Shared roads, shared risks: understanding the needs of youth with severe and enduring mental health problems

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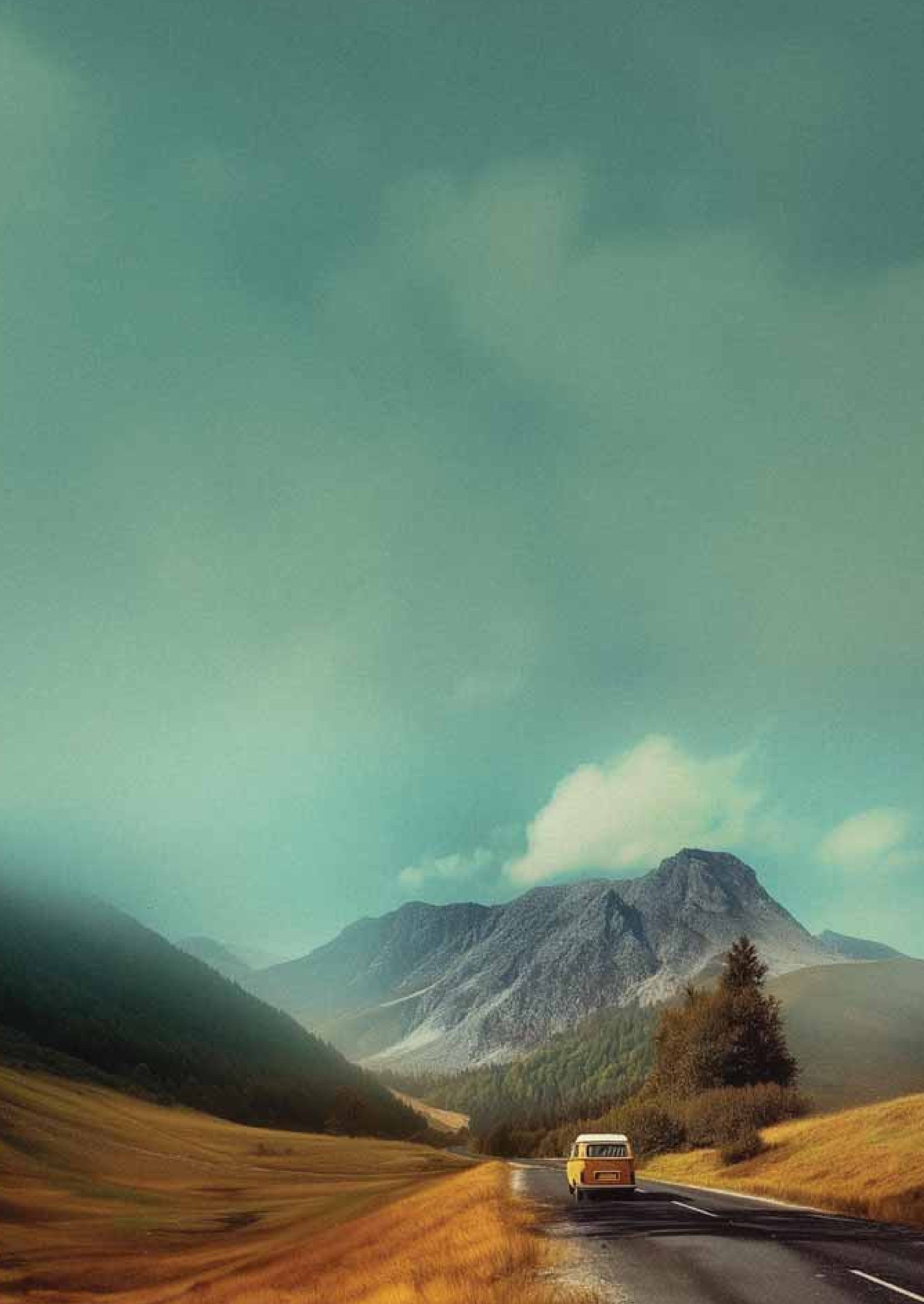

Chapter 6

General discussion

Youth with SEMHP are among the most complex and vulnerable groups within CAP. Despite the increasing awareness of rising mental health concerns among youth in general (McGorry, Gunasiri, Mei, Rice, & Gao, 2025), this specific subgroup continues to fall through the cracks of existing care systems. These youth often experience persistent, multi-faceted, and severe mental health problems, leading to dysfunction across various domains of life, even after years of specialized treatment (Bansema et al., 2023; Bansema et al., 2024; Woody et al., 2019; Wright et al., 2017). Many disengage from care or remain stuck in cycles of repeated interventions without sustainable improvement, leading to profound personal distress, significant societal costs, and growing concerns among caregivers and professionals alike (Dean, 2017; Sellers et al., 2019).

Despite the urgency of these challenges, limited knowledge exists about what underlies treatment failure for this group and what is required to develop an effective and responsive mental healthcare system for youth with SEMHP. This dissertation, conducted as part of the broader *DevelopRoad* research initiative, aims to fill this gap by exploring the treatment experiences and perceived barriers and facilitators from the perspectives of youth, caregivers, and CAP professionals. Its main objective is to explore the treatment needs of youth with SEMHP in CAP, a group that has been rarely studied before, with the goal of informing improvements in care and outcomes.

Using a grounded theory methodology, complemented by the principles of Patient-Oriented Research, this dissertation presents four consecutive studies. First, a systematic literature review was conducted to identify factors associated with treatment failure in youth with SEMHP (Chapter 2). Second, a qualitative study explored the barriers and facilitators in CAP treatment for youth with SEMHP (Chapter 3). Third, a mixed-method study examined the perceived and preferred treatment focus in CAP (Chapter 4). Finally, an in-depth qualitative study investigated how the concepts of autonomy and safety are understood and negotiated in residential CAP settings (Chapter 5).

This general discussion begins with a summary of findings per chapter. This is followed by a reflection on the main findings of the dissertation, structured around several key themes that emerged across the studies: the role of high-risk behavior in treatment, the importance of (epistemic) trust and recovery-oriented care, and the challenges professionals face in balancing risk, responsibility, and relational work. The chapter concludes with methodological reflections, implications for clinical practice, policy, education and future research, and suggestions for next steps.

Summary of findings

Chapter 2 presents a systematic review aimed at identifying and describing factors associated with treatment failure among youth with SEMHP. A total of 36 studies were included for data extraction and qualitative data synthesis, covering a wide range of mental health problems and treatment settings. Using descriptive thematic analysis, the findings were categorized into three main domains: client factors, treatments factors, and organizational factors. Although many themes showed limited or contradictory evidence, strong associations were found between treatment failure and factors such as the type of treatment, engagement, transparency and communication, the quality of the therapeutic match (goodness of fit), and the perspective of the practitioner. Thematic analysis suggests that treatment often fails when there is a mismatch between the youth's needs and the type of treatment offered (e.g., group-based intervention), and when practitioners' perceptions of the youth and their problems do not align with their actual difficulties and needs. Moreover, this review shows that little research has been done on the impact of organizational factors on treatment failure among youth with SEMHP (e.g., waiting lists, accessibility of care, transition to adult care, and financial coverage). This systematic review was the first to thematically explore treatment failure factors in youth with SEMHP within CAP. While previous work has primarily emphasized individual client factors, our findings highlight the critical need to tailor interventions to the unique needs of both youth and their caregivers. Crucially, the practitioner's perspective emerges as a pivotal factor in treatment failure. These insights call for a more nuanced and reflective clinical approach, where practitioner awareness and responsiveness are central to effective care for youth with SEMHP.

To deepen our understanding of the needs of youth with SEMHP in CAP treatment, Chapter 3 presents a qualitative study into the perceived barriers and facilitators to care. Semi-structured interviews were conducted with three key stakeholder groups: youth with lived experience (n = 10), specialized practitioners (n = 10), and caregivers of youth with SEMHP (n = 10). We identified barriers and facilitators in five categories: (1) before treatment, (2) engagement and accountability, (3) trust-based treatment, (4) organization of care, and (5) hopelessness. The findings show that a lack of epistemic trust plays a central role in the difficulties encountered in treatment. Youth often do not feel heard or understood, which hampers engagement and reinforces existing feelings of hopelessness, feelings that were also reported by caregivers and practitioners. Furthermore, care trajectories are often fragmented, shaped by reactive crisis management rather than long-term continuity. Practitioners describe how a strong sense of perceived accountability makes them more cautious and focused on safety procedures, which limits room for tailored, relational care. At the same time, this risk-avoidant approach often conflicts with the youth's need for autonomy and trust. Based on the findings, we concluded that restoring trust requires a relational approach within a safe and predictable care environment. Additionally, attention should be given to foster continuous and tailored care to prevent youth from slipping through the cracks of waiting lists and receiving inadequate treatment.

Because youth with SEMHP often undergo long-term treatment trajectories, participants in the interviews regularly reflected on what treatment should focus on for this specific group of youth. Chapter 4 therefore examines the perceived and preferred treatment focus for youth with SEMHP in CAP, using a sequential exploratory mixed-method design. Qualitative data from a thematic analysis of interviews (n = 30) informed a subsequent online questionnaire (n = 116), offering insight into the perspectives of youth with SEMHP, caregivers, and CAP practitioners. Findings show that CAP treatment is currently strongly focused on symptom reduction. Although youth and caregivers do not necessarily wish to reduce this focus, they express a clear need to broaden it. All participant groups emphasize the importance of addressing underlying issues, fostering autonomy, exploring future perspectives, and recognizing personal strengths as a treatment focus in CAP. While practitioners indicate that these broader elements are already part of treatment, youth and caregivers often experience this differently, suggesting a disconnect between professional intentions and what is perceived in practice. This study highlights the need for treatment that is responsive and adaptable to youth's changing circumstances over time. Structural and regular evaluation together with youth and families is seen as essential to ensure that care remains aligned with their evolving needs.

Chapter 5 builds on recurring themes throughout this dissertation, offering an in-depth exploration of how autonomy and safety are understood and balanced in residential care for youth with SEMHP, a context in which these concepts are highly relevant but rarely explicitly examined. Drawing on two focus groups and eleven interviews with youth, caregivers, and practitioners, this qualitative study sheds light on the relational and context-dependent nature of both autonomy and safety. Three main categories were deducted: (1) foundation for safety and autonomy, (2) regulation of safety and autonomy, and (3) tensions and risks. The findings show that these concepts are not opposites but deeply interrelated: youth feel unsafe when they lack autonomy, and true autonomy cannot exist without a sense of safety. In high-risk situations, however, tensions often emerge. Youth express a strong need for proximity and shared decision-making, whereas practitioners tend to rely more on procedures and boundaries. Caregivers' perspectives vary, often shaped by their child's care trajectory and previous experiences. A key insight is that restricting autonomy, while mostly intended to protect, can carry long-term risks, such as diminished trust or disengagement, that are less immediately visible. Our study suggests that effectively balancing autonomy and safety requires a stable and reflective clinical team that can tolerate uncertainty, slow down during crises, and remain connected with both youth and caregivers. Such a relationship-centered approach is essential to support gradual development and continuity of care in residential CAP.

Discussion of main findings

No single factor by itself explains why youth with SEMHP often do not benefit sufficiently from treatment. Nor is there a straightforward solution to improve care for these youth and their families. The complexity of youth mental health problems cannot be reduced to one popular cause or solution (Stevens, 2025). This dissertation expands upon that understanding, showing that meaningful progress requires society, organizations, health care professionals, and youth and their families to learn to work with uncertainty and unpredictability, rather than trying to eliminate it. While this may sound simple, it demands a fundamental shift in mindset, organizational structures, and clinical practice.

Although youth with SEMHP are often referred to as 'complex', the DevelopRoad project shows that it is not the youth themselves that are complex but rather a combination of factors, rooted in the histories of care the youth and their families already have been through, treatment factors, and elements related to our care system. As this dissertation demonstrates, there are several dynamic (changeable) factors to consider in the treatment of youth with SEMHP, such as the role of high-risk behavior, epistemic trust, and the therapeutic relationship. Building on the foundations given in the previous chapters in this dissertation, the following elements will be further elaborated upon: (1) high-risk behavior in treatment; (2) the importance of trust; (3) symptom reduction and recovery-oriented care; and (4) accountability and the support of practitioners.

1. High-risk behavior in treatment

"When you remove any potential harmful items, it might seem safer to the outside world. But whether that actually makes things safer in practice… We have seen that youth are incredibly creative when it comes to harming themselves." (Caregiver)

One of the most striking findings of this research project is the prominent role of high-risk behavior, such as suicidal behavior, disordered eating, and self-harm, among youth with SEMHP (Bansema et al., 2024), and its impact on treatment. While these behaviors reflect the depth of their suffering, they also become central to how treatment is organized, evaluated, and experienced. When care does not lead to meaningful improvement, a vicious cycle can emerge: youth feel increasingly hopeless, engage in more severe self-destructive behavior, and withdraw from treatment altogether. This cycle affects not only the youth but also their families and practitioners, leaving all parties feeling powerless.

Several youth and caregivers who participated in this project shared the devastating loss of a child or peer who died as a result of mental health problems. These deeply personal accounts are not isolated incidents, but rather part of a broader systemic pattern. A recent case report by Van de Koppel et al. (2024) describes how girls with chronic suicidality often become trapped in stagnating care. In these cases, the focus gradually shifts toward enforcing safety, such as preventing self-harm, while the root causes of suffering are increasingly sidelined in favor of risk management. This aligns closely with our findings: when youth with SEMHP receive care that repeatedly falls short of meaningful progress, they (and their caregivers) often experience increased feelings of despair, disengagement, and isolation. This illustrates what Joiner (2005) described in his theory of suicidal behavior: suicidal ideation often emerges from perceived burdensomeness and thwarted belongingness (Van Orden, Cukrowicz, Witte, & Joiner Jr, 2012). Many of the youth we spoke with articulated these feelings during their care trajectory, believing they were a burden to their families and no longer part of any meaningful social world. Crucially, these perceptions were not always rooted in their internal state, but seemed to be shaped by how the care system responded to their distress.

Institutional responses to high-risk behavior often focus on managing immediate danger, such as preventing suicide, rather than building long-term trust or promoting autonomy. Treatment teams may feel compelled to use coercive measures, driven by fear of adverse outcomes and professional accountability (Kaijadoe et al., 2023; Turner, Stapelberg, Sveticic, & Dekker, 2020). Yet paradoxically, these same responses can worsen the problem: youth become increasingly isolated, and the belief in personal agency deteriorates. When care professionals react defensively, out of fear rather than connection, they often fail to meet youth in their most vulnerable moments. Many youth and caregivers described feeling most abandoned during times of crisis. What these experiences underscore is that safety is not only a matter of risk management, but of relational presence. Youth with SEMHP do not only need to be protected, they need to be seen, heard, and supported in a way that fosters hope and restores trust in themselves and others.

2. The importance of trust

"Especially in the beginning, it is important to really get to know someone, to learn to trust them, to feel that there's understanding for how hard that can be - that it takes time. That it is frustrating when the people you see keep changing. […] That there's an understanding that it matters who it is, how long that person has been involved with you, that they truly listen, and that something is actually done with what you say - in a broader sense." (Youth)

Throughout this dissertation, a lack of epistemic trust emerged as a central barrier to effective care for youth with SEMHP and their caregivers. Epistemic trust - the openness to accept information from others as trustworthy and relevant (Fonagy & Allison, 2014) – is often severely compromised in youth who have undergone years of failed treatment. Their guardedness or disengagement is not resistance to change, but a loss of belief that treatment can offer something of value. Caregivers, too, frequently lose trust in the care system they depend on. Many described years of navigating fragmented and crisis-driven services. Some had to leave their jobs, lost touch with friends and family, and gradually found themselves feeling exhausted, isolated, and desperate in finding the right support for their child. This emotional burden often goes unseen, however, it plays a significant role in how families engage with care.

Our findings indicate that epistemic (dis)trust in both youth and caregivers is shaped by two interconnected factors: (1) the quality of the therapeutic relationship, and (2) the continuity of care.

First, a strong therapeutic relationship was consistently described as the foundation for (re)engagement. Youth emphasized mutual trust, genuine interest, transparency, and relational presence as essential building blocks of trust (Chapter 2, 3, and 5). Importantly, granting autonomy was often experienced by youth as an expression of trust, provided it stemmed from a safe, consistent relationship (Chapter 5). Caregivers similarly valued care professionals who truly listened and acted on their concerns. When such relational qualities were absent, even well-intentioned treatment offers were met with hesitation or resistance.

Second, continuity of care was recognized as a precondition for trust. For youth with SEMHP, whose trajectories are long and complex, disruptions such as frequent staff changes, transfers between services, or gaps caused by waiting lists undermine the sense of safety needed to build lasting relationships. Continuity implies a steady and reliable presence of professionals who 'stay on board' despite crises, transitions, or fluctuating symptoms. However, in care trajectories for youth with SEMHP, often many care professionals from different organizations are involved. Research indicates that implementing integrated care is particularly difficult in families facing multiple and complex problems involving several professionals (Nooteboom, Mulder, Kuiper, Colins, & Vermeiren, 2021). Families in our studies repeatedly stressed how disruptive it was when treatment was organized around institutional boundaries rather than their child's ongoing needs. Without structural continuity, trust cannot develop, and without trust, treatment engagement and outcomes remain fragile.

Taken together, the lack of experienced trust among both youth and caregivers underscores that effective care for youth with SEMHP is inseparable from relationship-based practices and continuity of care. While practitioners are generally aware of this, they face systemic barriers such as limited resources and staff shortages (Centraal Bureau voor de Statistiek, 2023), which hinder their ability to invest in long-term relationships. Sustainable support requires not only therapeutic skills, but also the organizational conditions that allow care professionals to stay present, consistent, and connected.

3. Symptom reduction and recovery-oriented care

"The goals set are unachievable, and when my child regresses, all attention is once again focused on her (self-)destructive behavior, and the set goals are abandoned." (Caregiver).

To effectively support youth with SEMHP, it is not sufficient to merely organize continuity of care or enhance the therapeutic relationship. It requires a more fundamental shift in treatment orientation: from a narrow focus on symptom reduction to a broader recovery-oriented approach. While symptom reduction remains an important goal in treatment, participants in our study consistently expressed the need for a wider treatment focus that includes addressing underlying issues, fostering autonomy, exploring perspectives, and recognizing personal strengths (Chapter 4).

Although the field of CAP has begun to engage with recovery-oriented care (Wallström, Lindgren, & Gabrielsson, 2021), its strong grounding in the medical model continues to pose barriers to implementation. Deegan (1988) defined recovery not as symptom elimination, but as "*a way of life, an attitude, and a way of approaching daily challenges […] to re-establish a valued sense of integrity and purpose within and beyond the limits of the disability*" (p.15).

This orientation requires a fundamental rethinking of the essence of treatment, from ‘what is wrong’ to ‘what is possible’.

Importantly and with a great overlap of the recovery movement, our findings align with the Self-Determination Theory (Ryan & Deci, 2000), which posits that motivation and well-being are strongly shaped by the extent to which individuals experience autonomy, competence, and relatedness. In the narratives of youth and caregivers, we saw that these three elements are often what is missing: care that feels imposed to secure safety rather than chosen by youth themselves (lack of autonomy, Chapter 5), repeated experiences of failure or exclusion (incompetence, Chapter 3), and a segregation of ‘normal life’ (thwarted relatedness, Chapter 3 and 4). Conversely, when youth are supported to articulate and pursue their own meaningful goals, and when care is delivered within stable and affirming relationships, their motivation and trust tend to increase (Chapter 3 and 4).

A recovery-oriented approach thus requires more than individual clinical techniques. It calls for a shared organizational stance that centers on ‘being with’ rather than ‘fixing’, and that values the long-term development of identity and meaning, even when symptom relief is not immediately attainable. As Pelzer and Winters-van Eekelen (2024) noted, mental health care is often compared to somatic care in public discourse. In a hospital setting, patients are admitted with the hope of recovery, yet there is a shared understanding that not every case leads to full healing. In mental health care, however, the expectation often persists that individuals enter ‘ill’ and leave ‘cured’. This assumption fails to acknowledge that, as in somatic care, outcomes may include partial recovery or even death.

Importantly, this shift in perspective cannot be the responsibility of individual practitioners alone. It requires structural and organizational support, as well as a broader societal and educational paradigm shift - topics that will be explored further in the section *Implications for policy and organization, and education*.

4. Accountability and the support of practitioners

“To be able to bear it, you have to carry it together.” (CAP Practitioner)

One of the most pressing tensions in the care of youth with SEMHP lies in how care professionals relate to risk and responsibility. Faced with high-risk behavior such as suicidality, professionals often find themselves navigating a fine line between intervening promptly and respecting youth’s autonomy. This balancing act is further complicated due to external pressures, such as the public opinion, institutional guidelines, the involvement of medical emergency services and the police, and the anxiety of facing blame or legal consequences if an intervention fails or leads to adverse outcomes (Centrum voor Consultatie en Expertise, 2025; Janssen, Snijders, Gerritse, & van Veen, 2025). In such high-stakes situations, risk-averse handling by professionals becomes understandable, however, not always helpful. Care teams may fall back on protocols, adopt rigid decision-making, or even end treatment prematurely when the perceived risk becomes unmanageable. This tendency, while aimed at ensuring safety, may lead to unintended iatrogenic harm. Youth are deprived of autonomy, caregivers feel excluded, and practitioners themselves become emotionally detached. Over time, this pattern can contribute to moral injury or moral stress among practitioners: the psychological distress of knowing what care is needed but being unable to provide it due to external constraints (Dean, Talbot, & Dean, 2019). A recent report highlights that care professionals operate within a complex web of relationships, ranging from colleagues and supervisors to clients, families, institutional policies, and governmental regulations, all of which shape the moral dynamics that give rise to moral stress (Centrum voor Consultatie en Expertise, 2025). Importantly, moral stress should not be seen as an individual issue, but as a systemic challenge that requires collective responsibility across the entire care network.

Our findings echo concerns raised in broader research: when practitioners are overwhelmed or feel unsupported, the quality of the therapeutic relationship deteriorates. Compassion fatigue, disengagement, and cynicism may set in (Maslach & Leiter, 2016; McNicholas, Sharma, Oconnor, & Barrett, 2020), particularly in teams that lack reflective practices such as supervision, peer feedback, or moral case deliberation. Yet, as described in section 2 of this discussion (the importance of trust), these very relationships are what youth with SEMHP depend on most. The practitioner's perspective, as this dissertation shows in Chapter 2, is not a neutral variable; it shapes treatment outcome.

At its core, care for youth with SEMHP is relational work. In line with recent guidelines for persistent suicidality, there should be less emphasis on risk assessment and more on understanding youth's despair from a relational perspective (Hawton, Lascelles, Pitman, Gilbert, & Silverman, 2022; Landelijke Agenda Suïcidepreventie 2021–2025, 2023). Practitioners need space to regulate themselves, connect with others, and make sense of complex cases without becoming overwhelmed. Organizations and disciplinary frameworks must recognize this and create conditions in which relational, compassionate, recovery-oriented, and ethically attuned care can genuinely succeed. These considerations will be further explored in the implications section.

Methodological considerations

The following section outlines key methodological choices made throughout the research project and reflects on their implications. It also discusses important limitations of the study, providing context for interpreting the findings.

The importance of rigorous flexibility

This dissertation was guided by a dual methodological orientation: constructivist grounded theory (Charmaz, 2017; Corbin & Strauss, 2014) and the principles of Patient-Oriented Research (POR) (Forsythe et al., 2019). This approach was chosen to ensure that the research remained grounded in the lived experiences and perspectives of youth with SEMHP, their caregivers, and practitioners. A key premise of the chosen methodology, mirroring one of the main findings of this dissertation, is the importance of tailoring approaches to the needs of those involved. Just as mental health care for youth with SEMHP must be individualized and responsive, this also accounts for the research process that aims to understand their needs.

Flexibility proved essential in navigating the realities of working with this population. For example, interview formats and recruitment strategies were adjusted based on participants' needs, and research questions evolved iteratively in response to emerging data and dialogue with the broader research team. At times, methods had to be adapted entirely, such as replacing a planned focus group with individual interviews, when they proved unworkable or inaccessible for the intended participants. These adaptations made it possible to include voices that would otherwise have remained unheard.

At the same time, such flexibility can pose risks to the perceived rigor of the research. To address this, great care was taken to uphold the core qualitative research criteria of *credibility* (i.e. confidence in findings), *transferability* (i.e. applicability in other contexts), *dependability* (i.e. consistency of findings), and *confirmability* (i.e. the extent to which the findings are free from researchers' biases) (Bingham, 2023; Tierney & Clemens, 2011).

- Reflexive processes were built into every stage of the project to enhance *credibility and confirmability*. Working within a multidisciplinary research group, we ensured that data collection, coding, and interpretation were evaluated by multiple team members with varied perspectives (Ritchie, Lewis, Nicholls, & Ormston, 2013). The inclusion of experts by experience was particularly valuable: they ensured the relevance of research questions, improved access to participants, and provided essential contextual understanding when interpreting the results.

- To enhance *dependability*, established reporting frameworks were followed throughout. Chapter 2 adhered to PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) for systematic reviews, and Chapters 3, 4, and 5 followed the COREQ checklist for qualitative research (Tong, Sainsbury, & Craig, 2007).
- Through triangulation of methods (e.g., interviews, questionnaires, review, and focus groups) and participant perspectives (i.e., youth, caregivers, and practitioners), we were able to generate a richer and more nuanced understanding of both the group itself and their experiences in care (Evers & Staa, 2010). While these strategies do not eliminate the limitations inherent to studying a complex and heterogeneous group, it does enhance the *credibility, transferability,* and contextual richness of our findings (Tierney & Clemens, 2011).

The value of an open dialogue

An unexpected yet powerful insight emerged from the research process itself: the value of simply being listened to within a research project. Many youth, caregivers, and practitioners expressed appreciation for the opportunity to share their stories without the pressure of having to immediately justify or resolve their experiences. The interviews created a rare opportunity to speak freely and be met with genuine curiosity and attention. Interestingly, the very group often considered difficult to motivate for research participation, expressed profound appreciation for being included.

This mirrors one of the core findings of the dissertation: the therapeutic power of relational connection, slowing down, and being present. Just as effective care for youth with SEMHP requires time and space to build trust, qualitative research practices that embody these values can foster richer understanding and greater engagement. By making room for stories rather than just answers, the research itself became a small act of relational care.

These principles align closely with the principles of Person-Oriented Research, which guided this study. This approach holds that those most affected by a research topic must be actively involved throughout the research process: not only as participants, but as co-creators of knowledge (Forsythe et al., 2019). Their involvement is essential not just for ethical reasons, but for ensuring that research genuinely reflects lived realities and contributes to meaningful change. We therefore advocate to consistently adopt participatory approaches, engaging the people concerned in all phases of the research cycle, from defining the questions to interpreting the findings. Such collaboration is not an optional add-on, but a prerequisite for generating knowledge that is relevant, respectful, and capable of driving meaningful change in care systems.

Limitations

Several methodological limitations must be acknowledged. First, the diversity of our sample was limited. Most youth participants were white, highly educated girls. While this aligns with a broader trend showing an increase in referrals of adolescent girls with severe mental health problems to CAP (Leyenaar, Freyleue, Arakelyan, Schaefer, & O'Malley, 2025), it raises critical questions: Does this reflect the broader SEMHP population, or are we missing the voices of youth from other cultural, social, or economic backgrounds? It is well-documented that youth with a migration background or lower educational attainment are underrepresented in both child and adolescent psychiatry and in research (Markkula et al., 2018; Place et al., 2021). Some may receive care in other domains, such as child and youth services or addiction services, rather than in specialized mental health care. This raises structural questions: are some youth systematically excluded from care and research, and if so, how does the organization of our care system contribute to this exclusion? While this dissertation cannot fully answer those questions, they are vital for future research and policy. What it does underline is that the findings presented here should be interpreted with caution when it comes to *transferability*. The results offer valuable insights into a particular segment of the SEMHP population, but do not necessarily reflect the full diversity of youth facing severe and enduring mental health challenges.

A second limitation concerns the definition of the target group itself. "Youth with SEMHP" remains a loosely defined and heterogeneously described population, lacking a standardized defined category. This posed a methodological challenge, as we were studying a population whose contours were still being shaped. Here, the use of grounded theory proved particularly valuable (Corbin & Strauss, 2014). Rather than starting from strict diagnostic labels, as is common in traditional quantitative research, we allowed our understanding of SEMHP to evolve inductively throughout the research process. Each phase of research built upon the previous one, using earlier findings as a framework to inform subsequent data collection and analysis. This stepwise design allowed us to gradually build a more nuanced picture of the group and their needs.

Third, our studies focused on the care of youth within CAP treatment. We chose this focus because little is known about this particular population, and both organizations and practitioners in specialized youth mental health care often struggle to meet their needs. Our qualitative and mixed-method studies explored the experiences of youth and caregivers. However, due to the large number of professionals and services involved in the lives of these youth and their families, it was sometimes difficult to determine which experiences were tied to which care settings. This complexity is itself a meaningful finding, as it reflects the fragmented reality of daily life for youth with SEMHP and their families. Future research should therefore include a more comprehensive focus on youth with SEMHP, taking into account the complexity of their care trajectories and the interplay between different services and providers.

Implications and recommendations

In this section, we further outline implications for clinical practice, policy and organizations, education, and future research, highlighting opportunities for applying findings in practice.

Implications for clinical practice

Improving care for youth with SEMHP requires a shift toward a more relational and reflective approach. As explored throughout this dissertation, trust forms the foundation of meaningful treatment. Central to a relational and reflective approach is the capacity for practitioners to slow down and tolerate distress, both in youth and in themselves, even amidst crisis or perceived risk. This requires several preconditions:

Multidisciplinary teamwork: Care for youth with SEMHP should never rest on one practitioner alone. Even in outpatient settings, multidisciplinary teams are essential to ensure mutual support, continuity, and collective reflection. Initiatives such as Non-Violent Resistance help practitioners and families share responsibility and tolerate uncertainty together (Omer & Dolberger, 2015; van Gink et al., 2018). Furthermore, across all participant groups, the presence of someone who genuinely listens and stays involved made the difference. Involving peer support workers or professionals with lived experience within a multidisciplinary team can strengthen this trust and relational continuity (de Beer et al., 2024).

Embedded reflective practices: Building on findings from Chapters 3, 4, and 5, reflective practice must be foundational within clinical teams. The ability to pause, connect, and jointly reflect, especially during crises, often proves more therapeutic than reactive, fear-driven interventions. Formats such as Balint groups (Kjeldmand & Holmström, 2008), Schwarz rounds (Taylor, Xyrichis, Leamy, Reynolds, & Maben, 2018), and moral deliberation (Vellinga & van Melle-Baaijens, 2016) offer structured opportunities for teams to explore the ethical, emotional, and interpersonal dimensions of care. Moreover, such practices promote team cohesion, reduce burnout, and foster greater self-awareness, ultimately enhancing patient outcomes. Organizations should actively facilitate these sessions as part of routine professional development. This means embedding them into daily schedules and supporting participation across disciplines.

Shared Decision-making (SDM): Youth with SEMHP and their families should be involved in decisions not only about treatment goals (Chapter 4), but also about the pace and structure of care, especially during crises, when autonomy is most at risk. As demonstrated in Chapter 5, SDM fosters predictability, which offers youth a sense of safety and autonomy. Truly personalized treatment cannot exist without recognizing the perspectives of all those involved: youth, caregivers, and practitioners. Therefore, SDM and regular joint evaluations should be a structural component of treatment.

Evaluations: Professionals must learn to recognize and address the gap that can exist between what is offered in treatment and what youth and families experience. Our studies revealed a disconnect between what practitioners believe they offer and what youth and caregivers actually experience. This discrepancy underlines the importance of regular, collaborative evaluation of treatment. Tools such as the Individual Recovery Outcome Counter (I.ROC) or other recovery-informed instruments (Kraiss et al., 2019) may help structure these conversations and embed recovery principles more deeply in clinical routines. Ultimately, recovery begins not with fixing symptoms, but with restoring trust and re-establishing connection, both vital to effective care for youth with SEMHP.

Implications for policy and organizations

This dissertation identifies structural barriers and facilitating factors in the organization of care for youth with SEMHP. Accordingly, we propose the following recommendations for policymakers and organizations.

Continuity of care: Continuity of care must be enabled through the deliberate structuring of care services for youth with SEMHP. It forms the foundation of trust, engagement, and recovery (Chapter 3) and should therefore become a structural priority rather than a logistical afterthought. Accessible, tailored, and collaborative care is fundamental to successful treatment. To achieve this, several policy and organizational shifts are required:

- Interdisciplinary collaboration: Each youth with SEMHP should be assigned a care coordinator, ideally situated in primary care, who remains involved throughout the care trajectory - even when care becomes highly specialized. This coordinator ensures oversight, facilitating transitions, and safeguarding the responsiveness of care to evolving needs and therefore does not assume a therapeutic role. Seamless care requires structural collaboration between professionals across primary, secondary, and tertiary services, supported by shared case management, interoperable information systems, and joint decision-making. Crucially, this also calls for flexible regulatory and financial structures that incentivize integration. Current funding models often reinforce fragmented care, for instance, during transitions to adult mental health services. A shift toward a needs-based financing is vital to ensure continuity and equitable access to specialist care.
- Accessibility of care: Timely access to appropriate care must be guaranteed. While waiting lists may be unavoidable for youth with less acute needs, those with SEMHP must be fast-tracked to suitable interventions. This requires improved triage systems that differentiate between levels of severity and urgency. Equally important is the capacity to scale down care when appropriate, without terminating all support. Specifically, care systems must allow for ongoing, low-intensity contact from CAP settings even after formal treatment has ended. This also includes access to drop-in centers, daytime activities, and informal support networks with short lines of communication to CAP. Initiatives such as the Dutch @ease centers - modeled after Australia's Headspace approach - offer valuable examples of low-threshold support that prevent abrupt disengagement and enable early re-engagement when needed (Leijdesdorff et al., 2020; Rickwood et al., 2022). It is crucial that these youth are not excluded based on the severity of their (prior) problems or the risk of relapse. Instead, policy should focus on enabling collaboration between specialized and low-threshold services, supported by financial mechanisms that allow care to be scaled up or down responsively.

Accountability and coercive measures: In addition, this dissertation draws attention to the current handling of risk in Dutch mental healthcare (Chapter 3 and 5). Fear of liability or escalation can lead to coercive measures that undermine autonomy and erode trust. Although the Dutch Compulsory Mental Healthcare Act (Wet Verplichte GGZ) emphasizes proportionality and accountability, reports from the Health and Youth Care Inspectorate (Inspectie Gezondheidszorg en Jeugd, 2022) indicate wide variation in how these principles are applied in practice. From a global perspective, the UN Committee on the Rights of Persons with Disabilities calls for the elimination of coercive practices and promotes supported decision-making as a human rights-based alternative (Committee on the Rights of Persons with Disabilities, 2021). Similarly, WHO standards urge minimal coercion and respect for personal agency, even when individuals lack full decision-making capacity. These standards, however, are often framed as a minimum (World Health Organization, 2021).

This dissertation demonstrates that youth with SEMHP are particularly vulnerable to losing autonomy and experiencing harm through coercive care practices (see Chapter 3 and 5). Therefore, we advocate for an update to current mental health legislation and its implementation in practice, with a stronger emphasis on developmentally appropriate, dignity-protecting care. This should include:

- Embedding supported decision-making in youth mental health law, even when full decision-making capacity is questioned.
- Developing alternatives to coercion that center on relational engagement and recovery-oriented support.
- Creating legal and systemic structures that enable shared and proportionate risk-taking. Practitioners should not be held individually responsible for complex risks that exceed rigid protocols. Just as youth require safety in care, professionals and care teams need systemic trust to respond flexibly. Liability frameworks must be revised to enable collective responsibility without fear of individual blame. This aligns with a broader shift in supervision and governance, such as the movement within Dutch regulatory bodies like the IGJ, toward learning-oriented structures that emphasizes reflection and shared accountability over punitive control (Inspectie Gezondheidszorg en Jeugd, 2023).

Implications for education

We suggest two key implications for the education of future healthcare professionals.

Recovery-oriented learning: First, education for care professionals should incorporate recovery-oriented principles and reflective practices early in their training. Embedding a recovery-oriented mindset in CAP requires more than introducing new tools; it demands a fundamental shift in how professionals view youth and their role in care. Especially for future specialists from medical backgrounds, it is essential to challenge traditional symptom-focused approaches and emphasize relational, strength-based engagement. One method is the use of strengths-based group supervision (Rapp & Goscha, 2011; Wolf & Jonker, 2021), which can support professionals in shifting the focus from risk and pathology to potential and preferences. Integrating such reflective practices in education, and later in clinical routines, encourages a more engaged, responsive, and relational way of working with youth and families.

Interprofessional collaboration: Second, both clinical and academic education must place greater emphasis on interprofessional collaboration. Our findings show that coordination between sectors is often insufficient, particularly when working with youth with complex needs. Future healthcare professionals must be equipped from the outset to work across disciplinary and organizational boundaries. To achieve this, interprofessional competencies should be structurally embedded within curricula. This requires both practical and academic education programs to actively collaborate in designing and delivering joint learning experiences. By learning to work together during their training, students become familiar with each other's expertise, develop perspective-taking skills, and cultivate the ability to listen and reflect across professional boundaries. Integrating such practices at an early stage normalizes collaboration as a fundamental aspect of healthcare delivery.

Implications for future research

This dissertation underscores the urgent need for more targeted research into youth with SEMHP, particularly regarding what is needed to improve care. Our findings reveal that youth with SEMHP, their caregivers, and practitioners often experience profound hopelessness. The need to support these youth effectively is evident, and the results presented here offer initial insights for improving clinical practice. However, this study is among the first to explore this specific population and is exploratory in nature. Therefore, future research should build on these findings and address the following areas:

Interprofessional crisis care: The experiences of youth and caregivers in this study show that current crisis care for youth with SEMHP often falls short. Precisely when youth feel most vulnerable, the response tends to be impersonal, temporary, or fragmented. Previous research suggests that moments of crisis can serve as critical turning points in a care trajectory (Olthof, 2023). It is therefore essential to examine how crisis care is currently experienced by all stakeholders involved, and how the system can be improved. Particular attention should be given to interprofessional collaboration across disciplines and institutions, and the role of shared decision-making during and after crises.

Balancing autonomy and safety: This study repeatedly highlighted the tension between promoting autonomy and ensuring safety in situations involving high-risk behavior. While our research provided valuable insights into this dynamic, it primarily captured retrospective reflections. To deepen understanding, future research should focus on how decisions related to autonomy and safety are actually made in practice, especially in moments of acute risk or uncertainty.

Suggested research approaches: Although initiatives such as the Dutch research project 'Ketenbreed Leren' offer valuable retrospective insights into treatment trajectories across institutions (Spijk-de Jonge, Lange, Serra, van der Steege, & Dijkshoorn, 2022), they remain limited by recall bias and post-hoc interpretation. Instead, longitudinal and multi-perspective designs are needed that follow youth, caregivers, and practitioners over time. We specifically call for mixed-method longitudinal studies, including observational research within CAP settings, to capture how experiences of crisis care, autonomy, safety, and trust evolve in daily practice (Audulv et al., 2023). Such approaches will allow for a more nuanced and practice-oriented understanding of what works, when, and for whom.

Conclusion

This dissertation was the first study to examine the needs of youth with severe and enduring mental health problems (SEMHP) in child and adolescent psychiatry (CAP). By centering the voices of youth, caregivers, and practitioners, it revealed that meaningful change requires a shift from fragmented, risk-driven systems toward a relational and recovery-oriented approach that slows down, supports shared responsibility, and builds trust. Building trust is not only essential for youth with SEMHP, but equally for their caregivers and for the professionals working with them. Practitioners must be supported and enabled, both structurally and organizationally, to remain present, tolerate uncertainty, and work collaboratively, especially in moments of crisis. Taking shared and proportionate risks is not opposed to safety; rather, it is a precondition for creating the kind of long-term safety in which trust, autonomy, and meaningful recovery can take root. For youth with SEMHP, effective care starts with presence, not just protection, and with the willingness to share the road - and the risks - together.