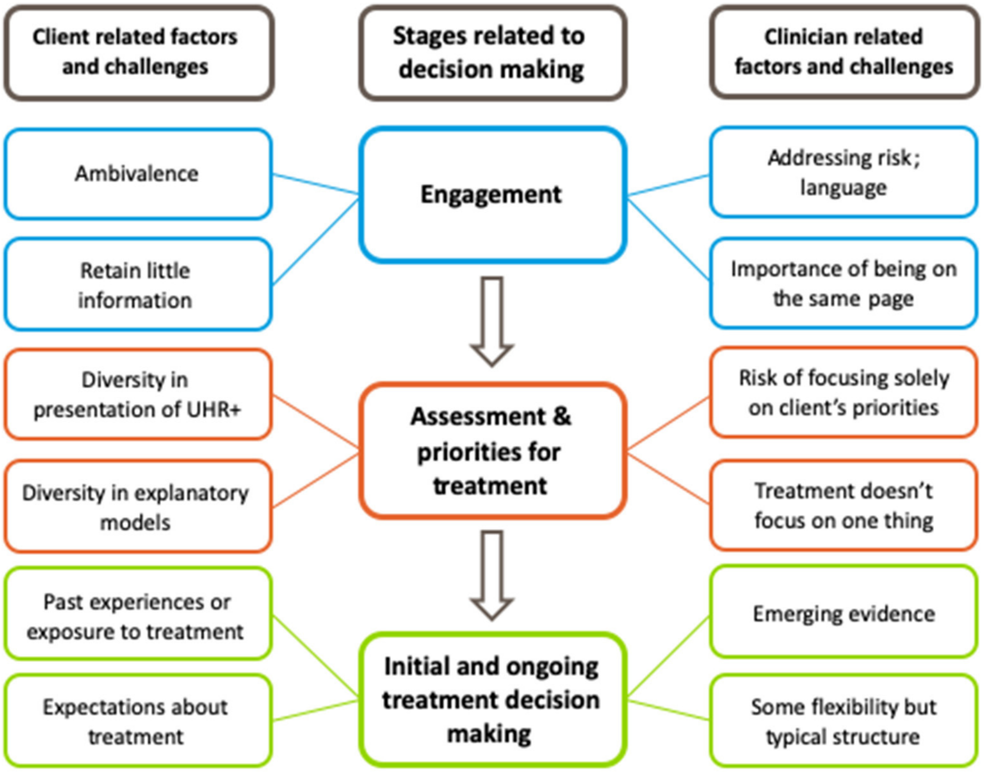

FIGURE 1 | Thematic map of clinician reported experiences and beliefs about treatment decision making for young people who meet the "Ultra High Risk" (UHR) criteria.

must be provided. However, they also felt that the rapport between client and clinician was more important than in physical health, and often part of treatment itself in mental health settings. Therefore, addressing risks and discussions about the potential for developing psychotic disorders must be done in considered ways. Clinicians didn't always feel like they achieved this balancing act, and after discussion about each of these issues, one clinical psychologist reported how this tension played out in his own work:

> *"Well, there's a tension and it's an obvious one, to say that the psychoeducation or discussion about psychosis and transition, when we deliver that and how we deliver it, and sometimes it feels a bit inappropriately like playing God if we think we can only give it in this way to these people at this time. Whereas, if it was for a physical illness, we would generally have… very little reservation about giving the most comprehensive information… for some reason… there can be a kind of squeamishness, in case we cause some stigma or trauma (or) we increase the vulnerability by the discussion somehow, or by talking about something by naming it, we may make it happen or make it more likely to happen, which I guess rationally that's ludicrous. (But) I can act in that way I think. I can enact that in my practice at times. So I do think that for some people, there is a… timing issue, but sometimes we can put kid gloves on a little bit about transition, when perhaps we shouldn't. We should think about it in the same measured way we think of all psychoeducation."*

Language was one important related consideration, and some clinicians described their practice of avoiding the term "ultra high risk."

> *"I think one of the questions with the language, like, while I talk to people about potential risk and so forth, I never use the term 'ultra high risk.' For me, that is something that's read in journals and professions kind of communicate around but it is not the language that I would use in the room… 'ultra high risk' sounds so imminent."*

Alternatives to this phrase included "risk," "chance," and "symptoms worsening." At the same time, although clinicians wanted to acknowledge that they were trying to prevent symptoms from worsening, they were also careful not to frame the event of transitioning to psychosis as "terrible." One participant compared discussion about transition to that of relapse prevention in first episode psychosis, where clinicians aim to "balance that message with the client, so that relapse, when it comes, is not catastrophic."

Assessment Phase, Including Establishing Priorities for Treatment

When discussing the assessment and treatment decision making phases, clinicians raised a number of factors that made it necessary for them to take a flexible and individualized approach with each client. Firstly, although clients all met the UHR criteria in order to be referred to the PACE Clinic, there was great diversity reported in both the different groups in the criteria (i.e., vulnerability group, attenuated psychotic symptoms groups, and the BLIPS group) and the individuals meeting criteria for each group or combinations of groups. This included differences in experiences and reasons for referral. Most notable was the differentiation between whether or not a client was experiencing attenuated positive psychotic symptoms.

> *"Yeah, it's kind of like the UHR stuff is 'why you are here' but what we do when you are here, it can be anything... we don't always focus on attenuated (positive psychotic) symptoms or sometimes there aren't any attenuated symptoms. When people come in on a family history, you don't work on psychotic symptoms. So the focus of care is often not attenuated symptoms."*

The different ways in which clients accounted for their experience also contributed to this need to personalize care, and sometimes created challenges for clinicians when trying to work in a client-centered way.

> *"Each and every person comes with a different explanatory model of their… symptoms, the cause and their prognosis and the treatment options. So sometimes I find it very difficult to incorporate their model and our model and make a common model for the treatment…"*

Language was seen as an important consideration when reconciling different understandings or "frameworks" for understanding the experiences of clients. "…trying to get a shared language" was valued in this phase of assessment and treatment decision making because, as one clinician noted, "you can't even negotiate a decision if you are not speaking the same language." Some clinicians were willing to relinquish their own way of describing mental health issues.

> *"I try and sometimes distance myself from the (professional) language, so that I can open up the idea that I am very happy to have their understanding… it's really important for us to have a shared way of talking about things."*

Another issue that shaped the nature of assessment and treatment decision making was the fact that treatment didn't focus on one thing, which meant that a structured approach was not well-regarded by clinicians. However, one caveat to this flexible and personalized approach was that there was a possible disadvantage in focusing solely on the presenting problem of each client and not addressing the risk of psychosis. In doing so, clinicians were concerned that clients would not be able to make a fully informed decision about treatment: "In order for it to be informed decision making, you need to have information (about risk)." It was also noted that although the treatment might focus on other symptoms or life stressors, that this in itself can reduce the risk of psychosis and should be framed in such a way.

> *"These symptoms might have a complex and subtle relationship with each other. So although we are not working directly on attenuated (psychotic symptoms), they might improve anyway as we gain, say, on depression or something like that. That is a message that can be communicated too."*

Overall, addressing risk was seen as necessary but inherently complex.

Initial and Ongoing Treatment Decision Making

When it came to making decisions about treatment, aside from the heterogeneous nature of the individuals meeting the UHR criteria, additional issues included any past experiences of symptoms and treatment clients had. This included either directly (i.e., personal experiences) or indirectly (e.g., observing the experiences of a family member). This was seen as most notable in relation to medication,[1] where both direct and indirect past experiences as well as expectations were seen to play a role.

> *"And there is a very perhaps undue influence or undue emphasis on what the medication should be able to achieve in a short period of time. If it is not (working), then it's 'junk' and 'you're a fraud.' So it's difficult sometimes."*

In response to this, clinicians were generally supportive of the idea that clients should be routinely informed about "stats around effectiveness, efficacy, but also how long they are likely to be on it." This was seen as particularly important when multiple clinicians are involved in the care of clients and where information provision needs to be consistent. However, clinicians were also aware of both inadvertent and strategic "underselling" of the length of time clients may need to take medication for. One message that was seen as important, however, was the limitations of the emerging evidence base for the area.

> *"I think the other thing, in particular (with) UHR and psychosis, (is) there's still a hell of a lot that we don't know. So whatever education we give, we have to include that… I think in this particular area, that we need to be quite clear about… where we are (at) with our evidence base."*

In line with the provision of evidence-based information, clinicians also reported favoring a collaborative approach to making decisions with clients. They saw it as essential for clients to be "on board," and felt that this was necessary for treatment to work.

> *"It is also tricky, isn't it? Because treatment is only going to work if you have got the young person on board. You see the young person for an hour in that week (but) treatment needs to occur outside of that 1 h, otherwise it's not going to be effective. At the end of the day if you don't have the young person on board… you can't do anything. You think about graded exposure, you think about [Cognitive Behavioral Therapy], you think about [Cognitive Analytical Therapy]—all these therapies rely on young people—and medication—rely on them doing things outside that 1 h."*

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[1] Although antipsychotic medication is not prescribed outside of research studies at the PACE Clinic, some clients may be on other medications for non-psychotic mental disorders (e.g., antidepressants).

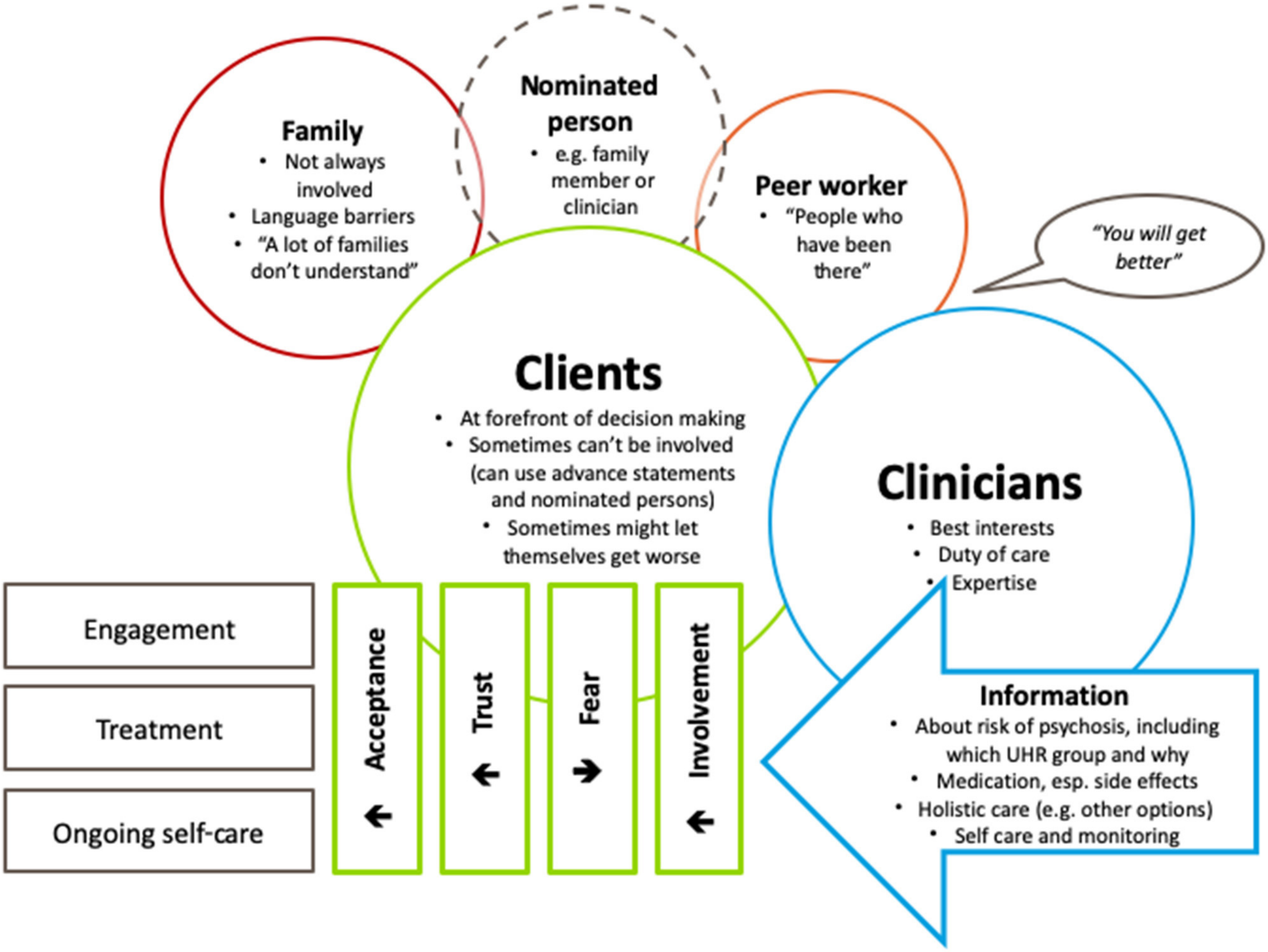

FIGURE 2 | Thematic map of client reported experiences and beliefs about treatment decision making for young people who meet the "Ultra High Risk" (UHR) criteria.

Although limitations to achieving this were noted, including the basic structure of treatment at the PACE Clinic (i.e., in general, weekly appointments with a case manager and medical reviews as necessary) and the ability of clients to participate in decision-making processes.

> *"I strongly encourage it to be a collaborative experience and try to lay out lots of the options at the start (saying) 'the best way I can help you is if I can see you weekly because then I can get a good sense of things, I can monitor things and we can maximize the time that you have got available (in the service)' but for some people it's very difficult for them to make a decision and understand what the implications of the decision are."*

Clients' Experiences and Beliefs About Treatment Decision Making

In contrast to the clinician participants who focused on the decision-making processes in relation to a linear progression through assessment then initial and ongoing decisions, client participants more strongly referenced the context in which the decisions were made. This was particularly so in relation to feelings of initial resistance and then acceptance, be it acceptance of symptoms, of diagnoses (where relevant) or of different types of treatment. Throughout this journey, clients highlighted the need to be involved, for their clinicians to be involved and for clients themselves to be equipped with the knowledge and tools to take care of themselves (see **Figure 2**). Other people potentially involved in decision-making processes (family members, nominated persons, and peer workers) were seen as peripheral by most clients and are discussed below. In general, clients focused on their roles and the roles of the clinician.

Involvement in Decision Making

In line with the clinician data, clients acknowledged the importance of their contribution to the decision-making processes.

> *"I think the client should sort of be at the forefront of the decision making, so when clinicians come to the client with the treatment plan, I think the patient should be consulted and their decision or*

> *their input should be taken very highly and should be understood as much as possible."*

Client involvement was seen as important for engagement, particularly in relation to accepting the proposed treatment plan.

> *"I think as well with the client, if they're more involved with (deciding about) their treatment I think they'll be more accepting of it as well. So, they won't be as hesitant as they are… when the clinician tells them exactly what to do. If they get consulted more they might be more willing to get better."*

In terms of how to achieve this, "being told about alternative pathways" and being able to visualize the possible outcomes were suggested. Although this was seen as important, clients stressed that this needed to be in the context of a recovery framework in that it had to focus on the individual needs of the person and how they perceived "getting better." Encouraging the client to accept their situation, including symptoms and treatment, was seen as a key part of this process that could be facilitated by involvement and the sharing of information, thereby building trust in the clinician.

> *"I think it's important to let the person know that if they want to get better they can get better. That they can come in with their symptoms wanting to recover… you can tell them all the treatments, all the risks and benefits, but in the end if the person is not capable of accepting themselves and saying 'okay yeah I can deal with this' it becomes confusing and harder. Saying 'do you want to get better?' and from there onwards working on therapy that works for them and seeing what works for them."*

Information Provision

Alongside the perceived responsibility of the client to work toward getting better, was the responsibility of the clinician to provide information about being at risk for psychosis, potential harms, and benefits of treatment options (including medication), psychological therapies (e.g., what type they were engaging in), alternative therapeutic options, hospitalization, and how clients could take care of themselves both outside of sessions during their time at the service, and also beyond their time at the service. In terms of information about risk, clients wanted to know why they were at the PACE Clinic, that they met one of the groups from the UHR criteria and *why* they met criteria. There were mixed experiences of what information was provided to clients about risk. For example, one client reported that they were told "immediately," another said that they probably were told but could not remember, and a third was told that they were at the "right clinic" because they had a family history. Another client reported that they didn't know the name of the clinic, just where to go.

> *Client 1: "There were a lot of words that we were never told"*
> *Facilitator: "That's what I'm interested in"*
> *Client 2: "Because (when) we came to Orygen we don't really get to know…"*
> *Facilitator: "Did you know what clinic you were in?"*
> *Client 1: "I just knew that I turned right at the corridor"*
> *[Group laughter]*

For those clients who were told about their risk of developing psychosis, this information could be reassuring.

> *"I have siblings that have psychosis. I have parents that have psychosis, and my mum has other mental health issues as well so, and I was also experiencing some delusions and symptoms of psychosis I guess. So, I understood why I was in the clinic. It was scary for me as I… I didn't want to be in there. I didn't want to have psychosis. But after understanding and knowing what was happening, and where I was in the service, I did feel better about it. Now, it's not that scary."*

Clients showed a desire to have information provided to them unfiltered. This was particularly the case in relation to medication. Clients didn't want clinicians to "beat around the bush," which they felt would lead them to "find out down the track the hard way." Clients also resented experiences where they perceived clinicians to be withholding information, which affected their ability to trust them.

> *"And sometimes I find that, you know, the psychologist, or the psychiatrist, sometimes I question them. Are they lying to me? Because everybody, my relatives, my friends who haven't seen me for a couple of months will be like, 'how much weight did you stack on?' and I'm thinking my doctor never told me that. Are they lying to me? […] then I start resenting my doctors, and thinking are you lying to me because you only want me to keep taking these pills?"*

Most clients had experienced side effects (e.g., feeling "slummed out," restlessness), with the most commonly reported side effect being weight gain. Several clients reported information about the risk of weight gain being withheld from them to encourage adherence. There were variations in the degree to which clients felt this was justified. Although most clients felt that the benefits of the medication outweighed the risks (e.g., "I'd rather have side effects than be how I was before"), there was a general desire for more information to be provided from the outset, and a strong desire for a holistic approach that included being told about alternative treatments and ways to live with both side effects and ongoing symptoms.

Clients also wanted information to be ongoing, interactive and meaningful. They valued instances when clinicians had facilitated self-monitoring, as "you see (treatment's) working or whatever you're doing is working, the medication's working, everything's working." This tied in with client's perceived need to be able to take care of themselves outside of sessions and beyond their time at the service. This was achieved in a number of ways, for example with subjective scores.

> *"We did have goals every 6 months, we would check on those goals and see how they were progressing. I think a good thing we did was um they gave me like a scale, I don't know if you guys did this as well, but they would just they would ask me how I was feeling on a scale from one to ten, compared to 6 months ago… I thought that was really helpful and a big thing they did was focus on things that we could achieve."*

The Role of Clinicians, Family Members, and Peer Workers in Decision Making

In terms of knowing how to be involved in making decisions, clients described clinician practices that they felt involved them (e.g., tailored goal setting), and formal mechanisms provided by the service (e.g., the use of advance statements and nominated persons forms). However, clients had experienced both benefits and challenges of such approaches. Where there was trust, the use of nominated persons was perceived to have the potential to facilitate person-centered care:

> *"I've nominated at the moment. I'm planning to have my old psychologist from Orygen to be my nominated person because I have full trust in him being off the relationship that we built in the past and he was upfront into medication and stuff. He sat me down and walked me through medication and decided all that kind of thing. So, to have him as a nominated person and to trust him in terms of what my treatment should be I think that really will definitely help with my treatment in (the) future and puts me at the forefront of my decisions and a psychologist created plan."*

However, barriers existed for others, including a lack of people to nominate, and the suitability of these mechanisms for early intervention settings.

> *"The problem with the advanced statement and the nomination thing is that with Orygen Youth Health, a lot of us are just, we just, that's the first time that we have become unwell. It's hard to choose a nominee sometimes, or to have an existing nominee and to have an advanced statement."*

The challenges related to the use of advance statements and nominated persons processes were not the only caveats to the importance of involving clients in making decisions about their own treatment. Clients noted that there were times when they were unable to be involved (e.g., when experiencing psychotic symptoms) and that if decisions were left entirely to them then they would sometimes choose to let themselves get "worse," which they wanted to be taken into consideration. In relation to this, clients were keen to stress the importance of the clinician's role in making decisions about treatment.

> *"Well, at the end of the day, the clinician is the person who treats people all the time, has the qualifications, they know the most about the subject. I mean while, while the person's own personal problems should come into it obviously because you know, everyone's mind is different, I think at the same time, trying to, if people have too much if a person has too much input in treatment they could, actually make themselves worse as opposed to better."*

Although clients felt that it was useful to have clinicians taking an active role in making decisions together with clients, the role that family should play was more contingent on certain factors. One client did not have any family who lived locally, and another said that it was difficult for her parent to be involved due to language barriers. There was also a concern that not all families were understanding and supportive.

> *"I don't think it should be left up to the family, because my family, lots of families don't understand it. They don't see it, they think becoming unwell is being physically ill."*

At times of crisis, some clients found a coordinated effort between families and clinicians useful for keeping them safe and making decisions they felt unable to participate in (e.g., hospital admissions).

Regardless of who was involved in the decision-making processes, clients wanted the opportunity to feel hopeful about the prospects of recovery. They described an interplay between information provision, framing of information, and fluctuating stages of engagement with the service and treatment. Ultimately, they felt a tailored approach according to the needs and experiences of the client was necessary to promote meaningful engagement and recovery.

Clients wanted to have something more than just being told that they could get better—they wanted to believe it too, and they suggested that visualizations (e.g., mapping out possible trajectories) and meeting with peer workers as some examples that could bring to life the possibility of recovery.

> *"I think that people should be told they can get better. I mean it was told to me but I didn't believe it. I guess that's why we have peer support workers and people who have been there but yeah someone telling them that they can get better because it does feel like you're going to die and your life's over."*

Phase Two: Pilot Testing of the Decision Aid

In total, $n = 10$ client participants and $n = 6$ clinician participants were involved in the piloting of the decision aid; however, client-rated data are only available for $n = 9$ client participants as one participant chose not to complete the questionnaires but gave permission for their clinician to provide the clinician-rated data. Clients were aged between 16 and 23 years (mean = 19.7; SD = 2.3) and 6 (60.0%) were female and 4 (40.0%) were male. Clinicians were aged between 30 and 42 years (mean = 34.5; SD = 4.2) and were all female. Clinicians had been working in their respective disciplines for between 4 and 10 years (mean = 6.3; SD = 2.5). Five of the clinicians were clinical psychologists and one was an occupational therapist; three were in senior roles.

Decision Related Outcomes

Scores on the SWD scale ranged from 12 to 29, with a mean score of 23.1 (SD = 5.3), indicating variability within the sample, but on average relatively high levels of satisfaction. These scores include participants who were unable to decide and one participant who was an outlier, as their scores indicated they had high decisional conflict and were not satisfied with the decision. This same participant provided minimal responses to the open-ended feedback questions (e.g., "no" and "boring"). Overall, all but two client participants reported being able to decide on a treatment option; one client participant reported still feeling undecided and another said they were unsure if they were decided. All treatment choices involved either CBT, supportive therapy or both, plus eight of the nine clients chose to treat their mental health challenges in general and two clients chose to take Omega 3 tablets. Both client and clinician participants unanimously reported that the treatment choice was in line with the client's preferences. At follow-up (approximately 6 weeks post decision), there were clinician-rated data for seven client participants. All but one participant continued with their treatment as intended; one client experienced first episode psychosis and their care changed accordingly. All but one client had failed to attend sessions, which is not unusual for the service. Several additional treatments and related options were noted, including inpatient admission, different psychological therapies (e.g., schema therapy, cognitive analytical therapy), medications, peer support, alcohol and other drug counseling, and "systems work" (liaising with the school, family, and social services).

Feedback on the Decision Aid

Client and clinician participants were invited to provide feedback on each section of the decision aid, including how useful they found it, whether the information was relevant to them; the appearance; and what they would change about the section. Results are summarized in **Table 1**. Clients and clinicians were generally positive about each section of the decision aid. One exception to this was clinician feedback on the "Treatment Options" page, which raised some concerns about its content and practical use. Clinician participants highlighted a mismatch between the options presented and what was offered at the service.

DISCUSSION

This project sought to develop an online decision aid for young people at increased risk of developing a psychotic disorder. To date, the majority of decision support tools for young people have been designed for parents to make decisions for their children (47); this study focused on the young people (adolescents and young adults) as the decision makers themselves. This project contributes to a growing number of studies that demonstrate young people in this age group can be supported as the primary decision makers (35, 37, 48). This decision aid was developed in the context of significant academic and clinical debate about the ethical merit of identifying young people who meet the criteria for being at increased risk for developing a psychotic disorder, informing them of this risk, and delivering interventions to delay, prevent, or otherwise ameliorate the impact of first episode and/or recurrent psychotic episodes [e.g., (22, 23)]. We have previously proposed SDM as a practical way in which to address these ethical issues (19), and the current study sought to provide decision support to clients to allow them to be active participants in deciding whether or not to access treatment, and if so, collaboratively choose their preferred treatment.

This project was conducted across two phases: phase one involved qualitative focus groups with past clients and current clinicians at an early intervention service; and phase two pilot tested a decision aid at an early intervention service. Phase one highlighted the similarities and differences between the perspectives and frames of reference that clients and clinicians had about treatment decision making in this area. For clinicians, this was focused on entry to the service, time with the service, and discharge from the service, whereas for clients these decisions were described more in relation to the context of the time at the service in their overall lives. Phase two highlighted that although the decision aid was well-received overall, it had some limitations in terms of utility and relevance.

A consistent theme for client participants across both phases was the desire for the possibility of recovery to be brought to life through peer support (phase one) and personal stories (phase two). This highlights the value that young people placed on lived experience and the contribution to both decision-making processes and treatment itself. Although this pilot trial was focused on decision making as a collaboration between clinicians and clients, it is possible for youth peer workers to be involved in supporting young people to make decisions about mental health care (49). Exploring this model for young people at increased risk of developing psychosis may not only reduce decisional conflict, but also enhance the degree to which young people feel involved in decision making with clinical staff (35).

Pilot testing of the decision aid showed mixed results for which sections client and clinician participants found useful and relevant. A number of clinicians felt that certain sections of the decision aid (e.g., treatment options) were limited in their utility and relevance given that one treatment option (Omega 3) was perceived to be unavailable at the service. We note that some clients were listed as having chosen this treatment option, but reasons for this discrepancy were unclear. It is possible that clinicians were aware of the specific composition used in clinical trials [e.g., (50)] and how that was not available at pharmacies at the time, whereas others considered readily available fish oil tablets to be sufficient to recommend to clients. There was also concern raised that more recent, at the time unpublished, results of a trial that involved the PACE clinic failed to replicate the effectiveness of that treatment option (51).

When young people present to services for psychosis prevention, their priority for treatment may not be reduction of attenuated psychotic symptoms (52, 53). Although interventions for this cohort have been shown to reduce psychotic symptoms and rates of developing a psychotic disorder, they have not been effective in other important outcomes such as symptoms of depression or functioning (13). The findings of phase two highlight the limitation of support tools for specific decisions, in that they don't account for the specific decision in the context of all of the related decisions the user is facing. Comments made by clinicians on the usefulness and relevance of the decision aid highlighted how complex the overall treatment decisions were for many clients. The types of treatment options that client participants ended up receiving included options beyond the scope of the decision aid (e.g., referral to alcohol and other drug services, specialized psychological therapy for personality disorders). Although they could be collectively labeled as "treatment for other mental health issues," which is a recommendation of the clinical practice guidelines and therefore an option presented in the decision aid, it was not possible to include all possible referral options for related decisions. This highlights the need to consider how a decision aid for a specific decision (or in this case, two decisions) might be embedded in

TABLE 1 | Feedback from client and clinician participants on each section of the decision aid.

	“Information, factsheets, and resources” page	**“What matters to me” page**	**“Am I at risk?” page**	**“Treatment options” page**
Client Feedback				
Usefulness	• 1 neutral response • 1 negative response (not useful) • 7 positive responses, including ease of navigation, amount and type of information, practical application e.g., “It is a useful starting point for a conversation” e.g., “It lets the people know how I want to be treated”	• 1 did not use • 2 didn’t find it useful e.g., “made me feel like getting over these things was really easy, when in reality it’s the hardest thing I’ve ever done” • 6 found it useful e.g., “You can express what you like and don’t like”	• 1 negative • 8 positive e.g., “was quite detailed in what an at risk mental state is” e.g., “because it’s a question I ask myself”	• 2 didn’t find it useful e.g., “left with doubts” • 1 appreciated finding out about treatment options they weren’t aware of (e.g., Omega-3 fatty acids)
Relevance	• All positive responses, including noting that the diagrams and facts were useful, as were the personal stories e.g., “It was good hearing people’s personal experiences and seeing stats”	• 1 negative: “I didn’t agree with some things and I found that most of it was already what I thought” • 8 positive, including that the content related to their personal circumstances e.g., “I liked being able to find out what is important to me”	• All positive responses, including that it was reassuring, told them “what I need to know about what could potentially happen,” and they found it useful to read about “people with my condition”	• All clients found it relevant e.g., “I will be going through these treatments at some point and it explains what they are,” e.g., “it really helped me understand there’s more help than just counseling.” • One client found it reassuring to be provided with information, saying “I have been terrified of institutions since opening up about my condition. It’s nice to know what’s actually going on.”
Suggestions	• More interviews • Larger font size • Additional links to resources • Additional interactive components	• Boring • Clearly displayed • Easy to navigate • More options and categories	• Additional information • More interactive features	• Additional information e.g., “personal experiences of success stories for each treatment” • More information about side effects of medication • More interactive components • More color: “a tad bland”
Clinician Feedback				
Usefulness	• All positive, including that it looked good, was engaging, easy to navigate e.g., “range of topics and different mediums useful” e.g., “lots of info in one place, easy access, videos were good option”	• All positive apart from one who replied “somewhat” but did not elaborate; two could not remember section e.g., “very engaging” e.g., “Like videos and consumer testimony”	• All positive but one clinician noted they were unsure the client understood the risk concept e.g., “Useful to have visual ways of presenting this concept” e.g., “Diagram was good [at] showing increased risk without being scary”	• 2 positive e.g., “Yes, able to talk about different options” • 6 conditional responses (e.g., “somewhat,” “didn’t find it as useful”) and related caveats about mismatch between options presented in the decision aid and what the service can offer e.g., “need to be careful that it doesn’t set expectations in [service] there is a standard package of care eg don’t offer omega”
Relevance	• All positive apart from one participant who said “mostly” but didn’t elaborate e.g., “helpful when providing psychoed to young person” e.g., “yes emphasized drop in functioning yet hopeful about recovery”	• All positive except one negative “didn’t seem as relevant as first section” and one who could not remember the section e.g., “[very] helpful to explain stress-vulnerability model in a fun way” e.g., “animations and visual interactions are most useful”	• All positive, including “ARMS focus good” and “relevant to PACE cohort, visuals helpful to explain concepts” • Three caveats, including that “less text is more engaging,” that it was a “difficult concept to convey and needed more explanation,” and that “young people still find the ‘longitudinal’ paradigm less of ‘relevance’ than the here and now”	• 2 positive e.g., “Yes, given I had discussed some of these options already with the young person” • 6 noted caveats around including Omega-3 fatty acids as a treatment option when it wasn’t available at the service • 1 noted that more recent evidence (not incorporated into the clinical practice guidelines) was not reflected in the decision aid • 1 noted the limitations of the decision aid for young people with other mental health challenges

(Continued)

TABLE 1 | Continued

	"Information, factsheets, and resources" page	"What matters to me" page	"Am I at risk?" page	"Treatment options" page
				e.g., "Mostly, I'm unsure how to talk about use of fish oil and unclear what current recommendations should be. Also one client had BPD too so also talked about CAT" e.g., "We don't usually present fish oil as an option and the diagram presents it as very effective whereas neurapro didn't show this so it feels very prominent in the choices given, and at the point that the decision aid was used it's a little hard to describe therapy as a choice between supportive and CBT and to differentiate that from treating mental health in general as often these are combined"
Suggestions	• 4 said no changes required • Additional information required for some clients • Too much information to cover in one session • Balance provision of information with engagement • Include fact sheet on role of general practitioner • Preference for videos over "boring" fact sheets	• Make it less simplistic for some clients • Being able to print out section • Interactive version for client to use at home or handout to accompany online decision aid used in session	• Try and emphasize how here and now affects the "at risk" concept • Include audio to explain each graph • Risk communication graphs were too big—suggestion to reduce them to be out of 10 people instead of 100	• Additional details about different therapies • Have a function so that clinicians can tailor it to the young person and/or what is available at the service • Additional details about options beyond the clinical practice guidelines (e.g., psychosocial recovery groups, vocational support, medication, family work)

an overall collaborative approach to decision making. Clinical trials often test interventions for narrowly defined conditions, resulting in a lack of evidence about what works for comorbid presentations, affecting translational resources such as clinical practice guidelines and decision aids (54). In mental health, and especially in youth mental health, there is a lack of data to inform decisions for people experiencing any combination of emerging or established mental disorders, personality disorders, and/or substance use disorders. This limits the degree to which complex decisions can be supported by these types of decisions aids, and emphasizes the importance of general decision support interventions, such as generic decision aids (to support any decision) [e.g., (35)], training in SDM for clinicians with well-defined core competencies (55), and interventions designed to increase mental health literacy, empowerment, and decision making skills for clients and their families [e.g., (56)].

Other approaches involving clients were discussed by client participants in phase one, namely the use of advance statements and nominated person forms. These forms represent legal mechanisms designed to uphold the rights of people to make decisions about their own mental health care (57). However, participants felt that the utility of these were limited in early intervention services where young people may experience being acutely unwell for the first time, so aren't able to express their preferences in advance or make informed experience-based choices. A qualitative study of clients, caregivers and clinicians from the first episode psychosis service at OSPs (EPPIC) showed that these tools were not commonly used in the clinic, and a number of barriers to use were described by all three participants groups (58). Nevertheless, participants were equally enthusiastic about the potential of these tools and about collaborative decision-making approaches in general.

These findings have direct and indirect implications for early psychosis services. Ensuring that young people have positive experiences with mental health services requires strong, positive relationships with clinicians that are genuinely collaborative and prioritize the needs and wants of clients (59). This is important not just at entry to the service, but is critical for meaningful engagement across the duration of care (60). Collaborative approaches, such as SDM, are likely to enhance the strength and quality of relationships, but need to be embedded in the overall culture and policies and practices of youth mental health services; one approach alone will be insufficient (61).

A strength of the current study is that it contributes to the neglected area of how to involve young people in making decisions about their own mental health care. A limitation is that we did not include caregivers (e.g., family members) as participants. Future research should incorporate these perspectives, as there are likely to be unique contributions to understanding how decisions are made within and beyond clinical sessions. Another limitation is that this was a pilot trial and not designed to test the effectiveness of the decision aid. Given that across healthcare settings decision aids consistently demonstrate effectiveness in reducing decisional conflict (27), such an effectiveness trial may not be the most important research question to pursue. It may be more fruitful to focus on how decision aids can be part of a larger, more complex intervention designed to embed SDM across a service or service system. This will require the use of implementation science to fully understand the barriers and enablers to creating sustainable change. Finally, this study is limited by the small number of participants and the lack of the proper co-design methodologies we would now use and which may prevent and/or address some of the critical feedback from participants more rapidly.

Overall, this study highlights the importance of incorporating SDM practices into youth mental health settings when working with young people at UHR of psychosis. The decision aid that was piloted demonstrated utility within this population and while some limitations were highlighted by both clinicians and client participants, in general it was found to be both useful and relevant in supporting young people to make decisions about their treatment options.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Melbourne Health Human Research Ethics Committee. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin. Participants who were aged 18 years or older provided their own consent.

AUTHOR CONTRIBUTIONS

MS, AP, and BN contributed to the conception and design of the study. MS, AE, and AM recruited participants and collected data for the study. MS and AM performed the qualitative analysis. MS wrote the first draft of the manuscript. MB wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2021.683775/full#supplementary-material

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SDM Training Modules for Health and Social Care Professionals in Israel

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While the strategy of Shared Decision Making (SDM) originated in the medical field and was later adopted into the mental health arena, little attention has been paid to practice in the broader fields of the allied health and social care professions. These professions are grounded in the recognition of a need for practice that reflects the partnership and collaboration of the professional and the service user working together to further the health and well-being of the user. A pilot training module was developed to introduce and support students in their journey from exposure to the co-production ideology and the SDM strategy into clinical practice in the allied health and social care professions. The aim of the present article is to describe the students' experiences while learning about SDM and their use of this knowledge in their field practice in Israel. The students' experiences highlighted the complexity of integrating SDM into practice both at the individual student level as well as the macro environment. Moreover, it pointed to the need to further develop this co-production paradigm and the SDM strategy into the education of the allied health and social care professions.

Keywords: shared decision making, attitudes, training, clinical practice, lived experience, non-medical professions, allied health and social care professions

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> *"I felt a lot of things were done to me rather than with me".*
> *(Adelphi Research UK, 2018 p.11. https://www.adelphigroup.com/adelphi-research-uk/)*

BACKGROUND

The present article focuses on the need for integrating the central professional concept of partnership into the clinical practice of allied health and social care professionals. We argue for investing in the training of these professionals on Shared Decision Making (SDM) as a tool to support this professional value system. Framed in this context, and based on previous SDM training principles, the introduction of a pilot SDM training module into two academic programs for allied health and social care in Israel is described.

Historically, the work of professionals in the health and social care fields (such as social workers, occupational therapists and nurses) is grounded in the core values of self- determination and client-centered practice. This translates into the workers' collaborating with their clients to ensure their active partnership in the process of effecting change in their lives (1). Accordingly, these principles are reflected in the different professions' codes of ethics (2, 3).

However, the allied health and social care professions are often conducted in host settings such as hospitals, schools or care homes where value discrepancies between "hosts" and "guests" can impinge on professional practice (4). Here the traditional, yet still dominant, medical model of practice that rules these settings by focusing on the clients' impaired functioning and dependency, results in the continuation of a paternalistic hierarchy between the participants in the helping relationship. Thus, while our professions charge us to work in partnership with our clients, professional practice often reflects a different reality, resulting in clients characterizing their hierarchical relationships with us as experiences of oppression with the delegitimization of their knowledge (5) creating a sense of powerlessness, especially in areas of control over resources, legitimization of knowledge, assessments, and determination of needs (6, 7).

The era of civil rights activism in the 1960s in western countries such as the US and UK created the impetus for questioning this traditional medical model of practice and creating a new discourse, emerging in particular from the disability rights movement (8).

Today, this new discourse, grounded in principles of participation and partnership, have become buzzwords in the allied health and social care professional literature. For example, it is suggested that the term partnership incorporates concepts of equality and equal power sharing between workers and clients, recognizing that each brings areas of strength and expertise and each enjoys rights and choices (9). Furthermore, work in the mental health field suggests that providing people with more choice within the context of a strong therapeutic relationship appears to predict better user outcomes (10).

Therefore, it seemed important that ideas of client partnership be expanded and more fully incorporated into the professional training and practice with people needing our professional services.

The Shared Decision Making process (SDM) was developed first in the context of terminal physical illness (for example cancer), at those significant intersections where decisions concerning intervention (11), consultations, and primary care are taken (9). The earliest mention of SDM was in 1982 (12), but the idea draws on and deepens the principles of patient centered care (11, 12).

Policies to promote shared decision making have become visible in countries such as the United States, Canada, and the United Kingdom (13). In Israel, SDM has also been introduced into the health field (14, 15) and more recently into areas of mental health and appears to be showing promise as a positive contribution to clinical practice. SDM is increasingly well-established in the medical literature (16) with a growing evidence base in mental health. Here, SDM was used initially, as a response to the well-documented difficulties in decision making regarding psychiatric medications (17). A recent review on SDM in mental health (18) reported that SDM was aligned with the core principles of user involvement and participation, person-centered care, and personal recovery, principles which are increasingly becoming appreciated in the Western world (19).

Despite a growing body of evidence in the mental health field (20) it has not explicitly adopted structured "shared decision making" (21) nor prepared users and providers for its use (22).

Moreover, it has increasingly been appreciated that clients/users are cared for not only by physicians. It is therefore important that SDM be incorporated into the practice of allied and social care professionals. In the field of social work, there are voices claiming that there is a need for SDM to be promoted as a way to further client participation in policy practice (23). Levin (23, 24) had commented that while social work professionals view SDM as representing ideas of hope, change, identity and choice, they also express frustration that the rhetoric of client participation is strongly challenged by the clients' characteristics such as their degree of knowledge and responsibility and assertiveness as well as by the challenges resulting from the disparity between the principles of SDM and the professional frameworks where they are to be implemented.

Most of the SDM literature focuses on work undertaken in the medical field and little data exists about the implementation of SDM in the allied health and social care professions. Bringing about change in these fields is complex. Drawing from research in the aligning field of social policy, findings on the implementation of a reform in social services in Israel with regard to child protection and treatment, Alfandari (25) maintained that adoption of a good reform is not enough for it to be implemented. Policy makers cannot suffice with the development of good ideas and plans that are not professionally accepted. They are required to make well-defined efforts for building and anchoring a system and an action force that will create the conditions that will allow implementation in the field.

Therefore, in order to bring about more widespread use of SDM, changes have to occur not only at the organizational/policy levels but also in the value system that frames the professional's clinical practice. This begs the need to look at professional training, both for established practitioners as well as for students and neophyte professionals.

The training of professionals in SDM has burgeoned in recent years, focusing mainly on the health professions, and aimed mostly at physicians and nurses, with the majority being developed and conducted in the US and the UK (26, 27). These trainings vary between face-to-face workshops and courses to internet based models, varying in length, aimed at particular professions and even particular fields within the profession. There is however a shortage of trainings available for the allied health and social care professions (26).

An important development in the field of SDM training other than for physicians has been recently developed in the UK (28) with SDM training programs for social workers, nurses, occupational therapists, and others, in the mental health field. This article will describe our experience with developing and conducting a pilot SDM training program in Israel, which specifically targeted a wide audience of a variety of allied health and social care professions in different settings.

The Training Module

The training module in Shared Decision Making (SDM) was based on the previously mentioned UK model (28) that was originally designed for both mental health professionals and service users in the UK. We adapted this model to expand its use from mental health to other fields in the health and social care professions in Israel.

Content

The current module in Shared Decision Making (SDM) was based on SDM training principles for both mental health professionals and service users. These principles affirm adoption of SDM as a process rather than an outcome that demonstrates co-production within the partnership where the user is recognized as the expert by experience; and, the importance of encouraging service users to shape their preferences and to express these in ways that can be heard by professionals.

Additionally, this training module was designed to introduce the students to the values and practice of SDM, thereby opening up opportunities for its adoption in the everyday practice within the health and social care professions.

The core content of the training module comprised the following topics:

- overview and rationale of SDM history, key components of SDM and definitions
- barriers and facilitators of SDM
- recognition of power imbalances in the professional relationship
- the components of collaborative relationships
- the contributions of decision aids to the SDM process
- identification of potential ethical dilemmas in professional decision making processes

This content, largely based on current experience on SDM in the medical and mental health fields, was delivered in this pilot training using a range of interactive methods that included:

- slide presentations with video clips from different countries
- especially developed video material with a variety of clinical scenarios
- small group exercises
- handouts and referrals to resource materials
- general group discussions
- guest speakers involved in local SDM projects

The integration of these multiple teaching methods provided the setting for introducing the implementation of SDM into the students' practice as an integral part of their professional value system.

The pilot SDM training module was conducted face-to-face at each of two higher education sites: the first with graduate student practitioners in the OT department at Tel-Aviv University and the second at Tel Hai College in the Social Work department with undergraduate social work students.

The module comprised three full day workshops for a total of 24 h.

Participants

The participants in the Tel Hai training module were 22 final year undergraduate social work students (18 female and four male) who were part of the Social Policy track in the undergraduate program and who were enrolled in the track's Research Seminar. The training for the Tel-Aviv students was conducted in the Occupational Therapy department with 18 graduate students (16 female and two male) from a variety of disciplines: Physiotherapists, occupational therapists, psychologists, speech therapists, and nursing who were currently working in a variety of social and health settings.

Evaluation

The data for the pilot study was drawn from quantitative and qualitative sources:

Quantitative Data

A feedback questionnaire was developed by the training team and was administered at the close of the training. The questionnaire used a 5-point Likert scale and addressed the students' views on the training process and the relevance of SDM to their clinical practice. Descriptive statistics were used to analyze the responses to the Likert scale.

Qualitative Data

1. A short open-ended questionnaire at the outset of the module looked at the students' knowledge of SDM, where they had heard about it, it's perceived relevance to their clinical practice and their learning expectations.
2. A written assignment was given for the students to complete between the second and third workshops. Here they described a planned shared decision making intervention and implemented it. They were then asked to reflect on the barriers and facilitators of the SDM process from the material that arose throughout the different stages of their preparation and practice and that of their clients'.
3. Transcriptions of notes taken by the team members during the different stages of the module. For example, material was drawn from the third workshop when the students presented their experiences with the assignment and shared their insights with the group. They also discussed their examples of using SDM with different intervention modalities (individual, family, group and community levels) as well as with diverse population groups (the elderly, children and youth).

The team's notes during workshop discussions throughout the module together with the written material obtained from the practice assignment were transcribed. Then, the qualitative data was analyzed according to a modified method of qualitative content analysis (29) in order to elicit meanings and insights from the text and identify major themes.

RESULTS

Quantitative Data

Replies to the Likert scale administered at the end of the module on the training process and the perceived relevance of SDM to clinical practice provided further information. Response rate for this form was 66% ($n = 27$).

Interestingly the overwhelming majority of students (78%) from both sites underscored the importance of using SDM in their practice, and they also positively rated the content of the module as providing them with sufficient practice and feedback (see **Table 1**).

Qualitative Data

The responses to the open-ended questions of the feedback questionnaire prior to the first workshop highlighted that while the overwhelming majority of the students' recognized the importance of SDM in their practice, they also acknowledged that

TABLE 1 | Quantitative summary of the module.

		0	1	2	3	4	5
		N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1.	The workshop highlighted for me the importance of using SDM					6	21
2.	I received sufficient information about the overall goals of the module		1		7	10	9
3.	These workshops matched my expectations		3	7	6	7	4
4.	The content of the workshops is relevant to my work		1	2	3	7	14
5.	The goals of each workshop were clear to me		1	3	8	8	7
6.	The activities in the workshops stimulated my curiosity		2	7	8	2	8
7.	The activities in the workshops provided me with sufficient practice and feedback		1	3	8	10	5
8.	The degree of difficulty of the workshops was good				9	11	7
9.	The pace of the workshops was right for me		5	5	6	7	4
10.	I reached the goals of the module		1	3	4	9	10

they did not have the tools to implement it. On the question about the use of SDM with different user populations, all the students claimed that SDM could be implemented with all types of users and their families.

Following the training module, most of the students acknowledged many of the components of SDM and recognized the centrality of the users' place in the process. However, some of them referred to the importance of involving the user in the decision making process rather than genuinely creating a partnership with them. The content analysis based on the multiple sources of qualitative data yielded two main themes: the first addresses the challenges of moving from theory to practice ("Knowing and Doing" SDM: bridging the gap). The second theme focuses on the role of the practice settings ("We don't do it here": pressures and excuses). Each theme is described below with illustrative comments.

"Knowing and Doing" SDM: Bridging the Gap

The first theme relates to the gap that exists between the students' knowledge of the value systems driving their professions, in this case, user involvement and partnership in the helping relationship, and that of its practice. The students' understanding of the theoretical underpinnings of the allied health and social care professions did not serve them to realize true user involvement. In line with their theoretical knowledge, at the outset of the module, the students expressed enthusiasm and support regarding the value and need for partnering with users in making decisions about their lives.

> *"I believe this will be suitable for work with a lot of our client groups, and will benefit the development of cooperation with the client."*

However, during early discussions, some of the students expressed their disappointment that, in their view, the training content did not enrich their existing knowledge, as they had already previously learned about user involvement and user participation in their studies.

> "[T]*his isn't new, we have heard this all before – last year in our practice course and field work ....*"

Yet following the completion of the module, these students acknowledged that, despite previously learning the value system surrounding SDM in their studies, they had been limited in their knowledge and skills to implement it into their practice.

> "Here *I learned how to do SDM ... before I knew about it cognitively and rationally and now, I have grasped the importance from an emotional place."*
> *"I learned ways to do it [SDM] from examples where it is good."*

The gap between "knowing and doing" is clearly reflected by this student who sheepishly admitted,

> *"It is one thing to know about SDM and something different to do it. At the beginning I didn't understand what was different between what we had already learned throughout our studies but toward the end of the module I understood – the training really sharpened the point."*

As part of the learning process, the students now needed to reflect on the importance of alternative knowledge sources such as the value of experiential knowledge. Previously the students' knowledge base had prepared them to attribute far more to listening to their own expertise than to users' voices and experiences. This recognition was heard through the students' voices throughout the module,

> *"It is important to involve the client in a transparent way about decisions and changes that are related to him and his treatment – it is critical as a base for trust that is essential for the success of the intervention."*
> *"Until my participation in the course, I gave more importance to 'expert knowledge'. However, my way of thinking has changed greatly regarding the 'expert from experience' and I would very much like to share what I learned in the course with my patients and not to make any decisions for them. Their decision is central even if it is very different from the way I perceive things."*
> *"During the assignment, I noticed that I don't really listen to users. I rely mostly on my expertise."*

Some students addressed their difficulty in recognizing the power hierarchies that were inherent in their professional interactions with users.

> *"Although sometimes I feel that I know what the right thing is for the child, we need to step back and llisten to our clients – their voice is what is important – the client is the expert".*
> *"One time while I was listening carefully to the words the mother said, I also tried to understand the words she did not say - the distress she was in, and her difficulty in making the decision - she wanted the best for her child, but it was difficult for her to decide which of these choices was best for him. I realized that in the next meeting it would be important for me to strengthen her ability to choose - not only on the technical side, but also on the emotional side."*
> *"I tried to use it [SDM] with my clients, and then I started to realize that there are a lot of things that I want for them and the training made me see that I need to give more space for what they want…"*
> "*The client knows what is best for her… everything needs to be out there on the table … our solutions as professionals are mistaken and undermine the autonomy, the freedom, the independence and the responsibility of the client."*

"We Don't Do It Here": Pressures and Excuses

The second theme relates to the role of the practice settings in the learning experience. While this is a pilot study of delivering a training model into the allied health and social care professions, the findings illustrate how frequently professional practice is shaped by the approach of the host profession in the organization namely, the medical model. The following description, through the students' voices, draws attention to the barriers and challenges they faced when introducing SDM into their practice settings. These barriers were recognized by the students to occur in two areas in the care setting: the first is integral to the organizational structure and the second in the cultural context.

The Organizational Structure

Firstly, the barriers and challenges that were perceived by the students relate to the different types of care settings, whether it be a hospital, a school or a prison, grounded in bureaucratic structures such as in the development of practice protocols.

As one student working in a prison complained that "… *where I work is not in line with this approach [SDM] and I feel the gap in the field."*

One student pointed out the difficulties of the SDM process as being time consuming,

> *"Sometimes it is hard to give the clients their autonomy. Particularly in a system where an important focus of our work is placed on time constraints."*

The same student went on and pointed to the reporting procedures that did not recognize the time needed to carry out the SDM process. She admitted that,

> *"Even when I asked my supervisor how to report the intervention process, she said it was too long to fit the computer's definitions."*
> *"Sometimes it is hard to stay with the client's pace and wishes as the system is rigid and wants to speed up the client's discharge process from hospital. I feel like we as professionals even if we want to stay attuned to the patients we are on our own and there is no support from the hospital for being with the clients."*

The Cultural Context

The second area relates to the cultural environment surrounding the practice settings as characterized by the workers and users themselves as reflected in the students' words. Here the cultural context represents an environment that is not open to new value systems and the accompanying discourses, such as co-production or partnership and SDM with users. This unfamiliarity hindered open communication between the students and their professional colleagues and supervisors.

> *"It's a method that hasn't been adopted enough because there are people who don't believe in it and find it difficult to use in certain areas, such as the prison service"*

Furthermore, the students also reported on their difficulty in introducing the principles of SDM into their relationship with clients. Specifically, they pointed to cases of users who could not access needed resources to be partners in the SDM process, whether in the form of limited knowledge about locating information and other material resources or in the form of personal characteristics such as passiveness or cognitive issues.

As one student related,

> *"[C]hanging the balance of power between a patient and a provider is not so easy especially in hospitals and other systems".*

Another example of the difficulty in engaging users into the SDM process was voiced by a mature student who told of her clients' unease with questioning professional judgements. For instance when facing a panel.

"One of my patients had to face a room full of people… professionals who discussed my client's life between themselves. They decided that she should go to a community hostel as the best option. She told me afterwards that because all the professionals were sitting together, she didn't really feel she could say anything."

> *"Our clients don't see themselves as the experts and there needs to be a lot of work to make them feel empowered enough to be able to take on their share in the responsibility for the joint work process"*
> *"For me the difficulty was integrating active listening, exploration of different possibilities, and letting the client to take more responsibility on their journey, especially with my clients [with cognitive disabilities]".*
> *"Shared Decision making is not a one-time event … and what do you do with young children?"*

DISCUSSION

The present article follows the delivery of a pilot SDM training module into the students' curricula in the allied health and social care professions at two sites in Israel. It explores the potential for expanding SDM integration and training beyond the medical field for these professions. We described a pilot training module for these fields in two different sites with students from a variety of allied health and social care professions such as social work, occupational therapy, speech therapy and psychology. These students reflected their learning experiences throughout the module with practice experiences from fields such as child welfare, prisons, schools, residential care, and rehabilitation.

The following section is a discussion of the main themes that were identified from the students' voices throughout the training module together with thoughts on the practical implications. The section will conclude with lessons learned for strengthening the implementation of SDM into professional practice in the allied health and social care fields.

"Knowing and Doing" SDM: Bridging the Gap

At the outset of the module, the students expressed enthusiasm and support regarding the focus of user's participation in making decisions about their lives. In the literature on SDM, medical professionals also value its place in practice (18). However, the key message from our students related to the gap that exists between the values and content of the SDM training module and the reality of the dominant medical discourse that they encounter throughout their professional education and also later in the practice arena. This gap echoes the view of Kienlin et al. (30) who stated, "Although, shared decision making (SDM) is a best practice approach for decision-making communication about health-related issues, it has not yet been routinely adopted by most health-care professionals" (p. 2).

Looking at this discrepancy, we suggest that both health and social care knowledge and practice are traditionally anchored in the values, principles, and practices that comprise each profession's academic training, despite the fact that this existing knowledge is still infused with a predominantly positivist and traditional medical model of care (31). Within this context, subjective experience and personal meaning are not seen as part of the "medical hegemony" (32) and there is little recognition of users' knowledge (33).

At the outset of the training our students voiced their sense of familiarity with SDM principles based on their previous learning, both in course work and in practice. They articulated their prior expertise and wisdom to practice partnership, empowerment and authentic listening. This expertise had been formed from the building blocks of the helping professions which emphasize collaboration and client involvement. In a similar vein, this view seems to replicate the responses of family physicians following SDM training where "Most of the competencies sounded intuitively obvious to the physicians and close to what they already do or try to do" [(34), p. 329].

Even though the students claim to work with SDM, the first step in "doing" the SDM process requires identifying the existing power hierarchies that exist in professional relationships particularly regarding the role of users' experiential knowledge compared to professional academic knowledge. Here the students tended to attribute far more to listening to their own expertise than to users' voices and experience.

"We Don't Do It Here": Pressures and Excuses

Although patient involvement and participation in healthcare decision making has been associated with enhanced users' compliance and improved treatment outcomes, implementation of SDM by medical health practitioners is still rare (35). Consequently, there is little guidance on how to implement SDM in clinical social care practice (36). Students who started to integrate the SDM principles during the training module often reported on barriers that they confronted in the field which mirror findings from the mental health field (21). These barriers were perceived by the students to exist in two areas: the first is inherent in the organizational structure of the care setting whether it be a hospital or a school or a prison, which is grounded in a bureaucracy such as in the development of practice protocols. The second area relates to the cultural environment as characterized by the workers and users themselves.

In order to address the first area, turning to the healthcare literature for guidance, various organizational-level characteristics have been identified that may impact the implementation of SDM. For example, Scholl et al. (37) focus on characteristics such as the extent to which the organization's main purpose and vision for the future supports SDM and the degree to which organization heads proactively support SDM. Also, it depends on the extent to which an organization's culture supports SDM, as well as the degree to which other aspects of service provision conflict or align with SDM. These authors emphasize that many features have also been shown to influence implementation at the system level such as the degree to which SDM is included as a criterion in the accreditation of healthcare institutions, or whether legislation requires the practice of SDM. However, perhaps of relevance to our present discussion is the extent to which the initial and continuing education and licensing of health professions includes genuine SDM training (37).

Furthermore, implementation models can inform us about how to practice in the face of organizational barriers. This includes individual or collective evaluations of the concept and worth of user involvement, the quality of the relationships that exist between the different participants, the organizational environments in which these relationships occur, as well as the autonomy and abilities of the relevant figures involved in facilitating the change process (33). We agree that for significant involvement to occur there needs to be new patient/user definitions of how to address the quality of care relationships. Just as importantly perhaps, future organizational planning should support the time spent with users and be more flexible in meeting their needs (33).

Secondly, the cultural context was addressed by some of the students in both sites who spoke of how their professional colleagues and supervisors had not previously been exposed to discourses on partnership work and SDM. These same students anticipated the barriers they would face as professionals and spoke of the need for a real change such as accepting experiential knowledge as valid knowledge within the profession and not merely feigning "lip service." Here too, research with physicians had previously identified similar barriers to shared decision making and user involvement among professionals (38). These barriers included conceptual differences in the interpretation and meaning of involvement between service users and professionals, and a professional resistance to sharing or transferring power (33).

Thus, it became clear that, like physicians who had undergone such a training, one training module seemed insufficient to promote lasting change in their perceptions and behavior. "The complexity of the barriers to SDM means that a single educational intervention is unlikely to be effective in changing behavior even among predisposed physicians" [(34), p. 330].

There are also barriers on the side of the users. The students reported on the limited resources that the users were able to access, whether in locating information and other material resources or in the form of personal characteristics such as a cognitive impairment. Furthermore, the accepted norm of "passiveness" has been grounded in a long history of role socialization within the professional relationship and this too hinders the users' engagement. The students pointed to user expectations from professionals to lead and make the decisions. Some students suggested that there is a need to teach users how to become partners, a comment that is borne out in the literature on SDM in mental health (16, 39). In recent studies, the SDM process was linked to users' personal recovery, person-centered care, and engagement in the process (16, 18). In addition, users who were involved in educating professionals developed partnerships with the providers that reflected the users' own priorities (40).

Finally, user involvement in professional education has benefits for both sides. For professionals, to expand their knowledge base and for users to increase their confidence, self-respect, and feelings of empowerment that support their ability to become active partners (40, 41).

Lessons Learned

This study highlighted the relevance of SDM for both groups of students in the allied health and social care professions. However, it became clear that one training module seemed insufficient to promote lasting change in their perceptions and behavior. We therefore believe that an essential prerequisite to the expansion and promotion of the values and practice of SDM necessarily requires that students are challenged by a variety of critical ideologies and discourses throughout their professional education in a wide variety of areas. These alternative discourses, such as those grounded in critical theory (42, 43) are all but absent in such curricula, as are innovative pedagogic methods that can challenge the existing dominant discourse and perspectives (44). This type of pedagogy could be strengthened by a modeling of the student-teacher interaction that reflects the principles of partnership and collaboration across the various courses in the academic degree. Furthermore, the inclusion of service users throughout their professional education in a variety of roles would expose the students to the value of user knowledge and its role in developing professional relationships.

One of these roles is that of co-teacher. This pedagogy enables the development of partnership and dialogue within the classroom setting which can facilitate the development of an inclusive knowledge base and may address the concerns raised by our students regarding users' disempowerment in the professional relationship. Examples of such a pedagogy have been reported in both social work and occupational therapy in Israel (45, 46) and can be replicated in additional allied health and social care professions. Moreover, following Simmons (47) who reports on the contributions of young people as co-trainers, we believe that a co-teaching pedagogy needs to be incorporated into the ongoing design and development of future SDM training modules.

An important contribution to the effectiveness of SDM implementation into clinical practice is the use of SDM aids. This tool comprises tasks that promote a structured conversation for conveying the complexity of information which helps the user to participate more meaningfully. Thus, aids can increase user self-determination and engagement that effectively supports the decision-making process itself (48, 49) and we suggest that it may support students in their move to practice.

CONCLUSIONS

This module was developed as an initial endeavor to expand the use of SDM into the health and social care professions. This article brings a modest look at the students' experiences, but we suggest that future trainings need to be developed and evaluated in a systematic way.

While the training module was to our knowledge the first to be introduced to students at two sites in the allied health and welfare professionals, they were both conducted in the same geographical region, namely Israel. Therefore, some aspects of the structure of the module and our resulting conclusions may not be applicable to similar academic settings in other countries.

Building on the burgeoning literature on SDM trainings with physicians and other medical professions, we hope that our experience with this pilot training module encourages others to develop additional training modules and thereby further the vision of social justice and an improved implementation of shared understanding and undertaking between service users and providers.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

AUTHOR CONTRIBUTIONS

CG, AC, and DRA contributed equally to the research and writing of the manuscript. All authors approved the final version.

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