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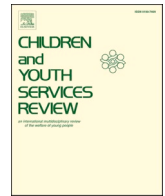
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How to meet the needs of youth with severe and enduring mental health problems: A qualitative study to barriers and facilitators in treatment

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ABSTRACT

Youth with severe and enduring mental health problems (SEMHP) do not profit from regular child and adolescent psychiatric (CAP) treatment. Their changing and complex problems cause enormous suffering. To understand why these youth inadequately profit from CAP treatment, this qualitative study aimed to examine the experiences of youth with SEMHP, practitioners, and caregivers to identify barriers and facilitators in treatment. We conducted 31 semi-structured interviews with youth (n = 10), practitioners (n = 10), and caregivers of youth with SEMHP (n = 11). A thematic analysis was performed both deductively and inductively, and the perspectives of participants were compared. Results showed barriers and facilitators in five categories: before treatment, engagement and accountability, trust-based treatment, organization of care, and hopelessness. To restore epistemic trust, a shift from a risk-avoidance approach towards trust-based relationships in treatment is required. Additionally, organizing continuous and tailored care can prevent youth from slipping through the cracks of waiting lists and receiving inadequate treatment.

1. Introduction

Youth with severe and enduring mental health problems (SEMHP) often do not profit sufficiently from treatment in child and adolescent psychiatry (CAP). These youth experience substantial impairment in various life domains and show severe self-destructive behavior (Herpers, Neumann, & Staal, 2020; Woody et al., 2019; Wright et al., 2017). Due to the heterogeneous and shifting mental health problems resulting from changes in their developmental stages and altering symptomatology, youth with SEMHP commonly slip through the gaps of existing evidence-based treatment programs that primarily target single classifications (Woody et al., 2019). Consequently, therapies continuously shift with the changing classifications of these youth, leading to discontinuity and inadequate care (Norcross & Lambert, 2018; Woody et al., 2019). Evidently, if treatment fails, mental health problems are likely to deteriorate, creating a societal burden of waiting lists and high healthcare costs, and increasing the risk of long-term mental health problems as these youth transition into adulthood (Friele, Hageraats, Fermin, Bouwman, & van der Zwaan, 2019; Kessler et al., 2007; Sellers et al., 2019; Warren, Nelson, Mondragon, Baldwin, & Burlingame,

2010). To address these imminent clinical and societal issues, this study aims to explore treatment experiences of youth with SEMHP, practitioners, and caregivers to gain insight in barriers and facilitators youth with SEMHP encounter in treatment.

Previous research on patients with Borderline Personality Disorder, which could be relevant in the treatment of youth with SEMHP, demonstrates the importance of epistemic trust - the degree to which a person trust the relevance and reliability of the knowledge offered by the other (Fonagy & Allison, 2014). Epistemic trust is vital for learning from others and for treatment success. However, youth with SEMHP commonly experience little epistemic trust due to instability at home, traumatic events, social exclusion, and insecure attachment (Bevington, Fuggle, & Fonagy, 2015). Moreover, when youth suffer from persistent mental health problems, the risk of treatment failure increases and may reinforce the already existing lack of epistemic trust. This creates a downward spiral, which complicates treating these youth (Bevington et al., 2015).

Furthermore, treatment failure of youth with SEMHP, that often show high-risk behavior (Woody et al., 2019), often leaves practitioners with feelings of discouragement and uncertainty, subsequently affecting

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the therapeutic relationship (Piselli, Halgin, & MacEwan, 2011). This is problematic as the therapeutic alliance – the interpersonal processes occurring in parallel with specific treatment techniques but are theoretically independent of them – play a major role in treatment success (Baier, Kline, & Feeny, 2020; Elvins & Green, 2008; Horvath, Del Re, Fluckiger, & Symonds, 2011). Studies show that a poorer therapeutic alliance between the practitioner, youth, and caregivers increases the risk of treatment failure (Hauber, Boon, & Vermeiren, 2020; Ormhaug & Jensen, 2018; Pereira, Lock, & Oggins, 2006; Stige, Barca, Lavik, & Moltu, 2021). However, the construct of alliance varies across studies and some alliance factors, such as having a ‘real bond’ with the practitioner, may be more critical for adolescents than other alliance constructs, such as the mutual understanding of treatment goals and tasks (Stige et al., 2021; Summers & Barber, 2003).

A recent systematic review suggests that previous research has been concerned with outlining client factors (e.g. age, gender, and classification) resulting in treatment failure for youth with SEMHP (de Soet et al., 2023). However, this review demonstrates that these outcomes are contradictory, and fail to acknowledge constructs such as treatment alliance and epistemic trust. While the risk of treatment failure for youth with SEMHP is known, as well as the importance of epistemic trust and alliance for treatment success, in-depth research into barriers and facilitators in treatment for this group is limited (Bevington, Fuggle, Fonagy, Target, & Asen, 2013). To date, qualitative studies focusing on within-treatment factors show that practitioners should be aware of the variety of problems youth in treatment experience that can lead to disengagement (Andersen, Poulsen, Fog-Petersen, Jorgensen, & Simonsen, 2021; O’Keeffe, Martin, Target, & Midgley, 2019). Although these studies provided meaningful results, they focus solely on specific patient groups, and have failed to account for youth with SEMHP who have interrelated mental health problems. Furthermore, treatment effectiveness studies rarely include youth with SEMHP because of exclusion criteria such as comorbidity and instability (e.g. high risk of self-harming behavior and suicidality) (Hauber, Boon, & Vermeiren, 2017).

Studying the experiences of youth with SEMHP, their practitioners, and caregivers will likely inform us about why these youth do not profit from current care and what could enhance treatment success (Cleveland, 2017). By integrating scientific evidence with the clinical experience from practitioners and the lived experience of patients and family members (i.e. caregivers), we can develop an evidence-based practice that fits the needs of youth with SEMHP (Kuiper, Munten, & Verhoef, 2016). Therefore this qualitative study aims to increase insight into the experiences, barriers and facilitators of treatment in CAP for youth with SEMHP by examining the perspective of youth, practitioners, and caregivers. We will describe themes related to treatment success and failure. In addition, we will also explore the differences between the perspectives of youth, practitioners, and caregivers. As a result, we aim to gain a deeper understanding of the elements required to improve the quality of care and make treatment more compatible.

2. Method

2.1. Setting and study design

This qualitative study is part of ‘DevelopRoad’, a research project with the objective to enhance our understanding of the characteristics and needs of youth with SEMHP, focused on child and adolescent psychiatry (CAP) in the Netherlands. The project team consisted of researchers, patient experts, and experts in the field, associated with LUMC Curium (a CAP facility in the Netherlands). The Medical Ethics Review Board of Leiden University Medical Center concluded the overall research project ‘DevelopRoad’ is not subject to the Medical Research Involving Human Subjects Act (WMO). The board also concluded that the overall research project complies with the Dutch Code of Conduct for Research Integrity (reference number: N21.094).

For the overall project ‘DevelopRoad’ we opted for a grounded theory as our methodological orientation, in which a conceptual idea is constructed inductively in several stages (Strauss & Corbin, 1994). Since there is limited knowledge on youth with SEMHP, the grounded theory provides the opportunity to establish a framework with several complementary studies. For this specific study, we conducted semi-structured interviews and analyzed the data using thematic analysis (Braun & Clarke, 2023). The thematic analysis method we employed is exploratory in nature, where themes are developed both deductively – based on existing literature research (de Soet et al., 2023) – and inductively from the data itself. The Consolidated criteria for Reporting Qualitative Research checklist (see Appendix A) was used to provide a transparent and accurate representation of the research (Tong, Sainsbury, & Craig, 2007).

2.2. Participants

Participants were recruited through theoretical sampling (Chun Tie, Birks, & Francis, 2019), Practitioners and youth were interviewed, followed by caregivers because of their role in the treatment of their child (Ormhaug & Jensen, 2018). To select suitable participants fitting our profile, participants were sampled purposively – a non-probability sampling method based on the judgments of the researchers (Chun Tie et al., 2019). We defined youth (aged 16–25 years) with SEMHP as youth (1) who are (or have been) in treatment in child and adolescent psychiatry (CAP), because of (2) interrelated and enduring mental health problems that necessitate care. To be eligible for this study, participants had to meet to the following inclusion criteria:

Youth key informants were defined as youth (1) aged between 16 and 25 years old, who participate in a youth commission, such as the Dutch National Youth Council (NJR) or work as an experienced expert/peer specialist via a Dutch organization called Experienced Experts (ExpEx), and (2) have experience as a patient in CAP before the age of 18 years old, and (3) recognize themselves in the description of youth with SEMHP. We chose to include youth key informants because of their personal lived experience with receiving care for SEMHP, and ability to represent and advocate for others receiving treatment for SEMHP (de Beer & Nootboom, 2022). Youth key informants were recruited by contacting organizations working with experienced experts (ExpEx and NJR) and by approaching the contacts of project team members.

Caregivers refers to parents and/or legal guardians of a child with SEMHP, according to the definition of SEMHP above. No specific inclusion criteria were set for caregivers, except for their involvement in their role as a caregiver for the child’s mental illness and its treatment. Caregivers were recruited through requests made in caregiver network groups and through announcements made on social media.

Practitioners in this study were defined as mental health specialists who bear final responsibility for treatment trajectories of youth with SEMHP (e.g. head practitioners, such as psychiatrists and case managers). They were recruited in four academic CAP facilities in the Netherlands (i.e. LUMC Curium, Level, Accare, and Karakter). Information about the project was provided through information letters sent by email, including information about the overall research project, practical information about the interviews, and agreements on the utilization and safe storage of study data. Subsequently, potential participants were contacted via email or telephone. All eligible participants signed an informed consent before taking part in the interview. Participants were offered a 25,- euro voucher for their time invested. We interviewed a total of 31 participants: youth key informants (n = 10), practitioners (n = 10), and caregivers of youth with SEMHP (n = 11). Of the 11 caregivers, one interview with a mother was excluded in the final analysis because it appeared that the caregiver did not fully meet the inclusion criteria (experience with CAP). Her interview was only used as reference material.

2.3. Procedure

A topic list (Appendix B) with open-ended questions was created based on a previous literature review (de Soet et al., 2023). To ensure the acceptability and relevance of the questions, the topic list was pilot tested on two peer specialists and two (clinical) psychologists (Baarda et al., 2018). The topic list covered several themes: current treatment services and accessibility of care; barriers and facilitators in CAP treatment; involvement in CAP treatment decisions; and 'out of the box ideas' to improve care for youth with SEMHP. The topic lists were adjusted to the group of participants. For example, the topics for the interviews with caregivers focused more on parental involvement and their views on their child's treatment.

The semi-structured interviews lasted approximately one hour and were conducted by one of the researchers with experience in interviewing (RS or CB, both female) together with a research assistant, under supervision of an experienced qualitative researcher (LAN). Interviews with practitioners and youth took place during the period of March to June 2021, and the interviews with caregivers took place during the period of October 2021 to March 2022. Interviews were conducted individually and digitally by using Microsoft Teams, a secure digital platform within the online environment of the Leiden University Medical Center. Interviews were carried out in Dutch, and audio recordings were transcribed verbatim. Field notes were taken during the interviews and discussed with the other researcher (RS or CB) or research assistant directly after the interview. The transcripts and fieldnotes of the interviews were pseudonymized and saved on a secured domain of the Leiden University Medical Center. Participants were given the opportunity to make additions by telephone or email after the interview. These additions (n = 3) were content clarifications and were added to the transcripts.

2.4. Data analysis

Interviews were transferred to ATLAS.ti version 9, a qualitative data analysis and research software program. The process of data analysis followed the principles of thematic coding, whereby grounded theory coding techniques are used to form a theory, developed from the systematic collection and analysis of data, as described below (Braun & Clarke, 2023; Chun Tie et al., 2019). Data were analyzed using thematic analysis (van Staa & Evers, 2010). First, a coding framework was deductively formulated based on a previous literature review (de Soet et al., 2023) and during reflexive meetings with the project team. In addition, new codes were inductively explored through line-by-line open coding of the interviews. To limit interpretation bias, the transcripts for the first five interviews with youth and practitioners were coded separately by two researchers (RS and CB). Subsequently, all discrepancies in coding were discussed and resolved to reach consensus, if needed with a supervisor (LAN). No additional codes were added after coding 13 transcripts for the practitioners and youth key informants, indicating that inductive thematic saturation was reached (Saunders et al., 2018). The same process was repeated for the interviews with caregivers. During the coding process of the interviews with caregivers, seven additional codes were added to the original coding framework (see Appendix C).

After the open coding process, axial coding was performed to form overarching themes by connecting open codes and concepts in the coding framework. Finally, selective coding was applied; the themes resulting from axial coding were combined into overarching categories. In this stage, barriers and facilitators in relation to the treatment of youth with SEMHP were listed per theme. Afterward, a conceptual analysis was conducted to quantify the occurrence of themes (Elo et al., 2014). Because this study was based on the perspectives of youth, as well as practitioners and caregivers, differences in perspectives were to be expected. The analysis included a systemic record of whether reports of youth, practitioners, and caregivers matched or contradicted each other.

This data source triangulation enhanced the credibility of the findings (van Staa & Evers, 2010).

3. Results

3.1. Demographics

Demographic data were not explicitly requested, however, from the interviews we extracted the following information about the included participants: youth (female n = 7, male n = 3) had a mean age of 21 years old (age range 19–24). The caregivers (biological mothers n = 8, and biological fathers n = 2) had a mean age of 53 years old (age range in years 46 – 64). Their children with SEMHP were mostly girls (80%, mean age 19.6 years) of which one child deceased at the age of 24. The mental health problems mentioned by youth themselves and caregivers of youth were a combination of depression, personality disorders, eating disorders, autism, suicidality, anxiety, and impaired functioning in several areas of life. The practitioners (female n = 5, male n = 5, age range in years 35 – 57) consisted of nine (child and youth) psychiatrists and one CAP case manager/therapist.

3.2. Findings

The identified themes were divided into the following five categories: before treatment, engagement and accountability, trust-based treatment, organization of care, and hopelessness (see Table 1). Themes are described in more detail below, first listing barriers followed by facilitators. An overview of barriers and facilitators in the treatment for youth with SEMHP can be found in Appendix D.

3.2.1. Category 1. Before treatment

Prior to the commencement of treatment, participants described several factors during the diagnostic phase that impacted the treatment process. These factors are described below and include: overlooking the complexity of problems and (a lack of) focus on the context.

3.2.1.1. Complexity of problems. A barrier both youth and caregivers experienced included the diagnostic process, whereby the diagnostic classification was often established too quickly, and based on observable symptoms that distressed youth and their environment the most. Although these symptoms did not always correspond to the underlying problems, the classification was thereafter leading in the choice of treatment. Youth and caregivers perceived this to be problematic as this prevented practitioners from exploring the core of the problem leading to suboptimal results in treatment (see caregiver quote below). Another barrier mentioned by participants was that instability was often invoked as a contraindication for treatment, while in many cases, the complexity of problems contribute to the instability of youth with SEMHP.

"You know, those floating air mattresses in the water that you lie down on in the pool and then try to get it under water. In many cases, our experience is that we only push one side of the air mattress underwater, causing the other side to rise. So, they don't look at the whole picture." Caregiver2

As facilitators in dealing with the complexity of problems, participants described the need for triage by experts and time to get to know youth before a treatment plan is formulated. Secondly, instability should not be a contraindication when deciding whether or not to initiate treatment in youth with SEMHP, as illustrated in the quote below.

"... what makes the difference is whether you really want to make a difference. (...) I was turned down for three years before I found a practitioner. And then they treated me super well. I really made enormous progress in a few months, while being told for three years that I was not stable enough. What ultimately matters is the choice you do or do not make. And that can really be the difference in life and death with these youth." Youth10

Table 1
Conceptual analysis of components of treatment factors in youth with SEMHP.

Category	Description	Themes from coding scheme	Frequency of themes by # of participants ^a
1. Before treatment	Factors relevant to the course of treatment prior to the start of treatment, such as the diagnostic process.	Complexity of problems Context	Y: 5 / PR: 4 / CA: 4 Y: 9 / PR: 10 / CA: 10
2. Engagement and accountability	Describes the impact of a lack of trust in treatment on youth's engagement, and the experienced accountability of practitioners.	(Dis)engagement Risk avoidance Accountability	Y: 7 / PR: 7 / CA: 8 Y: 7 / PR: 10 / CA: 9 Y: 4 / PR: 8 / CA: 0
3. Trust-based treatment	Treatment based on trust and autonomy, and a transparent relationship.	Relationship Autonomy of youth Transparency	Y: 9 / PR: 8 / CA: 9 Y: 6 / PR: 5 / CA: 10 Y: 8 / PR: 6 / CA: 8
4. Organization of care	The extent to which youth experience continuity and coordinated clinical care, and smooth transitions as youth transfer between different parts of health care.	Accessibility Collaboration Tailored care	Y: 6 / PR: 3 / CA: 10 Y: 7 / PR: 9 / CA: 6 Y: 7 / PR: 8 / CA: 8
5. Hopelessness	Hopelessness as a consequence of perceived barriers in treatment.		Y: 6 / PR: 8 / CA: 5

^a Y = youth; PR = practitioners; and CA = caregivers.

3.2.1.2. *Context.* A frequently mentioned barrier included a lack of focus on the context in which youth were situated. Too little attention was paid to improving functioning in different areas of life (school, home, leisure activities), and to the influence of their environment, such as friends and family, on youth's functioning and vice versa.

A facilitating factor often mentioned by participants was involving and offering support to youth's environment in order to enhance treatment success. This means, treatment should be offered in youth's own context whenever possible, although participants emphasized that this is not always possible for reasons of safety for either youth or caregivers. The choice of inpatient or outpatient treatment needs to be made more carefully with the involvement of caregivers. In addition to evidence-based treatment, attention should be paid to a daily routine and perspectives in other domains, such as school/work and housing, as explained by one youth in the quote below.

"I have a cycle of being manic and depressed. When I am depressed I fall behind in school, which causes so much stress. School is never included in treatment. Because my treatment facility assumes school can do that. They don't actually communicate." Youth9

3.2.2. Category 2. Engagement and accountability

During treatment of youth with SEMHP, there are various factors associated with (dis)engagement of youth and the behavior of practitioners (risk avoidance and feelings of accountability) that seem to influence the treatment process.

3.2.2.1. *(Dis)engagement.* A barrier linked to treatment of youth with SEMHP was youth's disengagement in treatment, also described as a lack of motivation. Participants indicated that youth were often not open to treatment nor actively cooperative. Youth's disappointment of failing treatments led to despair and loss of trust in improvement, which in turn led to disengagement. According to some practitioners, offering treatment to someone who does not seem to be motivated is pointless. However, caregivers and youth indicated that when practitioners lose hope, practitioners tend to interpret obstacles in treatment as a lack of motivation in youth. One practitioner agreed with this perspective as illustrated in the following quote.

"I think motivation is a bit of an unpleasant word. It has a very negative connotation as if you very consciously don't feel like it. That's why I talk more about avoidance behavior because it keeps them away from something very stressful." Practitioner2

According to participants, facilitators to increase engagement are actively asking and taking time to explore youth's motivation for treatment. Moreover, outlining a problem analysis that youth and caregivers can identify with was also stressed as being helpful. In addition, attention should be paid to individual strengths and qualities in order to give youth ownership of their lives. Accordingly, youth should be able to retain their own life (e.g. school, home, leisure activities) as much as possible.

3.2.2.2. *Risk avoidance.* A barrier reported by participants in treatment of youth with SEMHP was the frequent tendency of practitioners, caregivers, and treatment facilities to adopt a risk avoidance approach in response to youth's high-risk behavior (e.g. suicidality, self-harming behavior, extreme weight loss, aggression, and loss of contact). In such situations, a pitfall of practitioners is to take over control. Everything is done to prevent the child from harmful behavior, which reinforces avoidance and high-risk behavior, particularly in the case of a crisis situation. One practitioner described this process in the quote below. Additionally, compulsory medication and coercive measures, and the unpredictability in the response of treatment facilities regarding the treatment process, contribute to distrust by youth and caregivers.

"In a society where the pressure is high, where problems have to be made manageable, and where there is a big claim culture when something happens (...). That leads to an image of suicidality were, if we just follow the protocols and guidelines properly, then it must be preventable. That makes you start seeing suicidality as something that has to be controlled, and then you start working in a protocol-based way. (...) while sometimes we also have to stand next to youth and dare to take the risk with them to move forward. Then it matters what kind of pressure is put on you and how you look at a particular situation as a healthcare practitioner." Practitioner5

Facilitating elements according to some participants, are implementing policies within treatment facilities and on a national level, that aim to prevent crisis admissions (i.e. admission to a treatment facility following a crisis assessment). Furthermore, in case of crisis, it is important to have a crisis plan embedded in a clear organizational structure: it should be evident how crisis can be managed and who bears responsibility, as this can increase trust among youth. Practitioners and youth agreed that practitioners should not become risk-avoidant when dealing with high-risk behavior of youth with SEMHP. To help facilitate this, practitioners should be able to openly discuss the mortality risk of youth with SEMHP with their co-workers, youth, and caregivers (see the

quote below).

“Sometimes you only need someone to listen to you, hear your story, and if possibly help you get through your day. Instead of being told right away; ‘we are going to assess you now, someone from crisis care is coming over.’ That makes you much less likely to ask for help if you already have negative experiences. (...) It is important to be able to feel that there is someone who wants to listen to me and help me, without all the alarm bells going off, which only makes me more anxious. Then I won’t say anything because then the next psychiatrist will come and give me a pill or say I have to be hospitalized.” Youth5

3.2.2.3. Accountability. A barrier experienced by practitioners in the treatment of youth with SEMHP is the culture of accountability in the healthcare sector. Practitioners mentioned as barriers: little trust in the expertise of practitioners; along with a high degree of accountability to protocols and administrative burden; and limited time for self- and team reflection. Moreover, due to under-capacity, not all necessary treatments can be provided (e.g. trauma treatment). In line with the theme ‘risk avoidance’, practitioners reported that organizations redirect youth to other healthcare organizations because they are afraid to take risks and to be held responsible when a crisis escalates.

“Colleagues are falling by the wayside as a result of prolonged high work pressure: they either become persistent and start working in a controlling manner ‘I tried and it didn’t work out’. Or they quit working in the sector: ‘I’ve given so much and I’m done’.” Practitioner3

To reduce feelings of high accountability, participants described that it is important to bear treatment responsibilities as a team with a clear agreement on the different roles of the team members. Furthermore, more time and attention should be paid to the possibility to reflect as practitioners and CAP treatment facilities on one’s own behavior and the treatment process. Practitioners emphasized normalizing peer-to-peer coaching in order to break through powerlessness, shame, and loneliness among practitioners.

3.2.3. Category 3. Trust-based treatment

Participants described several elements that influenced the amount of trust in treatment, including the therapeutic relationship, autonomy of youth, and transparency.

3.2.3.1. Relationship. The aforementioned ‘disengagement and accountability’ (category 2) seems to have a negative impact on the therapeutic relationship between youth and practitioners. For example, participants identified several barriers to establishing a good therapeutic relationship, including overreliance on personal perspectives and practices, not taking youth seriously, being judgmental, little time investment to get to know youth, and frequent changes between practitioners, as illustrated in the quotation below. At the same time, youth explicitly reported that it is unhelpful when practitioners are too accommodating and fail to ask questions or challenge them when needed.

“I noticed that every time she had to change to a new therapist and had to tell her story again, she would have another setback. It resulted in her going completely down the drain again. She had a good connection with her first therapist.” Caregiver7

A facilitator reported by participants to increase trust in the therapeutic relationship was the proximity of a practitioner who is involved for a long-term period, thus providing accessibility and stability. Also, youth and practitioners mentioned the positive effect of self-disclosure by the practitioner. Youth indicated that they should be able to change practitioners when they experience no connection with the practitioner. Contrary, practitioners indicated that switching should only be done as a last resort. Finally, according to participants, regular reflection in treatment on the therapeutic relationship with youth is

essential.

3.2.3.2. Autonomy of youth. The participants had different views on the level of autonomy (i.e. youth’s ability to make decisions regarding their treatment plan and care) youth should have in treatment. All youth, most practitioners, and a minority of caregivers described a lack of autonomy for youth in treatment as a barrier. According to them, youth are (unintentionally) held back by bounding rules in treatment facilities and develop feelings of incapability. As a result, avoidance behavior persists, making it increasingly difficult to put the responsibility back in the hands of the youth. Depriving autonomy of youth in treatment hinders enhancing their trust in treatment. In reverse, most caregivers felt that the autonomy of these youth, who exhibit high-risk behavior, should be restricted, as illustrated in the quote below.

“But at a certain point, with these youth and complex psychiatric problems, you just have to set aside their autonomy for a moment, because in these moments they can no longer care for themselves. And you have to take over control. So forbid them things.” Caregiver4

Both youth and practitioners underlined the importance of youth experiencing autonomy in treatment to regain trust. Facilitators mentioned by the participants included: providing information about treatment options, engaging in shared decision-making, and leaving responsibilities with youth. For practitioners, this entails ‘sitting on their hands’ at times. It involves finding a balance between guiding and explaining, while also acknowledging youth’s hopelessness and accepting the potential consequences of high-risk behavior. Promoting autonomy also requires allowing youth to make personal choices, even when these choices may be considered ‘wrong’. Nevertheless, a majority of caregivers did not agree with the perspectives above, and indicated that restricting youth’s autonomy in treatment is necessary to protect them and their surroundings.

3.2.3.3. Transparency. Transparency is defined as a way of communicating and providing insight to make informed decisions in the treatment process. Participants reported that a lack of transparency represented a barrier to restoring trust in treatment. This could manifest as woolly language, inadequate information about treatment options (described in the quote below) and exclusion from the decision-making and reporting processes.

“Once towards the end of my treatment, I was given an option between psychomotor therapy and creative therapy, but neither was explained properly to me. So then I didn’t know how to decide and I just said; ‘which one is available first... I don’t know?’ (...) I think it would have helped me a lot when they had given me options, so I could actually choose what I wanted.” Youth4

To facilitate transparency, participants underlined the need for open discussion of treatment options where obstacles and risks are discussed, preferably before the start of treatment. Furthermore, participants described the importance of allowing youth to openly discuss suicidality without direct risk avoidant consequences, such as immediate admission. Participants also emphasized the importance of openly discussing when treatment does not lead to results, without the risk of transfer to another treatment facility or clinician. Finally, caregivers emphasized the importance of clear agreements on communication with caregivers and (weekend) leave in case of clinical admission.

3.2.4. Category 4. Organization of care

Participants described that during the treatment of youth with SEMHP, the organization caring for youth has an important role. Factors that were associated with the organization of care included accessibility, collaboration, and tailored care.

3.2.4.1. Accessibility. A barrier experienced by youth and caregivers in

the organization of care for youth with SEMHP was the lack of accessible care. For example, it was often not clear to youth and caregivers where they could ask and find appropriate mental healthcare. Caregivers indicated that receiving care depended on the caregivers' commitment to finding such help. In addition, the practicalities of being able to go to treatment (e.g., transportation and scheduling outside school hours) were not always adequately considered by treatment facilities.

In order to increase accessibility for youth with SEMHP, the following facilitators were identified: clarity on where caregivers and youth can ask for help, possibly with the help of a peer support worker for caregivers; and the ability to bypass waiting lists, especially when youth have been in treatment before. In addition, youth would prefer a low-threshold facility that is accessible (also outside office hours) to prevent a crisis admission.

3.2.4.2. Collaboration. A common barrier experienced by participants is the fragmented, disorganized healthcare network surrounding youth with SEMHP. According to participants, a lack of collaboration among practitioners and treatment facilities leads to confusion and disagreement regarding responsibilities and tasks. Joint risks are not being taken because of the above-mentioned experienced accountability by practitioners (*Category 2. Engagement and accountability, theme accountability*). This lack of collaboration, in combination with the crisis sensitivity of youth with SEMHP, increases the likelihood of youth being transferred to other healthcare facilities or being refused to enter specialized care. When treatments fail, new interventions and care pathways are put into place, resulting in changes and fragmentation of care, as illustrated in the quote below.

"If there are eight care workers involved in a case, sometimes care workers feel that they are not making any progress, that things are not improving, and they throw in another intervention or involve another party, with the idea that maybe that will help. But the impact this has on youth or families, to have to start working with a new stakeholder again, that is very intense. This is done with good intentions, but youth may think: okay, they don't know what to do with me either." Practitioner9

Participants emphasized the importance of interprofessional collaboration in the treatment of youth with SEMHP. Facilitating elements described were related to an integrated approach: a long-term and broad focus on youth's wellbeing, with shared goals, in one coherent treatment plan, with a coordinating supervisor. Youth in particular expressed the wish for expertise to be consulted instead of youth being referred to another healthcare facility. Moreover, youth and caregivers indicated the importance of involving experts by experience, to bridge the needs of youth and caregivers with professionals.

3.2.4.3. Tailored care. Participants emphasized that regulations within and between healthcare facilities often limit the provision of tailored care for youth with SEMHP. Barriers include rigidity in treatment, the lack of specific (e.g. more expensive) therapies, and the strict boundary between youth and adult care at 18 years of age. Participants described that these barriers resulted in long waiting lists for youth with SEMHP and youth being sent from one place to the other. Another perceived barrier was that the first assessment of care is largely being done by primary care providers who often lack the necessary expertise to make timely and accurate decisions. Those care providers with knowledge and expertise commonly do not have enough time or are in no position to decide on treatment and finances for care, thus hindering the provision of tailored care.

"What would be required is that you should look at what the child needs, regardless of whether that fits the mental health care facility or not. I think you should build your treatment team based on that. A child doesn't mind whether they (practitioners) come from the mental health service or from somewhere else or whether they are consulted behind the scenes; they don't care. But I think then you will have the best people sitting together

instead of having them (youth) move from institution to institution." Caregiver11

Participants advocated for the possibility of longer trajectories without the need to transition to adult care when they reach the age of 18. They also advocated for attention to the after-care trajectory. In addition, a focus on individual qualities of youth, including enabling daytime activities, allows for more tailored care.

3.2.5. Category 5. Hopelessness

In almost all interviews with youth, caregivers, and practitioners, feelings of hopelessness were described. These feelings were related to barriers mentioned in the categories above, such as a lack of experienced control, (care) rejection, and changes in both care facilities and the environment (e.g. school/housing facilities) due to the complexity of youth's problems. Negative experiences of youth during treatment had a profound impact, and often resulted in problems getting worse: iatrogenic damage (i.e. damage caused by the treatment itself).

Caregivers indicated that they felt hopeless when their child did not want to be helped or refused to share information with the caregiver, especially during the adolescent phase.

At the same time, practitioners mentioned they themselves, or colleagues became desperate and tired, or started working from a position of harshness. A certain (management) culture often emerged in teams working with youth with SEMHP, as exemplified in the following quote.

"When the tension rises, the dynamics are more tangible. The seriousness of the situation becomes more apparent. Then youth are shifted around and the distrustful youth becomes even more distrustful." Practitioner5

4. Discussion

This study focused on youth with severe and enduring mental health problems (SEMHP), who often do not profit from treatments in Child and Adolescent Psychiatry (CAP) (Bevington et al., 2013). To improve care for these youth, this qualitative study aimed to explore the barriers and facilitators in CAP treatment from the perspectives of youth with SEMHP, caregivers, and practitioners. The multitude of deducted themes with barriers and facilitators indicate the complexity in treatment and organization of care for youth with SEMHP. Already during the diagnostic phase, the overfocus on classifications and a lack of focus on the context of youth, impact the treatment process. In line with a recent literature review (Bansema et al., 2023), we found that the fluctuating problems of these youth, combined with high-risk and avoidant behavior, present a challenge in organizing adequate treatment for this group. Overall, youth, caregivers, and practitioners emphasized similar themes, however within these themes there were some differences in their interpretations and viewpoints. For example, regarding the amount of autonomy youth with SEMHP should be given in treatment (caregivers versus youth and practitioners).

Notably, two findings recur in different contexts and affect all categories. First of all, results show that current approaches to youth's high-risk behavior, such as risk avoidance and a lack of trust seem counter-productive as it leads to crisis management and fragmented care. Secondly, the results of this study demonstrate the pivotal role that a lack of epistemic trust plays in the treatment of youth with SEMHP. For youth, past treatment failures leads to disengagement, decreasing the likelihood for them to seek another type of treatment in the future, reducing their chances for success. For practitioners', providing treatment to someone who experiences a lack of trust in treatment and/or the therapist, becomes a challenging task. To address the perceived hopelessness of youth, practitioners, and caregivers, solutions should be sought in a trust-based relationship, with a focus on a collaborative approach and providing continuous care.

The current study shows that a lack of epistemic trust creates a downward spiral, whereby in response to youth's high-risk behavior and

disengagement, risk-avoiding behavior of practitioners and healthcare facilities increases. This is often due to pressure of concerned caregivers and the accountability that practitioners experience. Our findings indicate that securing and referring these youth to other facilities only exacerbates the problem as it creates an environment of distrust and hinders open communication. Moreover, participants expressed their concerns on harmful experiences because of clinical admissions in youth with high-risk behavior. Institutionalizing youth with high-risk behavior entails a risk of iatrogenic harm, as also described in previous research (Hawton, Saunders, & O'Connor, 2012).

In the Netherlands, there is currently a shift taking place that intends to transform the approach towards youth who exhibit high risk behavior. This shift entails a transition from an approach marked by mistrust and seclusion to one grounded in trust and active participation in society. Initiatives such as the 'Small Scale Consortium' (in Dutch: Consortium Kleinschaligheid) and the learning network for preventing involuntary seclusion exemplify this movement. 'Small Scale Consortium' focuses on maximizing youth's autonomy within a society, by living in small groups under the supervision of professionals. Key recommendations aimed at reducing forced seclusion within youth services include advocating for the discontinuation of involuntary isolation, investing in professional development through supervision, incorporating the perspectives of youth and utilizing peer experts by experience, fostering collaborative learning within a movement, and enhancing the foundational conditions required for working with high-risk youth (Van Dorp, Mulder, & Scholten, 2021). These results are based on residential youth care facilities, however, this transition is also seen in our research within child and adolescent psychiatry services. Nevertheless, this shift in approaching youth with high risk behavior requires a lot from treatment providers. As also reported in our study, it is challenging to collaborate with different treatment providers, there is often too little guidance for practitioners, and youth are still under involved in their own treatment process. Nevertheless, given the hopeful results for youth, it is worth continuing to invest in this transition.

Reflecting on the risk-avoidance behavior of practitioners, treatment facilities, and caregivers, and the lack of epistemic trust in youth, a key challenge is determining the level of autonomy that should be given to youth during treatment. The results of this study demonstrate a lack of consensus among youth, caregivers, and practitioners on this issue. While it is understandable for caregivers to seek assurances about their child's safety, especially considering the severity of mental health problems, both youth and practitioners emphasize that a lack of autonomy can hinder recovery. In particular, severe mental illness during the transition period to adulthood can interfere with self-determination and youth's need to form their own identity (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Ward, 2014). Adding to the existing knowledge, this present study emphasizes the importance of giving youth authority to make decisions during treatment. Even when this can lead to reluctance and fear among people caring for youth (Racine et al., 2014). The issue of autonomy also raises larger societal questions about the responsibility of healthcare facilities, practitioners, and caregivers in monitoring youth's safety. In situations where numerous institutions and professionals are involved, specific responsibilities often become unclear (Nooteboom, van den Driesschen, Kuiper, Vermeiren, & Mulder, 2020). Our study highlights that the emphasis on individual responsibility of practitioners contributes to crisis-driven and authoritative interventions. Professionals involved should share responsibilities. Whereby, it is important that there is continuous evaluation and coordination between those involved - not only at the level of practitioners but also at the level of the organizations (Nooteboom, Mulder, Kuiper, & Vermeiren, 2019). Further research on this topic from various perspectives (youth, caregivers, practitioners, and organizations) is strongly recommended.

Working with youth with SEMHP who feel hopeless and exhibit high-risk behavior also puts a burden on practitioners, as frequently pointed out in this study. Previous research has shown it is critical to pay more

attention to the impact that working with this population of youth has on practitioners (Piselli et al., 2011). Adding to the existing knowledge, a collaborative approach to support youth with SEMHP is needed. By establishing clear agreements, and by ensuring youth understand who is involved in their treatment, we can create a safe space for youth in which they are free to communicate their needs and concerns. This does not mean ignoring potential risks, but rather acknowledging and discussing them to ensure appropriate support is provided. Also, in line with previous research, we found that a well-established therapeutic relationship is essential (Ormhaug & Jensen, 2018; Stige et al., 2021). According to youth, this includes active listening, honesty about possibilities and limitations in care, and providing support, also during difficult times. This finding aligns with a recent study examining group workers' reactions to suicidal behavior of female adolescents (Kaijadoo et al., 2023). This study underscores the critical role of practitioners' coping in situations involving high-risk behaviors. Furthermore, especially in times of a high workload and crises, it is important for practitioners to be able to slow down, to provide them with tools to deal with youth's behavior and to reflect with colleagues on their thoughts and actions. Therefore, it is crucial for organizations to create a culture of trust and a focus on learning - parallel to what is important for youth with SEMHP.

Moreover, a suggestion to empower youth and their families is the implementation of the methodology and philosophy of 'Non Violent Resistance' and 'New Authority'. These methods could provide practitioners and caregivers with tools to cope with high-risk behavior, and break through feelings of hopelessness (Omer & Dolberger, 2015; van Dongen et al., 2023). Moreover, the Adolescent Mentalization-Based Integrative Treatment approach (AMBIT) can support practitioners, as it works from a mentalizing stance toward 'hard to engage' youth through a shared team culture (Bevington et al., 2015).

Furthermore, the current organization of care in the Netherlands, and in other countries (Memarzia, St Clair, Owens, Goodyer, & Dunn, 2015) seems to contribute to the exacerbation of mental health care problems for youth with SEMHP. Due to youth's previous experiences with frequent changes in health care facilities and practitioners, youth experience low epistemic trust. Moreover, as also found in our recent literature review (de Soet et al., 2023), because treatments are based on a specific classification, treatment is often not adapted to these youth, leading to disengagement. These findings highlight the importance of taking time to conduct a more personalized and more descriptive diagnostic process, rather than relying on classifications as a guiding principle in treatment. Furthermore, tailored care involves formulating customized plans that deviate from standard care and pre-established institutional programs, by considering what the youth and their surroundings require at that time (Kraak & Rietbergen, 2022). For some youth with SEMHP, facilitating for example music lessons, a side job, or a peer buddy in the neighborhood may be of value in addition to evidence-based treatment. Tailored care, for example, the Youth Flexible Assertive Community Treatment (Youth Flexible ACT), means thinking out-of-the-box, in collaboration with youth, their environment, and the care workers involved, to provide the best support possible (Broersen, Frieswijk, Coolen, Creemers, & Kroon, 2022). Current financing systems in healthcare must be adjusted accordingly. Additionally, accessible care could be provided by involving peer workers/experts by experience, who can assist youth and caregivers in navigating and finding appropriate services (de Beer et al., 2022) and by low-threshold facilities, such as the Dutch @ease that is based on the Australian Headspace centers (Leijdesdorff et al., 2020; Rickwood et al., 2022). Finally, consistent with other studies, the transition to adult care should be tailored to the youth's readiness, with transfer planning meetings and parallel care by all parties being essential in the transition (Hovish, Weaver, Islam, Paul, & Singh, 2012).

Strengths and limitations.

A major strength of this study is the in depth and exploratory way using qualitative methods to study the experiences of youth, caregivers,

and practitioners with current treatment in CAP. Semi-structured interviews provided an opportunity to gain in depth insight into experiences and contexts of a group that has not been previously researched, is difficult to define, and therefore is often excluded from quantitative research. The theory based topic list guided the interview, while there was also room for new insights based on the participants experiences. The COREQ (COnsolidated criteria for REporting Qualitative research) checklist has been used to ensure a comprehensive and transparent description of our research (Tong et al., 2007). Another strength is the involvement of youth experts and practitioners in all parts of this study: from compiling the topic list to interpreting results. In this way, we ensure the findings are of significance to current clinical practice.

This study also carries limitations. First of all, our purposive sampling strategy was useful to include youth, caregivers, and practitioners who are familiar with the specific topic of ‘severe and enduring mental health problems’. However, we spoke to a relative small group of participants (n = 31), who were motivated to participate in the interviews and whose experiences might vary from those of youth and caregivers we did not reach. As we asked for experiences that mostly happened in the recent past, there is a risk of recall bias. Another limitation is that we mainly focused on CAP facilities, while youth with SEMHP can also be found in other youth-serving contexts, such as forensic settings and substance use services. Also, in this study, we lack detailed information regarding youth’s classifications, treatment duration, and types of treatments received. This information could potentially have given us more insight into the individual experiences of the participants. Finally, we opted for a qualitative approach to investigate barriers and facilitators in treatment in a heterogeneous group of youth with SEMHP. Through a thematic analysis, we identified recurring themes based on data collected from the interviews. This approach has its limitations, as our separation of themes may have led to confirmation bias if they were interconnected. To counteract this, we conducted reflective meetings to challenge our themes and arrive at a final thematic model through consensus (Ritchie, Lewis, Nicholls, & Ormston, 2013).

5. Conclusion

The results of this qualitative study indicate that current approaches to addressing youth’s high-risk behavior may be counterproductive, as they often lead to crisis management and fragmented care. Additionally, a lack of trust in the treatment of youth with SEMHP plays a vital role in exacerbating the perceived hopelessness of youth, practitioners, and caregivers. To address these issues, it is suggested that solutions should be sought in a trust-based relationship with a focus on providing continuous care. This approach may help to build a sense of trust and hope among youth with SEMHP, which is critical in promoting positive outcomes.

Ethical Approval

The Medical Ethics Review Board of Leiden University Medical Center concluded the overall research project ‘DevelopRoad’ did not require to be evaluated in accordance with the Medical Research Involving Human Subjects Act (WMO) and that it complies with the Dutch Code of Conduct for Research Integrity (reference number: N21.094). Written informed consent for participation in the study and publication of the results was obtained from all participants in this study.

Authors’ contributions

All authors contributed to the study’s conception and design. Data preparation and collection were performed by Rianne de Soet and Chanel Bansema. Analysis was executed by Rianne de Soet and Laura Nooteboom. The first draft of the manuscript was written by Rianne de Soet and all authors commented on previous versions of the manuscript.

All authors read and approved the final manuscript.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data supporting the findings of this study are not public but can be made available upon reasonable request to the corresponding author.

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Appendices. Supplementary material

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