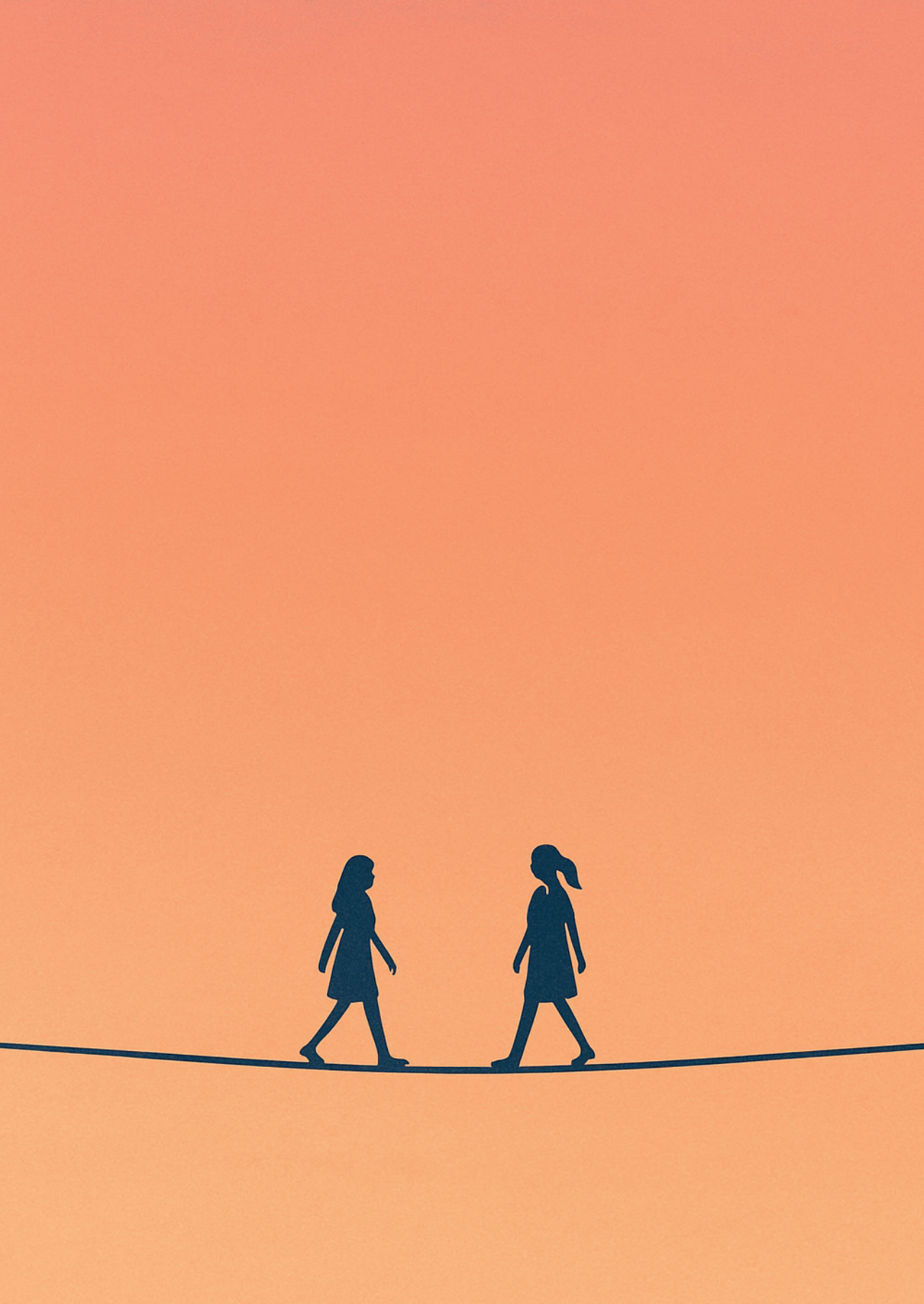
In between and unseen: exploratory research into the characteristics of youth with severe and enduring mental health problems

Bansema, C.H.



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Chapter 1

General introduction

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"*When I was 13 years old, something happened that turned my world upside down. Yet I managed to go on seemingly happy. I threw myself into school and was a star at distractions. At the age of 15, it broke me: I did not want to live anymore. When school became aware of the situation, they encouraged me to talk. But when help was offered, they did not know how to manage it. My problems – depression, sleep problems, despair, suicidality – were seen as "too severe". However, at the time I did not realize how severe it was. I thought everyone around me was experiencing similar emotions, and my surroundings made me feel like I was exaggerating. I was then referred to a specialized treatment facility, which led to my first group treatment. Despite the treatment and my efforts, I did not feel any better. It was not until another crisis that I had a conversation with a doctor, and for the first time, I finally felt heard.*

At the age of 18 I graduated from high school, but then collapsed. The first long-term hospitalization followed. I was locked inside myself and as soon as I walked out of my room to therapy everything in me seemed to disappear. People thought I just did not want to. A single therapist saw my effort and – especially – my powerlessness. Multiple admissions and diagnoses followed. To qualify for the next treatment, my clinician diagnosed me with borderline disorder, even though she claimed that I did not have it. Trauma therapy was rejected each time because I could not talk about what happened. Attempts at suicide and severe side effects of medication were ignored. My integrity was constantly doubted.

At the age of 24, after 6 years of voluntary and forced admissions across the country, my psychiatrist at the time suggested I give trauma therapy one last try, as I had already exhausted all other options. I felt incredibly anxious, but I understood that this was the last option. Again, I did not get past the intake procedure. Later, a dissociative disorder was diagnosed by a trauma therapist who happened to review the extension of forced seclusion and concluded that something was wrong. However, his colleague did not believe in the existence of dissociative disorders and insisted on the diagnose of borderline, which he described in detail in his discharge letter. After a while, when trauma therapy finally seemed possible, I turned out to be pregnant – and thus once again - excluded from help."

Jantine – My summarized journey in the Dutch mental healthcare service

This is the story of Jantine. In 2019, she found herself powerless after not receiving the care she needed. Her story, and the stories of other youth with "too severe" mental health problems during that time, exposed the critical gaps in the mental healthcare services in the Netherlands for this group of youth. She asked pressing questions about the effectiveness of existing diagnostics and interventions for youth considered "too severe". These are questions that require careful exploration and reflection, and therefore her experience, along with the experiences shared by other youth, served as the key reason for the research presented in this dissertation.

BACKGROUND

News articles, national reports, and stories from youth, caregivers, and clinicians have highlighted a rising prevalence of adolescents and emerging adults (16-25 years) with "complex" mental health problems or "complex" needs that fall through the cracks of current mental healthcare systems. While most mental health problems are temporary and treatable, a subset of youth faces severe and enduring mental health problems (SEMHP) (Broersen et al., 2020; GGD GHOR, 2021), with approximately 8% requiring long-term psychiatric care (Systema et al., 2006). The growing demand for specialized youth mental health services has strained resources to meet the complex request for help (Inspectie Gezondheidszorg en Jeugd, 2021). Paradoxically, those who seem to need help most are least likely to receive it.

Youth with SEMHP encounter multifaced mental health problems, including suicidality, behavioral problems, eating disorders, and self-harm, along with social difficulties in family dynamics, relationships, and education (Broersen et al., 2020; Inspectie Gezondheidszorg en Jeugd, 2021; van den Steene et al., 2019). Acute care is often required due to the severity and multiplicity of their problems (Inspectie Gezondheidszorg en Jeugd, 2021). However, identifying a clear psychiatric profile remains challenging, as these youth frequently fall outside of conventional diagnostic categories.

Unfortunately - and somewhat surprising - hardly any research has been done on youth with SEMHP to date. Traditional research has often emphasized designs focusing on narrowly defined psychiatric classifications, excluding those who do not meet these rigid criteria. Clinicians recognize the complexity of SEMHP in clinical practice, yet scientific support remains insufficient to describe and characterize youth with SEMHP.

This primarily exploratory dissertation examines SEMHP in youth from multiple perspectives, including those of youth, caregivers, and clinicians. We seek to unravel the complexity of SEMHP and deepen our knowledge of its development and persistence. This introductory chapter outlines recent trends in SEMHP among youth, alongside the study's setting, framework, design, and origin.

Trends in SEMHP

The past two decades have seen a global increase in mental health problems among youth that seems a genuine public health crisis, rather than merely an effect of improved awareness or diagnosis (McGorry et al., 2025). Of particular concern is the increasing prevalence of severe psychological distress, self-harm, suicidal behavior, and depression among youth across diverse contexts (McGorry et al., 2025). Data from the American Psychiatric Association have indicated that 6% to 12% of youth experience severe mental health problems (Fosbenner & Al-Mateen, 2019), while suicide remains the third leading cause of death among individuals aged 15-29 years (WHO, 2024). Recent research has identified risk factors linked to the increasing prevalence of severe mental health problems, including problems in identify formation, worsened due to societal stressors, cyberbullying by peers, and the COVID-19 pandemic, which increased social isolation among youth (McGorry et al., 2025).

In the Netherlands, reports indicate increasing rates of depression, hopelessness, and suicidality, with suicide being a major cause of death for youth (Hilderink & Verschuuren, 2018). Care

trajectories for youth with SEMHP often involve chaotic transitions and crisis placements. Meanwhile, underlying mental health problems have frequently remained insufficiently analyzed and inadequately understood (Tempel & Visserberg, 2018). A national report on youth care trajectories in specialized care has revealed that youth with SEMHP often experience fragmented care, leading to an incomplete understanding of their problems and needs (Spijk-de Jonge et al., 2022).

CHILD-AND-ADOLESCENT PSYCHIATRY (CAP) SETTING

This dissertation focuses on the CAP setting, as the complexity of SEMHP has been emphasized by CAP institutions. To understand the complexity of SEMHP in clinical practice, we briefly discuss the CAP setting, its current classification methods, and a prior description of SEMHP in adult psychiatry.

Traditional CAP

CAP is a specialized field of psychiatry dedicated to diagnosing, treating, and preventing, or limiting the escalation of, mental disorders in children, adolescents, and their families (Sadock et al., 2009). Traditional CAP typically employs the medical model, which conceptualizes problematic thoughts, feelings, and behaviors as mental disorders (Huda, 2021). This system includes two interrelated models: explanatory models, which describe the nature and origin of these problems, and practice models, which guide how physicians assess, classify, and treat patients (Huda, 2021). Communication about mental health can be confusing due to terms like “diagnostics,” “diagnosis,” “disorders,” “classifications” and “mental health problems” (Ruissen, 2014). Various differences in usage and disagreements on how to understand these concepts preclude clear definition (Tse & Haslam, 2023).

This dissertation adopts the following definitions: “diagnostics” is the ongoing process of evaluating information to understand the causes of problems within a theoretical framework. A “diagnosis” is the result of this process, where a clinician combines all the information including medical history, clinical signs, and symptoms that match established criteria in manuals like *the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) (APA, 2013), or *the International Classification of Diseases, Eleventh Edition* (ICD-11) (WHO, 2018). “Mental disorder” is a general term for conditions (with an underlying psychobiological dysfunction) that disrupt functioning and cause distress, whereas a “classification” is a standardized categorization of mental disorders (APA, 2013). Each mental disorder has established criteria that must be met for a classification: for example, major depressive disorder (DSM-5) (Ruissen, 2014). In this dissertation we prefer “mental health problems” instead of “disorders”, given that youths’ problems are not necessarily pathological in nature and that terms such as “disorder” and “classification” often suggest a sense of permanence.

Classification models

In the Netherlands, the DSM-5 is predominantly used for public health, research, and administrative purposes, as a DSM-5 classification is often requiring to determine eligibility for reimbursed care (Nederlandse Zorgautoriteit, n.d.). While the DSM-5 acknowledges that mental health problems often exist on a continuum rather than as discrete entities (APA, 2013; Clarck et al., 2017), the tendency remains in psychiatry to overemphasize classifications without considering the continuum (Newson et al., 2021). This tendency is particularly harmful for youth with SEMHP, who often do not fit a specific classification or fit multiple at once, such that they fall through the cracks of the system. Additionally, while the DSM-5 may assist clinicians in conceptualizing and naming youths’ difficulties

(Werkhoven et al., 2022), youth frequently do not identify with these classifications, leaving them feeling misunderstood or unheard (Bjønness et al., 2020). Therefore, relying on classifications alone is insufficient to fully capture the complexity of youths' SEMHP.

Severe mental illness (SMI) in adult psychiatry

Adult psychiatry also necessitates a clear description of individuals with SMI, as this group frequently requires enduring therapeutic support and is at elevated risk across multiple domains of their lives (Delespaul & de consensgroep EPA, 2013). The consensus group SMI reached consensus on its definition as (a) a psychiatric disorder that necessitates care, (b) with severe impairments in social and community functioning (which may fluctuate), (c) in which the impairment is cause and effect, (d) which is not transient, and (e) in which coordinated care from professional caregivers is indicated (Delespaul & de consensgroep EPA, 2013). This description of SMI is based on a large population, consisting mostly of adults. While these criteria are helpful to describe SEMHP among youth, they may also be only partially applicable to youth, as it can be challenging to determine whether a youth' mental health problems are temporary or may resolve as that youth develops into adulthood (Patalay & Gage, 2019). Hence, a fitting description of SEMHP for youth is currently lacking.

THEORETICAL FRAMEWORKS

The basis of three theoretical frameworks forms the foundation to explore SEMHP among youth: youth development, the biopsychosocial model, and the influence of multiple contexts. These frameworks are essential to understand the broader context of SEMHP in youth, as they expand our perspective by incorporating interpersonal, environmental, and systemic factors.

Youth development

Youth with SEMHP aged 16-25 years are in a developmental period of their lives called "adolescence". This period is characterized by biological, psychological, and social changes that can increase the vulnerability for the development of mental health problems (Worthman & Trang, 2018). Youth can experience a shift from dependence on caregivers to peer relationships and an increasing need for social belonging (Morningstar et al., 2019; Tomova et al., 2021). Difficulties during adolescence can have detrimental consequences for youth's current and long-term mental health (McDougall, 2011). Prior research has shown that most mental health problems have an onset between ages 12 and 25 years, making this developmental period crucial for early diagnosis and intervention (Solmi et al., 2022; Uhlhaas et al., 2023). Therefore, a developmental perspective should be considered in the exploration of SEMHP in youth, to understand its development and continuation, as well to enable timely recognition.

Biopsychosocial model

The biopsychosocial model is an extension of the traditional medical model, focused on biological, psychological, and social factors that contribute to the development and continuation of mental health problems (Bolton, 2019; Engel, 1981; Wong et al., 2021). This model consists of biological factors such as genetics and biomarkers; psychological factors such as thoughts, emotions, behaviors, and distress; and social factors such as socioeconomic status and family circumstances (Engel, 1981; Harris & McDade, 2018). According to this model, these biopsychosocial factors can be interconnected in shaping mental health problems (Bolton, 2019). While this framework is not

comprehensive, and therefore continues to evolve, it is often used to study factors in mental health problems. Therefore, in our initial search for existing knowledge on SEMHP, as well as the mental health problems and factors that contribute to the development and continuation of SEMHP, we start with this framework (Chapter 2).

Multiple contexts

In addition to biopsychosocial factors, the contexts in which youth live and the interactions between these contexts can affect their mental health problems. One framework that emphasizes the interactions between various contexts is Bronfenbrenner's ecological system theory (1979). According to this theory, environmental systems are linked and shape the development of children and youth (Bronfenbrenner, 1979). This theory categorizes five ecological systems: (1) the microsystem, which are the closest to youth (e.g., caregivers); (2) the mesosystem involving connections such as family and friends; (3) the exosystem including indirect influences, such as the mental healthcare sector; (4) the marcosystem, including cultural influences; and (5) the chronosystem reflecting the time and life stage of the youth (Bronfenbrenner, 1979). Various factors in these systems can contribute to the development and continuation of severe mental health problems in youth (McGregor et al., 2025). Therefore, to expand our knowledge on SEMHP in youth, the systems described in Bronfenbrenner's theory should be taken into account. To capture these systems, our exploration of the characteristics of SEMHP includes various contexts such as the individual, family, peer, mental healthcare, and societal context (Chapter 3).

EXPLORATORY RESEARCH

The approach of this dissertation is primarily explorative, as research on SEMHP in youth is limited. Given the vulnerability of these youth, it is essential to apply research methods that minimize burden, align with youths' perspectives, and needs, and are inclusive and flexible. We therefore prioritize qualitative research methods, the inclusion of multiple perspectives, and cocreation in research with youth.

Exploratory qualitative research

Exploratory research is often performed when researching a novel topic with limited existing knowledge (Casula et al., 2021). In the absence of an established theoretical framework, an inductive approach is typically adopted, where qualitative data forms the basis for theory development (Turner & Astin, 2021). The Grounded Theory is a systematic methodology facilitating theory formation by inductive reasoning (Glaser & Strauss, 1994). Researchers begin by reviewing qualitative data to identify emerging concepts, which will be refined, organized, and reflected as more data is collected, ultimately forming a new theory (Lim, 2024). Combing inductive with deductive approaches, based on an existing theoretical framework, can contribute to a more complete understanding of a topic (Proudfood, 2022). This dissertation adheres to the grounded theory method by adopting an iterative cycle of evolving data collection, analysis, and reflection to explore the characteristics of SEMHP in clinical practice and form a theory. After a preliminary review of the literature, field research will be conducted using qualitative research methods with continuous reflection on the findings (Cullen & Brennan, 2021; Sonuga-Barke, 2024). By centering the stories of youth, caregivers, and clinicians, this qualitative research provides a rich understanding of their perspectives (Palinkas, 2014).

Multiple perspectives

To ensure a thick description of SEMHP, it is critical to avoid explaining SEMHP through a single perspective (Kostova, 2017). This dissertation therefore adopts a multi-perspective approach including multiple viewpoints from different stakeholders. Fundamental stakeholders include youth with SEMHP, caregivers of youth with SEMHP, and clinicians working with SEMHP (De Los Reyes et al., 2022). Unfortunately, youth often feel excluded from the discussion of their mental health, while their involvement offers unique insights into their feelings, experiences, and perspectives on their mental health (Bjønness et al., 2020). Furthermore, the inclusion of caregivers in research can provide valuable insights into the context of youth with SEMHP outside the clinical setting, such as their home environment, family history, youths' development, and behavior at home (Haine-Schlagel & Walsh, 2015). Lastly, including the perspectives of clinicians in research enhances the understanding of the presentation of SEMHP in clinical practice. Clinicians can offer their professional expertise on mental health problems and share valuable experiences with treatment (Leger et al., 2023). Their inclusion can help to bridge theory and clinical practice (Linderborg et al., 2024). Since these perspectives often differ, recent research on individual with severe mental health problems emphasized including multiple informants to promote mutual understanding and recovery (Burger et al., 2024).

In cocreation with fundamental stakeholders

Aside from the inclusion of fundamental stakeholders as informants in research, integrating their perspectives in the design and analysis is important. A potential danger of conducting research based on existing theoretical frameworks is that the voice of those it is about is ignored (Uhlhaas et al., 2023). The motto "Nothing about us, without us" from the disability rights movement emphasizes the importance of involving the people directly affected by decisions that impact their lives (Charlton, 1998). Youth are competent and have the right to participate in research about them (Wilkinson & Wilkinson, 2024). In alignment with this motto, this dissertation actively involves clinicians, caregivers, and most importantly, youth with SEMHP in hypothesis formation, data collection, and analysis interpretation. Their inclusion in research offers unique insights (Wilkinson & Wilkinson, 2024), and foster opportunities for their personal development and empowerment (de Beer et al., 2024; Watson et al., 2023).

DISSERTATION

This dissertation is part of DevelopRoad, a research project within a broader initiative to seek ways to improve the future perspective of youth with SEMHP. A crucial first step is to better understand these youth, identifying their characteristics, recognizing them accurately and in a timely manner in clinical practice, and determining effective approaches to help them regain a sense of future perspective. We briefly describe the DevelopRoad project, preliminary research, and the objectives of this dissertation.

The DevelopRoad project

The DevelopRoad project is an initiative of LUMC Curium, an institution for CAP in The Netherlands. The project was funded by the Dutch organization "Fonds NutsOhra (FNO) Geestkracht" (103601) for the period of 2021–2024. DevelopRoad has two main objectives, studied in two parallel and interlinked PhD projects: exploring the characteristics of youth with SEMHP, and exploring their

treatment needs. This dissertation addresses the first objective, while the dissertation of my colleague in DevelopRoad Rianne de Soet, focuses on the second. Given the objectives' strong interconnection, both PhD projects involve close collaboration. To develop a deeper, more personalized, and practical understanding of youths' characteristics and needs, DevelopRoad prioritizes the voices and lived experiences of youth. It embraces cocreation, working with a strategic youth advisor from LUMC Curium, a youth representative from Team Geestkracht, and from the National Youth Counsil (*Nationale Jeugdraad, NJR*) during the entire project: from forming the initial research plan, to implementing results in practice.

Preliminary research

In 2019, small-scale preliminary research was conducted to gain initial insight into identifying and describing youth with SEMHP (unpublished, available upon request). This research included two focus groups with youth (n = 6, n = 5) from the National Youth Council; a member check with youth (n = 5) from a psychiatric facility; and interviews with clinicians working at psychiatric facilities (n = 4). The outcomes showed that SEMHP was described as multiple, complex, comorbid problems in which there is limited functioning in different areas of life. Youth expressed feeling a compromised sense of self, a lack of belonging, and being unheard. Additionally, it was mentioned that SEMHP can almost never be captured within diagnostic criteria as described in the DSM-5 (APA, 2013), as it seems a broader issue than solely the presence or absence of certain symptoms. Clinicians reported prolonged treatment for these youth, therapy resistance, and dysfunctional support systems as intensifying factors. The findings of the preliminary research prompted further research into the characteristics of youth with SEMHP, and how they can be supported.

Objective of this dissertation

The goal of this dissertation is to deepen our understanding of severe and enduring mental health problems (SEMHP) in youth. Therefore, the main objective of this dissertation is to explore the characteristics of youth with SEMHP, including the factors contributing to the development and continuation of SEMHP, and the impact of SEMHP on youth and their environment. To fulfill this objective, we will explore: the existing literature on youth with SEMHP; the manifestation of SEMHP in child-and-adolescent psychiatry based on the experiences of youth, caregivers, and clinicians; and the current assessment of SEMHP characteristics during diagnostics in child-and-adolescent psychiatry.

OUTLINE

Deepening the understanding of SEMHP among youth serves as a connecting thread throughout the following chapters, which are built upon each other to form a theory.

Chapter 2 explores the existing knowledge of the characteristics of SEMHP in youth by systematically reviewing the literature, aiming to identify the meaning and usage of the terms "severe" and "enduring", the factors contributing to the development and continuation of SEMHP, and the impact of experiencing SEMHP on youth, their environment, and society. In total, 39 studies are included, representing multiple combinations of mental health problems, from a broad variety of settings and with diverse methodologies. Both a thematic and content analysis were conducted, and for each theme, the strength of evidence was calculated.

Moving from text to clinical practice, Chapter 3 explores the manifestation of youth with SEMHP in the CAP setting by conducting semistructured interviews. The exploration aims to define the terms "severe" and "enduring" in CAP and to identify contributing factors to SEMHP in CAP. In total, 10 youth with lived experience and 10 specialized clinicians were interviewed, based on a topic list formulated in advance. Both a thematic and content analysis were conducted, resulting in a division of the characteristics among different contexts of life.

Subsequently, Chapter 4 verifies our results from Chapters 2 and 3 using Likert-style questionnaires. The questionnaires were aimed to examine the extent to which the SEMHP characteristics were recognized by youth with SEMHP, caregivers of SEMHP, and clinicians working with SEMHP, and to explore potential differences in perspectives between participant groups. A total of 155 questionnaires were completed by 81 youth, 43 clinicians, and 31 caregivers. A one-way analysis of variance (ANOVA) was conducted for each characteristic, with group (youth, caregivers, clinicians) as the independent variable. After significant ANOVA results, a post-hoc comparison using Tukey's test was performed, displaying the differences between specific groups on the SEMHP characteristics.

Chapter 5 explores how SEMHP characteristics are addressed and assessed in the diagnostic process, by conducting preparatory interviews and focus groups. The exploration aims to map the diagnostic process in a CAP facility, to examine whether SEMHP characteristics were addressed in the diagnostic process, and to identify potential facilitators and barriers in the assessment of SEMHP characteristics during diagnostics. First, eight mental health professionals within the CAP institution were interviewed to map the diagnostic process. Second, focus groups were conducted with eight youth with lived experience, 10 clinicians, and five caregivers. A reflexive thematic analysis results in an overview of factors facilitating and hindering diagnostics of SEMHP characteristics.

Chapter 6 summarizes the SEMHP characteristics identified in the literature (Chapter 2) and clinical practice (Chapter 3), as well as their validation among a larger group of youth, clinicians, and caregivers, including similarities and differences in perspectives (Chapter 4) and the facilitators and barriers in the assessment of SEMHP characteristics in the diagnostic process (Chapter 5). Key findings are reviewed, and their implications for clinical practice, future research, policy, and youth and caregivers are discussed.