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ORIGINAL PAPER

Walking the Path Together: A Qualitative Analysis on How to Overcome Challenges of Shared Decision-Making in Families with Multiple and Enduring Psychosocial Problems

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Abstract

Shared decision-making (SDM) in families facing multiple and enduring psychosocial problems across life domains is hampered by the diverse needs and preferences of multiple family members, as well as differing opinions and roles of the various professionals and care services involved. In this qualitative study, we explored challenges of SDM when aiming to provide integrated care to families with complex psychosocial needs, and the facilitating strategies professionals and families adopt to overcome these challenges. Semi-structured interviews were conducted with 18 parents, 3 youth and 22 professionals. Moreover, 40 observations of multidisciplinary team case meetings of Specialist Integrated care Teams were conducted. Combining thematic, context, and strategy coding provided an in-depth understanding of SDM in this specific context. In our analyses, we identified challenges in SDM from the interplay of families' and professionals' context as well as facilitating strategies, described in three themes: (1) balancing roles of families and professionals, (2) trust and collaboration in making decisions, and (3) multiple stakeholders. To overcome these challenges, professionals and families are recommended to approach SDM as a continuous cycle throughout the care process, foster continuity in relationships, and engage in a human-to-human partnership with families.

Keywords Shared Decision-making · Child and Adolescent Mental Health · Integrated Care · Complex Problems · Families

Highlights

- SDM in families with multiple and enduring psychosocial problems and various professionals and services involved in families' care, is challenging.
- Our findings showed challenges in SDM regarding families' autonomy in care, building mutual trust and engaging multiple stakeholders.
- Professionals and families may approach SDM as a continuous cycle throughout the care process.
- Fostering continuity in relationships with families and professionals involved proved essential in building trust, needed for SDM.
- Engaging in a human-to-human partnership with families deemed crucial to establish equality and openness in SDM.

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Shared decision-making (SDM) is an important approach to tailor care to families' needs, by effectively engaging families and professionals in decisions on care (Liverpool et al., 2021a, 2021b; van der Horst et al., 2023). Moreover, SDM is known to improve client satisfaction on care and its quality (Langer et al., 2022; Liverpool et al., 2021a, 2021b; Simmons et al., 2011). In practice, however, professionals encounter major barriers in realizing SDM with families with multiple and enduring psychosocial problems (Hayes et al., 2020; Knutsson & Schön, 2020; Wolpert et al., 2014). Difficulties in these families can be described by a

combination of severe, persistent and interrelated problems of both youth and parents (including parents' individual problems) on various life domains (e.g., mental health, parenting, finances, and social network), leading to diverse needs and preferences in care (Bodden & Deković, 2016; Holwerda et al., 2014; Tang et al., 2024). Moreover, addressing the various needs of youth and parents requires involvement of multiple professionals from both youth and adult care services in different domains (e.g., mental health, youth and parenting support, intellectual disabilities, social welfare). These various professionals with different expertise (e.g., social workers, psychologists, and psychiatrists) typically hold different opinions, authorities and roles in families' care, which complicates SDM (Nooteboom et al., 2020a, 2020b). Finally, the ethic principle of families' and professionals' equality in deciding on care underlying SDM, may in practice conflict with professionals' active role in engaging often vulnerable families in SDM (Salzburg Global Seminar, 2011; Stiggelbout et al., 2015; Vooijs et al., 2021). To overcome these difficulties, in-depth insight is needed into the specific challenges of SDM with families with multiple and enduring psychosocial problems, as well as the facilitating strategies professionals and families adopt.

SDM is the process in which professionals and families make decisions on care in partnership, incorporating evidence-based practices, clinical perspectives, and the families' preferences and values (Bjønness et al., 2020a). SDM provides a means to actively involve families in their care process and encourage professionals to focus on families' needs and autonomy, thereby strengthening collaborative relationships and engagement in care (Bjønness et al., 2020a; Langer & Jensen-Doss, 2018; Wolpert et al., 2014). This is crucial, as a major issue in care is that families with multiple and enduring psychosocial problems all too often do not feel heard by professionals in their needs and preferences. As a result, these families receive inappropriate care, lose motivation and, eventually, drop out of care (de Soet et al., 2023; Spijk-de Jonge et al., 2022). Moreover, families tend to be approached as a stacking of problems requiring professional care, thus fostering the perception of families as dysfunctional and help-dependent (Tausendfreund et al., 2016). These processes hamper the collaborative relationships, engagement in care, and empowerment known as key factors in families' care, and, eventually, enhanced family functioning (King et al., 2014; Sousa & Rodrigues, 2012; Visscher et al., 2022).

Although professionals strive for SDM as a desirable ideal (Huang et al., 2020), its implementation in practice proves intricate, as shown by clients experiencing not being taken seriously in their opinions, having no real choice in care or feeling disempowered by professionals (Bjønness et al., 2020a; Farrelly et al., 2016; Knutsson & Schön, 2020; Vooijs et al., 2021). Reviewing previous studies on SDM in the care domains typically providing care to families with multiple and enduring psychosocial problems (e.g., youth and adult mental health, intellectual disabilities and social welfare), we found both facilitators and barriers in implementing SDM (Gondek et al., 2017; Knutsson & Schön, 2020). Facilitators are, for example, found in professionals' intrinsic motivation to collaborate with clients in treatment and a genuine interest in clients' preferences and needs (Chong et al., 2013; Hayes et al., 2019; Langer & Jensen-Doss, 2018). Moreover, clients and professionals emphasize the importance of sufficient time to establish collaborative relationships and enable clients to feel safe in decision-making (Bjønness et al., 2020a, 2020b; Teale et al., 2024; Ten Brummelaar et al., 2018). In addition, professional skills needed for decision-making are identified as facilitator, such as listening and negotiation skills (Hayes et al., 2019; Hayes et al., 2020; Knutsson & Schön, 2020).

Previous studies also show barriers in implementing SDM. First, when clients, their relatives and professionals hold differing opinions on care decisions (Liverpool et al., 2021a; Nooteboom et al., 2020a). Since youth in care always involve parents participating in SDM, depending on youth's age either responsible or co-responsible in decisions, decisions need to be reached in the triangle of youth, parents and professionals (Edbrooke-Childs et al., 2016; Hayes et al., 2023; Liverpool et al., 2021b). Second, clients' vulnerability in coping capacity or mental ability can impact their decision-making skills, especially in moments of crisis or mental relapse (Chong et al., 2013; Farrelly et al., 2016; Teale et al., 2024; Verwijmeren & Grootens, 2023). Concerning youth, professionals need to consider their maturity in making choices, which will also develop over time (Cheng et al., 2017). Third, other impeding factors are related to client-professional relationships, such as a lack of trust, power imbalances or social desirability in expressing clients views (Bjønness et al., 2020a; Knutsson & Schön, 2020; Kooijmans et al., 2022). Finally, organizational factors may hinder SDM implementation regarding a lack of time among professionals, unavailable options of care (e.g., due to waiting lists), and inflexibility to tailor the care process (Gondek et al., 2017; Hayes et al., 2019; Nykänen et al., 2023).

As previous studies on facilitators and barriers in SDM focus on a specific care domain (such as youth mental health care or social welfare), they lack specific recommendations for practicing SDM with families facing a combination of problems of both youth and parents across different life domains, that need to be addressed jointly by different care services. Obviously, SDM is impacted by the specific context of these families, such as the involvement of multiple family members in decision-making and the multitude, interconnectedness and changeability of families'

problems (Nooteboom et al., 2020b; Tausendfreund et al., 2016). In addition, since the multiple needs of families often exceed the expertise and possibilities of a single professional or care service, providing integrated care for the whole family from different care services is a necessity (Lennox-Chhugani, 2021; Nooteboom et al., 2021). When providing integrated care, professionals strive for coherent, coordinated and continuous support, across different care levels and services and tailored to the needs of families (Nooteboom et al., 2021). In practice, however, conflicting values, visions and interests of the multiple professionals and care services involved complicate making shared decisions with families (Cloin et al., 2022; Ndibu Muntu Keba Kebe et al., 2020; Nooteboom et al., 2020b; Stacey et al., 2014). Hence, both the context of families and of professionals and care services lead to specific challenges for professionals in practicing SDM, however, this has rarely been studied (Tausendfreund et al., 2016).

Therefore, this study aims to gain in-depth insight into the specific challenges of SDM in families with multiple and enduring psychosocial problems when providing integrated care, from the perspectives of families and professionals. First, by identifying elements from the context of families and from the context of professionals and care services hampering SDM. Second, by exploring the interplay of the context of families and of professionals, leading to specific challenges in SDM. Finally, by unraveling strategies professionals and families adopt to overcome these challenges. This knowledge can guide practice in improving SDM with families with multiple and enduring psychosocial problems by enhancing professionals' and families' strategies, eventually leading to care fitting families' needs and preferences.

Method

Setting

This study was part of the qualitative research project 'The specialist nearby?!' (2020–2022) in which we collected data in five Specialist Integrated care Teams (SITs) in four regions (i.e., The Hague, Midden Holland, Alphen aan den Rijn and Katwijk) of the Netherlands. In these fully integrated care teams, professionals from various youth and adult specialized services (e.g. in the domains of mental health, youth and parenting support, intellectual disabilities, and addiction) collaborate on a daily basis to provide outpatient support to families with multiple and enduring psychosocial problems (Barnhoorn-Bos et al., 2025). Families supported by SITs (including families participating in this study) experience a combination of problems of youth and siblings in the family (e.g. in mental health, intellectual disability, addiction/crime, education/work), an individual problems of the parents (e.g. in mental health, intellectual disability, addiction), and socio-economic problems (e.g. finances, work, household, housing, social network). Problems are described as severe, enduring, and interrelated, leading to frequent safety issues (Barnhoorn-Bos et al., 2025). Families are referred to SITs from other primary or specialized care services, often after a long history of care. The teams include child and parent social workers, psychologists, and psychiatrists. SITs provide diagnostics, treatment, and counseling for youth (4–18 years old, e.g. for mental health, social, and school problems) and their parents (e.g., for parenting, social, and financial problems), with a maximum care period of one year, and work locally to deliver specialized care close to families. The Medical Ethics Review Board of Leiden University Medical Centre concluded that the research project, including this sub-study, was not subject to the Medical Research Involving Human Subject Act (WMO), complied with the Netherlands Code of Conduct for Research Integrity and informed consent must be given by interview participants (N20.200). The Consolidated criteria for Reporting Qualitative Research (COREQ) were applied to promote transparency and ensure clear and comprehensive reporting of the study methods (Tong et al., 2007).

In this study, a qualitative design from a constructivist paradigm was applied, enabling us to explore the challenges of SDM within a practical context and gather perspectives and experiences on SDM in a setting not previously studied (Ritchie et al., 2013; Varpio et al., 2017). Our design comprised both semi-structured interviews with a wide range of participants and observations of SITs multidisciplinary case meetings (De Boer & Smaling, 2011). In SITs multidisciplinary case meetings, care processes were evaluated with the various professionals involved, providing insight in actual practices and subconscious processes of professionals. In a participatory design, three professionals from SITs were involved as research practitioners as a side project during their daily task (Hawkins, 2015). They approached families and fellow professionals to participate in the study, assisted in data collection (after training by the researchers) by observing their own team's multidisciplinary case meetings and participated in reflective meetings with the researchers. Time invested by the research practitioners was compensated. Two SITs did not supply research practitioners, due to practical reasons (time or human resources) or their preference to have research conducted by external researchers. These SITs were supported by the researchers (AB and EH). By the triangulation of data (i.e., semi-structured interviews and observations) and participants groups (i.e., parents, youth and professionals), comparing and combining multiple perspectives,

we gained full understanding of SDM in this specific context (Jonsen & Jehn, 2009; Onwuegbuzie & Leech, 2007).

Participants

Interviews

To obtain a broad range of perspectives on SDM reflecting the diverse population of SITs, we applied a purposive heterogeneous sampling method. We predetermined the number of participants in each group and aimed to include participants with a wide variety of demographic characteristics and backgrounds (Etikan et al., 2016; Robinson, 2014). Concerning families, we aimed for a representative mix of both parents and youth, with variation in gender, cultural background, family status, and educational level. Within the group of professionals, we sought to include participants with varying expertise, occupation, educational level, work experience, and gender as much as possible.

To reach the families, who are often highly burdened by their problems, recruitment of parents and youth was conducted directly by the research practitioners or other professionals from the teams. In achieving the required number of youth and parents, eventually all families receiving care from the SITs were invited to participate in an interview using an accessible flyer, formulated in collaboration with a parent representative. Professionals were invited (by email, telephone or face-to-face) by the researchers (EH, AB) or the research practitioners of the SITs.

All participants were provided with verbal information and an additional letter describing the project and process of interviewing (audio-taping, confidentiality, and the right to withdraw at any time). After their (mainly digital) written informed consent, participants were contacted by the researchers (AB and EH) to schedule the interview at their preferred place (at home, the team's location or the researchers' office) and modality (online or face-to-face). Necessary demographic data of all participants were documented before or during the interview, such as gender, age, cultural background, and educational level. Parents and youth received a gift voucher (of 20 euro) in acknowledgement of their participation.

Observations

Participants of the observed SITs multidisciplinary case meetings included the professionals involved in the case being discussed and the team psychologist or manager chairing the meeting. The number of professionals attending the case meeting varied by team and case discussed, with an average of five participants. Some participants of observations also participated in an interview.

Data collection

Semi-structured interviews and observations of multidisciplinary case meetings were collected between March 2021 and April 2022.

Interviews

Based on previous studies of facilitators and challenges in SDM (Bjønness et al., 2022; Bjønness et al., 2020a, 2020b; Bjønness et al., 2020a, 2020b; Hayes et al., 2019; Hayes et al., 2020; Knutsson & Schön, 2020) a topic list with open-ended questions (Appendix A) was formulated, including questions on: (1) how participants experienced SDM and what they considered as facilitating or impeding SDM, (2) collaborative relationships between families and professionals, and characteristics or skills of professionals and families influencing this collaboration, (3) professionals' and families' roles in taking control in the care process. The topic list was modified to fit the language and experiences of youth and parents in collaboration with a parent representative (CT).

In total, 43 interviews (mean duration of one hour) were conducted by two researchers (EH and AB) with parents ($n = 18$), youth ($n = 3$) and professionals ($n = 22$). Four parent couples wished to be interviewed together. In these cases, all parents were counted as individual participants and an interview with two parents was analyzed as a whole, including perspectives of both parents in the analysis. Two parents requested to be interviewed in the presence of a professional for support. The interviews were audio-recorded and afterwards pseudonymized and transcribed (verbatim) by the researchers (AB and EH) and students (two from Medical University and one from University of Applied Sciences). The presented quotes have been translated from Dutch to English by the researchers (AB and EH).

Observations

Observations of multidisciplinary case meetings in four SITs ($n = 40$) were monthly conducted. These included non-participant observations in two SITs ($n = 23$) by the researcher (EH) and participant observations in two SITs ($n = 17$) by the research practitioners, participating in their own SITs case meeting (Busetto et al., 2020; Mulhall, 2003). All observations were reported applying an observation framework (Appendix A) based on previous studies of facilitators and barriers in SDM (Bjønness et al., 2022; Bjønness et al., 2020a, 2020b; Bjønness et al., 2020a, 2020b; Hayes et al., 2019; Hayes et al., 2020; Knutsson & Schön, 2020). Additionally, the non-participant observations ($n = 23$) were transcribed (nearly verbatim) by

the researcher (EH). Each observation report was pseudonymized by the researchers.

Analysis

All transcripts were imported into ATLAS.ti (version 9), a computer program for labelling and organizing text content. We applied thematic analysis as an appropriate method to identify themes across our data set, including different types of data (interviews and observations) and participants (families and professionals) (Kiger & Varpio, 2020). To obtain a deep and broad understanding of SDM in this specific context, we combined different coding and analysis techniques (i.e., thematic, context, and strategy coding) (Evers, 2015; Saldaña, 2021). Appendix B provides a visualization of the analysis process.

First, we thematically analyzed the interviews on challenges in SDM, applying both deductive and inductive strategies (Kiger & Varpio, 2020). In deductive coding of the transcripts, we applied a framework of predefined codes based on previous research on challenges in SDM (Appendix B) (Bjønness et al., 2022; Bjønness et al., 2020a, 2020b; Bjønness et al., 2020a, 2020b; Hayes et al., 2019; Hayes et al., 2020; Knutsson & Schön, 2020; Langer & Jensen-Doss, 2018). In inductive coding, the coding tree was supplemented with other themes arising. All interviews were coded, and after coding 25 interviews (an equal number of each participant group) no new themes were identified, indicating inductive saturation. Moreover, the themes gained conceptual depth when coding the remaining interviews, achieving theoretical saturation (Saunders et al., 2018). By summarizing and synthesizing the initial framework codes and open codes, three main themes were formed (Smith & Firth, 2011).

Second, we further analyzed the three main themes that occurred in the thematic analyses by applying both context and strategy coding (Saldaña, 2021). In context coding, we coded elements in the specific context of families or professionals and care services hampering SDM. Using strategy coding we analyzed families' and professionals' strategies in addressing challenges in SDM.

Third, we coded and analyzed the transcripts of the non-participant observations and the observation framework reports of the participant observations by the coding framework, containing the thematic, context and strategy codes derived from coding the interviews (Appendix B). The code framework was then supplemented by new themes or depth and nuance within themes, emerging from the observations.

Finally, we combined and interpreted the results of the thematic, context, and strategy coding (Evers, 2015). We described the interplay of the context of families and of professionals and care services, leading to specific challenges in SDM and the strategies of professionals and families in addressing these challenges. Due to the limited number of youths participating, we analyzed the perspectives of parents and youth together as families' perspectives. When differences were identified between parents and youth, we reported them separately.

A reflexive stance considering the researchers' perspectives, previous experiences and assumptions in interpreting and construct meaning to the data was fostered by keeping a research journal, noting reflections after each interview and observation, and by peer debrief meetings with the researchers (AB, LN, EH) and a parent representative (CT) (Barber & Walczak, 2009; Olmos-Vega et al., 2022; Tufford & Newman, 2012). During these meetings the researchers discussed e.g., research aims, design of observations and interviews, and meaning of the generated data and themes from different backgrounds and expertise (AB also working clinically in youth mental health care, LN as expert on integrated care and qualitative research, EH conducting doctoral research on integrated care, and CT contributing from a parent experiential perspective), while reflecting on their roles, interests and biases (Braun & Clarke, 2024). To increase the internal credibility of the results, informant feedback was obtained through four learnings sessions in which participants (i.e., research practitioners, participating professionals and the parent representative (CT), including one session with youth representatives) reflected on the recognizability, interpretation and applicability of preliminary study outcomes (Onwuegbuzie & Leech, 2007). These sessions also served as a member check (Varpio et al., 2017).

Results

Demographics

Demographics of youth, parents and professionals are outlined in Appendix C. The three participating youth were 15, 16 and 17 years old, one female and two males. They varied in cultural background, educational level and family structure. The group of parents (of children of different ages) showed variation regarding age, educational level, and family structure, although not in cultural background (mainly Western) nor gender (majority of mothers). The participating professionals varied in age, work experience, educational level, expertise, and occupation, but not in gender (mainly women).

Qualitative Findings

Elements from the context of families and of professionals and care services hampering SDM

In this study, we first explored which elements from the context of families and the context of professionals and care

services hamper SDM. These are presented in Table 1 (families) and Table 2 (professionals and care services).

In the context of families, we found families' (1) vulnerability due to high stress and the (2) changeability of problems and coping strategies impede families' overview on problems and their decision-making skills. Moreover, (3) disturbed family relations hamper SDM by the intricate communication among family members and with professionals. Finally, families' (4) distrust in care and vulnerable feelings (e.g., fear of professionals' disapproval), often reinforced in cases of (5) lack of family safety, affect families' openness on problems and their attitudes towards professionals in SDM.

In the context of professionals and care services, we found the (1) multitude of professionals and care services, each expecting families' commitment and openness, and professionals' differing care perspectives overwhelm and confuse families in decision-making. Moreover, (2) lack of clarity in dividing roles and responsibilities of professionals and care services in families' care, especially between youth protection and voluntary care, complicate and delay decision-making. Finally, (3) formal and inflexible approaches of professionals and care services (i.e., inflexible care processes, set care protocols and distant approaches of families) hinder making decisions from equal and collaborative relationships of families and professionals.

Challenges in shared decision-making

In this section, we describe the interplay of the context of families and of professionals and care services, leading to specific challenges in SDM and the strategies of professionals and families in addressing these challenges.

We describe these challenges in three themes: (1) Balancing roles of families and professionals, (2) Trust and collaboration in making decisions, and (3) Multiple stakeholders. We focus on the shared perspectives of families and professionals, but separately describe perspectives mentioned only by parents, youth or professionals. A perspective referred to as a families' implies that it was mentioned by both parents and youth.

Balancing roles of families and professionals: follow and guide Although families and professionals emphasized striving to make decisions in care based on equality and autonomy of both families and professionals, elements from families' context necessitate professionals to regularly take control in the SDM process. Considering families' vulnerability due to high stress, the changeability of problems, and in cases of lack of family safety, professionals are expected to compensate for families' limited overview on problems and decision-making skills at that time. Elements from the context of professionals and care services further endanger families' autonomy in SDM. In the multitude of professionals and services involved, regularly consulting each other in families' absence to align tasks and roles, families acknowledged losing control of their own care process. Challenges in balancing families' and professionals' roles in SDM were further described in two areas.

First, it is about balancing professionals' knowledge with families' lived experience. Where professionals provide clinical knowledge (including evidence-based practices) regarding the explanation of problems, overview of care options, and long-term vision in care; families contribute lived experience on the interrelatedness of their problems, goals regarding family life and the efficacy of an intervention for this family.

> That you are truly seen as an expert by experience and that seriously is listened to what you think as a parent. Regarding what might be causing things, why things are the way they are, and also what does not work. Even though a professional always has to keep thinking critically and ask critical questions around that (Parent 16).

Second, balance is needed in taking control of the care process. Generally, families expected from professionals to provide the overall direction in care, prioritize problems and options and use their professional power in organizing support. Professionals acknowledged to sometimes take over decisions from families if mentally unable or in case of lack of family safety. Most families allowed professionals doing so, provided they were transparently involved in the decision-process.

> I think the key is to leave control with the family. But in such a way that you manage to guide them, that they actually take the control (Professional 16).

Strategies of Professionals. To address challenges when balancing roles, professionals mentioned to take an active role in SDM, while stimulating families' own responsibility, self-reliance and exploration of lived experience.

Regarding balancing professionals' clinical knowledge and families' lived experience, families valued when professionals emphasize the importance of contributing families' lived experience, support in identifying families' values and preferences, and actually incorporate these into the shared explanation of families' problems and care plan. Moreover, to balance families' and professionals' control in care, professionals schedule regular evaluations with families throughout the care process, but also at key

Table 1 Elements from the Context of Families with Multiple and Enduring Psychosocial Problems, Hampering SDM

Context of families with multiple and enduring psychosocial problems	Impact on shared decision- making
(1) Vulnerability of families	
Families experience high levels of stress, have lost control in daily life and find themselves in a downward spiral of escalating problems. Parents feel vulnerable, e.g., feelings of failure as a parent, fear of being rejected by professionals or a potential out-of-home placement of their child. Or have traumatic feelings due to upsetting past and present family incidents (e.g., youth's suicide attempt or physical aggression).	Families experience limited ability to consider solutions and make decisions. Families are sensitive to professionals' attitudes: when insufficiently matched with families' needs, families hesitate to be vulnerable and open on problems in decision-making.
(2) Changeability of families' problems and coping capacity	
Families' problems and coping capacities in managing daily life fluctuate during the care process. Suddenly emerging or rapidly worsening problems (i.e., youth's school suspension, imminent house eviction or parent's depressive episode) demand immediate attention from professionals.	Due to families' fluctuating (overview on) problems and decision-making skills, families' and professionals' roles in decision-making change likewise. Families and professionals focus on urgent problems, losing sight on long-term goals.
(3) Long and troubled care history and built-up distrust of care	
In their long care histories, families describe adverse experiences with care professionals and care services (e.g., not being taken seriously in their concerns, disappointment in the benefits of professional care, frequent changes of professionals or professionals not keeping appointments).	Families approach professionals in decision-making in two different ways: (i) Acting reluctant to decision-making, e.g., in holding off meetings or hesitation in disclosing themselves to professionals. (ii) Assertively, sometimes aggressively, standing up for and strongly adhere to their needs, avoiding being disappointed again.
(4) Disturbed relations within families	
Disturbed relationships between parents (i.e., relational problems or complicated divorces) and between parent(s) and youth (i.e., conflicts or refusal of contact).	The intricate communication and information exchange on care between family members hampers shared decision-making.
(5) Lack of safety in families	
Concerns about family members' safety from neglect or abuse require professionals to assess family safety. Families are often supervised by youth protection and, in cases, being forced to accept care to prevent youth's out-of-home placement.	By professionals' assessment of family safety or in cases of coercive care, families are anxious and reluctant to share their problems in decision-making, or even avoid any contact with professionals.

Table 2 Elements from the Context of Professionals and Care Services, Hampering SDM

Context of professionals and care services	Impact on shared decision- making
(1) Multiple professionals and care services involved in families	
Often many different professionals and care services are involved in families, simultaneously or sequentially.	All professionals and services expect families' commitment, time and openness in decision-making, thereby overwhelming and burdening families.
Professionals and care services hold differing perspectives and practices in care, also by failing to share or use available information on families.	Differences of opinion or practices among care professionals lead to ambiguity for families in decision-making.
(2) Different roles and responsibilities of professionals and care services	
Roles and responsibilities in families' care often remain unclear, both for families and for professionals themselves.	Unclear roles and responsibilities of professionals complicate and delay shared decision-making.
The division of roles and responsibilities between voluntary care and youth protection, when both involved in families, is intricate.	Voluntary care and youth protection holding differing views on their mutual roles in families' care complicate assessing family safety and making decisions accordingly.
(3) Formal and inflexible approach of professionals and care services	
Professionals and services too often adhere to inflexible care processes, work by protocol rather than tailored to families and hold distant approaches to families.	Making decisions on family-tailored care from equal and collaborative relationships of families and professionals is hindered.

decisions (such as determining the explanatory analysis or treatment plan, youth's out-of-home placement or school dismissal). Regarding these evaluations, professionals emphasized providing time to prepare evaluations with families and empowering them to explore their own opinions and solutions in problems.

Strategies of Families. Families, on their part, sought to voice their lived experience in care decisions, which may require accessing unconscious knowledge, such as parental intuition or logical thinking on possible solutions. Moreover, families and professionals emphasized families engaging in creating care plans and openly express their potential disagreement.

Trust and collaboration in making decisions: walking the path together Professionals and families acknowledged well-established collaborative relationships between families and professionals can lead to mutual trust, allowing shared decision-making to proceed smoothly. However, adverse interplays between elements from families' context and the context of professionals and services disrupt building mutual trust and collaboration.

First, families experiencing high stress levels and vulnerable feelings (e.g., feeling failure as a parent or fear of professionals' disapproval) are expected to disclose themselves and establish relationships with multiple professionals involved. Consequently, parents and youth acknowledged not being open about their problems in decision-making, either by avoiding contact or by presenting the situation more favorably in fear of professionals' opinions. Families further experienced reluctance to repeatedly share their story, due to frequent changes of professionals by staff turnover or families' referral to another team or service.

> Eventually mother came to trust me. […] Because we got to know her patterns better and better. […] I could also discuss that with her, and she became more and more open about it (Professional 3).

Second, parents and youth emphasized being sensitive to the match with professionals, e.g., from personality problems or experienced trauma, often reinforced by previous negative experiences in care. They highlighted formal and inflexible approaches of professionals and services leading to additional barriers in building trust for SDM. For example, by being assigned to professionals in the care process, instead of being offered a choice based on a potential match.

Finally, cues of lack of family safety and professionals needing to assess safety accordingly, can lead to tensions in building trust and making shared decisions. Not only within a compulsory framework, but also in voluntary care,

parents recognized hesitation to share all concerns, due to fear of their child's out-of-home placement. Consequently, we found families' closure reinforces professionals' concerns about family safety, requiring them to assess safety and leaving families feeling controlled rather than supported.

Strategies of Professionals. In addressing the aforementioned challenges, professionals recommended approaching building trust as a process underlying and necessary for SDM, requiring time and attention. In this process, we found professionals need to continuously adapt their strategies to the current dynamics between family and professionals and keep connecting, also during breaks in trust. Four strategies for professionals were described in building trust for SDM.

First, families and professionals emphasized to engage in a human-to-human contact, rather than formal, distant professional-family relationships, to understand families in their context and consequently find solutions that fit families' needs.

Second, parents and youth stressed the importance of professionals truly listening to families' needs, preferences and lived experience, and actually including families' perspectives in the care plan.

Third, in cases of lack of family safety, transparent information on professionals' practices in safety assessment was valued by families. Professionals aimed to openly discuss with families any tensions in mutual trust arising from appointing cues of lack of safety.

Finally, fostering long-term collaborative relationships with families was considered key in making decisions from mutual trust. In these relationships, time must be available to connect to families and explore their needs, planning small steps rather than quick goals, preparing families to key decisions, and overcome potential barriers in trust together with the family.

Strategies of Families. For families it was deemed important trying to adopt openness in decision making, despite potential distrust in care. For example, by sharing their problems and concerns and assertively expressing their wishes and preferences. Some parents acknowledged accepting their child's problems or parents' own part in the family problems was needed to open up in SDM.

> And then they just did whatever and I thought: 'Yeah, that doesn't help either'. But maybe that was also because I was not completely telling the true story myself. (Youth 2)

Multiple stakeholders in decision-making: a softer conversation Families as well as professionals emphasized to involve all relevant stakeholders in decision-making (i.e., the youth in care and its parents, other relevant family members, key persons from the social network, school, and professionals from the formal care network), ensuring the care plan is supported by all persons involved. However, we found this process to be strained by the interplay of elements from the context of families and of professionals and services.

Obviously, the different family members and the various professionals and services involved yield differing opinions in care, e.g., on the shared explanation of families' problems, goals in care or prioritization in the care process. Moreover, both disturbed relations within families and differing, unclear roles and perspectives of professionals often result in conflicting opinions between family members and among professionals. Especially, differing views between voluntary care and youth protection on family safety, and their respective roles in assessing and intervening in cases of lack of safety provide uncertainty for families. In addition, families' approach in decision-making from built-up distrust of care (acting reluctant either strongly standing up for their needs), in particular when matched with professionals holding formal and inflexible approaches, can lead to polarized positions between families and professionals in SDM.

Participants experienced barriers in involving all stakeholders in the contact and information exchange, necessary for SDM. Parents' or youths' refusal to share information on care with family members or professionals (deriving from disturbed family relations or distrust in care) impedes professionals in maintaining multiple relationships with family members and monitoring the family situation. Especially parents of youth 16 years or older struggled with their child's right to make decisions on care and withhold parents from information. In the end, parents are responsible for their child and experience consequences of care decisions in daily life.

> What we would like is to be involved as parents. Right now, we are actually just standing on the sidelines. You feel powerless, frustrated. […] He (their son) determines a lot and the professionals go along with it. (Parents 8 and 9)

Strategies of Professionals. In addressing the challenges of multiple stakeholder involvement in decision-making, we found professionals to approach (potential) disagreement between different stakeholders as a specific focus in care. For example, by addressing family members' mutual understanding and integrating professional perspectives as part of the care process, rather than a precondition for starting care. In doing so, we found two strategies described by professionals and families.

First, professionals aim at establishing trustful relationships with different family members from multiple partnerships. Matching parents and youth each with a designated professional, ensures all parties to feel involved, heard and supported in decision-making. However, information exchange in the triangle of parents, youth and professionals ought to be covered by clear agreements on what, when and with whom is shared.

Second, in dealing with conflicting professional opinions, professionals use interprofessional consultation and reflection (e.g., in multidisciplinary case meetings) to gain insight in their own perspectives, roles and responsibilities in families' care. Clearly distinguish their role in care prevents professionals from being assigned an inappropriate role by other services involved. Regular consultations with families, the social and care network were deemed important for transparent information exchange and decision-making. However, families and professional recommended to specifically determine for each consultation and decision concerned which participants should be invited.

> I stay away from things that may endanger my position as a professional. […] I need to be able to stay involved to offer support to the family. So […] I never take on the role of an organization that is involved from a mandatory framework, thereby jeopardizing my role. (Professional 8)

Strategies of Families. Both families and professionals emphasized the importance of youth and parents assertively presenting their own perspectives and needs in care. For example, when families openly express potential disagreements with the shared explanation of families' problems, care plan or care process. In addition, parents and youth acknowledged to deliberately choose being receptive to professionals' perspectives and arguments, even in cases of limited trust in care.

Discussion

To our knowledge, this study is the first to provide insight into the specific challenges of SDM with families facing multiple and enduring psychosocial problems when aiming to provide integrated care from different care services. Moreover, we have attempted to gain in-depth insight into the complex interplay of impeding elements, beside solely focusing on impeding or facilitating factors in SDM as common in previous studies (Bjønness et al., 2020a, 2020b; Hayes et al., 2019; Hayes et al., 2020). In SDM, families who experience high-stress, distrust in care, and fluctuating problems, are expected to adopt openness and make well-considered care decisions with multiple professionals and services, holding different opinions, roles and responsibilities. It is precisely this interplay leading to complex, adverse processes in SDM regarding families' autonomy, mutual trust and multiple partnerships. Specifically, we found (suspected) lack of safety in families disrupts families' trust in professionals, openness on families' problems and equal partnership in SDM, as in these cases professionals have conflicting roles of supporting families on the one hand and ensuring youths' safety on the other. Although the resulting intricate power dynamics in SDM between families and professionals are known from previous research (Toros et al., 2018), our study shows that the differing responsibilities and practices of professionals in SITs voluntary care and youth protection regarding intervening in lack of family safety, reinforce uncertainty and tensions in SDM for both professionals and families.

Whilst several barriers we found are known from other care settings (such as distrust in care or differing opinions among stakeholders), our study specifically highlights the combination and mutual reinforcement of these challenges in SDM with families facing complex psychosocial needs. Moreover, these complex challenges seem resistant to clear-cut solutions and require a specific approach in SDM.

In finding ways to address these challenges, professionals and families recommended various facilitating strategies. In the following section, we draw four practical implications for promoting SDM with families facing multiple and enduring psychosocial problems when aiming to provide integrated care.

Practical Implications for SDM with Families with Multiple and Enduring Psychosocial Problems

SDM as a continuous cycle throughout the care process

First, SDM may be approached as a continuous cycle of decision-making interweaving the entire care process, rather than a demarcated phase to be completed at admission or start of treatment. Since both the family situation (needs, preferences and development of the various family members) and the professional care network are constantly changing, the care plan and professionals' and families' roles in its implementation need to be adjusted accordingly. As indicated in prior research, regularly scheduled evaluations of the care plan with families and professionals deemed essential to adequately address newly emerging problems or barriers in the implementation of the care plan (Nooteboom et al., 2020b). We specifically found that in these sessions, time and support can be provided for families to express values and preferences and exchange differing opinions between family members and with

professionals in an open and respectful way. Moreover, since decision-aids to support clients in SDM are widely adopted in (youth) mental health care, it is noteworthy that in our study neither families nor professionals mentioned to use decision-aids (Cheng et al., 2017; Langer & Jensen-Doss, 2018). This could be related to the complexity and interconnectedness of problems in both youth and parents, limiting the applicability of decision-aids, usually targeted at specific, individual problems. Therefore, family-focused decision-aids supporting decision-making on the assessment of families' problems and the care plan (such as the explanatory analysis of families' problems (Tempel et al., 2022) may be further developed and implemented in practice. Finally, professionals in our study advocated to use interprofessional reflection and evaluation (e.g., in multidisciplinary case meetings) to navigate across fluctuating family situations and varying professional care networks (Nooteboom et al., 2022).

Fostering continuous relationships with families and the care network

Second, trustful and equal relationships with youth and parents are key in making shared decisions, yet intricate due to the interplay between the context of families and professionals. We found continuity in families' relationships with professionals proves essential in building trust and cultivating hope. Professionals holding on to relationships, despite or across conflicting opinions or lack of trust, may prevent stagnation of care, drop-out or referral to other care services, only further decreasing families' trust and motivation in care. These findings are consistent with previous research, emphasizing the value of continuity in relationships, especially needed in engaging youth and their families with enduring problems in care (de Soet et al., 2023). However, fostering continuous relationships with families and the care network (Huang et al., 2020; Verwijmeren & Grootens, 2023) requires time and flexibility in the care process to enable professionals building partnerships with multiple family members and other professionals. Echoing previous studies, establishing open relationships in the triangle of parents, youth and professional(s) is recommended to promote transparent information exchange and decision-making between parents and youth, especially considering the often disturbed family dynamics (Fitzpatrick et al., 2022). Also, in adapting to changing roles of youth through maturity in decision-making and with age increasing rights to make decisions without parents, professionals are advised to ensure parents remain involved in decision-making. Especially in (suspected) lack of family safety, straining mutual trust and partnership, professionals in our study recommended to not only reflect on their own perspective and role in family safety assessment and related interventions (Cloin et al., 2022), but also align with other professionals and services (especially when involved from a mandatory framework) on mutual roles in safety issues. For families, transparent communication on professionals' roles in family safety issues, given their (often unspoken) concerns of forced interventions, seems essential to build mutual trust. However, further research is needed to more deeply explore families' and professionals' perspectives in SDM regarding families' safety, specifically on the interface of voluntary and mandatory care, as previous studies mainly focused on professionals' decision-making or the specific setting of youth protection (Bartelink et al., 2018; Cloin et al., 2022; Toros et al., 2018).

Engaging human-to-human partnerships with families

Third, engaging in a human-to-human contact deemed crucial to establish equality and openness in SDM. Rather than specific skills or tools in SDM, often emphasized in previous studies (Hayes et al., 2023), we found particularly professionals' attitudes were mentioned as facilitating SDM. Thus, reflecting previous research, professionals are valued when truly believing in the value of families' lived experience and autonomy to effectively provide families with tailored care (Box et al., 2023; Drivenes et al., 2019; Verwijmeren & Grootens, 2023). However, this requires both professionals and families to adopt new roles (Verwijmeren & Grootens, 2023). Professionals need to actively identify and utilize youth and parents' lived experience or disclose own decision-making processes and related uncertainties. Families, on their turn, have responsibility in exploring their lived experience, values and preferences in care, adopt openness on their problems, and assertively express their opinions to professionals. By supporting families in practicing autonomy in care, power imbalances and families' dependency in care may be mitigated (Simmons & Gooding, 2017; Sousa & Rodrigues, 2012; Vooijs et al., 2021).

SDM as part of care

Finally, although professionals fear SDM will take extra time in addition to regular sessions, as shown in previous studies (Gondek et al., 2017; Huang et al., 2020), we advocate to consider SDM as part of care instead of an extra task (Clayman et al., 2024). By investing in trustful relationships with youth and parents, integrating perspectives on care among family members and with professionals, and supporting families in discovering goals and values in life, professionals practice SDM while working on main goals in care. Hence, therapeutic relationship and alliance on goals and tasks in care are

known as common effective factors in treatment (Wampold, 2015). Moreover, previous research shows SDM as an effective approach in navigating discrepancies among youth, parents and professionals to promote treatment engagement (Fitzpatrick et al., 2022; Verwijmeren & Grootens, 2023). However, follow-up mixed-methods research is needed to provide insight into both families' experiences and treatment outcomes when implementing the identified facilitating strategies in SDM (Langer et al., 2022). Moreover, organizations and policy hold a significant role in facilitating professionals to adopt the proposed strategies, e.g. by embracing SDM and equal client-professional relationships in organizational vision and policy, providing professionals with sufficient time to invest in long-term relationships with families and other professionals, and supporting interprofessional reflection and multidisciplinary case meetings (Waddell et al., 2021).

Limitations and Strengths

A strength of this study is its qualitative design: combining different perspectives (i.e., parents, youth, and professionals), multiple data sources (semi-structured interviews and observations), and various analysis techniques (thematic, context, and strategy coding) provided in-depth insight in the complex process of SDM (Evers, 2015; Onwuegbuzie & Leech, 2007). Moreover, the structured and theoretically grounded method in which the study was conducted, e.g., following the COREQ guidelines, using a predefined coding framework based on previous research, and applying multiple analysis methods, enhances the validity and reliability of this qualitative study (Onwuegbuzie & Leech, 2007; Tong et al., 2007).

From a hard-to-reach and often vulnerable group of families, we were able to include 18 parents in our study. However, the limited number of three participating youth implies a limitation for this study. We mitigated this limitation by analyzing perspectives of parents and youth together as families', reporting any differences between parents and youth separately. Further research is needed to explore the perspectives and experiences in SDM of youth from families with complex needs. Moreover, although we encouraged research practitioners to invite all parents and youth, professionals felt inhibited by their fear of overburdening the family or doubts about parents' or youths' ability to participate. This may have affected the composition and size of the participant group.

The specific setting of Specialist Integrated care Teams in which we collected our data impacts the external generalizability of our findings (Onwuegbuzie & Leech, 2007). We included participants with varying demographic characteristics considering age, educational level and family structure, however the vast majority of parents was female and from Western backgrounds. As we know preferences and needs in SDM may vary across cultures, it is important to reach participants from different ethnic backgrounds in future studies (Qin et al., 2024). Moreover, given the small sample of families and the exploratory nature of our investigation of challenges in this study, we chose not to assess the type of problems per family. However, in further research differentiation in the type of problems or combination of problems per family can give more insight into which strategies are helpful or less helpful for which family. Additionally, since we found SDM is a continuous process throughout care and roles of families and professionals change over time, it is important in follow-up research to take into account the stage of care participants are in.

Although the interview transcripts were not returned to the participants for correction or comment, we did obtain feedback on the preliminary results from participants through learning sessions. Moreover, a parent representative contributed families' perspective in reflexive meetings on the study outcomes.

Implications for Research

Given the exploratory nature, the small sample of youth, and the specific setting of our study, further research is needed on the validity and applicability of our findings. For example, to identify perspectives on challenges and strategies in SDM from a larger group of youth, as their unique perspective needs to be included when fitting SDM to the preferences of the whole family. Further analyses can provide insight into potential differences between youths', parents' and professionals' perspectives. Moreover, other settings in which care services provide integrated care for this specific group of families (such as in co-location or with cooperation agreements) should be explored on challenges in SDM and strategies applicable in diverse settings. Thus including a larger number of participants from diverse settings in integrated care and applying complementary research methods, such as surveys, focus groups or a Delphi method, the applicability and transferability of our results can be explored (Onwuegbuzie & Leech, 2007). Additionally, further research aimed on differentiation in the type or combination of problems, demographic backgrounds, and the stage of care per family can give more insight into which strategies are helpful or less helpful for which family at which time in care. Finally, follow-up mixed-methods research can provide insight into the effectiveness of the found strategies when implementing these in practice. For example, by investigating treatment outcomes and families' experiences on quality of care (e.g., regarding SDM, collaborative relationships, and trust in care). A specific focus on facilitators and barriers on the levels of organization and

policy is needed to explore which factors influence the long-term success or failure of the found strategies, e.g. training of professionals, fostering client engagement, developing and implementing decision-aids, staff turnover, financial resources, and institutional policies (Waddell et al., 2021, Clayman et al. 2024).

Conclusion

In SDM with families facing multiple and enduring psychosocial needs, the interplay of impeding elements from families' and professionals' context lead to complex, adverse processes regarding families' autonomy in care, mutual trust needed for SDM, and engaging the various family members and professionals in multiple partnerships. To address these challenges professionals are recommended to approach SDM as a continuous cycle throughout the care process, foster continuity in relationships, and engage in a human-to-human partnership with families. In this way, families and professionals can walk the path together.

Data availability

The datasets used and analyzed during the current study (transcripts of the interviews and observations) are not publicly available due to privacy related issues. Information on transcripts is available from the corresponding author on reasonable request. Topiclists, observation framework, and coding frameworks and are available in the Appendices.

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Author contributions AB, LN, EM and RV contributed in the conceptualization, methodology and fundraising of this study. AB and EH conducted the interviews. AB, LN and EM developed the coding framework. AB and EH coded all interviews; LN contributed in reflexive meetings. AB, as the first author, wrote the major part of the manuscript, all other authors contributed in writing the manuscript. We confirm that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all authors. All authors read and approved the final manuscript.

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Compliance with ethical standards

Conflict of Interest The authors declare no competing interests.

Ethics Approval and Consent to Participate The Medical Ethics Review Board of Leiden University Medical Centre judged that this research project should not be subjected to evaluation according Medical Research Involving Human Subject Act (WMO) and complied with the Netherlands Code of Conduct for Research Integrity.

Consent for Publication Written informed consent for participation in the study and publication of the results was obtained from all parents, youth (from 12 years), and professionals participating in this study. Participants were guaranteed non-traceability of personal data. A copy of the consent form is available for review.

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