Lived experience matters: on the healing power of peer support and mental health experiences of professionals

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Chapter 1

General Introduction

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> *"I have been inpatient, also on closed wards, multiple times. During this time, I experienced a deep sense of isolation. I felt a distance between myself and the professionals on the units. They couldn't connect with me on a personal level. It never felt as though someone was truly standing beside me, saying, 'We're in this together, and I understand what you're going through.'. This lack of genuine connection made it difficult to accept help. Looking back, I realize how powerful it would have been to have someone who could speak to me from shared experience. Someone who simply acknowledged what I was feeling." (young person, 2020)*

This personal reflection, shared by a young person from the National Youth Council at the start of my PhD trajectory, highlights a key challenge within child and adolescent mental health services (CAMHS): despite the availability of CAMHS, many young people do not fully benefit from existing care (Brimblecombe et al., 2017; McGorry et al., 2013; Gibson, 2021). One promising approach to enhance these services is the inclusion of youth peer support workers (YPSWs), young people with lived experiences of mental health challenges who are often trained to support other young people facing similar challenges (Gopalan et al., 2017; Tisdale et al., 2021; Ojeda et al., 2021). Studies suggest that among others, YPSWs promote treatment engagement, validate experiences, and enable young people to better manage stigma regarding mental illness (Ojeda et al., 2021; Tisdale et al., 2021). These studies also suggest that young people perceive YPSWs as more reliable and credible compared to other clinical staff, because YPSWs self-disclose lived experience of mental illness and hardships (Gopalan et al., 2017).

Despite this promising evidence, the literature on youth peer support remains limited, and numerous challenges exist in fully integrating them into CAMHS (Hopkins et al., 2021; Gopalan et al., 2017). While notable progress has been made towards integrating peer support workers (PSWs) in adult mental health services, as well as involving young people with lived experiences in research, participation, and policy, the integration of YPSWs within the care process for young people with mental health challenges remains minimal (Janssen & Van Lier, 2014; Shalaby & Agyapong, 2020; Swist et al., 2022; James, 2007; McCabe et al., 2023). Importantly, studying this integration requires specific attention to the developmental stage of YPSWs, who are often still young adults navigating personal growth and may have limited employment skills (Gopalan et al., 2017). As a result, YPSWs can face unique challenges compared to their adult counterparts.

Given these complexities, a comprehensive overview of the existing literature on YPSWs in CAMHS is essential, as well as deeper insight into their value and the system-wide barriers and facilitators to their integration (Gopalan et al., 2017). Therefore, this dissertation aims to address this gap by examining how YPSWs can be integrated in specialist CAMHS to be of value to the treatment of youth with severe mental illness. In addition to exploring the integration of YPSWs in specialist CAMHS, this dissertation examines how physicians' experiences with mental health challenges and treatment affect their own medical practice, treatment needs

and help-seeking behavior. While this examination differs in focus from research on YPSWs, both aim to deepen our understanding of how lived experiences of mental health challenges can be supported, understood and valued in (child and adolescent mental) health systems.

Transforming Child and Adolescent Mental Health Services

Over the last decade, there has been a concerning rise in poor mental health among children and adolescents (McGorry et al., 2022; Gore et al., 2011). When young people face mental health challenges during childhood or adolescence, it can result in both long-term and short-term negative consequences in all areas of life (Gore et al., 2011; Brimblecombe et al., 2017). Short-term negative consequences of untreated mental health challenges include difficulty in initiating or maintaining friendships; low self-esteem; not reaching full educational potential; and increased stress on family members or caregivers (Brimblecombe et al., 2017). When mental illness persists into adulthood it can restrict occupational opportunities; increase societal and intergenerational burden of mental illness; lead to involvement in criminality; and result in lower life expectancy (Brimblecombe et al., 2017). CAMHS offer treatment and support to young people experiencing mental health challenges. However, despite receiving care, many young people continue to experience persistent mental health symptoms and functional impairments. Today, many young people describe that rapid social, cultural, and digital advances (e.g. constant exposure to social media) have made navigating the journey to adulthood vastly different from 20 years ago (Gibson, 2021; Bonnie et al., 2015; Berry et al., 2021). Consequently, there is a need to enhance support offered by CAMHS, to ensure care is timely, developmentally appropriate, and reaches those young people who do not currently fully benefit from existing services (McGorry et al., 2013; Gibson, 2021). In this context, it is important to study how lived experiences, particularly through the role of YPSWs, who are often close in age to the young people they support, can be meaningfully integrated into CAMHS to improve engagement, support, and treatment for young people navigating mental health challenges.

History of Youth Peer Support

While the presence of (Y)PSWs in practice has grown substantially in the 21st century, history shows that the involvement of peer roles was not always welcomed or possible (de Beer & Nooteboom, 2021; Hunsche & Van der Lans, 2016; Davidson et al., 2012). Having mental health problems was often perceived as a threat to society and led to exclusion, confinement, and abuse (Neuvel, 2023). In the 19th century, developments such as the medical classification of psychological complaints gradually opened the door for understanding and treating mental health challenges in more structured forms of care and support (Rössler, 2013). These changes slowly laid the groundwork for recognizing lived experience as a source of expertise alongside clinical expertise and research evidence (Hunsche, & van Andel, 2008). Today, numerous adult mental health services employ paid peer support workers, and adults with lived experience are actively involved in research, advocacy, and practice (Hunsche & Van der Lans, 2016; Shalaby & Agyapong, 2020; Myrick & Del Vecchio, 2016). These developments have also begun to influence CAMHS, where interest in youth peer support has grown in the last decade

(Shalaby & Agyapong, 2020; Gopalan et al., 2017). While the involvement of YPSWs is still relatively new in CAMHS, lived experience of young people is actively utilized in client advisory boards, youth councils, and research (Janssen & Van Lier, 2014; de Beer & Nooteboom, 2021; Swist et al., 2022; James, 2007; McCabe et al., 2023). Nevertheless, the integration of YPSWs into CAMHS is still evolving, and a deeper understanding of structural, cultural, and practical challenges is necessary to support their inclusion in practice (Janssen & Van Lier, 2014; Gopalan et al., 2017).

Experiential Knowledge

The employment of peer support workers in adult mental health services, and the growing presence of YPSWs in CAMHS reflects a broader movement of valuing lived experiences as a form of expertise in mental health care. Central to this movement is the concept of 'experiential knowledge'. While the concept of experiential knowledge remains loosely defined, for the purpose of this dissertation, we define experiential knowledge as expertise gained from reflecting and processing lived experiences with mental health challenges and disruptive life events (Karbouniaris, 2023; Weerman, 2016; Dings & Tekin, 2023; Bjønness, 2024; Castro et al., 2018). This process not only requires self-reflection, it also requires someone to reflect on and engage with others with similar experiences, allowing for a deeper understanding of its contexts, shared understanding and improved transferability (Castro et al., 2018). To represent youth and include their voice in service delivery and structuring, the use of experiential knowledge, alongside clinical expertise and scientific knowledge, has received increasing attention (Weerman, 2016; Murphy et al., 2024). By integrating experiential knowledge into CAMHS, services can provide care that resonates more deeply with the experiences of young people facing mental health challenges (Bjønness et al., 2024).

Youth Peer Support Workers

YPSWs are young people who have transformed their lived experience with mental health challenges into experiential knowledge and have attained skills to use this knowledge to support young people and enhance care (Gopalan et al., 2017; Tisdale et al., 2021). Research on both adult peer support workers and YPSWs suggests that by drawing on experiential knowledge, (Y)PSWs are able to promote treatment engagement, offer hope, role modeling, guidance, and empathy to other (young) people (Puschner, 2019; Oldknow, 2014; Lambert, 2014). The social comparison theory can help us understand why the involvement of YPSWs can be particularly beneficial for young people in treatment for mental health challenges (Wood, 1989; Barton & Henderson, 2016). This theory stipulates that people form an identity and evaluate themselves through comparison with others. Thus, suggesting that YPSWs who are further along in recovery, can inspire young people by providing a relatable example that recovery is attainable. Allowing for positive comparison through providing young people with motivation and hope. Beyond (emotional) support to young people, YPSWs can contribute experiential expertise to education, advocacy, and research by providing insider perspectives and representing young people with mental health challenges who are unable

to do so themselves (Erangey et al., 2022; Vojtila et al., 2021; Gopalan et al., 2017). However, more research is needed to fully understand the value of YPSWs in various roles in CAMHS.

A Human Rights-Based Approach

Examining the integration of YPSWs in CAMHS aligns with international efforts to improve care for (young) people with mental health challenges. In 2021, the World Health Organization (WHO) published a Comprehensive Mental Health Action Plan to advocate for more integrated community-based and person-centered care that respects human rights, combats stigma and promotes inclusion of people with mental health challenges (WHO, 2021). An important component of this vision is the involvement of people with lived experiences as partners in care and consultants guiding mental health system reform. Through integrating YPSWs, CAMHS can uphold both the WHO Comprehensive Mental Health Action Plan and young people's rights to participation, dignity, and recovery as outlined in the United Nations Convention on the Rights of the Child (UNCRC, 1989). Through studying how YPSWs can be valuable in CAMHS, we create opportunities for young people to influence and co-create services that are more responsive to their needs.

Physicians with Lived Experience of Mental Health Challenges

To deepen our understanding of how lived experiences can be supported, understood and valued within (child and adolescent mental) health systems, it is also important to consider the lived experiences of healthcare providers themselves. The second aim of this dissertation explores the experiences of physicians with mental health challenges, and how these experiences influence help-seeking, treatment needs and professional practice. Healthcare providers, including physicians, are not resistant to mental health challenges. Physicians often work in high stress environments that can negatively impact mental wellbeing (Chen et al., 2013; Patel et al., 2018; Kumar, 2011; Gold et al., 2016). However, workplace demands, along with (self-)stigma, role reversal from healthcare provider to patient, and professional norms might form barriers towards help-seeking and care (Brooks et al., 2011; Brooks et al., 2016; Stanton & Randal, 2016). Understanding the experiences of physicians and how they might influence medical practice, is vital for understanding existing cultures within (mental) health systems. By examining lived experience from both service users and physicians, this dissertation seeks to provide insights of how lived experiences of mental health challenges can be supported, understood and valued in (child and adolescent mental) health systems.

Dissertation

Aims of this dissertation

YPSWs have the potential to transform CAMHS into systems that are more responsive to the needs of young. Building on the historical context of lived experience and peer support, it is evident that youth peer support is not as well-established as its adult counterpart. Therefore, the aim of this dissertation is to examine how YPSWs can be integrated in specialist CAMHS to be of value to the treatment of youth with severe mental illness. To achieve this aim, this dissertation adopts a multi-method, exploratory approach. This dissertation starts

with a systematic review of the international evidence base on YPSWs in CAMHS, followed by qualitative studies and a case study examining the perspectives of YPSWs, healthcare professionals, and young service users. These studies focus on the practical, relational, and systemic factors that influence the integration of YPSWs, as well as the perceived added value of YPSWs in CAMHS. Finally, the scope of this dissertation is expanded by including a qualitative study on the lived experience of physicians with mental health challenges and its impact on help-seeking, treatment needs and professional practice. By examining both youth peer support and the experiences of physicians with lived experience, this dissertation aims to advance our understanding of how lived experiences can be valued, integrated, and supported within (child and adolescent) mental health systems.

Methodological approach

Given the exploratory nature of this dissertation and its focus on understanding how YPSWs and, more broadly, lived experiences can be valued, supported, and integrated into CAMHS, a multi-method research approach was adopted. (Gaglio et al., 2020; McCusker et al., 2015; Braun & Clarke, 2019). We started with a systematic literature review to establish a theoretical foundation for this dissertation and to map the existing evidence base. Following the systematic review, four qualitative studies were conducted for its ability to capture rich, nuanced and exploratory insights regarding youth peer support and lived experiences from diverse stakeholders, including: YPSWs, healthcare professionals, young people in treatment for mental health challenges, and physicians in treatment for mental health challenges (Gaglio et al., 2020; McCusker et al., 2015). One of the qualitative studies included, was a qualitative case study, which enabled exploration of the integration of YPSWs within a specific CAMHS setting, including the relational dynamics, organizational context, and barriers and facilitators encountered throughout the process. Through combining these methods we were able to generate comprehensive explorative insights on youth peer support and lived experiences, enabling broad implications for (child and adolescent) mental health services. Moreover, throughout the research on YPSWs, we consulted and involved a YPSW as co-researcher during the development of the study, data analysis and conduction of interviews with YPSWs and young people. The relevancy of involving a YPSWs lies within the ability of researchers with lived experiences to provide enriched perspectives into the findings, but also to ensure a more responsive research design (Kool et al., 2013; Karbouniaris, 2023; Vojtila et al., 2021).

Researcher positionality

In qualitative research, the positionality of the researcher plays a crucial role in shaping the research process. From design of the research to the analysis and interpretation of the findings, transparency of one's background and experiences is important for understanding potential biases and how they may influence the research outcomes (Holmes, 2020). Therefore, this section explores my own positionality as the main researcher during this dissertation.

I identify as a female and was between 26 and 30 years old during the course of the dissertation research. I hold an interdisciplinary bachelor degree from Leiden University College in Liberal

Arts and Sciences and a Master's degree in Clinical Psychology. My academic background is complemented by professional experience as both a psychologist and a researcher in child and adolescent mental health settings. My interest in the topics of my dissertation is shaped by both personal and professional experiences. I have my own personal lived experiences with mental health challenges and recovery from when I was younger, and during that time I received care from healthcare providers who occasionally disclosed their own lived experiences. I found these disclosures valuable and impactful. Later, during an internship at an addiction treatment center, I worked alongside PSWs, which further deepened my interest in the role of lived experience within clinical settings. Throughout this dissertation, I approached the research with a belief in the value of YPSWs, and lived experiences in a broader sense, while also recognizing the real and complex barriers to their integration. I understand the importance of critically reflecting on where, when, and how lived experiences can be valuable, while also recognizing that not everyone may find meaning in such experiences. Throughout the research, I remained reflexive, continually examining, together with the research team, how my own experiences, assumptions, and positionality may have shaped both the research process and the interpretation of findings.

Outline

This dissertation is structured into seven chapters: Chapter 2 will present a systematic review to describe the existing evidence-base on youth peer support. This systematic review includes published peer-reviewed studies with the aim of providing insight in different YPSW roles, as well as barriers and facilitators for implementing and pursuing youth peer support in CAMHS. The quality of the included studies was critically assessed using the Critical Appraisal Skills Program (CASP) 2018 checklists and an objective quality scoring system based on a study by Ibrahim et al. (2020). Following the quality assessment, data extraction and thematic synthesis was performed. For each subtheme included in this systematic review, the strength of evidence was calculated based on the quality of the studies that made up a subtheme, size of evidence, consistency, and context.

Chapter 3 presents the barriers and facilitators in the collaboration process between YPSWs and their non-peer colleagues. This study consists of 10 semi-structured interviews with YPSWs from the National Youth Council and Experienced Experts (ExpEx), as well as 17 semi-structured interviews with healthcare professionals from various occupations at three different CAMHS facilities in the Netherlands: LUMC Curium, Pluryn, and iHub. The interviews were transcribed and thematically analyzed. The thematic analysis was further enhanced using a content analysis. Based on the barriers and facilitators, Chapter 3 provides recommendations for improving collaboration between YPSWs and their non-peer colleagues.

In addition to exploring factors to improve collaboration between YPSWs and their non-peer colleagues, Chapter 4 provides insight into the unique socio-relational contributions YPSWs can make alongside clinicians in CAMHS. Chapter 4 also underlines how these contributions can be safeguarded in practice. The study reports on 37-semi-structured interviews conducted

in the Netherlands with young people, YPSWs, and clinicians from LUMC Curium, Pluryn, iHub, ExpEx and the National Youth Council. A reflective thematic analysis was applied to analyze these interviews.

Chapter 5 is a qualitative case study which examined the integration of two YPSWs at LUMC Curium, a Dutch child and adolescent psychiatry (CAP) facility. The study mainly focused on the autism spectrum disorder (ASD) unit at LUMC Curium for young people with ASD and comorbidities. A thematic analysis was conducted on bi-monthly meeting notes between two YPSWs and two coordinating sociotherapists (the key stakeholders), and interview transcripts from two rounds of interviews with the key stakeholders and other members of clinical staff (n=7). In addition to the thematic analysis, a timeline was also developed in collaboration with the key stakeholders to report on the integration process. The chapter describes the barriers and facilitators witnessed during the integration process between May 2021 and January 2024, and provides recommendations to implement YPSWs in practice.

Chapter 6 presents the findings from a reflexive thematic analysis on 14 in-depth semi-structured interviews with physicians in treatment at AerreA. AerreA is a specialist treatment facility for healthcare professionals with mental health challenges. The interviews covered topics related to factors contributing to mental health challenges in physicians, barriers to finding and receiving suitable care, treatment needs of physicians, and how their experiences with mental health challenges and treatment impacted their professional roles. This included whether they practiced self-disclosure about mental health challenges with patients, colleagues, and managers.

Chapter 7 is the final chapter and constitutes the discussion of this thesis. In this chapter, the key components of the YPSW role in treatment contexts is summarized, as well as the barriers, facilitators, underlying processes, and recommendations for integrating YPSWs in practice. Moreover, this chapter provides an in-depth discussion of the strengths, limitations and implications for practice and policy linked to studies included in this dissertation. This chapter also explores the next steps forward for youth peer support and other members of the lived experience workforce.

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