In between and unseen: exploratory research into the characteristics of youth with severe and enduring mental health problems

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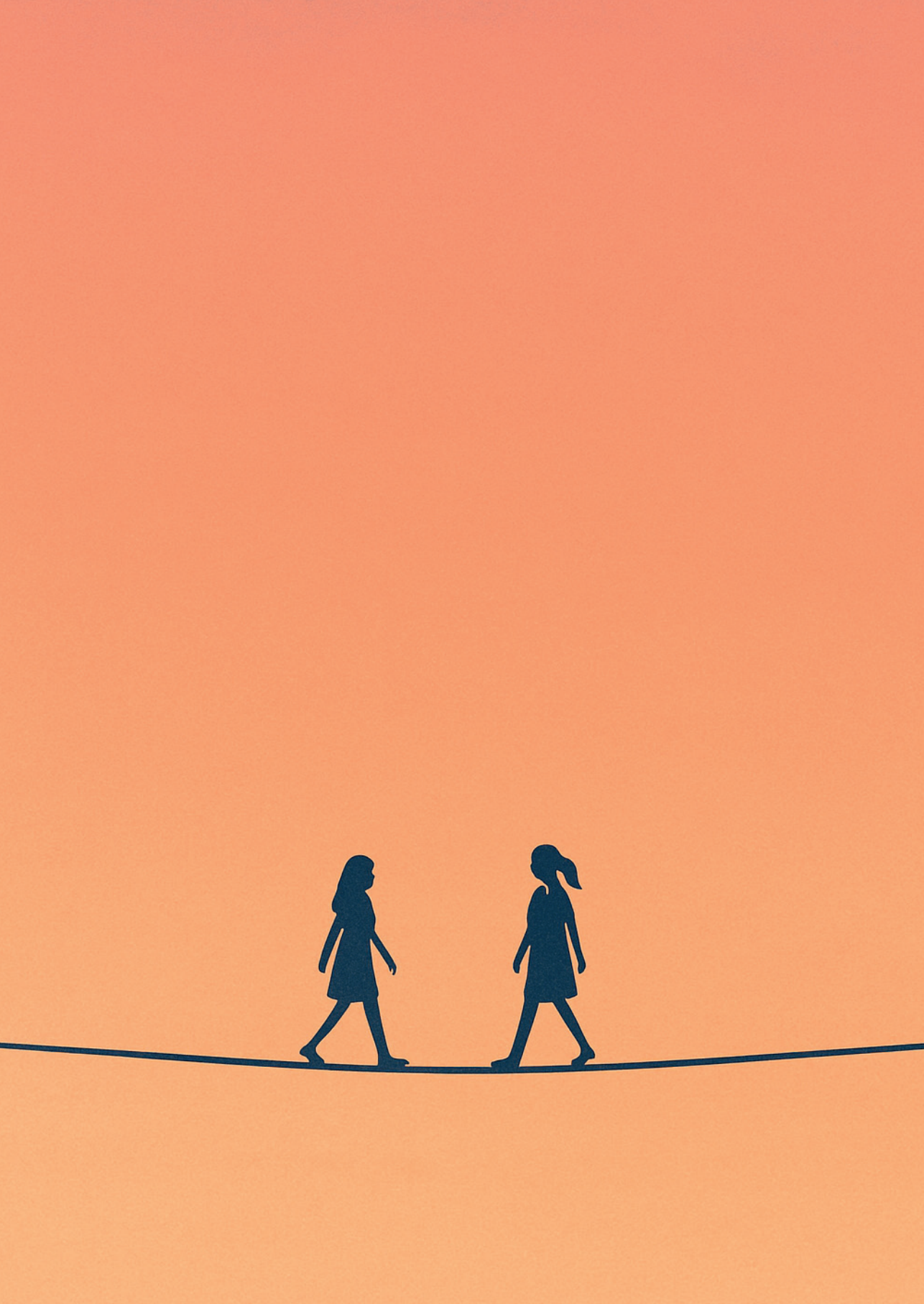

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Chapter 6

Summary and General discussion

Mental healthcare often falls short in addressing the needs of youth who experience severe and enduring mental health problems (SEMHP) (Algemene Rekenkamer, 2020; Decoene et al., 2018; Kraak & Rietbergen, 2022; van Sonsbeek & Oosterling, 2020). These youth face multiple problems, including with their mental health, across various domains of their lives (Broersen et al., 2020; van den Steene et al., 2019; Woody et al., 2019), and many of these problems do not fit a specific classification as defined by the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) (APA, 2013). Notably, these problems are frequently labeled "complex" and the youth who have them in need of "complex care". Yet who these youth are remains little known. Research on this population is scarce, largely because they are often excluded from studies due to the multiplicity and variety of mental health problems they face. This dissertation is among the first to explore youth with SEMHP in the setting of child-and-adolescent psychiatry (CAP), providing a unique contribution to the field.

This dissertation is primarily explorative, an initial step informing and advancing clinical practice and research by deepening our understanding of SEMHP among youth. Its primary objective is to explore the characteristics of youth with SEMHP, including the factors contributing to these problems and their impact on the wellbeing of these people. We systematically reviewed the international literature on contributing factors (Chapter 2), providing insight into what is already known about this under-researched population. We then completed a qualitative study on how SEMHP manifest in the CAP setting (Chapter 3). A questionnaire deploying a Likert scale was then conducted to validate these findings with a larger group of youth, clinicians, and caregivers (Chapter 4). Finally, we examined how SEMHP characteristics are currently addressed and assessed within the diagnostic process in CAP (Chapter 5).

The general discussion starts with a summary of the findings from these four chapters. We then address methodological considerations, including study limitations and implications. Subsequently, the main findings are explained. We close by providing implications and recommendations for clinical practice, future research, policy, and youth and caregivers.

SUMMARY

Chapter 2 reports a systematic literature review exploring the existing knowledge on youth with SEMHP and their characteristics. It explores (1) the definition of severe and enduring in terms of mental health problems; (2) biopsychosocial factors contributing to the development and continuation of SEMHP; and (3) the impact of SEMHP on youth, their environment, and society. For data extraction and qualitative data synthesis, the review included 39 studies on SEMHP (or synonymous terms) among youth 12-25 years. Identified characteristics were clustered in six themes and 20 subthemes. Most studies reported severe distress, recurrent mental health problems, trauma, suicidality, low socioeconomic status, and problems in family function. In addition, the impact of SEMHP on youth was reported to be mostly psychological and scholastic. Only a few studies reported on the societal impact of SEMHP regarding cost and policies. This review suggests that suicidality and trauma are prominent concerns among youth with SEMHP. The findings of this review grounded further exploration of SEMHP characteristics in clinical practice.

Chapter 3 advances our understanding of SEMHP characteristics among youth by exploring the manifestation of SEMHP in the CAP setting. Its two aims comprise defining the terms “severe” and “enduring” in CAP, and identifying factors contributing to the development and continuation of SEMHP in CAP. We conducted semistructured interviews with ten youth with lived experiences and ten specialized clinicians. The outcomes showed that “enduring” described both the duration of mental health problems and the duration of care received or not, while “severe” indicated multiple mental health problems across many life domains. SEMHP characteristics were divided among five contexts: individual, family, peer, mental healthcare systems, and society. Youth described individual factors such as masking behavior to unburden caregivers, as well as out of shame and fear of not belonging among peers. Moreover, clinicians described the high-risk behavior of youth as leading to rejection to treatment or an escalation of care, sometimes resulting in hospitalization. Based on the interviews, we conclude that SEMHP characteristics seem to have a persistent and sometimes hidden nature, to be interrelated across multiple contexts, and to be affected by deficits in current mental healthcare systems and society.

Chapter 4 verifies our qualitative results from Chapters 2 and 3 among a larger group using Likert scale questionnaires. The chapter examines the extent to which SEMHP characteristics were recognized by youth with SEMHP, caregivers of youth with SEMHP, and clinicians working with youth with SEMHP. It also explores potential differences in perspective between these participant groups. This quantitative study included 81 youth, 43 clinicians, and 31 caregivers. All participant groups consistently recognized the characteristics: prolonged suffering, impacts across life domains, interpersonal distrust, negative self-conception, SEMHP internalization, limited daily function, and hopelessness. Notably, these characteristics are the opposite of those needed for resilience. Differences among participant groups emerged concerning trauma, caregiver involvement, societal stigma, and youth self-harm to feel numb or mask behavior. The questionnaire results indicate that key stakeholders perceive crucial SEMHP characteristics in varying ways. These differences in perspectives can contribute to feelings of distrust and social alienation. Therefore, it is essential to carefully consider the experiences of all relevant stakeholders throughout the diagnostic process to avoid misunderstanding, feelings of being unheard, and the potential to overlook important characteristics.

Previous studies on existing literature (Chapter 2), experiences of youth with lived experiences and specialized clinicians (Chapter 3), and ratings of youth, caregivers, and different types of clinicians (Chapter 4) have resulted in increased insight into a broad variety of SEMHP characteristics among youth. Chapter 5 explores how SEMHP characteristics are addressed and assessed in the diagnostic process. We first mapped the diagnostic process of a CAP facility in the Netherlands by conducting preparatory interviews with eight mental health care professionals. Second, we conducted focus groups with eight youth with lived experiences, five caregivers, and ten clinicians to gain in-depth insights into the current assessment of SEMHP-specific characteristics. The main finding was that although all examined SEMHP-specific characteristics were addressed during diagnostics, youth and caregivers still mentioned feeling misunderstood and unheard. Barriers and facilitators affecting proper assessment of SEMHP-specific characteristics during diagnostics were divided into five categories: fear, (in)visible behavior, time and trust, perceptions, and sociocultural considerations. The results suggest that the barriers to assessment of SEMHP characteristics can lead to a vicious cycle wherein youth feel unheard, causing them to mask their true emotions, potentially deepening

mistrust, and disconnection. Therefore, it is essential for clinicians to balance between information gathering and fostering connection, trust and openness in a genuine dialogue.

METHODOLOGICAL CONSIDERATIONS

This section addresses methodological considerations and limitations related to study population, qualitative research methods, and research in cocreation with stakeholders.

Study population

It is challenging to define a study population with limited understanding of their characteristics. Given the lack of prior research on youth with SEMHP, no theoretical framework has been established to define strict inclusion or exclusion criteria. We therefore drew upon existing definitions from the adult literature, where Severe Mental Illness (SMI) has been defined by Delespaul and the consensusgroup (2013, 2019). Based on this definition, we described the mental health problems of youth with SEMHP as severe, interrelated, and non-transitory in nature (enduring), requiring professional care in the CAP setting. However, since the terms “severe” and “enduring” may hold different meaning for youth, we also adopted an approach allowing participants to define these terms within their personal context.

The lack of an a priori theoretical definition of SEMHP for youth has several implications for this dissertation. First, youth who would have met the criteria from a clinical perspective may have not recognized their own mental health problems as “severe” or “enduring”, resulting in underreporting or even self-exclusion from our studies. Second, since we have adopted an approach that allows for participants to define “severe” and “enduring” based upon their own perspectives, our findings have reflected a broad range of different experiences. However, this subjectivity may increase the risk of inconsistency across studies and can complicate direct comparison with other research that is relying on standardized classifications, which limits the integration of our findings with existing literature. However, the iterative design of this dissertation, consistently validating our previous findings, helped to uncover differences in perspectives while identifying shared characteristics within the SEMHP group, thereby strengthening the internal validity of the research.

A limitation of our study population is that youth with SEMHP were drawn from a convenience sample, as this sample mainly consisted of accessible youth with lived experiences who came from organizations such as the National Youth Counsil (*Nationale Jeugd Raad,* NJR) (Stratton, 2021). While we aimed to balance female and male participants in the qualitative studies and attempted to reach a broader and potentially less accessible group of youth through social media in the quantitative study, certain subgroups were underrepresented, such as male youth and youth with a migration background. This exclusion raises important questions about whether these groups are less likely to access CAP services (Place et al., 2021), perceive or label their mental health problems differently from SEMHP, or if they are less likely to experience SEMHP. The underrepresentation of these youth may have skewed our findings towards white female youth who are highly educated. These discrepancies could result in biased conclusions about SEMHP characteristics among youth or suggest that these characteristics are more common among female youth in CAP. Future research should examine how different subgroups of youth experience SEMHP.

Reflections on qualitative research methods

The main strength of the qualitative approaches in this dissertation lies in their ability to capture the authentic and meaningful experiences of youth, caregivers, and clinicians on SEMHP. The qualitative research methods contributed to a unique perspective on the "what, how, and why" behind youth with SEMHP (Aspers & Corte, 2021).

Qualitative methods, similar to quantitative methods, adhere to established criteria, such as trustworthiness, credibility, transferability, dependability, and confirmability (Ahmed, 2024). This dissertation applied data triangulation and reflexivity to ensure these criteria (Ahmed, 2024). Data triangulation here involved multiple sources, such as interviews and focus groups, and it thereby facilitated the validation of findings and enhanced their transferability (Carter et al., 2014). Operationalized via critical reflection during research team discussions, reflexivity contributed to confirmability and supported transferability further on (Olmos-Vega et al., 2022). To ensure methodological transparency and substantially reduce reporting bias, we followed PRISMA guidelines (Chapter 2: Page et al., 2021) and COREQ guidelines (Chapters 3 and 5: Tong et al., 2007).

A limitation of qualitative research is its reliance on small sample sizes (Stenfors et al., 2020). Our sample sizes were small, yet the data provided substantial richness and depth because participants with lived experiences were deliberately included (Sonuga-Barke, 2024). However, it may have restricted the transferability of our findings, as the participants who had been included may not fully represent the diversity of youth with SEMHP. To address this limitation and to gain broader insight into whether these findings resonate more widely, we followed an exploratory sequential design using Likert scale questionnaires. By including a larger sample of youth, caregivers, and clinicians we validated and expanded upon our qualitative results.

Another limitation of qualitative research is its inability to statistically test for interaction between characteristics and to analyze causality in SEMHP (Hennink & Kaiser, 2022; Oplatka, 2021). We identified key SEMHP characteristics and observed their interrelations in the narratives of participants, however, the underlying dynamics of these interactions were not statistically tested. This limitation reflects the exploratory nature of this dissertation and emphasizes the need for future research to examine interactions between SEMHP characteristics among youth. Such research would require a multifaceted approach including a longitudinal design to track changes in the development and continuation of SEMHP characteristics (Anstey & Hofer, 2004). Subsequently, the findings can be tested using structural equation modeling to examine the relationship between SEMHP characteristics simultaneously (De Carvalho & Chima, 2014). However, this approach also requires a substantial sample size and a control group of youth without complex and multifaceted mental health problems, or a "healthy" control group; despite existing studies, these requirements remain challenging.

Lastly, we advocate for qualitative research. As the editor of *The Journal of Child Psychology and Psychiatry* has pointed out, few recent papers have incorporated qualitative methods (Sonuga-Barke, 2024). The absence of qualitative methods could be due to the popularity of quantitative methods in traditional science or because qualitative studies are more often rejected in journals out of lack of understanding for its approach by peer-reviewers (Clarke et al., 2025). The lack of qualitative papers in peer-reviewed journals is a pity, as it can strengthen translational science as well as help develop

strategies that prevent or treat mental health problems among youth (Sonuga-Barke, 2009; Sonuga-Barke, 2024). Qualitative approaches have a particular importance for youth experiencing mental health problems that do not conform to existing frameworks, including youth with SEMHP. Furthermore, as highlighted by youth with SEMHP during our interviews, qualitative methods gave them a voice in research about their own mental health, something often absent in traditional science.

Reflections on research in cocreation with stakeholders

The DevelopRoad project was dedicated to integrating youth voices and perspectives, incorporating elements of patient-oriented research (POR) (Poitras et al., 2024), participatory action research (PAR) (Cornish et al., 2023), and evidence-based practice (Hoagwood et al., 2001). We involved youth with SEMHP as research participants and project members. Youth participants, including both trained and nontrained youth with lived experience, shared their personal stories, providing an initial understanding during the prefocus groups and contouring our understanding of SEMHP throughout the project. Affiliated with the National Youth Counsil (*Nationale Jeugd Raad,* NJR), the Fonds NutsOhra (FNO) Geestkracht Youth Panel, or serving as strategic advisors for Leiden University Medical Center (LUMC) Curium, our youth project members pivotally shaped the project and ensured it aligned with participants' needs, allowing them to share their stories. They cowrote the research proposal to ensure a youth-centered design and integrated their voices into the process. They also helped refine the research questions and topic lists, ensuring our research reflected the language and experiences of youth. Additionally, they led recruitment efforts, using social media to reach youth demographics that the researchers might not otherwise have connected with. Furthermore, we worked with creative youth affiliated with the NJR to present our findings and considered clinical and practical recommendations from youth with SEMHP, in a way that resonated with and engaged other youth with SEMHP. While collaborating with various youth in the project crucially shaped the research outcomes, it also has been time-intensive for all parties involved. Coordinating with multiple stakeholders demands time and effort and can sometimes lead to decision-making delays. Ensuring successful collaboration required proper work conditions including substantial flexibility, adequate compensation, clear communication, and clear task descriptions (de Beer et al., 2024).

Another essential collaboration within the DevelopRoad project lies in the dual approach to understanding both the characteristics and needs of youth with SEMHP. While this dissertation focused on identifying who these youth are, the dissertation of Rianne de Soet addresses what these youth need in treatment. These two areas of inquiry are deeply interconnected. Therefore, we collaborated intensively from start to finish, which included the joint development of research questions and topic lists, the conduction of interviews, the analyzation of results, and the reflections on the findings to determine our next steps. This collaborative approach allowed us to adopt a broader perspective on the characteristics and needs of youth with SEMHP, enhancing our understanding of its complexity and implications for treatment. Additionally, our complementary professional and personal skills created a safe dynamic in which we continuously improved and reinforced our research. Lastly, the dual approach contributed to a more satisfactory and team-based research experience in the often-individual focused academic world. We recommend that future research projects should consider a collaborative dual-perspective approach, as it can lead to a

better understanding of research topics, improve research outcomes, and contributed to increased positive research experiences.

Lastly, future (implementation) projects should also involve other relevant stakeholders, such as schoolteachers and policy makers. In the context where youth spend much of their time, namely school, schoolteachers can provide students with valuable insights into their mental health and it may be a key opportunity for school-based mental health services (Zabek et al., 2023). Policy makers are essential to achieve systemic change in the mental healthcare context. Achieving change in clinical practice can be complex due to numerous stakeholders both within and outside the organization. However, to effectively organize input from all different stakeholders, a participation matrix can be a valuable tool (Kenniscentrum Revalidatiegeneeskunde Utrecht, 2017). Such a matrix can help define *which* stakeholder contributes, *when,* and in *what* respects, allowing for a more targeted and structured involvement of stakeholders in the research process (Concannon et al., 2019; Kenniscentrum Revalidatiegeneeskunde Utrecht, 2017). A structured involvement of multiple stakeholders, including schoolteachers and policy makers, contributes to a wider understanding of SEMHP and ultimately may increase timely recognition of youth in different communities.

DISCUSSION OF MAIN FINDINGS

This dissertation represents the first in-depth exploration of the characteristics of SEMHP among youth in the CAP setting in the Netherlands. We illuminate a group of youth often falling between the cracks of the current mental healthcare systems and research because their mental health problems are perceived as "too complex". Our findings affirm that the complexity of SEMHP cannot solely be attributed to the individual, but rather arises from the dimensions of SEMHP including the multiple contexts involved with SEMHP, the diverse perspectives on SEMHP, and the dynamic nature of SEMHP.

We found that SEMHP among youth is characterized by how an individual relates to themselves (individual context); to their caregivers, family, peers, and friends (social context); to the mental healthcare systems (mental healthcare context); and to societal factors (societal context). Additionally, SEMHP among youth is characterized by the impact of SEMHP on the functioning of both youth and their surroundings, including their caregivers and clinicians (impact). It is also characterized by how SEMHP is perceived by youth, their social environment, mental healthcare, and society (multi-perspectivity). Lastly, SEMHP among youth is characterized by the stage of adolescence, shaped by developmental changes within youth themselves and in relation to their social environment, the mental healthcare system, and the current 21st century society (dynamism). This framework characterizing SEMHP in its multi-contextuality, multi-perspectivity, and dynamic nature aligns with the ecological theory of Bronfenbrenner (1994), which refers to multiple systems around a child, interrelated and affecting a child's development depending on the relations between the systems (Bronfenbrenner & Morris, 1998). The framework also aligns with the recent definition of mental health from the Trimbos Institute (2022): "Mental health is the way you relate to yourself and others, and how you cope with the challenges of everyday life. At the same time, it also involves how you and others in society experience this" (van Bon-Martens et al., 2022). According to the definition of mental health, every component (we refer to this as dimension) consists of positive

foundational elements (van Bon-Martens et al., 2022). However, for youth with SEMHP these positive elements are often absent.

In this section, we address the multiple dimensions of SEMHP in youth and its challenges for both youth and clinical practice. First, we summarize the characteristics of SEMHP among youth identified in our studies (Table 1). Next, we briefly discuss the three dimensions that encompasses SEMHP characteristics, namely multi-contextuality, multi-perspectivity, and dynamism. Finally, we reflect on how these three dimensions seem to problematically interact with one another in a continuous cycle - a process entailing what we call "interactional cycles".

Overview of SEMHP characteristics in youth

First, it is important to emphasize that the overview of SEMHP characteristics is intended to provide a description of youths' mental health problems and contexts, as well as the stakeholders involved. It is not a criteria-based checklist requiring youth to meet a minimum number of characteristics to qualify their problems as severe and enduring. Furthermore, the list is not exhaustive: differences in perspectives and experiences have been identified, and as such, the SEMHP characteristics likely differ across individuals.

Based on our findings in Chapter 2,3, and 4 the terms "severe" and "enduring" were described as involving many classified disorders, multiple mental health problems at once, various life domains affected, long suffering, and long-term care history. Table 1 provides an overview of the characteristics by chapter.

We found the characteristics of SEMHP to include negative view of self, interpersonal distrust, trauma (individual context), feelings of difference, lack of social support (social context), misunderstanding, rejection, distrust in mental healthcare (i.e., the mental healthcare context), and societal stigma and societal invisibility (i.e., in the societal context). It also includes feelings of hopelessness in youth, suicidality, problems with daily function, and powerlessness among caregivers and clinicians (impact). Moreover, we identified significant differences in perspectives on the characteristics of SEMHP between youth, caregivers, and clinicians, indicating disharmony in their understandings of what is means to experience SEMHP.

Our findings offer valuable new insights into youth with SEMHP in the CAP setting, building upon and extending, existing knowledge from the Severe Mental Illness (SMI) definition and the Flexible Assertive Community Treatment (FACT) groups description (Broersen et al., 2020; Delespaul & de consensusgroep EPA, 2013; Van Sonsbeek & Oosterling, 2020). As we have built upon the SMI definition it is not surprising that our findings align with Delespaul's et al. description (2013). This holds particularly for the severe problems in social and societal functioning. However, we found that it is less about identifying psychiatric disorders. Additionally, certain characteristics, such as trauma and self-harm, resonate with the FACT group's description (Broersen et al., 2020). However, characteristics such as poverty and migration were observed in certain local FACT groups in the Netherlands (van Sonsbeek & Oosterling, 2020), but were not found in youth participating in our studies. Our studies might have not observed these characteristics due to selection bias (Pannucci & Wilkins, 2010), necessitating further research.

Three key dimensions of SEMHP among youth

Building on the characteristics identified in our studies, we have outlined three dimensions of SEMHP among youth in clinical practice: multi-contextuality, multi-perspectivity, and dynamism. This section briefly discusses each of these dimensions.

Multi-contextuality

As confirmed by this dissertation, SEMHP it not narrowed to the individual. Rather, SEMHP unfolds throughout many contexts that affect youth. These environments include an individual's personal experiences; caregivers and family, school, mental healthcare systems; and the societal contexts in which youth live. Understanding SEMHP requires consideration of how these different contexts interact and shape the mental health experiences of youth.

Multi-perspectivity

When multiple contexts are involved, a range of perspectives inevitably arises. These perspectives held by youth, caregivers, and clinicians directly affect how SEMHP is understood and managed. Each perspective brings its own set of priorities, interpretations, and biases, complicating the process of fully addressing SEMHP. These differing viewpoints highlight the complexity inherent in both understanding and recognizing SEMHP.

Dynamism

Our findings indicate that SEMHP has a dynamic nature, with certain mental health problems becoming more prominent than other problems at different developmental stages. This variability may be linked to the gradual onset of mental health problems during adolescence (Uhlhaas et al., 2023). In this period of life, youth shape their identity and transition from caregiver-dependence towards independence and peer connections (Erikson, 1959; Zhang & Qin, 2023). They navigate the stages of identify formation and confusion, as well as intimacy and isolation (Erikson, 1959). Throughout adolescence, conflicts with caregivers and peer pressure can frequently occur, thereby leading to loneliness and isolation (Laursen & Veenstra, 2021; Morningstar et al., 2019). The dynamics within and between multiple contexts makes SEMHP among youth highly interactional, as the problems in multiple contexts can act both as cause and effect. If left unaddressed or not adequately addressed, SEMHP can worsen over time.

Interactional cycles related to SEMHP among youth

Considering the three dimensions, we believe that SEMHP characteristics should not be seen in isolation, but as part of an interactive, evolving process across time and contexts. In this dissertation, we expand on this idea by referring to the interplay between contexts, perspectives, and the dynamic nature of SEMHP that leads to vicious cycles difficult to break: interactional cycles. To illustrate these interactional cycles, we discuss four of its relevant aspects.

1. Invisibility and the enduring nature of SEMHP

Chapter 3 clarified that the enduring nature of SEMHP is part of the problematic interactional cycle. The term "enduring" has been associated with the duration of the problems, as found in the studies included in our review and the descriptions provided by youth and clinicians during the interviews. However, the interviews also highlighted the masking behavior of youth as a key characteristic. This characteristic recurs across all chapters, where youth themselves particularly highlight that they

mask their behaviors differently in different contexts. In the home environment, youth may hide their struggles out of fear or burdening their caregivers (Chapter 3). Youth often felt their parents underestimated the severity of their problems (Chapter 4), while caregivers may remain unaware of the underlying problems for an extended period (Chapter 5). In the mental healthcare setting, masking can manifest through different responses, such as high-risk behavior (Chapter 3), or self-harming behavior to confront underlying mental health problems (Chapter 4). Despite the use of numerous questionnaires and protocols in the diagnostic process (Chapter 5), this behavior may be misunderstood or misinterpreted, for example, as a sign of demotivation. While masking behavior is recognized among youth diagnosed with autism spectrum disorder (ASD) (Chapman, 2020), fewer studies have explored this behavior among youth and families with multiple mental health problems. Early recognition of youth masking underlying mental health problems is crucial, as prior research shows that feeling misunderstood can reduce motivation in care (Crockett et al., 2022). We believe this creates a vicious cycle where masking, feeling misunderstood, and lack of motivation reinforce each other. Consequently, treatment may inadequately address mental health problems, leading to serious consequences for the progression of youth's mental health problems.

2. Distrust

A second aspect of the interactional cycle is distrust between youth and other relevant stakeholders. Chapter 3 made evident that youth with SEMHP often lose trust in themselves, in clinicians, and in the mental health care system. Long waiting lists, repeated rejections, misaligned care, and dismissal due to behavior widens the gap between youth and care. Youth with a history of unsupportive social contexts often mistrust systems that are meant to help them, and treatment failure may reinforce these feelings of distrust (Bevington et al., 2015). Chapter 5 clarified that youth and their caregivers sometimes hesitate to share certain information, driven by a fear of the potential consequences and their distrust, while clinicians sometimes refrain from asking certain questions out of fear of losing connection with youth and caregivers. Consequently, difficult, and fearful emotions experienced by youth, caregivers or clinicians remain unaddressed and unspoken. However, it is known that transparency and open communication is effective with the treatment of youth with mental health problems (Lynch et al., 2021). We believe that a lack of open communication, out of fear of sharing or fear of asking, could reinforce a vicious cycle of distrust between stakeholders, who are often unaware of the cycle they are caught in or unsure how to break it.

3. Hopelessness and powerlessness

A third and recurring aspect of the interactional cycle is the hopelessness experienced by youth. In the scientific literature reviewed, hopelessness is often interpreted as part of depression or suicidality. However, our findings identify that feelings of hopelessness seem to transcend specific classifications. Chapter 3 showed that hopelessness can also been seen as the fear and feeling of the endurance of mental health problems. In Chapter 4, hopelessness among youth with SEMHP was recognized by all stakeholders, yet in Chapter 5, stakeholders reported that it received little attention in the diagnostic process. This is worrying, as hopelessness is associated with suicidality (Tonkuş et al., 2022), and suicidality and self-harming behavior are key characteristics of SEMHP among youth. This combination of SEMHP characteristics is particularly alarming, as in the last decades suicidality has risen by 17% among youth (Rijksinstituut voor Volksgezondheid en Milieu, 2023). Therefore, addressing hopelessness in youth properly is crucial, as we believe that it may contribute to a vicious cycle in which hopelessness both emerges from SEMHP and exacerbate its severity.

Moreover, the dynamic process of hopelessness exceeds youth, as it can also be seen in the desperate environment or in exhausted caregivers. In Chapter 3, clinicians noted they experienced their own feelings of hopelessness and powerlessness. Surprisingly, in Chapter 4, not all clinicians acknowledge these emotions, suggesting that some may unconsciously downplay their own struggles in treating youth with SEMHP. While research on clinicians' powerlessness in child-and-adolescent psychiatry is scarce, concerns for increasing pressure on mental health professionals are highlighted (Inspectie Gezondheidszorg en Jeugd, 2021). Moreover, although fewer clinicians reported powerlessness among themselves, they did recognize powerlessness in caregivers (Chapter 4). Youth and caregivers also acknowledged powerlessness in caregivers, which seemed not always adequately addressed in diagnostics of SEMHP in CAP (Chapter 5). It is essential to have proper attention for the wellbeing of clinicians (Delgadillo et al., 2018) and of caregivers (Miller et al., 2018). If left unaddressed, we believe this permeation of hopelessness throughout the care context could create a vicious cycle where powerlessness in the contexts around youth with SEMHP could reinforce each other, ultimately increasing stress and burden on all parties involved and hindering quality of care.

4. Complexity of mental healthcare systems

A fourth aspect of the interactional cycle is the context of the mental healthcare system itself. In Chapter 3, factors within the mental healthcare system, such as long waitlists, treatment rejections due to severity or misalignment of problems, hospitalization, frequent changes of clinicians, a focus on classifications, and misdiagnoses were described to negatively impact the endurance of mental health problems in youth. In Chapter 4, youth and caregivers recognized in the CAP setting an overemphasis on classifying, while clinicians did not. In Chapter 5, youth described that some SEMHP characteristics remained unseen, even while addressed during diagnostics. It is known that errors in diagnostics and therapeutic procedures in (mental) healthcare could cause iatrogenic harm on patients (Krishnan & Kasthuri, 2005). This harm can also result from miscommunication and misjudgment, as for example with a failure to "read" behavior or listen, professional discontinuity, overreliance on diagnostic categories (Rees, 2012), and treatment rejection (Treasure et al., 2011). The signals of potential iatrogenic harm in our studies on youth with SEMHP should therefore be taken seriously, requiring those in the CAP setting to be aware of its potential deficits. We believe that it could create a vicious cycle where mental healthcare system deficits could cause a temporary phase of youths' mental health problems to become an enduring one.

IMPLICATIONS

This dissertation is exploratory in nature, serving as an initial step toward a better understanding of SEMHP among youth. In this section, we discuss implications for clinical practice, future research, policy, youth, and caregivers.

Clinical practice

This dissertation is practice-based, with various implications for clinical practice discussed in the individual chapters. This section outlines two key implications for clinical practice in understanding SEMHP among youth: the adoption of a context-oriented approach and the fostering of a context-oriented collaboration.

First, a context-oriented approach during diagnostics is essential to recognize SEMHP characteristics among youth (Bussemaker et al., 2023). Our research showed gaps in attention to the underlying mental health problems, as well as youth often feel unseen of misunderstood during SEMHP diagnostics. A recent report has highlighted that many youth believe that contextual factors are often overlooked (NJR Hoofdzaken & Kenniscentrum Kinder-en Jeugdpsychiatrie, 2024). In addition, another research showed that specialized care frequently focuses on individual symptoms without addressing the deeper, interconnected factors driving mental health problems (Spijk-de Jonge et al., 2022). Building on our findings and prior research, clinicians should maintain a critical perspective on their approaches during diagnostics. Such maintenance would require a shift from the traditional cause-and-effect perspective to a more circular and interconnected view (Friedman & Allen, 2014; Rugh, 1981) in the CAP setting. This shift should both be integrated and expanded in the current clinical practice, as in the training of future clinicians.

For current clinical practice, we suggest that clinicians devote proper time to develop an overview of contributing factors and their potential interactions by employing or be creative with already existing techniques, such as case conceptualization (McTavish et al., 2024) or the holistic theory (Mack, 2023). These techniques are known to support the recognition of interactional cycles and to identify key points for intervention, even if those key points are not the root cause of youths' mental health problems (McTavish et al., 2024). Additionally, clinicians should continuously reflect, adjust, and collaborate with youth and their caregivers throughout the diagnostic process, as risk factors and protective factors may evolve over time. While these suggestions may seem as the obvious, we want to highlight that clinicians working with SEMHP often face high pressure, crisis situations, and time constraints that can challenge their ability to apply prior knowledge effectively. For the training of future clinicians, such as psychiatrist, we suggest improvement of the education of medical students. Currently, the medical model is often the foundation for medical education (Biesta & van Braak, 2023). This means that focusing on classifying problems with a linear approach instead of a circular and interconnected contextual view is the basis for future psychiatry. Incorporating existing insights derived from pedagogical studies can assist teachers to integrate a more context-focused education that emphasizes the role of youth and their caregivers in clinical practice. Furthermore, integrating youth with lived experiences in education can enhance a holistic understanding of mental health problems for students, as it provides contexts to patients' symptoms and allows students to practice communication techniques by asking questions (de Beer et al., 2024).
Second, context-oriented collaboration is essential to address the characteristics of SEMHP. Clinicians should work closely with youth and their caregivers to develop a diagnostic plan, incorporating shared decision-making (Montori et al., 2023) and a shared explanatory analysis (Tempel et al., 2022). The involvement of multiple relevant stakeholders entails multiple perspectives that can differ due to their own experiences and perceptions, and because of linguistic and generational differences. To address this complexity, we emphasize the importance of diagnostic language awareness and alternative communication strategies. Tools such as "a talking mat" or "a talking plate" can ease dialogue through visual aids (Hayden et al., 2024). We suggest the formulation of a talking plate, specifically for SEMHP, with youth, their caregivers, and clinicians. This step could create space to discuss sensitive, unspoken, or avoided characteristics, in addition to reflecting on moments where connection and understanding may have been lost in the care process.

Research implications

This dissertation discusses various relevant topics for future research in the separate chapters. In the methodological considerations, we reflected on our research methodologies and provided implications for improvement of the foundation of our research on youth with SEMHP. This section discusses two topics for further consideration: the prevalence of SEMHP and diagnostics of youth with SEMHP.

First, there is a need for future research into the prevalence of youth with SEMHP. Although the DevelopRoad project collaborated with various CAP facilities (Levvel, Accare, Parnassia Groep, Karakter, KieN GGZ) in the Netherlands for participant recruitment, the actual number of youth experiencing SEMHP remains unknown. In our studies, we collaborated closely with youth from the National Youth Counsil, which provided valuable initial insights as these youth could articulate their experiences and represent a broader group. In addition, we reached a broader group conducting online questionnaires. However, to strengthen the case for targeted mental healthcare and societal policies, a better understanding of the population size of youth with SEMHP is necessary. Future research could start by involving all CAP facilities in the Netherlands and expanding to other sectors, such as substance abuse services and other youth care services, where youth with SEMHP may also be present. Given the international relevance of SEMHP, expanding research to other countries could further enhance the understanding of the international prevalence. In this type of research, adequate collaboration between facilities within the Netherlands is crucial, as for example the DREAMS consortium initiative (DREAMS, n.d.).

Second, timely recognition of youth with SEMHP in clinical practice requires further research into diagnostics. As the DevelopRoad project aimed to explore youth's with SEMHP characteristics and needs, the next step is to implement our knowledge into clinical practice. For this dissertation, which focusses on the characteristics of youth with SEMHP, this step is particularly relevant for diagnostics as we believe that diagnostics are crucial for understanding youths' mental health problems. Chapter 5 of this dissertation has provided relevant insights into SEMHP assessment during diagnostics, but the study was solely focused on specific-SEMHP characteristics at one CAP facility. Therefore, more research is needed within multiple CAP facilities to assess whether diagnostics need improvement, adaptation, or implementation. This should be done in collaboration with youth, clinicians, and caregivers. In doing so, it is important to look at existing valuable initiatives, such as Patterns of Life (van den Berg et al., 2024) and Jouw Verhaal Nu Centraal (ZonMw, n.d.).

Policy implications

This dissertation has shown the important role of CAP systems and society in the continuation and development of SEMHP among youth. For this reason, certain policy implications should be considered.

First, in the past years, the mental healthcare sector has been under stress with shortages, increased work demands, and growing mental health issues within the workforce (Søvold et al., 2021). These challenges combined crisis situations and time constraints, increases pressure on clinicians working with SEMHP in CAP. In addition to organizational best practices, such as workplace policies and mental health resources (Wu et al., 2021), time seems an essential factor that is currently missing. Clinicians often mention a lack of time to get to know youth properly, youth mention a lack of time to

tell their story, and caregivers mention the demands of multiple appointments. Although time always remains a complicated factor, it is important to constantly ask ourselves how we can best use time. A longer period for diagnostics, where diagnostics is therefore also an essential part of treatment, is an example of rethinking time. This issue continues to require creative solutions and appropriate policies, with policymakers also need to rely on the experiences of clinicians.

Second, youth with SEMHP are dealing with societal factors of the 21st century. Our findings show persistent societal stigma and confusion about what is "normal", despite progress in raising awareness about mental health. Efforts such as mental health awareness in schools and national campaigns as "Hey, it is okay" can foster understanding and encourage youth to speak out (Ministerie van Volksgezondheid, Welzijn en Sport, 2024). However, it also important to normalize certain feelings among youth. Framing mental health challenges as illnesses reinforces the idea that sadness, loneliness, and anxiety are abnormal (Kraak, 2021). The view of not fitting in as an individual problem, fixable through therapy, is problematic because it can lower self-esteem and lead to social exclusion (Kraak, 2021; Wienen, 2021). Therefore, policies must advocate for mental health awareness and align with concerns of 21st century youth; they must also be developed in collaboration with youth. This implication is specifically relevant for youth with SEMHP, since in their experience they do not fit in, contributing to an interactional cycle of loneliness and of feeling misunderstood.

Youth and caregiver implications

Lastly, in this dissertation we have presented the results of each article to youth from the National Youth Counsil and the Youth Counsil of LUMC Curium, inviting them to identify the most important insights and offer recommendations for both youth and caregivers based on the results. While these insights are subjective and may resonate differently with everyone, we believe that youth are best positioned to determine what guidance is most meaningful to them. These recommendations were published in factsheets, created collaboratively with youth from Studio Bold (part of the National Youth Counsil). In this section, we highlight one key suggestion for youth and for caregivers.

For youth, we would like to emphasize the importance of interaction between clinicians and youth, particularly in cases where underlying mental health problems may go unnoticed, not due to malintent but potentially to a lack of awareness or understanding of the situation. While it is not the responsibility of youth to educate mental healthcare professionals on diagnostic practices, youth sharing their stories can crucially help clinicians to better understand their experiences. If youth are uncertain about the relevance of sharing specific aspects of that story, it may be helpful first to discuss them with a trusted person within one's personal network or a peer support worker (trained youth with lived experience). Additionally, we acknowledge that verbalizing certain experiences can be challenging. Finding alternative ways to communicate, such as writing or creative expression, may also provide a pathway for sharing.

For caregivers, the interaction between clinicians and caregivers is equally important, as are the dynamics between caregivers and youth. Our study focusing on different perspectives on SEMHP has revealed significant differences in how youth, caregivers, and clinicians perceive and interpret the characteristics. Since the process of assigning meaning to experience is critical in understanding SEMHP, it is valuable for caregivers to engage in an open dialogue with youth and clinicians. These

conversations can help caregivers to understand what it means for youth to experience these mental health problems and for clinicians to navigate these problems, while providing an opportunity for caregivers to share their own experiences and perspectives.

CONCLUSION

Understanding the characteristics of severe and enduring mental health problems (SEMHP) among youth is crucial for timely recognition of these mental health problems and the provision of adequate support. This dissertation has explored the characteristics of SEMHP among youth in the child-and-adolescent psychiatry (CAP) setting from multiple perspectives. We found that the problems are characterized by underlying trauma, high-risk behavior including suicidality, masking behavior, interpersonal distrust, low self-esteem, hopelessness and powerlessness among all those involved, factors in the family and social environment, such as parents with their own stress, isolation and problems at school, defects in the mental health care system such as long waiting lists and misdiagnoses, and social factors such as social stigma. These characteristics should not be viewed in isolation, but as part of an interactive, evolving process across time, contexts and perspectives. The three dimensions described in this dissertation, multi-contextuality, multi-perspectivity, and dynamic character, should form the basis for the diagnosis of these youth. Incorporating these dimensions requires a shift from the traditional linear view to a circular vision, both in current clinical practice and in the education of future clinicians in CAP. Understanding severe and enduring mental health problems requires diagnostics focused on building relationships and continuous evaluation of characteristics in collaboration with youth and their caregivers.

Table 1. Overview of SEMHP characteristics in youth

		Chapter 2	**Chapter 3**	**Chapter 4**
	Severe	Suicidality Comorbidity	Hampered functioning in various life domains Suicidality Multiple classifications Hospitalization High-risk behavior High burden	Multiple mental health problems Multiple life domains affected
	Enduring	Comorbidity Duration of mental health problems Duration of care	Duration of care Mental health care systems (waiting lists) Recurrency of mental health problems Invisibility of mental health problems	Prolonged suffering Long time in treatment
Individual context		Heredity Age/ Gender Trauma Hopelessness Psychosocial functioning Academic functioning Suicidality Substance abuse Criminal behavior	Genetic vulnerability Trauma Puberty Masking behavior High-risk behavior (auto mutilation/self-harm, eating problems) Interpersonal distrust Hopelessness Limited daily functioning	Low self-esteem Demotivation by interpersonal distrust Psychiatric identification Avoidance by self-harm Avoidance by not wanting to talk Numbing yourself by self-harm Masking behavior History of intensive live events Hopelessness Limited daily functioning
Social context	Family	Socio-economic factors Family functioning	Parental stress Parental psychiatric problems Communication Powerlessness among caregivers	Underestimation of severity Lack of involvement Avoidance of care Powerlessness among caregivers

	Peers	Social support	Social network Isolation Invisibility	Feeling of being different Loneliness
Societal context	Mental health care systems		Multiple classifications Hospitalization Elusiveness of mental health problems Powerlessness among clinicians	Focus on classifications in child-and-adolescent psychiatry Powerlessness among clinicians
Impact		Problems in academic functioning Problems in social and emotional functioning Hopelessness in youth Suicide attempts Substance abuse Criminal behavior	Hampered functioning/stagnation in multiple life domains Elusiveness of the mental health problems Hopelessness in youth Powerlessness in caregivers Powerlessness in clinicians	Limitations in daily functioning Feeling of despair, due to loss of hope for a normal life Feeling of despair, due to lack of future perspective Feeling of despair, due to not being able to get appropriate care Powerlessness among caregivers Powerlessness among clinicians The emergence of the problems lacks a single identifiable reason Changing severity of the problems