

Ain't no mountain high enough

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Ain't no mountain high enough

How to improve access to youth mental health care

Sophie Maaïke Jorinde Leijdesdorff

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Ain't no mountain high enough

How to improve access to youth mental health care

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Universiteit Maastricht,
op gezag van de Rector Magnificus,

Prof.dr. Rianne M. Letschert

volgens het besluit van het College van Decanen,
in het openbaar te verdedigen

op vrijdag 9 april 2021
om 14.00 uur

door

Sophie Maaïke Jorinde Leijdesdorff

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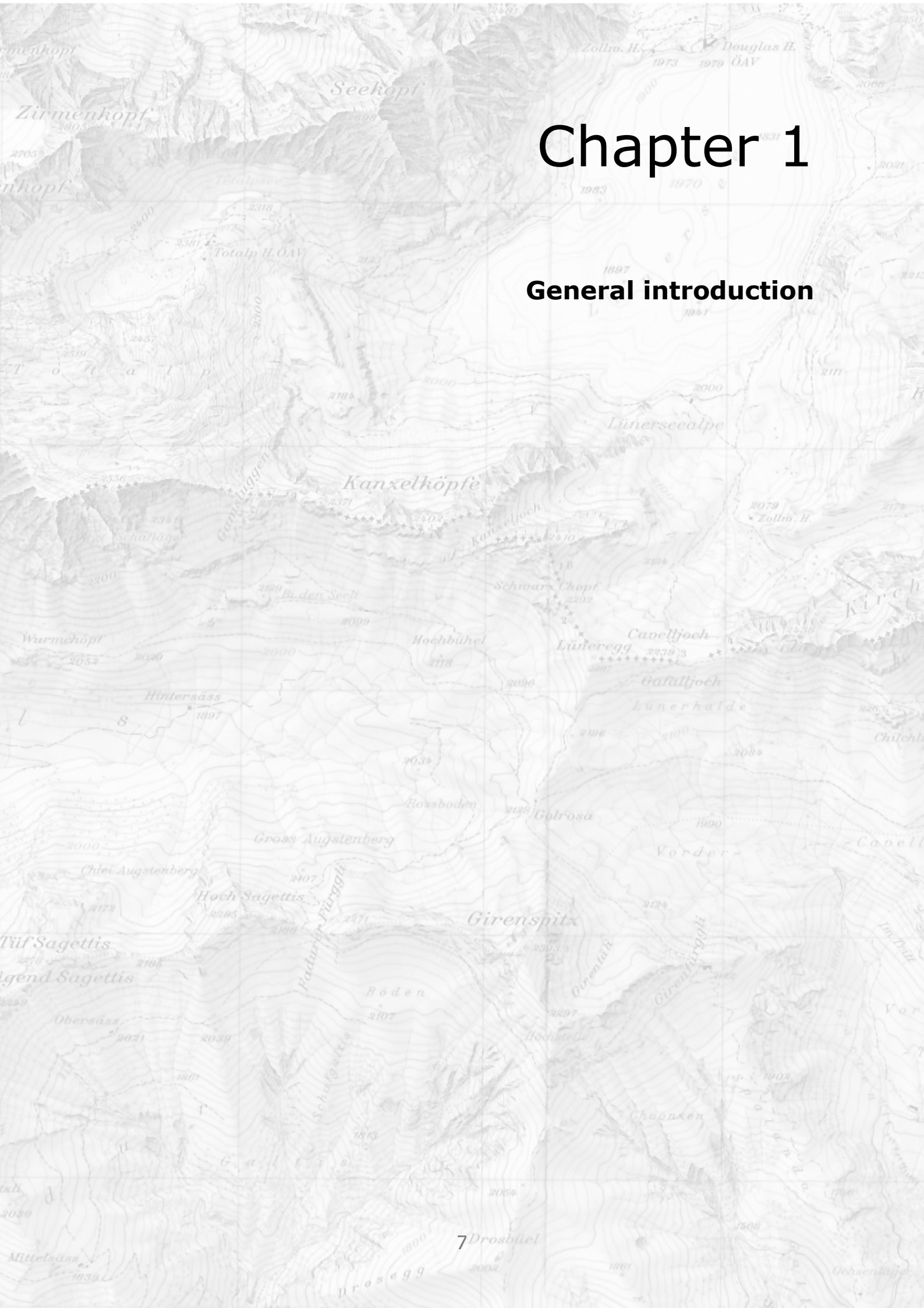
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Innovatiefonds Zorgverzekeraars, Health Foundation Limburg en de gemeentes Maastricht en Amsterdam hebben financieel bijgedragen aan de totstandkoming van de studies in hoofdstuk 2, 3 en 4. Stichting de Weijerhorst en Hersenstichting Nederland (MW, 20121-03) hebben financieel bijgedragen aan de totstandkoming van de studie in hoofdstuk 6.

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A detailed topographic map of the Lüneburger Heide region in Germany. The map features contour lines indicating elevation, with numerous peaks and valleys labeled. Key locations include Zirmenköpf, Seeköpf, Totalp, Kanzelköpfe, Lüneburger Heide, and Girensputz. The map is oriented with North at the top. The title 'Chapter 1' is overlaid on the right side of the map.

Chapter 1

General introduction

Background

With three out of four mental disorders emerging before the age of 25 (Kessler et al., 2005), young people (aged 12 to 25) have the highest prevalence of mental disorders across their lifespan (NIMH, 2017; Singh, 2009). The age of 12 to 25 is a critical period characterised by physical, emotional, cognitive and social development (Arnett, 2000). The onset of a mental disorder before the age of 25 not only causes disability at that very moment, but threatens age-specific, interpersonal, occupational and educational development in future life. The high incidence as well as prevalence of mental disorders amongst young people decreases the chance of a healthy development and fulfilling their potential. Arnett (2000) introduced the term emerging adulthood, indicating the transitional period between the dependency of childhood and the enduring responsibilities of adulthood. This time of life is identified by both a maximum of possibilities as well as uncertainties and risks. As a result, highly prevalent mental disorders place a significant burden on an individual as well as a societal level (Eaton et al., 2008; Lokkerbol et al., 2013; WHO, 2009). There is a growing body of literature that recognises the importance and effectiveness of early detection and intervention in youth mental health (McGorry et al., 2014; McGorry et al., 2007).

Individuals at risk

When discussing early detection of individuals at risk for mental disorders, children of parents with mental disorders (COPMI) deserve special attention. Because of both genetic as well as environmental factors, this group is particularly at risk for developing mental disorders themselves (Rasic et al., 2014). Despite effective preventive interventions (Siegenthaler et al., 2012), these young people are often not identified and offered help. The gap between Child and Adolescent Mental Healthcare (CAMHS) and Adult Mental Healthcare (AMHS) forms one of the major barriers for early detection of COPMI and the deployment of preventive interventions. Earlier research often focused on children of parents with severe mental disorders (SMI), mostly defined as schizophrenia, major depressive disorder, bipolar disorder, or severe borderline personality disorder (Leverson, 2003). However, a better understanding of the risks for children of parents facing a broader variety of mental disorders is required.

Unmet need

Despite studies and initiatives showing the importance and effectiveness of early detection and intervention in youth mental health, there is still a strong discrepancy between need for care and use of care amongst young people. Less than a third of all young people that experience problems with their mental health, receives any professional help (Jörg et al., 2016; McGorry et al., 2014; De Graaf et al., 2010; Slade et al., 2009; Aalto-Setälä et al., 2002). Research has shown that age specific barriers prevent help seeking, including stigma, shame and a lack of mental health literacy (Hetrick et al., 2017; Rickwood et al., 2007; Vyas et al., 2015). Another characteristic of youth which hampers early intervention, is the difficulty to predict future development of mental (ill) health. Symptoms often fluctuate in severity, sometimes at a subthreshold level (Jones, 2013; Kessler et al., 2007; Yung et al., 1996), making it hard to diagnose a specific mental disorder. Combined with long waiting lists, this leads to a situation in which treatment delay for help-seeking adolescents is often multiple years (De Graaf et al., 2010). In addition, even after entering the mental healthcare system, young people do not always receive appropriate care. In many countries the mental healthcare system is rigidly divided into CAMHS and AMHS. Transfer from CAMHS to AMHS usually takes place at 18 years, cutting right through the life-stage of youth as defined by the World Health Organisation (WHO). A British multi-centre study (Singh et al., 2010) revealed that for the vast majority of service users, the transition from CAMHS to AMHS was and is, despite huge efforts from both sides, poorly arranged, carried out, and experienced. In other words, there is a gap between the organisation of mental healthcare and young persons' needs.

The Dutch mental healthcare system (context)

The Netherlands has a well-organised healthcare system with fully covered general practitioners (GP) services and a standard procedure for all children at primary and secondary schools to be checked by youth physicians at least twice. Since 2015, a new law decentralised responsibility for youth mental health care for people up to 18 years old to municipalities. A compulsory healthcare insurance for all citizens covers mental health care costs for people over the age of 18. As the Netherlands is a small densely populated country, there are not many areas without health care facilities. In spite of these services and

regulations, and similar to other countries, there is still a gap between the number of young people with mental health problems and those who receive the appropriate care (De Graaf et al., 2010).

Improving access

Aiming at improving access to care and following a period of research into early detection of mental disorders (particularly psychosis) in adolescence, several innovative initiatives were developed worldwide. Active involvement of young people themselves is the common denominator. The most well-known initiative is the easily accessible Australian youth service headspace (www.headspace.au.org), open since 2006 (McGorry et al., 2007), accompanied by headspace Denmark and Israel, Jigsaw in Ireland, Maison des Adolescents in France and Foundry and Access Open Minds Canada (McGorry & Mei, 2018; Hetrick et al., 2017; Vyas et al., 2015). These initiatives are youth-friendly, allowing people aged 12 to 25 to discuss their mental health as well as physical, sexual, financial, vocational and social problems. Within this global movement, a group of Dutch mental health care professionals, together with stakeholders such as young people, municipalities, and other social and health care providers started to cooperate aiming at better matching the needs of young people. The feasibility and value of a Dutch version of headspace will be investigated, as well as what the key characteristics of this model should entail. Little is known about the burden of (sub-threshold) mental health problems in the critical group of young people who are in need for help, especially those without any form of professional care. Knowledge about this unknown group and their associated burden is needed, to further stimulate this topic on policy and research agendas, and to thereby encourage easily accessible youth mental health care. @ease visitors form a promising population to study this burden.

In addition, ways to reform existing services will be explored, aiming at continuity of care around the age of 18 and answering the complex needs of young people with mental health problems. Last, ways to improve early detection of individuals at increased risk, such as COPMI or young people with transdiagnostic (sub)clinical symptoms will be investigated. The value of social functioning as early detection marker in relation to transdiagnostic symptoms will be studied, using both traditional retrospective as well as innovative daily life measurements.

Aim and outline of the dissertation

In sum, the overall aim of this dissertation is to explore novel ways to enhance mental health, wellbeing and productivity of young people by investigating service accessibility, service reform and early detection in youth mental health.

The main topics to investigate are:

1. Barriers and facilitators on the pathway to mental health care amongst 12-25 year olds
2. Description of the innovative Dutch walk-in youth centres, its first visitors and the burden of their mental health problems
3. Adjusting existing mental health services to young persons' needs
4. Early detection: social functioning as a transdiagnostic marker and the increased risk for COPMI

These main themes will be studied in the following chapters:

The interview study in **Chapter 2** aims to provide in-depth and up-to-date insight in the experienced barriers and facilitators by young people aged 12 to 25 years old in the process of access to care. Targeting the question "What is the best way youth mental health initiatives can bridge the gap between adolescents with mental health problems and the professional help they need?".

Chapter 3 describes the working method of the innovative Dutch walk-in youth centres (@ease). In addition, a comprehensive profile of its first 2.5 years' visitors will be presented.

In **Chapter 4**, the burden of mental health problems in terms of health-related quality of life (HRQoL) and cost-of-illness in individuals first visiting the @ease youth walk-in centres will be calculated.

To bridge the gap between traditional mental health care and the needs of young people, a Youth Mental Health (YMH) team with a client-centred approach was set up within an existing mental healthcare organisation. **Chapter 5** describes the working method of this YMH-team and clinical characteristics of its population. To explore the effectiveness of the YMH-team, treatment effects will be analysed.

The study in **Chapter 6** investigates the value of social functioning as early detection marker in relation to transdiagnostic symptoms and as a predictor of psychopathology over time. Traditional retrospective versus innovative daily diary measurements of social functioning will be explored in youth.

Chapter 7 aims to give an up-to-date overview of psychopathology in children of parents with various mental disorders, based on recent literature.

The General Discussion in **Chapter 8** will present the main findings and conclusions of this dissertation. Moreover, directions for further research as well as implications for practice will be discussed.

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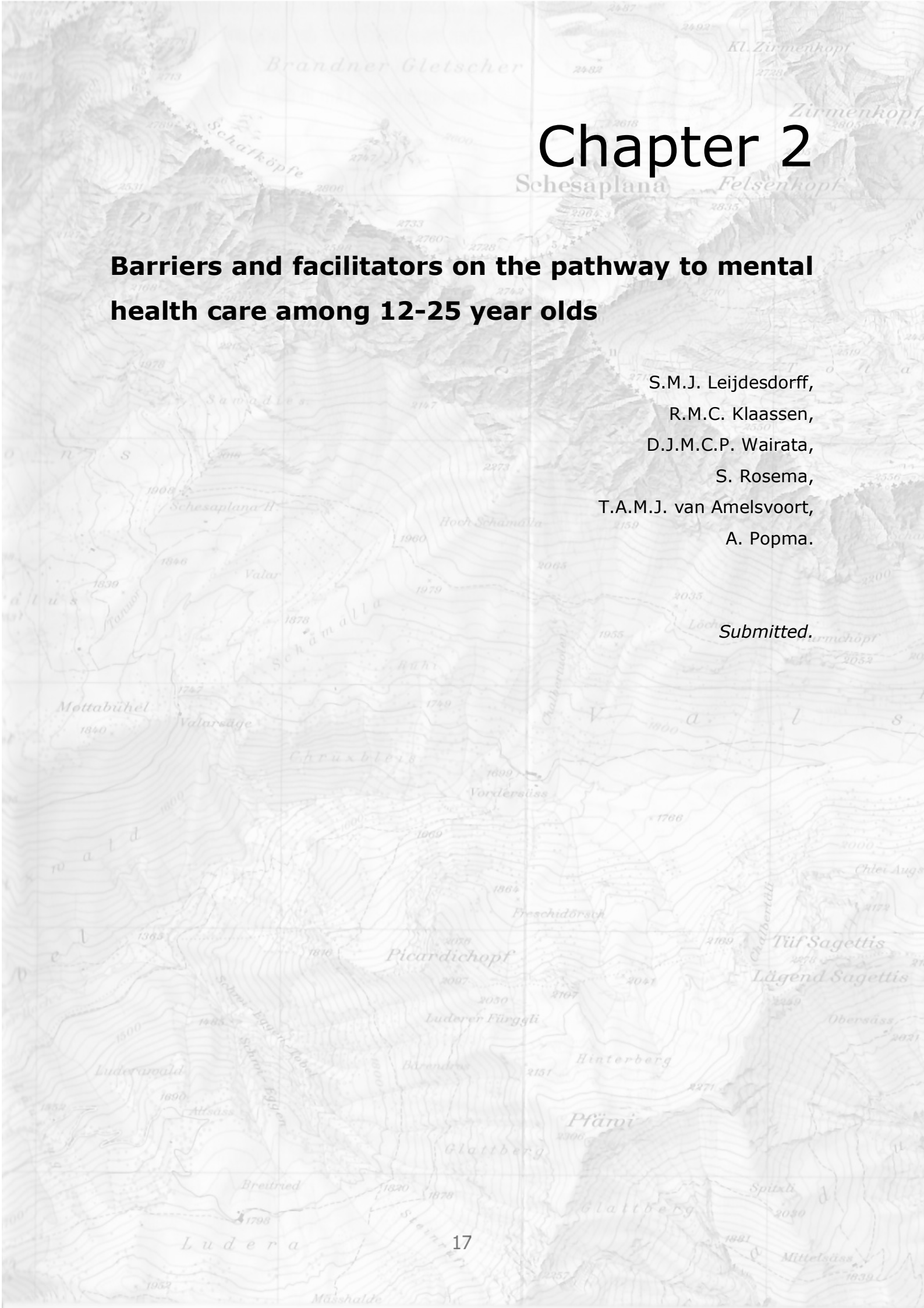
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Chapter 2

Barriers and facilitators on the pathway to mental health care among 12-25 year olds

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Submitted.

Abstract

Objectives

The vast majority of mental health problems emerges before the end of the crucial developmental period of adolescence. However, the number of adolescents receiving treatment for mental health problems does not match the corresponding prevalence. This mismatch between the number of young people that require mental health care and who actually receive it, questions perceptions and access to care.

This study aims to gain in-depth understanding of barriers and facilitators in the pathway to mental health care among 12 to 25 year olds as experienced by visitors of youth walk-in centres of @ease in the Netherlands.

Design and Methods

Open interviews were conducted to explore participants' experiences and attitudes towards mental health care. These were followed by inductive thematic analysis, describing the barriers and facilitators during phases in participants' pathways towards care.

Results

Fifteen participants were included, heterogenic with regard to age, sex and nationality. Three main themes identified in the process of seeking help were 'attitudes towards mental health problems and seeking help', 'entrance to care' and 'in care itself', and a fourth theme consisted of suggestions for improvement.

Conclusion

Negative attitudes towards mental health problems led to late recognition and acceptance of mental health problems among participants, making them seek help only when problems began to escalate. Suggestions for improvement involved more awareness for youth mental health problems; clear information about treatment options and care related costs; updates about waiting lists and alternative options, informal settings with walk-in option and personalised care with a maximum amount of therapists.

Introduction

The vast majority of mental health problems develops before the end of adolescence (Kessler et al., 2007; Kessler et al., 2005); a crucial phase with physical, social, emotional and cognitive developments (Arnett, 2000; Kessler et al., 1995). However, only 20-30% of young people with a mental disorder receives appropriate care (McGorry et al., 2014; Slade, Teesson & Burgess 2009; Aalto-Setälä et al., 2002; Graaf, Have & van Dorsselaer, 2010; Jörg et al., 2016). For adolescents who do seek professional help, the treatment delay is often multiple years (Graaf et al., 2010), which is associated with worse outcomes (De Girolamo et al., 2012; Patton et al., 2014) and potential negative consequences for future social and professional life. As a result, mental disorders play a major role in the total burden of disease globally (Eaton et al., 2008; Lokkerbol et al., 2013; WHO, 2009; Wittchen et al., 2010; Wittchen & Jacobi, 2005). The mismatch between the number of young people that require mental healthcare and the ones who receive it, raises questions regarding access to care: what are the barriers as well as facilitators?

Barriers to (youth) mental health care have been addressed before, showing themes as negative associations surrounding mental disorders, lack of mental health literacy, lack of (perceived) accessibility, lack of information as where to find help, insufficient financial resources to pay for treatment, long waiting lists, fluctuating symptoms that interfere with diagnostic processes that may be required to start treatment and no available time to seek treatment (Gulliver, Griffiths & Christensen, 2010; Thornicroft, 2008; Rickwood et al., 2005; Jorm, 2000; Frank & McGuire, 1986). Lastly, an organisational gap in mental health care around the age of 18 can be perceived as a barrier (Gulliver et al., 2010; Singh et al., 2010; McGorry et al., 2007).

Previous research has, however, focussed mainly on adult populations (Thornicroft, 2008; Schomerus & Angermeyer, 2008; Rüsch et al., 2009; Frank & McGuire, 1986; Salaheddin & Mason, 2016; Vanheusden et al., 2008), was conducted outside of Europe in the Australian or Northern American healthcare system (Gulliver et al., 2010; Rüsch et al., 2009; Frank & McGuire, 1986; Rickwood et al., 2005) or was conducted 10 to 34 years ago, in previous generations of adolescents, (thus) not accurately reflecting our current population (Gulliver et al., 2010; Thornicroft, 2008; Schomerus & Angermeyer, 2008; Frank & McGuire, 1986; Vanheusden et al., 2008; Rickwood et al., 2005).

To overcome above mentioned barriers, various initiatives to reform youth mental healthcare have gained momentum worldwide, joined in an International Association of Youth Mental Health with diverse initiatives expanding across the globe (Buckeley et al., 2011, Malla et al., 2016; McGorry, Trethowan & Rickwood, 2019). Headspace Australia is one of the first and leading models of this movement, followed by initiatives in Europe such as headspace Denmark, Jigsaw in Ireland and since 2018, @ease in the Netherlands (McGorry & Mei, 2018; Rickwood et al., 2015; O'Reilly et al., 2015; Leijdesdorff et al., 2019; Klaassen et al., 2019). @ease shares headspace's fundamental principles of easily accessible, anonymous and free psychological support to young people aged 12 to 25, and was adapted and locally designed by working with trained young volunteers offering peer-to-peer consultation, backed up by healthcare professionals, on a walk-in basis.

Easier accessible initiatives such as @ease offer a unique opportunity to study both the unexplored population with potential (unmet) needs as well as the population of young people that already seek (and receive) care. In-depth knowledge on perceived barriers and facilitators early on in the process of help seeking in this sample can inform further improvement of access to care and further development of youth mental health services. Qualitative research techniques, and in particular open interviews, are by nature appropriate to gain in-depth understanding because of their rich descriptions of experiences, attitudes and motivations during the help seeking process (Green & Thorogood, 2018).

This study aims to gain insight in the process of access to care by providing up-to-date qualitative knowledge regarding the experienced barriers and their facilitating counterparts in a heterogeneous group of young people aged 12 to 25 years old who reached out to @ease. This leads to our two main research questions. Firstly, what are the current barriers to mental healthcare for youth in the Netherlands? Secondly, what is the best way youth mental health initiatives can bridge the gap between adolescents with mental health problems and obtaining the professional help they need: which factors facilitate access to care from their own perspective?

Methods

Setting and procedure

This study was undertaken in two @ease centres in the Netherlands; in Maastricht and in Amsterdam. As part of the routine care, young people visiting @ease were asked to complete a questionnaire, including an invitation to participate in the present interview study. If consent and contact information were given, participants were contacted with comprehensive study information. Written informed consent was obtained before conducting the interviews and participants received a compensatory voucher of 20 euros. Withdrawal from participation of the study was repeatedly stated by the researchers and was possible at any stage in the process. The medical ethical committee of Maastricht University reviewed the study protocol and approved its procedure. The interviews were recorded with an audio-recorder and later transcribed to text in their original language, using Transcribe software (<http://transcribe.wreally.com>). A summary of themes per interview was sent back to the participants (member check; Lincoln, 2007). None of the participants disagreed with the interpretation by the research team.

Study participants

To gain insight into the full scope of barriers and facilitators, a heterogeneous group of young people between the age of 12 and 25 was selected (purposive sampling; Palinkas et al., 2015) with respect to age, gender, cultural backgrounds, educational levels and reasons for visiting @ease. Inclusion and data analysis ran in parallel, providing a constant feedback-loop between both processes. To provide adequate depth on this topic, inclusion was continued until no new insights with respect to the main research questions emerged (Braun & Clarke, 2006; Boeije, 2005).

Data collection

Open interviews were conducted to optimally explore participants' experiences and attitudes. Interviews were preferably performed at the @ease centres, since these were familiar places for the participants, and in case this was not possible, online via Skype. Interviews were conducted in a one-on-one setting in either Dutch or English, according to the preference of the participant.

Interviews started with an open-ended question such as: *"We're investigating barriers and facilitators experienced by young people in the process of seeking help when they're not feeling well. When you hear that, is there something that comes to mind?"*, followed by a discussion about barriers and facilitators that the interviewee describes, with the interviewer using probing questions to reach more in-depth answers. Only when the interviewee struggled with giving (further) information, a topic list consisting of sensitizing concepts -based on the researchers' experience, knowledge and literature- was used to stimulate further conversation. The structure and topic list formed the interview guide (Appendix A), designed during four pilot conversations with volunteers at @ease.

Data analysis

Inductive thematic analysis was conducted in three phases, based on comparisons within and across respondents (Braun & Clarke, 2006; Boeije, 2005). Analysis started with open coding of the first three interviews by two research team members together in order to achieve full consensus in real time. In this explorative phase, basic themes were defined. In the second phase, the following five interviews were analysed by means of axial coding; merging explorative themes that emerged from the first three interviews into more conceptual categories. These interviews were coded independently by the researchers, but discussed afterwards. The last seven interviews were coded independently. Throughout this process, the coding tree grew more complete. After the major topics were identified, codes were analysed further in the third phase of selective coding, identifying the most important themes. Software used for qualitative analysis was ATLAS.ti version 8.

As researchers in qualitative research form their own means of investigation it is important to reflect on the background of the research team. Our research team consisted of two psychologists (SL, SR), three psychiatrists (RK, TvA, AP), and one trained medical master student (DW). One of the psychologists (SL), the medical student and one of the psychiatrists (RK) supervised the inclusion, conducted the interviews and performed the thematic analyses. Transcription from audio to text and coding was executed by the one of the psychologists (SL) and the medical student. Careful attention was paid to not let own ideas or perceptions about the topic influence the interview.

Results

A total of 15 interviews were conducted. Mean age of the participants was 21, ranging between 15 and 25 years old, of which 5 identified themselves as male, 9 as female and 1 as transgender male. 2 out of 15 participants visited the @ease centre in Amsterdam and 9 participants had the Dutch nationality. Other nationalities included English, German, Italian and Ecuadorian. Main reasons to seek help were 'not feeling well', depressive symptoms including suicidality, attention problems and loneliness.

Thematic analysis showed four main themes. Three themes represented different phases in participants' pathways towards care, with corresponding barriers and facilitators. The fourth consisted of suggestions to improve accessibility of mental healthcare:

- 1) Attitudes towards mental health problems and seeking help;
- 2) Entrance to care;
- 3) In care itself;
- 4) Suggestions for improvement.

1) Attitudes towards mental health problems and seeking help

Barriers

Participants mentioned clear negative attitudes towards mental health problems. They saw their mental health problems as a weakness or their own fault, and therefore, something they should fix themselves. Needing help produced feelings of shame and only felt acceptable if mental health problems were severe or escalating. Participants felt unentitled to have mental health problems because they were growing up in privileged circumstances.

(R14) "It's all in my head, so it's something I'm doing myself. I should be able to solve it myself as well then."

There was fear of stigmatisation, as they felt that psychiatry is for "crazy" people, and participants were anxious about being subject of gossip, especially in subcultures such as student communities.

(R9) "It's just a small world actually [...]. Everyone knows each other, and yeah, if there's a rumour or something, then the next day, the whole city, or at least the entire student community knows about it."

Mental health problems were seen as something that comes only with an older age.

(R10) "These are adult's problems, not something someone my age should experience. Like people my age don't have grey hair."

They desperately wanted to be normal. Our participants compared themselves extensively to peers, in which they did not see similar issues, leaving them feeling lonely.

(R5) "Everyone else seems to be doing fine. Why do I need help? Why can't I just be happy, or normal"

Participants felt concerned to share their problems with friends or family members fearing a lack of understanding, downplaying of their problems or to be seen as a cry-baby. In addition, participants did not want to place a burden on their loved ones.

(R12) "I believe they would not understand it. And I was also afraid that they wouldn't care, or to place a burden."

Some participants tested their expectations and in some cases, their family members admitted that participant's problems were indeed burdensome. Others expressed that their parents never shared their emotions, making young people feel that they have never learned how to express themselves.

(R5) "I think some people just learn how important it is to talk to someone, so for them it's not a problem, I guess. In our family it's different."

In most cases, so called 'normalising', generally referring to cause something previously considered as atypical to be accepted as normal, was helpful, but by some participants it was experienced as downplaying as well; one participant mentioned a teacher who tried to normalise her suicidal thoughts, making her feel that she was not allowed to further talk about it.

Concerning mental healthcare professionals, participants did not feel worthy of occupying their time and described feelings of anxiety about having their mental health problems registered, which could thereby threat their future career. This last opinion was in particular vivid among international students in the current study population. Lastly, negative experiences of other people, as well as own adverse experiences with seeking help, resulted in negative expectations of future help seeking.

Participants mentioned lack of time as a factor preventing them of seeking help. They prioritised educational, occupational or social activities rather than seeking help. In addition, our population of youth was characterised by frequent relocating between different cities (e.g. to start a new study), causing them to see starting a new treatment as pointless without knowing how long they were staying in the particular city.

(R1) "It took too long because I have to be in therapy prior to the summer holidays to be able to get in class next year. Otherwise I won't make it."

Facilitators

In contrast to the perceived barriers, some facilitating attitudes were stated as well. Two participants who recently moved to the Netherlands experienced less taboo on mental health problems than in their home country. In addition, participants came up with helpful coping strategies such as restricting social media use leading to less comparison of themselves to their peers and a decrease in experienced symptoms. Luckily, participants felt that it was acceptable to ask for help when their problems escalated, in case of suicidality or self-harm. Furthermore, in most cases, talking about their problems to family and friends, appeared to be less negative than expected; their social networks reacted understanding and supportive. Moreover, hearing positive experiences of others receiving mental health care turned out to be encouraging.

(R14) "Some people reacted reassuring, that they experienced something similar or that they recognized my problems, only then you learn that there are other people struggling as well. And yes, that decreases the level of shame."

There were examples of friends, parents, partners, people from a church community or deans at school recognizing mental health problems, helping participants to open up or facilitating professional help.

(R14) "I think it made a difference that my parents knew quite a lot about it, that they were there for me."

Participants experienced less of a barrier in sharing their problems with professionals, as they expected it to be less burdensome for them. In addition, a professional is neutral to the situation, whereas friends and family members were seen as biased or prejudiced, and sometimes they were part of the problem itself. Some participants expected seeking help would lead to getting a diagnosis, which would justify their problems. Others expected that talking about their problems would be a relief.

(R9) "Close friends and family members are there for me but I found it nice to have this objective perspective"

2) Entrance to care

Barriers

When participants realised they needed help, it was not always clear where they could find help. Searching online or at school, participants often did not find what they were looking for, and they mentioned that there was not enough awareness for resources.

(R7) "I guess the first problem is not knowing. A few days ago career services from University came and that's when I first knew that you could apply for psychological support or to go to a psychologist at University for free, and that was already seven months after I started University here"

Waiting lists provided a next hurdle. Knowing there is a waiting list prevented some participants from seeking help. Participants perceived waiting lists as being long and unnecessary, while they needed help at that very moment. In some cases, participants experienced a worsening of symptoms during a previous waiting period, making them anxious about another waiting period. In addition, being on a waiting list led to insecurity among participants, including questions such as “did something go wrong” and more personal: “do they not want to help me”.

(R1) “It feels like no one in that building wants to help me, because I’m waiting so long already.”

Diagnostic assessment procedures formed another delay in the process towards help. Participants had to tell their stories multiple times to different professionals, which they found burdensome. In addition, they had to fill in long and overlapping questionnaires and in some cases incomplete childhood information prevented getting a diagnosis and therefore help could not be offered.

(R1) “I think it took an extra month because of all those questions [...]. During the intake there was someone who I won’t see again, the person with the questionnaires will I not see again, and then there was also this intern, who also wanted to know my story, and I don’t see that person anymore either. It makes me feel like, I tell you my story, [...] which is hard for me [...] and then I never see them again. [...] Yes, eventually I feel like, why even bother, because there will be other people again.”

Lastly, care related costs formed an obvious barrier for young people. Participants, mostly expressed a lot of uncertainty around financing of care. Several participants stated anxiety for being surprised by an invoice, even years after their treatment ended. Compensation by health insurance companies was unclear and while they already felt ashamed about their mental health problems, they felt an extra layer of shame about not understanding financial aspects.

(R10) "I was terrified, terrified so to speak, that I would wake up one day and would find an invoice in my mail, open it and that I would have developed an enormous debt."

(R12) "Even if someone tells you: 'yes, it is included in your standard insurance and will be reimbursed', many young people still won't really understand what that means."

Participants stated that budgeting can be challenging for young people and they were nervous about whether their diagnosis would be severe enough to receive reimbursements from health insurance. Some participants could not afford treatment themselves which refrained them from getting help to avoid placing a financial burden on their parents. Other participants lowered the amount of appointments with their mental health care professional because of financial aspects. One participant avoided a diagnosis to prevent health insurance's premium from increasing.

(R2) "I tried to keep the number of sessions as low as possible but I also knew that every time I had such a session I would definitely feel better."

Facilitators

For some participants, their general practitioner (GP) was the first person to seek help at. Especially walk-in possibilities such as @ease were appreciated, as well as a smooth referral by GP's to their in-house psychologists. Other participants visited University psychologists, found help by searching online, asked a teacher or had enough knowledge of the healthcare system due to their own specific education.

(R13) "And this doctor was like: 'okay well we'll tell..., we'll let you go to the psychologist that is just like upstairs'."

"Yeah I just googled therapy and nightmares and that's how I found them."

Some participants mentioned situations without waiting lists and described this as very pleasant. For some participants, the GP offered weekly counselling to overcome waiting periods. Remarkable were differences in experiences with care

related costs; international students in our study mentioned that their insurance would pay for their treatment and therefore, money was not seen as a barrier. Some of the native Dutch participants did not experience any financial barriers because their parents covered the healthcare costs, and free services were mentioned as easily accessible.

(R3) "I think someone told me like: there is a sort of GP psychologist who you can just visit, the first couple of conversations will be free."

3) In care itself

Barriers

Not all young people who managed to get into care, immediately received the care they needed. Some participants found out that their problems were too severe or too complex for the service they visited, leading to another referral followed by another waiting period.

(R15) "So I was referred in October and had an intake in February. The period in between was very heavy, I had another suicidal period."

Also within one facility, several participants experienced changes of therapists, or prematurely stopped treatments because of leaving therapists, leading to a decreased sense of trust. The relationship with the therapist seemed to be very important for a treatment to succeed.

(R4) "Wherever I come, I always get referred to someone else because a professional stops working there or goes traveling or something. And then I have to trust this new person enough to tell my whole story."

Sometimes, it was the participant who stopped treatment because of residential relocation, a satisfactory decline in symptoms or insufficient effect of treatment.

(R15) "It was like: 'How do you feel?' 'Well, like shit.' 'And how could you change that?' 'I don't know.' It didn't help me."

Some participants are still in need for help after a unfinished treatment trajectory and some still experienced problems for which they hold themselves accountable because they feel that they should be able to manage these problems after receiving care.

Facilitators

On the contrary, some participants were very positive about the care received. In general, it was highly appreciated when treatments were personalized with room for spirituality and autonomy, instead of following a strict protocol. One participant mentioned relief after finding out that receiving care did not automatically mean being hospitalized. Another person mentioned that it was nice to visit the same professional for a longer period as this person knew all relevant details. Several participants mentioned that treatment was very helpful as they learned to talk about their problems, discovered patterns in their behaviour, received tools to manage their situations, learned to involve their social circle and to ask for help in case of future problems.

(R14) "I now know how to handle it and I'm way more open to people around me. So I won't get as deep as I did before, and I can get out of it more easily."

Earlier positive experiences with their GP or a psychologist facilitated seeking help. Once young people were in the healthcare system, it was easier to find appropriate care.

(R14) "[GP] was always very helpful. I think that if you feel listened to by your GP, that that helps to visit your GP a next time when you're not well."

4) Suggestions for improvement

1. Young people wished for more awareness among youth around mental health problems. They hope that by sharing information and experiences it becomes normal to talk about mental health problems and to ask for help.

(R5) "The more we try to help each other, the more it might become normal that people who realize that they have problems actually go and seek help."

2. Combined with awareness, they asked for information about possibilities of care and what to expect when they would seek help. They request mental health education at schools, clear information online as well as leaflets and posters.

(R12) "Information about 'how do you get a psychologist?' How do you do that? [...] I, personally like it to know what to expect."

3. Young people underline the importance of an approachable psychologist at every School/University.
4. In an ideal world, there would be no waiting lists. Participants, however, were understanding about scarcity in time of psychologists, and suggested to give updates during the waiting period.

(R1) "Yeah, if they could just send an email or make a call, like: we're working on it, but it is busy [...] and in the meantime you could go here or there [...] then you might feel that they are trying. Now I'm just waiting... a long time, and I didn't hear anything. "

5. Participants liked informal settings and asked for more funding for these kind of initiatives.

(R4) "Well, that it's not like formal, with a psychologist and stuff, but that there're just people who you can talk to and who will actually listen."

6. A maximum amount of therapists per person.

(R4) "Try to really keep it to a maximum of 1 or 2 therapists and without extra referrals. Because it just doesn't work. It takes longer to trust a therapist enough to open up."

7. Accessibility would increase if it was possible to have a phone or online chat conversation prior to visiting a service.

(R3) "Online contact is easier to initiate. You don't have to go somewhere and you don't have to look someone in the eyes [laughs], like, in case that's difficult for you..."

Discussion

This study explored barriers and facilitators in the pathways to care for youth aged 12 to 25, struggling with their mental health, in the Netherlands. Results were structured into 'Attitudes towards mental health problems and seeking help', 'Entrance to care' and 'In care itself'.

Attitudes included clear negative cognitions about mental health problems for which participants hold themselves accountable. Although participants considered the current situation in The Netherlands to be better compared to other countries, mental disorders in general were still taboo. Remarkable was the idea that mental health problems develop with an older age: a strong contrast to the abundance of evidence advocating for mental health problems as (chronic) disorders of young people (Insel, 2009). When investing in awareness around mental disorders, this finding stresses the importance to particularly accentuate their existence in youth. Findings in the present study, showing that participants constantly compared themselves to their peers are in line with previous studies showing young people to be extremely sensitive to peer rejection and validation (Knoll et al., 2015), further underlining the significance of awareness for youth mental health problems.

Participants were concerned to share their problems with friends or family members and felt unentitled to have mental health problems as they were growing up in privileged circumstances. Although the objectivity of professionals was highly valued, participants did not feel entitled to occupy their time. In

addition, they prioritised educational, work or social activities above seeking help.

Above mentioned negative attitudes towards mental health problems led to late recognition and acceptance of mental health problems among our participants, only making them to seek help when problems began to escalate. This is in line with earlier research (Rickwood, Deane & Wilson, 2007) stating a growing need for independence during adolescence combined with believing that they should handle problems themselves, leading to the problematic situation in which even adolescents with serious suicidal ideation believed that they should be able to manage their own problems. This shows the magnitude of this problem and its possible consequences, with suicide being the main cause of death among youth (Statistics Netherlands, 2020).

In line with earlier research, experienced barriers in the phase of 'Entrance to care' showed that in spite of all well-designed awareness and early detection programmes and campaigns the issue of access to care has not yet been solved (Malla et al., 2016). This advocates for, in addition to funding the actual projects, incentives for (more thorough) evaluations concerning effectivity and reach of these programmes and campaigns. Concerning entrance to care, a less obvious but very helpful facilitating role could be played by healthcare insurers, by making information more youth friendly and easier accessible. Lastly, participants appreciated walk-in options and experienced GP's and psychologists with such options as easier accessible. Introducing walk-in options might benefit both young people and (mental) healthcare services as no-show rates form a significant problem in healthcare organisation (Van Dieren et al., 2013). Walk-in options may be a starting point to bridge this gap between waiting lists and no-shows.

Even after getting into care, not all young people reported to have received appropriate care. Earlier research showed continuity of care to be challenging as well as essential for youth, especially around the age of 18 (Singh et al., 2010; Leijdesdorff et al., 2019). Indeed, participants mentioned several changes of therapists or prematurely stopped treatments damaging the therapeutic relationship or leading to another waiting period and worsening of problems.

Practical implications

Clear suggestions for improving the pathway to care were more awareness for youth mental health problems; hearing experiences of others was supportive. There was a need for clear information about treatment options and care related costs. Our participants asked for updates about waiting lists and alternative options, informal settings with walk-in possibilities, phone or online chat possibilities and a maximum amount of different therapists, trustable and offering personalised care.

Strengths, limitations and future directions

Our study showed that shame and stigma still play a huge role in mental health problems in youth. It can therefore be considered a strength of the present study that 15 young people opened up about their experiences during a vulnerable period in their lives. We are thankful that these young people stepped out of their comfort zones to contribute to scientific research.

The current study showed a broad spectrum of experienced barriers and facilitators in youth with mental health problems. Their experiences, knowledge and attitudes however, are not generalizable to the whole population of youth in need of care, and are only valid in their specific context.

Although the sample of participants was already quite homogenous, future research could aim for more diversity by including people with a background of immigration, LGBTQ+, intellectual disabilities or parental mental illness. In addition, perspectives of people in the direct environment of young people, such as parents and siblings could add further information.

Conclusion

Our results were in line with earlier research and showed similarity in barriers and facilitating factors between the Netherlands and other countries. These shared factors can be seen as a validation of the shared approach in improving youth mental health services worldwide (Malla et al., 2016; Buckley et al., 2011; WHO, 2017). In addition, this study showed that further innovation in youth mental healthcare is still very topical to realize easy accessible care and early detection and intervention.

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Appendix A

Topic Guide: qualitative study @ease

English version

Requirements

- Audio-recorder
- Notes printed or digitally
- Topic Guide
- Socio-demographic questionnaire
- Informed consent form

Introduction

- **Introduce yourself + thank you for participation in this research**
- **Explanation of the purpose of this study:** We would like to know what the barriers are among youngsters to seek professional help when they feel down. We're also interested in the factors that make it easier to get help, these are called facilitators. Your opinion can help us to make mental health care more accessible when you need it.
- **Explanation use of data:** We will analyse the most common themes in the interviews and write an article about it. With this information we can better adapt the health care system to the needs of the young.
- **Length of the interview:** The interview takes half an hour to an hour.
- **Explanation of recording:** The audio is recorded and then anonymised transcribed to text. After transcription, the audio file is destroyed. All names and institute names are left out in the transcription.
- **Anonymity:** Everything you tell us will be processed anonymously. Nothing you say or give us can be traced back to you.
- **Informed consent:** Do you have any questions? Would you be willing to sign this consent form to give your approval?
- **Time management and note keeping:** Please feel free to elaborate as much as you want on any topic. The interviewer (me) will keep track of time. Additionally, I will be keeping notes as a reminder for myself during our conversation, so I don't have to interrupt you while talking.

Opening question (open):

We often hear from youngsters that it is sometimes hard to seek professional (psychological) help when you're feeling down. Do you recognize this? Are there things that made it hard for you to seek help? Or that made it easier? This can be anything, so thoughts or feelings, too.

Opening question (suggestions):

We often hear that someone is afraid to seek help because of **stigma**, not **trusting professionals**, concerns about your **future** job or **insurance**, not wanting to be a **burden**, those kinds of stuff. We also hear that some things make it extra hard to receive help, such as **health insurance** and long **waiting lists**. If you're hearing these things, is there something that comes to mind?

Topics and questions**Stigma****Confidentiality****Not wanting to be a burden****Self-reliance****Concerns on future or job****Negative or positive attitude toward mental health care****Past experiences with mental health care****Accessibility****Financial aspects****Waiting lists and intake****Fluctuating symptoms****Mental health literacy, recognition of the problem.****Fear of seeking help****Rather seek help from informal sources (friends or family)****Social support and stimulation****Already existing relationships with health care professionals.****Knowledge about where to seek help****Being too ill to seek help**

Probing questions:

- How does that work? Could you elaborate on that?
- Why is this a barrier, what makes it a barrier to you?

Miracle question

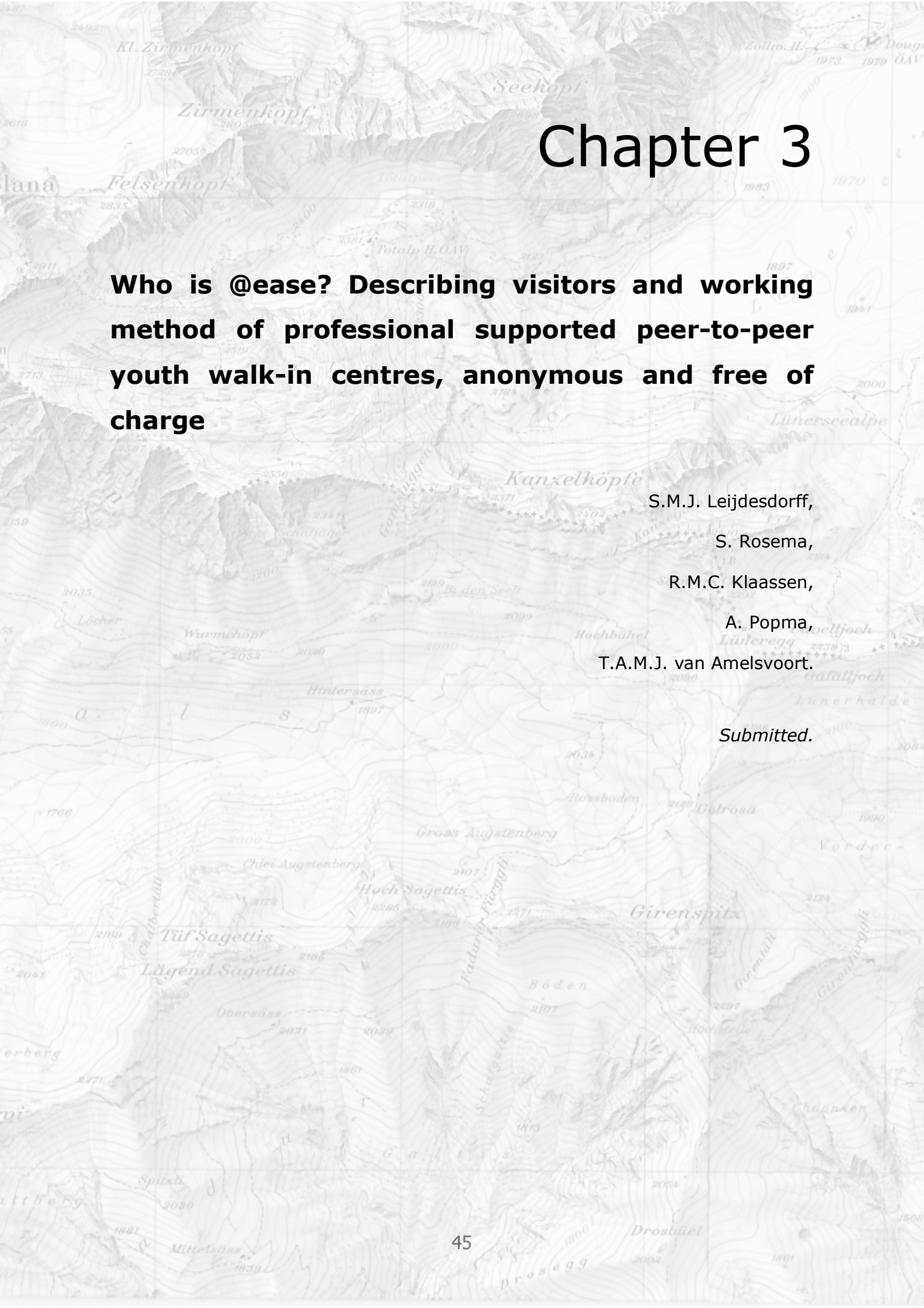
What would the ideal scenario be if it was up to you? If you could give a tip to the policy makers and health care professionals, what would it be? How would you do it if you were in charge of the mental health care?

@ease

- What do you like about @ease?
- What does @ease do to decrease barriers and make seeking help easier?
- What can @ease further improve to make seeking help even easier?

Closing

- **Check if all relevant topics are reviewed** (interviewer and participant):
- **Announce closing**
- **Check info; ask for missing information.**
- **Thank the participant and ask for questions**
- **Snowball sampling:** Do you know anybody in your environment (friends, family) that is struggling with mental health issues and might be interested in participating in this study? We are mainly looking for participants who haven't taken the first step yet toward professional help, but even if they have done, they are welcome to participate.

A detailed topographic map of a mountainous region, likely in the Alps. The map shows numerous peaks, ridges, and valleys, with contour lines indicating elevation. Key peaks labeled include Zirmenkopf, Seekopf, Felsenkopf, Kanzelköpfe, and Girenschpitz. Other labels include 'Totalp H. OAV', 'Lünerseealpe', 'Hochbühel', 'Gross Augstenberg', 'Hoch Sagettis', 'Tüf Sagettis', 'Lägend Sagettis', 'Obersäss', 'Mittelsäss', 'Spitzsä', 'Drosbüel', and 'Drossegg'. The map is oriented with North at the top.

Chapter 3

Who is @ease? Describing visitors and working method of professional supported peer-to-peer youth walk-in centres, anonymous and free of charge

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Submitted.

Abstract

Background

Although mental disorders often emerge early in life, only a minority of young people receives timely and appropriate mental health care. A worldwide youth mental health movement aims to prevent development and persistence of psychiatric disorders. As part of this movement, the first four @ease-centers were opened in the Netherlands. @ease is a youth driven, professional supported initiative, providing peer-to-peer counselling, anonymous and free of charge, for people aged 12-25.

Methods

Data consists of a detailed description of the working method of @ease, combined with characteristics of all young people accessing the services between the start in January 2018 and July 2020.

Results

Volunteers, including experts by experience, were trained in listening, motivational interviewing and solution focused strategies and supervised by a diverse group of healthcare professionals. A total of 291 visitors, aged 21 on average, were satisfied to very satisfied with @ease's services. Psychosocial distress, social functioning and quality of life measures at first visit showed moderate to severe levels of impairment and almost half of all visitors skipped school. One third reported parental mental illness, 28% suicidal ideations and 11% had made specific plans to end their life. Only less than a third of all visitors received mental health care in the three months prior to their visit.

Conclusion

Apart from the necessity, this study showed the feasibility of a youth driven, professional supported organization offering peer-to-peer counselling in the Netherlands. @ease showed to be a flexible organization, aiming at normalizing where possible and intervening when necessary.

Introduction

The majority of mental disorders emerges early in life (Kessler et al., 2005). To reduce the individual and societal burden and to limit further negative consequences of mental disorders, early detection and accessible intervention strategies are of utmost importance in youth (McGorry and Mei, 2018; McGorry and Van Os, 2013). Unfortunately, there is a strong discrepancy between need for care and use of care in this particular population.

In the Netherlands, the healthcare system includes a compulsory healthcare insurance for all citizens, free of charge for people under the age of 18. General Practitioners (GP) services are fully covered, it is standard procedure for all children at secondary schools to be checked by youth pediatricians at least once, and as the Netherlands is a small densely populated country, there are not many areas without healthcare facilities.

However, in spite of these services and regulations there is still a gap between the number of young people with mental health problems and those who receive appropriate care. Similar to other countries, less than a third of all young people (aged 12-25 years) that experience problems with their mental health receives any professional help for it (Slade, Teesson & Burgess, 2009; De Graaf, Ten Have, & van Dorsselaer, 2010). Age specific barriers, such as stigma, shame, a lack of mental health literacy, and a strict separation between child and adolescent and adult mental healthcare lead to a misfit between service structures and the needs of young people (Hetrick et al., 2017; Rickwood, Deane, & Wilson, 2007; Vyas, Birchwood, & Singh, 2015).

In the last two decades, worldwide, several innovative initiatives emerged, aiming to bridge this gap and improve access to care. The most well-known initiative is the Australian youth friendly walk-in service headspace (www.headspace.au.org), open since 2006 (McGorry et al., 2007), accompanied by i.e. headspace Denmark and Israel, Jigsaw in Ireland, Maison des Adolescents in France and Foundry and Access Open Minds Canada (McGorry & Mei, 2018; Hetrick et al., 2017; Vyas et al., 2015). Within this global youth mental health movement, and learning from these initiatives abroad, @ease was founded in the Netherlands in 2018 (www.ease.nl). During the first 2.5 years, four @ease centers were opened; one in Maastricht, two in Amsterdam and one in Heerlen.

Similar to above mentioned youth mental health initiatives, @ease centers are youth friendly and easy accessible, allowing youth aged 12 to 25 to discuss

their mental health as well as physical, sexual, financial, vocational and social problems. @ease differs from headspace Australia by offering peer-to-peer counselling by trained and supervised volunteers. @ease centers can be visited anonymous and free of charge. The current paper aims to describe the @ease working method combined with a comprehensive profile of its first 2.5 years' visitors.

Method

Design and setting

All visitors of the @ease centers were invited to complete the anonymous, online @ease-questionnaire on an iPad at the end of their conversations. First visit data were analyzed in the current study. The @ease-questionnaire takes approximately 5 minutes to fill in. Volunteers were trained to explain the goal of the questionnaire and to emphasize its non-obligatory character to the visitors; stopping completion of the questionnaire was possible at any moment, without any consequences for potential further visits to @ease. In addition, this message was, as well as the contact details of one of the researchers, included at the beginning of the questionnaire and in print available at all centers. In cases of visitors who were not able or willing to fill in the questionnaire, the volunteer part of the questionnaire was still filled in and included in the current study. The Medical Ethical Committee of Maastricht University assessed and approved the study (METC number 2017-0046). The data were anonymized and stored on a secured server at Maastricht University.

Participants

Since the start in January 2018 and until July 2020, a total of 291 young persons had visited or had contact online or via phone with one of the four @ease centers. To be able to complete the questionnaire, visitors needed to have sufficient knowledge of the Dutch or English language. There were no further in- or exclusion criteria.

Measurements

The @ease-questionnaire consists of two parts. The first and major part of the questionnaire is completed by the visitor. The second part of the questionnaire is completed by the two @ease volunteers whom the visitor spoke with.

The first part, completed by the visitor, includes questions assessing age, sex, country of birth, living situation, occupation, current level of education, parental history of mental illness, use of mental health care, truancy, and satisfaction with the @ease service, combined with two validated measures, evaluating psychosocial distress and quality of life.

Psychosocial distress was measured using the Clinical Outcomes and Routine Evaluation (CORE-10), a 10-item questionnaire designed for 17-25-year old's (Barkham et al., 2013). The CORE-10 is a short, acceptable and feasible measure for assessing the presence and severity of common mental health problems in the context of primary healthcare on a scale from zero (never) to four (most or all the time), translating the amount psychological distress into a total score between zero and forty. The questionnaire has an established cut-off score of eleven, meaning that a score of eleven or above denotes a clinically significant level of psychological distress (Barkham et al., 2013).

Quality of life was measured using the five-dimensional, five-level EuroQoL (EQ-5D-5L) consisting of the following dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has five levels: no problems, minor problems, moderate problems, severe problems, and not able to perform a certain activity. In mental health, the EQ-5D is proven to reflect the impact of common mild to moderate conditions on the quality of life and discriminate between subgroups in terms of severity (Brazier, 2010; Lamers et al., 2006).

In the last part of the questionnaire, the trained volunteers rate the young person's social functioning and answer two questions regarding suicidal ideation, including the question whether the young person has made specific plans to end his/her own life. Besides, the need for possible further steps to extra care, such as consulting the GP, a psychologist or other (mental) healthcare professional is explored by the volunteers together with the young person and noted in the questionnaire.

Social functioning was evaluated by the volunteers, using the Social and Occupational Functioning Assessment Scale (SOFAS; American Psychiatric Association, 2013). The SOFAS globally rates the current social and occupational functioning of a person with a score from zero to hundred, in which higher scores represent higher levels of functioning. @ease volunteers were trained in assessing social and occupational functioning.

Analysis

The present study comprises a description of @ease's current working method, extracted from a specific 'primary process' description.

The main characteristics of the first 2.5 years' visitors were described using abovementioned @ease-questionnaires data. Analysis was performed by means of IBM SPSS statistics software version 25, using descriptive statistic functions.

Results

Working method

Mission

@ease has a clear mission aiming to reach young people in order to increase resilience and consequently the chance of positive development. By doing so, the bigger aim is to prevent aggravation of emerging or existing mental health and developmental problems for young people, aged 12 to 25. This aim of the national @ease Foundation, is described in the working method and translates into its current four walk-in centers for young people with (emerging) mental health, social, vocational, sexual, physical or other problems. Thanks to continuous youth advisory involvement as well as input of young volunteers, all @ease centers are located, arranged and furnished to be youth friendly and welcoming.

Staff

To further establish an easy accessible ambiance, @ease staff members are carefully selected. Visiting young people are welcomed by two volunteers who are trained to actively listen to a variety of topics. Volunteers are mostly peers, with the majority being younger than 30 years old, with a minimum age of 18, experts by experience are well represented. Potential volunteers are screened and trained during a special two days @ease-training, covering @ease's working method, solution focused and motivational conversation techniques and dealing with crisis situations. The training is followed by a trial period to validate a match between the new volunteers and @ease.

Volunteers are supervised by healthcare professionals including psychologists, psychiatry residents, behavioral scientists, social workers and specialized nurses. This supervision comprises possible discussion of complex situations during the conversations, and mandatory discussions following all individual conversations.

During opening hours, there is a psychiatrist on call, easily accessible for phone consultation and arrangements with the crisis intervention team if needed. The diversity in professional backgrounds of the staff members combined with continuous effort into building bridges within the @ease regional contexts, enables offering the support needed to continue daily activities and intervention only when necessary.

Setting

Young people can either walk in unannounced during opening hours, which is clearly communicated online, or make an appointment online or by phone. @ease services are free of charge, anonymous, and young people may visit as many times as they prefer. Visiting @ease can be a first step towards seeking help, but may also be combined with receiving care elsewhere or forms a follow-up of care.

To continuously match the needs of young people and adapt the working method accordingly, regional youth councils attend staff meetings and provide solicited and unsolicited feedback. This allows the existence of subtle regional differences, fine-tuned to the local landscape. This flexibility enables @ease to be adaptable to changes, illustrated by the quick set-up of online chat and phone services during the Covid-19 lockdown regulations.

@ease-questionnaire data

Overall data

Of all 291 young people visited @ease between its start and July 2020, the majority was female and the mean age was 21 years old (range 10-55) (Table 1). The 10-year old was the only visitor younger than the age of 12, 15 persons were older than 25 years of age. Since @ease's anonymous working method, it was not always noticeable whether a visitor was older than 25 years of age. In case visitors did not fall into the target population, staff members guided them towards suitable options. Age was normally distributed. Of those who were involved in any form of education, 51.9% was studying at an university, 20.3% university of applied sciences, 19.2% secondary education, and 8.5% otherwise. 44.6% of all youngsters mentioned that they skipped school in the last three months, with a mean of 7.6 days (SD = 11.3). One third reported parental mental illness.

Although only one young person stated to be homeless, three other visitors mentioned to live in a homeless shelter or with friends as a temporarily solution. The visitors' countries of birth represented all continents, with 8.2% being born in Germany as biggest subgroup. Most visitors learned about @ease online (20.4%), via friends (20.8%), or otherwise (39.4%), namely via family members, people or events at school or university, or healthcare professionals. 68.1% visited @ease on his/her own initiative, whereas 20.4% was urged to visit @ease by a friend or family member. Wanting to discuss feelings was the mean reason for visit (Table 2).

Table 1. demographic characteristics

	N	Mean (sd)
Age	229	21.03 (4.2)
Core-10 total	214	20.43 (7.0)
Satisfaction with waiting time	178	4.72 (.8)
Satisfaction with conversation	179	4.40 (.8)
SOFAS	213	63.97 (18.0)
		n (%)
Sex	female	158 (65.0)
	male	83 (34.2)
	otherwise	2 (0.8)
Occupation	education	175 (74.2)
	work	25 (10.6)
	both	21 (8.9)
	none of both	15 (6.4)
Living situation	Parents	73 (29.9)
	Caregiver	2 (.8)
	Peers	71 (29.1)
	Alone	61 (25.0)
	Partner	19 (7.8)
	Homeless	1 (.4)
Country of birth	Other	17 (7.0)
	NL	124 (54.6)
In mental health care	Other	103 (45.4)
	NL	54 (28.7)
Parental mental health problems	mother	72 (33.8)
	father	48 (22.5)

father	15 (7.0)
both	9 (4.2)

Note: The item about being 'In mental health care' was assessed for the three months prior to their visit. Satisfaction with waiting time and Satisfaction with conversation: on a scale from 1 to 5, with 1 being 'very unsatisfied' and 5 'very satisfied'.

Table 2. Reasons for visiting @ease

Reasons of visit	N
their feelings	173
social relationships	51
education	50
drugs / alcohol	11
physical problems	6
sexuality	5
living situation	2
someone brought me here	3
for advice	63
for practical help	43
other	15

Note: multiple answers were possible.

7.9% of visitors scored below the Core-10 clinical cut-off of 11 points. 75.1% perceived at least moderate problems concerning anxiety and depression, 43.9% was hindered doing usual activities and 22.9% experienced at least moderate levels of pain / discomfort (Table 3). 28.4% expressed suicidal thoughts and 11.7% made specific plans to end their lives (Table 4).

Table 3. Frequencies of responded levels on the five dimensions of the five-dimensional, five-level EuroQol

	No problems N (%)	Minor problems N (%)	Moderate problems N (%)	Severe problems N (%)	Extreme problems N (%)
Mobility	175 (92.6)	11 (5.8)	3 (1.6)	0 (0.0)	0 (0.0)
Self-care	160 (84.7)	23 (12.2)	4 (2.1)	1 (0.5)	1 (0.5)
Usual activities	64 (33.9)	42 (22.2)	56 (29.6)	23 (12.2)	4 (2.1)
Pain/discomfort	91 (48.4)	54 (28.7)	30 (16.0)	10 (5.3)	3 (1.6)
Anxiety/depression	12 (6.5)	34 (18.4)	72 (38.9)	52 (28.1)	15 (8.1)

Table 4. Suicidality

Expressed thoughts and/or plans	N	%
No suicidal thoughts	154	71.6
Suicidal thoughts	61	28.4
Specific suicide plans	25	11.7

67.0% walked in without an appointment, 19.8% made an appointment within two weeks from the moment they contacted @ease. Visitors were satisfied to very satisfied with both the waiting time and their conversations.

Following their @ease visit, 13.9% made an appointment with their GP, 16.7% planned to visit a psychologist and 32.8% chose to make other arrangements, such as a student psychologist/mentor or returning to @ease. The remaining 36.6% experienced their visit to @ease as sufficient for the time being.

In response to the Covid-19 regulations during which @ease had to close its face-to-face services for a period of three months, online chat and phone support services were initiated in March 2020. During the lockdown period, 127 @ease conversations took place through the online chat service and 41 by phone. A total of 54 individual young persons filled in the @ease-questionnaire at the end of their online or phone conversation. Thus, of all 291 @ease service users of whom data were gathered, 237 visited @ease in person and 54 used @ease's services via online chat or phone conversations.

Differences and similarities between centers

As the first two centers opened in 2018 (Maastricht and first Amsterdam @ease center) and the Heerlen and second Amsterdam centers opened in 2020, a comparison between individual centers was only made for the first two.

The Maastricht center welcomed 228 visitors, with an average age of 21.6 of whom 53.0% was born outside the Netherlands. 84.8% was involved in education and the mean Core-10 and SOFAS scores were, respectively 20.3 and 63.6. Satisfaction was 4.3 on a scale from 1 to 5, and the mean reason of visit was to talk about their feelings.

63 young persons, aged 19.0 years on average, visited the Amsterdam center. 75.5% was involved in education and, in contrast to the Maastricht center,

84.8% was born in the Netherlands. The average Core-10 score was 20.9 and the mean SOFAS score 65.4. Satisfaction was 4.8 on a scale from 1 to 5, and the mean reasons of visit were similar to those at the Maastricht center.

Discussion

The current paper aimed to describe the @ease working method, combined with a detailed profile of its first 2.5 years' visitors. In line with its mission, young people indeed visited @ease's walk-in centers to discuss their mental health, social, vocational, sexual, physical or other problems. They did so mostly without an appointment and to their satisfaction. Apart from the necessity, this study thereby showed the feasibility of a youth driven, professional supported organization offering peer-to-peer counselling in the Netherlands. Lived experience and a diversity in professional and educational backgrounds of the volunteers and staff members made it possible to offer the support needed to be able to continue daily activities, and to intervene when necessary. Sensitivity to regional differences enabled cooperation with relevant services surrounding @ease.

Our results showed that most young people suffered from both psychological distress and impairments in social functioning. Moreover, one third of @ease's visitors expressed suicidal ideation. Still, less than 30% received care for their mental health problems during the three months prior to their visit. This shows the scale of this problem and its possible consequences, with suicide being the main cause of death among youth (Statistics Netherlands, 2020). Although the results are worrisome on an individual level, the fact that young people talk about their mental health problems and show their satisfaction (directly and by revisiting @ease) might be a sign that the @ease method (low threshold, accommodating the wishes of adolescents) might be a start towards bridging the gap between the needs of young people and the offer from the mental healthcare field.

A specific group of young people that needs attention is the group of adolescents with parents with a mental or addiction disorder. One third of all visitors reported to be children of parents with mental illness and/or addiction (COPMI); a high risk factor for the development of mental disorders (Leijdesdorff et al., 2017). If they feel welcomed and listened to, even if no symptoms or problems, specifically this high risk group might return to a walk-in center in

case mental health problems emerge. Our results might therefore contribute positively to the prevention of delay in treatment of psychiatric disorders.

Consistent with its mission, @ease showed to be accessible enough to reach at least part of the population of young people in need of help. For one third of visitors, having a conversation was enough for the time being. Perhaps the act of listening itself and being seen and heard might lead to higher resilience. Furthermore, the experience of being listened to as a positive first encounter with help might lead to a lowered threshold to seek help if things are getting worse in the future. For the two third of visitors in need of more support or care, @ease bridged the gap and guided them towards appropriate care and thereby facilitated early intervention.

Individual @ease centers seemed to be comparable in terms of visitors, yet, there are some differences of which country of birth is probably most noteworthy. Almost all visitors of the Amsterdam @ease center were native Dutch, whereas more than half of the Maastricht @ease visitors were born abroad. Most of these foreign visitors were international students, a highly represented population in Maastricht. A possible explanation for this high number of international students might be that barriers to care are even higher for people who are not familiar with the Dutch healthcare system, in combination with less of a social support system than they might have had in their home country.

Strengths, limitations and future directions

The current study contributes to a better understanding of the characteristics and needs of young people with (mental health) problems. Results showed that there is a clear need for help among young people; a need that is not yet fully met. In addition, the current study shows that @ease facilitates access to care for a population of young people.

The majority of visitors were involved in education, most of them at a high level, making it questionable whether the most vulnerable young people are reached yet. Future research might investigate the needs of vulnerable subpopulations, such as those with intellectual disabilities, COPMI and refugees. Increased knowledge about these subgroups is crucial to better match their specific needs.

To further adjust @ease's services to its visitors and their needs, the @ease-questionnaire could be optimized by further specifying questions about reasons for their visit with more options including education related stress, (sexual) violence and psychotic experiences. An additional challenge since the start of the online chat and phone services is to gather questionnaire data following these conversations which proved to be much more difficult than at the end of face-to-face conversations. A possibility might be to develop an extra, very short evaluation form for online use.

A final promising as well as challenging aspect is the growth in number of @ease centers while maintaining model fidelity (Bridgman et al., 2019). A constant investment in regional networks seems to be vital to fill in the local gaps aiming to help young people bridge the siloes of the healthcare system. In addition, continuous engagement of and input by young people as (potential) users must ensure youth friendly and high quality service. In this regard, youth council 'Be @ease' plays a prominent role.

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Chapter 4

Burden of mental health problems: quality of life and cost-of-illness in youth consulting Dutch walk-in youth health centres

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Abstract

Background

Little is known about the burden of (sub-threshold) mental health problems in youth.

Aim

To examine the burden of mental health problems in terms of health-related quality of life (HRQoL) and cost-of-illness, for first visitors of the Dutch youth walk-in centres (@ease).

Method

A bottom-up, prevalence-based burden of disease study from a societal perspective. HRQoL was assessed through the EuroQoL (EQ-5D-5L), and cost-of-illness via items about truancy and health care utilization.

Results

Participants (N=80) showed a decreased HRQoL compared to the general population of Dutch youth. In the three months prior to their 1st attendance, participants skipped on average 4.11 days of school and had 1.03 health care visits, leading to total costs of €512.64 per person. Females had significantly higher health care costs and lower HRQoL. Health care use was lower in those not speaking the Dutch language. Living alone was a significant predictor of truancy (costs), and therefore total costs.

Conclusions

Mental health problems in youth consulting @ease have a considerable impact on the individual's HRQoL, and an economic impact on society, yet almost 75% is not receiving care. A lack of interventions in this critical period in life may have major lifelong consequences.

Introduction

Mental disorders are the chronic diseases of the young (Insel, 2009). The onset is mostly in the first three decades of life; at 24 years of age, three quarters of all lifetime cases have started (Kessler et al., 2005). Therefore, the impact of mental disorders on individuals, the health care system and society is enormous. The World Health Organisation estimated 33% of years lost to disability in 15 - 29 year olds (World Health Organization, 2018). According to the Global Health Estimates 2016, mental and substance use disorders are the leading cause of non-fatal disease burden. This makes mental disorders a major challenge for health care systems worldwide.

Nonetheless, worldwide, less than 2% of government health expenditure is spent on mental health care (World Health Organization, 2017). Health care costs, however, are not the only costs caused by mental disorders as there is the societal burden of absenteeism from school and work (De Graaf et al., 2010, 2011). Studies describing the economic impact for society vary substantially, due to their methodology and setting (Hu, 2004), but indicated that 67% to 92% of the total costs of having a mental disorder are made outside the health care system, mainly due to productivity losses (Chevreul et al., 2013; Jager et al., 2008; Lee et al., 2017; Smit et al., 2006). In the Netherlands, the annual per capita excess costs of having any common mental disorder are calculated as €3,200, which is comparable to those of somatic disorders (Smit, et al., 2006).

Adolescence is both a crucial developmental period, and a vulnerable period in life, causing mental ill health in youth to be associated with negative life outcomes later on in life (Gibb et al., 2010). A major factor is the risk of school dropout, which is a dynamic process starting early in life and with potential major socioeconomic consequences (Theunissen-Lamers, 2016).

16% of adolescents suffer from symptoms of mental disorders with functional impairment and decreased quality of life (Roberts et al., 2014). Negative consequences are not exclusively seen in diagnosed mental disorders though; a recent study showed already a great impact on society caused by sub-threshold mental disorders in children (Fatori et al., 2018). Therefore, to prevent the development and persistence of mental disorders and its associated burden later in life, focus in mental health has to be on early stage improvement of wellbeing and resilience, specifically in 12 to 25 year-olds (McGorry & Mei, 2018; McGorry & Van Os, 2013). A huge challenge is the need for care versus the use

of care: adolescents are least likely to seek help, due to age specific barriers, such as a lack of mental health literacy, poor access, financial costs and a misfit between service structures and the needs of youngsters (Hetrick et al., 2017; Rickwood et al., 2007; Vyas et al., 2015). As a consequence, less than a third of all youngsters (aged 12-25 years) that experience problems with their mental health receive any professional help for it (De Graaf et al., 2010; Slade et al., 2009).

Aim

The burden of mental disorders is a rising theme on the research agenda, resulting in studies in adults and youth with a full-blown mental disorder, who are already involved in care. To the best of our knowledge, little is known about the burden of (sub-threshold) mental health problems in the critical group of youth who are in need for help, especially those without any form of professional care. Knowledge about this dark number of youngsters and the associated burden is needed, to underline the importance of the problem for policy and research agenda's, and to thereby stimulate easy accessible youth mental health care, prevention as well as early detection and intervention. The aim of this study is therefore to describe the burden of mental health problems in terms of health-related quality of life (HRQoL) and cost-of-illness in individuals first visiting the Dutch @ease youth walk-in centres to seek help for their mental problems.

Materials and methods

Study design and setting

This is a multicentre, bottom-up, prevalence-based study focusing on the burden of disease expressed in cost-of-illness (Euros) and HRQoL (utilities) from a societal perspective, partly based on the Dutch guidelines for economic health care evaluation (Knies, 2016). The Medical Ethical Committee of Maastricht University has assessed and approved the study (METC number 2017-0046). Data of @ease visitors who, after being informed about the study procedures, consented to participate were included in the study. Anonymized data were stored on a secured server of Maastricht University.

The Dutch multicentre organization @ease (www.ease.nl) has been adapted from the Australian headspace model (www.headspace.au.org)

(McGorry & Mei, 2018). It offers youth-friendly, easy accessible peer-to-peer support to persons between 12 and 25 years old with problems around mental health and wellbeing, currently in Maastricht and Amsterdam. Trained volunteers, together with healthcare professionals, offer sessions anonymous and free of charge.

Participants

Since the start of @ease in January 2018, all visitors were asked to fill in a digital questionnaire on a tablet. Of all visitors who agreed to fill in the questionnaire, first visit data, collected between January 2018 and May 2019, was included in the present study. Inclusion criteria were met when the person filled in at least one of the primary outcome measures: HRQoL, truancy and (mental) health care utilization.

Outcome measurement

The HRQoL was measured using the five-dimensional, five-level EuroQoL (EQ-5D-5L) consisting of the following dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has five levels: no problems, minor problems, moderate problems, severe problems, and not able to perform a certain activity. In mental health, the EQ-5D is proven to reflect the impact of common mild to moderate conditions and discriminate between severity sub groups (Brazier, 2010; Lamers et al., 2006).

To calculate the cost-of-illness, the societal perspective was broken down into mental health care utilization and truancy. These unities were measured with a three-month reference period by the following items:

- (1) During the last three months, how often did you visit a health care professional for mental health issues or addiction problems?
- (2) How many days have you skipped school in the last three months?

The item assessing truancy includes skipping days of all sorts of education, such as school and university, and because of the vast majority of @ease visitors were involved in education, productivity losses at work were not being assessed. All items were concise to maintain the feasibility of the questionnaire, and to stay in line with the low-threshold character of @ease.

In addition to the primary outcome measurements, the questionnaire contained questions on participant characteristics including age, sex, country of birth, language of the questionnaire, living situation, occupation, current level of education, and parental history of mental illness, and the young person's social functioning was rated by the trained volunteers using the Social and Occupational Functioning Assessment Scale (SOFAS; American Psychiatric Association, 2013).

Analysis

Each 5-level health state of the EQ-5D-5L corresponds with a utility on a scale of 0-1, where 0 indicates death and 1 full health. Utilities corresponding with the measured health states were derived from the Dutch tariffs (Versteegh et al., 2016).

To get insight into truancy and health care costs, the number of days skipped school and the number of visits to a health care professional were multiplied by a cost price. Valuation of truancy was based on data of Statistics Netherlands (2018a). The total expenditure per educational level in 2017 was used, including expenditure of the government, households, companies, non-profit institutions and organizations abroad. The total expenditure was divided by the number of students per educational level in academic year 2017/2018 (Statistics Netherlands, 2018b) to calculate the costs per student per year. Educational levels were primary education, secondary education, secondary vocational education, higher professional education, and university. For the cost price per day, the costs per student per year were divided by 200, based on an average of 40 school weeks of 5 days per year. The latter corresponds with the method used by Drost et al. (2014).

This study reports the proportion of the population who visited a general practitioner (GP) and/or a mental health care service for mental health problems. Which specific kind of health care professional was consulted was not addressed in the questionnaire. Therefore, we calculated a weighted average based on the health care utilization described in the Netherlands Mental Health Survey and Incidence Study-2 (NEMESIS-2) (De Graaf, et al., 2010) and the reference price for a GP and mental health care services consult as described in the Dutch costing manual (Hakkaart-van Roijen et al., 2016). The calculated weighted

average was used as the cost price for (mental) health care utilization. All costs were indexed for the year 2018.

We explored the correlation between total costs and utilities using Pearson's correlation coefficient, where a coefficient between 0 and $(-)0.35$ represents a weak correlation and a coefficient $>(-)0.35$ a moderate to strong correlation (Taylor, 1990).

We conducted stepwise multiple linear regressions to predict utility, health care costs, truancy costs, and total costs for sub groups based on the participant characteristics. As cost data are usually skewed and not normally divided, we had to take into account non parametric bootstrapping (1000 replications) for all cost categories. The alpha level was set at 0.05 for all analyses. Analyses were conducted using SPSS Statistics version 25, except for bootstrapping, which was conducted with Microsoft Office Excel 2003.

Sensitivity analyses

We performed four sensitivity analyses to check possible influences of assumptions in the base case analyses. First, a complete case analysis was done on both total costs and utility to investigate the influence of the inclusion of persons with missing scores on at least one primary outcome measure. Second, we used the reference price of unpaid work (Hakkaart-van Roijen et al., 2016) in combination with the standard hours per educational level per year (Ministry of Education Culture & Science, 2020) divided by 200 school days as the cost price for one day skipping school. Third, we compared the Dutch tariff with the European tariff of the three-level EQ-5D (Greiner et al., 2003), as there is no European valuation set for the five-level version available yet. Last, a possible relation between the use of mental health care and HRQoL in our sample was investigated.

Results

Between January 2018 and May 2019, 125 persons visited @ease for the first time. 64% of them responded to at least one primary outcome ($N=80$) (Table 1). 54.4% of the participants responded to the Dutch questionnaire, which was used as a proxy of being able to find his/her way in the Dutch society and health care system. Of the 34 persons (44.8%) who reported having at least one parent with

a history of a mental disorder, 5 stated that both parents (had) suffered from a mental disorder. The mean SOFAS score of 65.41 (SD 15.76), corresponds with some to moderate difficulty in social, occupational, or school functioning.

Table 1: Participant characteristics (N=80)

Participant characteristics	N (%)
Sex	
Male	32 (42.7)
Female	42 (56.0)
Other	1 (1.3)
Age (mean (SD))	20.52 (3.81)
Country of birth	
The Netherlands	38 (50.7)
Germany	10 (13.3)
Other countries Europe	14 (18.2)
Countries in Asia	10 (13.3)
Countries in North America	3 (3.9)
Countries in Oceania	1 (1.3)
Countries in Africa	1 (1.3)
Questionnaire	
Dutch	43 (54.4)
English	36 (45.6)
Living situation	
Peers	28 (35.2)
Alone	21 (25.9)
Parents	20 (25.0)
Partner	7 (8.8)
Care givers	1 (1.3)
Other	3 (3.9)
Parental history of mental illness	34 (44.8)
Daily occupation	
Education	64 (83.1)
Job	5 (6.5)
Education and job	6 (7.8)
None	2 (2.6)
Current education	
Primary school	1 (1.4)

Secondary education	18 (26.0)
Secondary vocational education	3 (4.3)
Higher professional education	9 (13.0)
University	38 (55.1)
SOFAS score (mean (SD))	65.41 (15.76)

Note: SD: standard deviation.

HRQoL

The mean utility of the study population was 0.62 (SD 0.21). The dimensions usual activities and anxiety/depression were highly affected, with respectively 47.3% and 74.3% having moderate problems or worse (Table 2). On the contrary, mobility and self-care had a minor influence on the loss of HRQoL.

Table 2: Frequencies of responded levels on the five dimensions of the five-dimensional, five-level EuroQoL (N=74)

	No problems N (%)	Minor problems N (%)	Moderate problems N (%)	Severe problems N (%)	Extreme problems N (%)
Mobility	69 (93.2)	5 (6.8)	0 (0.0)	0 (0.0)	0 (0.0)
Self-care	64 (86.5)	7 (9.5)	2 (2.7)	0 (0.0)	1 (1.4)
Usual activities	21 (28.4)	18 (24.3)	26 (35.1)	9 (12.2)	0 (0.0)
Pain/discomfort	35 (47.3)	23 (31.1)	12 (16.2)	2 (2.7)	2 (2.7)
Anxiety/depression	2 (2.7)	17 (23.0)	29 (39.2)	22 (29.7)	4 (5.4)

Cost-of-illness

27% of the population reported having visited a mental health care professional in the last three months (Table 3), leading to a population mean of 1.03 contacts per person with corresponding costs of €103.59 per person in the last three months.

Of the 69 participants following education, 58.8% reported that they skipped school at least one day in the last three months (Table 3), leading to a mean of 4.06 days skipped school in the total study population, corresponding with €402.29 per person in the last three months.

64 respondents answered both cost-of-illness items. Summing up their health care costs and truancy costs resulted in a total of €32,809.06, which equals €512.64 per person in the last three months, corresponding to €2,050.56

per person per year. 28% of these youngsters did not use health care nor skipped school.

Table 3: Resource use and costs in the three months prior to visiting @ease

	Unit	Users N (%)	Units per person Mean (SD)	Costs per person Mean (SD)
Health care costs (N=74)	Contact	20 (27.0)	1.03 (2.83)	103.59 (285.75)
Truancy costs (N=68)	Day	40 (58.8)	4.11 (6.03)	402.29 (580.96)
Total costs (N=64)				512.64 (641.12)

Note: all costs in Euros. SD: standard deviation.

Relation between costs and HRQoL

We calculated Pearson's correlation between total costs and utilities, resulting in a weak negative, statistically non-significant correlation coefficient of -0.136 ($p = 0.30$).

Sub group analyses

With the multiple regression analyses, both sex and SOFAS score were significant predictors of utility, with males showing a higher HRQoL compared to females ($\beta = -0.141$, $p = 0.012$), and a higher social functioning score relating to a higher HRQoL ($\beta = 0.004$, $p = 0.043$), explaining 20% of variance. Furthermore, living alone, compared to living with others in any form (parents, caregivers, peers, or partner), was the only significant predictor of truancy costs ($\beta = 623.35$, $p < 0.001$, $R^2 = 0.204$), and total costs ($\beta = 605.26$, $p = 0.003$, $R^2 = 0.161$). In the multiple regression analyses, none of the participant characteristics were significant predictors of health care costs. However, as our cost data were highly skewed, the normality assumption was violated. Therefore, we applied bootstrapping on four relevant variables: sex, living situation, the language of the questionnaire, and parental history of mental illness (Table 4a-c). The significant relation between living alone and both truancy costs and total costs was confirmed. Moreover, females and Dutch speaking respondents made significantly higher health care costs than males and non-Dutch speakers.

Table 4: Sub-group analyses

		Costs per person	Bootstrapped costs per person	Bootstrapped difference	
		Mean (SD)	Mean (SD)	Mean	95% CI*
(a) Sub-group analyses of health care costs					
Sex				123.49**	21.83 to
Male	34.78 (67.53)	34.83 (12.37)			267.91**
Female	155.17 (376.65)	158.32 (62.67)			
Living situation				72.45	-46.61 to
Alone	62.44 (202.92)	60.57 (42.51)			199.68
Other	133.05 (329.93)	133.02 (46.31)			
Dutch language				-113.49**	-231.55 to
Yes	156.33 (371.08)	153.41 (56.14)			-12.11**
No	39.73 (103.78)	39.93 (18.28)			
Parental history of mental illness				-3.53	-125.97 to
Yes	106.79 (185.71)	107.83 (32.23)			153.96
No	106.31 (365.16)	104.29 (60.59)			
(b) Sub-group analyses of truancy costs					
Sex				-24.33	-328.38 to
Male	411.81 (611.13)	413.09 (118.32)			259.17
Female	388.95 (590.75)	388.76 (95.70)			
Living situation				-589.56**	-985.34 to
Alone	872.19 (807.37)	869.63 (194.73)			-190.84**
With others	279.18 (410.70)	280.06 (58.16)			
Dutch language				88.31	-188.39 to
Yes	351.46 (533.81)	359.27 (87.37)			390.35
No	448.48 (639.45)	447.59 (113.77)			
Parental history of mental illness				-182.59	-450.25 to
No	491.05 (690.41)	487.39 (114.10)			89.50
Yes	306.31 (414.32)	304.81 (78.07)			
(c) Sub-group analyses of total costs					
Sex				130.33	-187.54 to
Male	423.58 (605.96)	429.50 (120.86)			465.65
Female	565.17 (700.13)	559.82 (116.40)			

Living situation			-542.40**	-985.47 to
Alone	954.14 (871.23)	953.43 (208.17)		-115.76**
Other	410.21 (484.88)	411.04 (75.79)		
Dutch language			-16.28	-330.31 to
Yes	510.71 (651.62)	516.54 (113.39)		284.84
No	505.24 (649.24)	500.26 (110.75)		
Parental history			181.47	-115.06 to
of mental illness				508.58
Yes	418.38 (451.58)	419.96 (86.34)		
No	602.82 (771.45)	601.43 (132.83)		

Note: all costs in Euros. SD: standard deviation. CI: confidence interval. If CI includes 0, no significant difference is found. ** Significant difference.

Sensitivity analyses

The sensitivity analyses showed negligible differences compared to our initial analyses. Including people with missing scores on one of the primary outcome measures only very mildly increased the utility (0.01) and the total costs (€6.67). Using the other cost price for truancy led to slightly higher costs (€21.54) in comparison with the base case analysis. When we used the three-level European valuation set, the mean utility of the population was only 0.04 higher than in the base case analysis. Linear regression analysis showed no significant relation between health care costs and utility.

Discussion

The present study shows the burden of mental health problems in youth consulting walk-in centre @ease in terms of HRQoL and cost-of-illness. Our results indicate a distinct decreased HRQoL combined with considerable costs for society in a population of help-seeking youth. It also shows a gap in care: despite the decreased HRQoL combined with high numbers of truancy, almost three quarters of our population had not yet received care.

The burden of the mental health problems becomes apparent when comparing their HRQoL (0.62) with that of peers in the Dutch general population (between 0.91 and 0.96) (Versteegh, et al., 2016), or adolescents with a chronic somatic disorder (between 0.77 and 1.00) (Hernandez et al., 2018; Tarride et al., 2010). The HRQoL in our population is in line with that of adolescents with a full-threshold depression reporting a utility between 0.50 and 0.76 (Byford,

2013; Lynch et al., 2016). The HRQoL impact was highest on the dimensions 'Usual activities' and 'Anxiety/depression'. The latter is directly related to common mental health problems (Byford, 2013). The impact on 'Usual activities' is also seen in the social and occupational impairment of the study population. Indeed, Chudleigh et al. (2011) has shown that those at risk for a psychotic episode have similar social impairments as patients, and significantly more than controls. This indicates that deficits in the ability of performing usual activities precede the diagnosis, and that our health care system should be focusing more on functional decline rather than diagnoses and disease specific symptoms only.

Since productivity losses are associated with work, absenteeism from school can be seen as loss of productivity in the educational sector. More than half of the first visitors of @ease skipped at least one day of school in the last three months, whereas in the general population, only 11-13% of the adolescents skipped at least one hour in the last month (Stevens et al., 2018; Vaughn et al., 2013). When comparing our study population to working people aged 15 to 25, our study mean of 4 days in three months is considerably higher than the general population mean of 3 days of absenteeism per year (Statistics Netherlands, 2020). It must be stated that research into truancy is mainly focussed on school aged children under the age of 18. Research into productivity losses, on the other hand, is often targeting working adults, leaving adolescents attending universities (of applied science) in a vacuum of knowledge, emphasising the importance of studying young people throughout their development to young adulthood (Kwan & Rickwood, 2015). The difference between our population and the general population, however, is in line with previous research indicating that mental health problems increase the risk of truancy in adolescents (Schulte-Körne, 2016), and the relation between mental disorders and production losses in adults (De Graaf et al., 2011).

The total costs, corresponding to €2,050.56 per person per year, have a close similarity with the total costs of mental disorders in adults, ranging between €2,000 and €3,200 (Chevreul, et al., 2013; Smit, et al., 2006), and the ratio of productivity costs, with almost 80% of the total costs made by truancy (Chevreul, et al., 2013; Jager, et al., 2008; Lee, et al., 2017; Smit, et al., 2006).

Female sex showed to be a predictor for a higher burden in terms of utility and health care costs compared to the male sex, which is also found in the general population (De Graaf, et al., 2010; Versteegh, et al., 2016). Our results

did not confirm a positive relation between using any kind of care and living alone compared to living with a partner (idem). However, in our population, living alone was associated with more truancy costs than living with others. Last, higher health care costs in those who filled in the Dutch questionnaire may indicate that not speaking the Dutch language is an extra barrier for seeking or receiving professional help.

Strengths and limitations

This study has several strengths. To the best of our knowledge, this was the first study investigating the burden of mental health problems in youth, especially in those in need for help, and therefore seeking help at @ease. Second, while youngsters with mental health problems form a challenging population to motivate for participation, the response to our questionnaire was quite high and complete. Third, we used the prevalence-based, bottom-up approach, where cost units were collected on the individual level, for all cases in a specific time period. This bottom-up approach has more informative power than its opposite (top-down) (Tarricone, 2006). A prevalence-based, compared to an incidence-based approach, best met the aim of our study, to draw attention to the burden of mental health problems. Last, the study had a societal perspective, which is most comprehensive and meets the principal aim of a Burden of Disease study, measuring the impact on society as a whole (Jo, 2014; Tarricone, 2006).

There are some limitations to be considered. First, we used only self-reported data with retrospective questioning, which can lead to recall bias (Bowling, 2014). To minimise bias, the time reference period was set at three months. Second, the EQ-5D-5L is not specific for mental health problems, which makes it less sensitive to small, disease-specific effects. However, the use of this generic HRQoL measurement makes it possible to compare utilities with other general or patient populations (Drummond et al., 2015). Third, the items to measure the cost-of-illness were concise in order to limit the non-response, which led to less detailed and specific information, and thereby to a less precise estimation of costs. We had to make this choice to maintain the feasibility for our population of youth. During the study, there might have been a linguistic uncertainty of the questionnaire, as for a considerable group, nor Dutch or English was their mother language, which may rise questions about how participants interpreted the HRQoL and cost-of-illness items. In addition, we

noticed the ambiguity of the term skipping school, as some interpreted this as absenteeism instead of truancy. This complicates the interpretation of our truancy costs.

Concerning the costs, a possible overestimation of costs should be considered. While absenteeism from school was asked, the compensation of this absenteeism, for example by catching up in the following weeks, was not measured. This might give an overestimation of the truancy costs. Moreover, it is debatable how to value skipping a day from school, as this does not lead to direct production losses, like skipping work does, nor leads directly to repeating a class. However, it does have an impact on the development of the youngster, with possible long-term effects (Theunissen-Lamers, 2016) and is an expression of the experienced burden. The valuation of absenteeism from school is still experimental, with less clear guidelines as for absenteeism from work. In our opinion, we have selected the most appropriate method to value truancy. Last, it might be argued that due to fluctuations in symptoms, calculation annual costs by multiplying the costs of three months by 4, might not be representative. On the other hand, the costs are calculated as an average of all youngsters in our study population and therefore also fluctuations within persons might be averaged.

There are also indications that we underestimated costs. The item about truancy can be interpreted as contact hours, while self-study, especially for those at university, is as important for their development. In addition, 9% of our population was not involved in any form of education, and therefore their truancy or absenteeism was not assessed, neither did we assess possible productivity losses by parents or caregivers of the youngsters in our population. Given the decrease in HRQoL in our population, we expect the proportion of health care use, and thereby costs, to even increase after their first visit to @ease, as for a great part of the participants, the visit to @ease was the first step in seeking help. Last, when looking at health care costs, we included the visits to a mental health care professional, thereby excluding additional diagnostics, therapies, and medication.

It can be considered unexpected that we found no significant correlation between the decreased QoL and total costs in our study. Improving QoL might therefore, not directly reduce costs. Young people with mental health problems, however, almost always experience comorbid psychosocial or environmental

difficulties (Leijdesdorff et al., 2019). Interventions should therefore not only target QoL, but should focus broader on improving well-being and resilience with a multidisciplinary approach, aiming to decrease the individual as well as societal burden.

Implications for clinical practice and research

This study indicates the severity of the burden that mental health problems have on youth visiting @ease and draws attention to the fact that intervening in this early stage matters, not only to reduce the burden of mental health problems at this moment, but also to prevent the individual and economic burden from persisting or escalating later on in life. This underlines the importance of having the right intervention, for the right person, at the right place and at the right time.

Further research into the burden of mental health problems in youth, especially with a direct comparison with the healthy population could increase the knowledge of this right intervention, person, place, and time. Follow-up studies of the population visiting @ease, describing the development of their burden over time, will follow. In conclusion, the extent of the burden of mental health problems for youth visiting @ease emphasizes the need for youth-appropriate early interventions in mental health.

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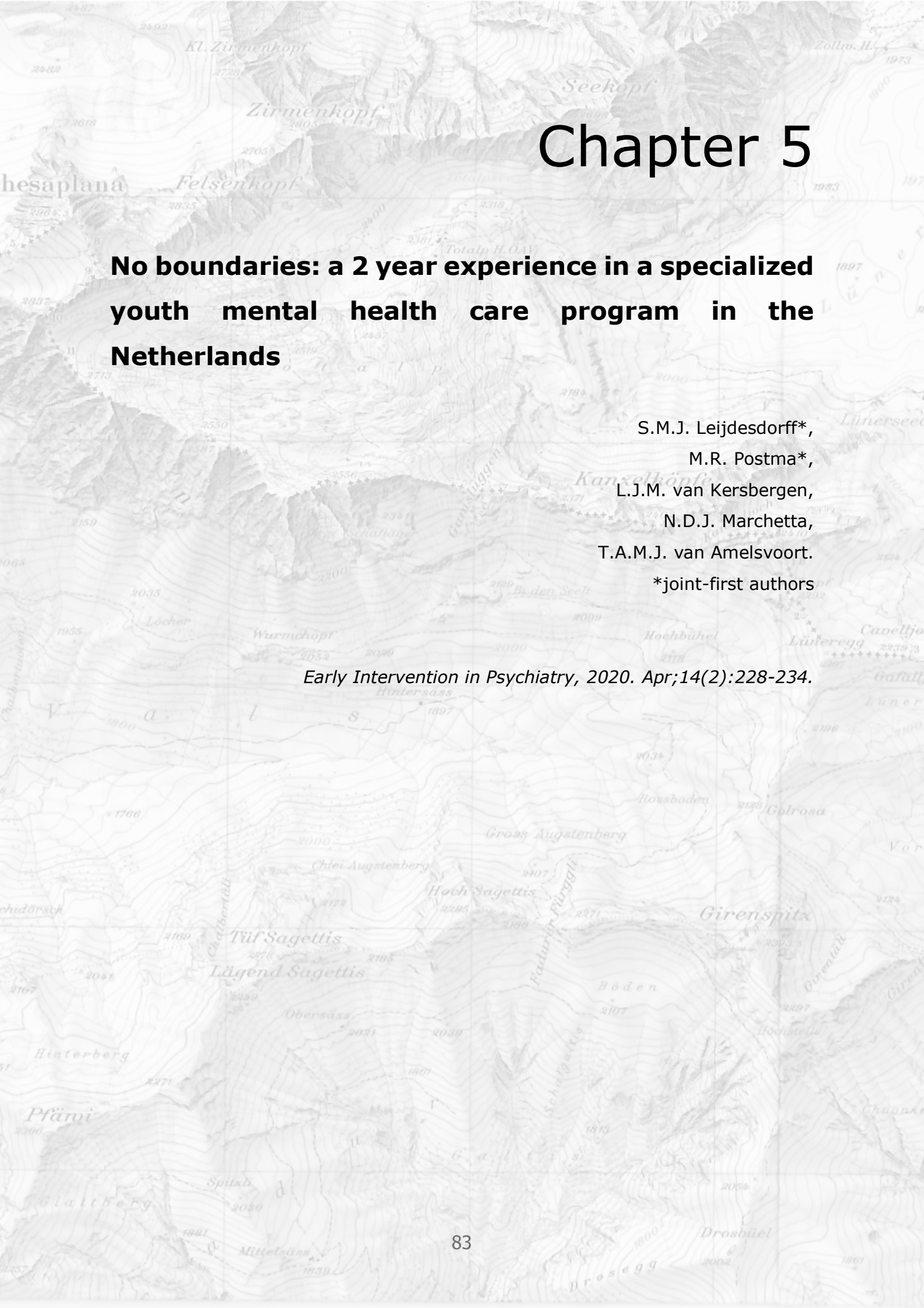
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A detailed topographic map of a mountainous region, likely in the Alps, serves as the background. The map features numerous contour lines indicating elevation, with peaks labeled in German such as 'Zirmenkopf', 'Felsenkopf', 'Seekopf', 'Kanzelhöhe', 'Hochbühel', 'Gross Augstenberg', 'Hoch Sagettis', 'Tief Sagettis', 'Lägend Sagettis', 'Hinterberg', 'Pfäwi', 'Glattberg', 'Spütsch', 'Mittelsäss', 'Drosbüel', 'Girenspitx', 'Gallros', 'Hochstätt', 'Chunak', 'Gallros', 'Hochstätt', 'Chunak', 'Gallros', 'Hochstätt', 'Chunak'. The map is oriented with North at the top.

Chapter 5

No boundaries: a 2 year experience in a specialized youth mental health care program in the Netherlands

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Abstract

Aim

Young people around the age of 18 receiving mental health care usually face the transition from child and adolescent (CAMHS) to adult mental health services (AMHS) bringing the risk of disruption in continuity of care. Recognizing the importance of early intervention in this vulnerable life-period, this study aims to emphasize the importance of a client-centred approach and continuity of care for this age group. For a deeper understanding of the specific needs of this group, the working method of a Dutch youth mental health (YMH) team working in a secondary mental health care setting is described, including some clinical characteristics and treatment results of patients who accessed this service.

Methods

Data consist of a detailed description of the working method of the YMH team combined with clinical characteristics of all patients aged 15-25 years accessing the services of the YMH team over a two-year period.

Results

The YMH team incorporated suggestions of earlier research into a client centred treatment. Key elements were multidisciplinary meetings, transcending diagnosis, flexibility and collaboration with other care providers. Clinical records showed a complex patient population and significant treatment effect.

Conclusions

The group of emerging adults accessing the YMH team can be described as a patient group with a high diversity and complexity of disorders and problems. Continuity of care was met when patients turned 18, allowing treatments to be successfully performed by the same team of professionals using a client-centred approach.

Introduction

Adolescence forms a period of high risk for the emergence of serious mental disorders (Singh, 2009). Approximately three-quarters of mental disorders emerge before the age of 25 (Kessler et al., 2005). Young people (aged 12 to 25) have the highest incidence and prevalence of mental disorders across the lifespan, and indeed mental disorders account for almost 50% of the total disease burden among young people (Pieris-Caldwell et al., 2007). Correspondingly, there is a growing body of literature that recognizes the importance and effectiveness of early intervention in youth mental health (Correll et al., 2018; McGorry, 2015; McGorry et al., 2018).

The comprehensive mental health action plan 2013–2020 (World Health Organization, 2013) provides a framework for strengthening capacities in countries to address the mental health needs of children and adolescents. It encourages the adoption of a life-cycle approach in implementing mental health policies and strategies, taking into account the health and social needs at all stages of the life course. However, in many countries the mental health care system is rigidly divided into child and adolescent mental healthcare (CAMHS) and adult mental health care (AMHS). Transfer from CAMHS to AMHS usually takes place at 18 years. This division cuts right through the life-stage for youth as defined by the WHO, namely 15-25 years. A British multicentre study (Singh et al., 2010) even revealed that for the vast majority of service users, the transition from CAMHS to AMHS was poorly arranged, poorly carried out, and poorly experienced.

Bearing in mind the specific needs of youth, it should be noted that during this period, brain development has distinct features and plays a crucial role in further development. Longitudinal neuroimaging studies demonstrate that the adolescent brain continues to mature well into the 20s (Blakemore & Robbins, 2012; Johnson et al., 2009). This dynamic process influences behaviour and in this specific life-stage, decision-making and behaviour are highly dependent on the social and motivational context (Crone & Dahl, 2012).

Another characteristic of youth is that it is difficult to predict future development of mental (ill) health. Symptoms often fluctuate in severity, sometimes at a subthreshold level (Jones, 2013; Kessler et al., 2007; Yung et al., 1996), making it hard to diagnose a specific mental disorder. In addition, co-morbidities are highly prevalent, with percentages ranging from 60%, when

referring to the presence of more than one psychiatric disorder (Pottick et al., 2014), to as much as 98%, when including also other presented psychosocial or environmental problems or needs (Social Exclusion Unit, Office of the Deputy Prime Minister, 2004). These characteristics show a high degree of complexity and variety in the development of psychopathology.

In sum, the above emphasizes the potential of (early) intervention, focussing on the crucial developmental period of 15-25 years, to greatly enhance mental health, wellbeing and productivity of young people (McGorry et al., 2014). Virenze, a mental health care organization in the Netherlands, aimed to do so and established a multidisciplinary youth mental health (YMH) team in Maastricht. Within the context of emerging integrated youth health care worldwide (Hetrick et al., 2017), the YMH team brings together CAMHS and AMHS, providing secondary care (Tier 3) (Appleton, 2000) including treatment of complex conditions.

This paper aims to gain a better understanding of the specific needs of help seeking youth between 15 and 25 years facing mental health problems, by describing both working method of the innovative YMH team and clinical characteristics of its population. To explore the effectiveness of the YMH team, treatment effects are analysed. By contributing to ongoing evaluation and program description within youth mental health care, the present paper is of importance in supporting systems transformation.

Methods

Subjects

Clinical characteristics of 158 patients aged 15-25 years who had been referred to the YMH team in Maastricht by their general practitioner, school doctor, or other health care professionals, were collected from the patient files. Data were collected retrospectively for a two-year timeframe; between July 2013 (start of the team) and June 2015. The data set was anonymous. The local internal scientific committee approved of the study.

Working method of the team

The YMH team can be described as a hybrid multidisciplinary team consisting of

professionals from CAMHS and AMHS, and with different fields of expertise. The team included psychologists, psychotherapists, family therapists, psychiatrists, running therapist and a psychiatric nurse practitioner, to ensure comprehensive care and meeting complex needs. Fields of expertise comprised Cognitive Behavioural Therapy (CBT), Eye Movement Desensitization and Reprocessing (EMDR), Schema Focused Therapy, Systemic therapy, Psychoanalysis, Mindfulness-Based Cognitive Therapy (MBCT), Acceptance and Commitment Therapy (ACT), Pharmacotherapy and sessions aimed at gaining competences (regarding ADHD or emotion regulation disorders). These therapies were offered individually and/or in a group setting. The YMH team provided both brief, less intense treatment as well as specialized treatment, or a combination of both. At weekly multidisciplinary meetings with a cross-developmental stage and trans-diagnostic approach led to a personalized treatment plan per patient. Different professionals within the team worked together to execute and evaluate the specific treatment plan, and if needed (mental health care) partners from other (primary care) facilities were involved. The YMH team hereby adhered to a client-centred approach.

Continuity of care was met when diagnoses or patient needs changed or when patients turned 18, allowing the complete treatment to be performed by the same, multidisciplinary team of professionals.

Measures

Patient sociodemographic characteristics comprised sex and age. Clinical characteristics comprised diagnoses according to the Diagnostic and Statistical Manual of mental disorders (DSM-IV-TR) (American Psychiatric Association, 2000) on axis I, II and IV. DSM-IV-TR diagnoses and Global Assessment of Functioning (GAF) (American Psychiatric Association, 2000) scores were assessed by the clinician using the Structured Clinical Interview for DSM-IV-TR axis I and/or II disorders (SCID-I and/or II) (First et al., 2002; First et al. 1997) and if indicated, further instruments such as the Diagnostic interview for ADHD in adults, version 2.0 (DIVA 2.0) (Kooij & Francken, 2010) and Autism diagnostic observation schedule, second edition (ADOS 2) (Lord et al., 2012) were conducted. To assess the intellectual capacity if indicated, the Wechsler Adult Intelligence Scale IV,

Dutch version (WAIS-IV-NL) (Pearson assessment & information BV, 2012b) was used, which is shown to be a reliable and valid instrument (Pearson assessment & information BV, 2012a).

To explore treatment effects, pre- and post- treatment Routine Outcome Measurement (ROM) as well as GAF scores were used. In the Netherlands, ROM is part of standard care to determine symptom reduction aiming to measure treatment effect. The Brief Symptom Inventory (BSI), the 53-item version, (Derogatis, 1993) is a standard ROM which uses patients' self-reports, validated for individuals from 18 years onwards. All measures were administered in Dutch.

Procedure and analysis

Clinical data mentioned above were extracted from the patient files, compiled and analyzed statistically using IBM SPSS Statistics software for Windows, version 23.0 (IBM Corp., Armonk, N.Y., USA). Firstly, to investigate clinical characteristics, frequencies were run on all disorder categories. To explore treatment effect, a repeated measures design was used comparing patients' symptoms and functioning at the beginning and end of treatment by performing a paired samples *t*-test on pre- and post- BSI (mean score) and GAF measures. Furthermore, to investigate if there is a specific need for care based on sex, a split-plot ANOVA was conducted with sex as the independent variable and pre and post BSI scores as repeated measured dependent variable. The same was done for GAF as dependent variable. For all analyses, statistical significance was set at $P < .05$.

Results

Between July 2013 and June 2015, the YMH team saw 158 patients with a mean age of 19 years when first accessing the team (range 15 – 25 years, $SD = 2.40$). For 139 patients, including 55 males and 84 females, diagnoses were available. The most common clinical disorders were anxiety disorders, mood disorders, and disorders usually first diagnosed in infancy, childhood or adolescence (Figure 1). Anxiety disorders were somewhat distributed over the different disorders within this category, with generalized anxiety disorder and posttraumatic stress disorder occurring more often. Among mood disorders mainly depression was found. Of the disorders usually first diagnosed in infancy, childhood or adolescence, ADHD

diagnoses were by far the most common, making up about two thirds of these diagnoses. Missing diagnoses were due to deferred decisions or end of treatment before the diagnosis was finalized.

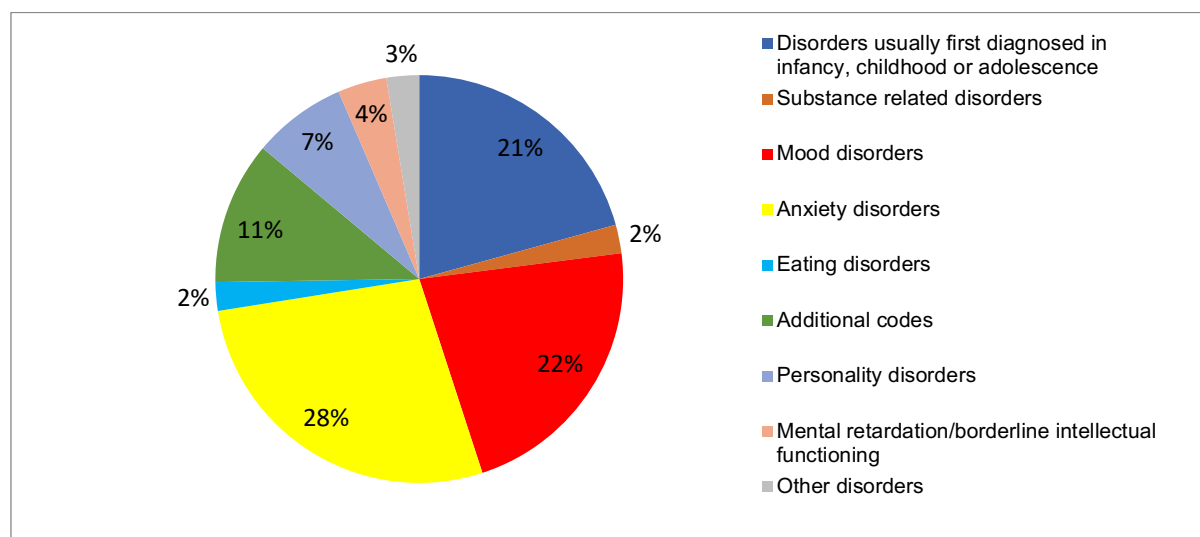


Figure 1. Distribution of all axis I and II disorders in patients from the Youth Mental Health team. Percentages are based on the frequency of diagnoses within the category divided by the total of all diagnoses.

Note: Additional codes meaning other conditions that may be a focus of clinical attention.

About 7% of patients were diagnosed with a personality disorder, including cases of axis II comorbidity. It should be noted that in 48 cases there was a deferred diagnosis, typically on axis II, additional to a disorder already diagnosed. About 66% of the patients had more than one clinical disorder, and when including axis IV co-morbidity, this percentage even reaches 98%. On average patients received 2.22 clinical diagnoses plus 1.83 diagnoses on axis IV.

As shown in Table 1, almost all patients presented axis IV problems, and almost half of all patients showed two or more factors. The two most common axis IV factors, each seen in about two-thirds of the patients, were educational problems and problems with a primary support group.

Table 1. Factors on axis IV present in the patient group

Factors on axis IV	Total of patients	Patients (%)	Total of diagnoses	Diagnoses (%)
Any psychosocial and environmental problem	129	92,81	244	
Problems with primary support group	85	61,15	85	33,46
Problems related to the social environment	29	20,86	29	11,42
Educational problems	89	64,03	89	35,04
Occupational problems	17	12,23	17	6,69
Housing problems	6	4,32	6	2,36
Economic problems	13	9,35	13	5,12
Problems related to interaction with the legal system/crime	2	1,44	2	0,79
Other psychosocial and environmental problems	3	2,16	3	1,18
No diagnosis/factor on axis IV	10	7,19	10	3,94

Note. Percentage reflects occurrence of factor/problem in patients of the Youth Mental Health team. Numbers add up to more than 100% due to co-morbidities.

A considerable number of patients, almost 10%, was found to have a low IQ and received the diagnosis of mental retardation or borderline intellectual functioning for the first time.

By June 2015, 116 patients were no longer in treatment. From 93 patients begin and end measures of GAF scores were available. Missing end scores are mostly explained by patients deciding to discontinue treatment, or due to unforeseen factors like for example moving. A paired samples t-test indicated that there was a significant difference between the GAF scores pre- treatment ($M = 54.15$, $SD = 7.22$) and post- treatment ($M = 65.61$, $SD = 10.33$), shown in Table 2. To investigate sex differences a split-plot ANOVA was conducted with pre- and post- GAF scores from males and females. The main effect of time was significant, $F(1, 91) = 6.36$, $MSE = 50.46$, $p < .001$, as was the effect of sex, $F(1, 91) = 7.66$, $MSE = 100.26$, $p = .007$. The interaction of these two factors was not significant, $F(1, 91) = .06$, $MSE = 50.46$, $p = .808$. Females generally showed lower pre- scores (meaning lower levels of functioning) compared to males, but there was a comparable improvement in GAF in both groups.

Table 2. BSI and GAF measurements pre and post treatment

	N	Pre M (SD)	Post M (SD)	p-value
GAF	92	54.15 (7.22)	65.61 (10.33)	.001**
BSI	45	1.01 (.62)	.46 (.45)	.001**

Note. M = mean. SD = standard deviation. GAF = Global Assessment of Functioning.

BSI = Brief Symptom Inventory. * significant at a $p < .01$ level. ** significant at a $p < .001$ level.

The same analysis was carried out on the BSI scores. Because the BSI only applies to patients of 18 years and onwards, both begin and end measures of the BSI were available for 45 patients (see Table 2). Again, the main effect of time was significant, $F(1, 43) = 6.36$, $MSE = .14$, $p < .001$, as was the effect of sex, $F(1, 43) = 6.36$, $MSE = .34$, $p = .015$. The interaction of these two factors was not significant, $F(1, 43) = 2.29$, $MSE = .14$, $p = .138$. This means that pre-treatment, females generally scored higher (meaning worse) compared to males on the BSI, but over time, symptoms improved for both groups.

In short, results show a complex patient population with significant improved functioning post treatment.

Discussion

This study reported on the working method of an innovative specialized YMH team located in the Netherlands and on its patient characteristics, thereby supporting systems transformation.

Working method

The working method of the YMH team demonstrated that, by being able to complete treatment within the same team of professionals and working transdiagnostically, continuity of care was met around the age of 18. The YMH team adhered to a client-centred approach by being flexible to adjust treatment to the complexity and changing needs of this patient group.

The above described complexity fits secondary mental health care, and seems an important follow-up to easy access services, like the integrated youth mental healthcare service Headspace in Australia (Hetrick et al., 2017), or @ease

in the Netherlands (McGorry & Mei, 2018): indeed 40% of Headspace users are too complex and need referral to specialized services.

Patient characteristics

Our findings support the need for a client-centred approach. Main diagnoses in the current study reflect previous research with anxiety, mood and behavioural disorders as most common diagnoses (Rickwood et al., 2014; Merikangas et al., 2010; Costello et al., 2005; Cooper & Sing, 2000; Tohen et al., 2000).

Our findings are in line with other studies of youth (15 to 25 years) where the percentage of patients with co-morbidities range from 60% (versus 66% in the present study), when comorbidity refers to the presence of more than one psychiatric disorder of mental healthcare service users (Pottick et al., 2014), to as much as 98% (as in the present study), when also other psychosocial or environmental problems or needs presented were included (Social Exclusion Unit, Office of the Deputy Prime Minister, 2004). Axis II diagnoses were often deferred. Therefore, our patients might have had more disorders than ascertained at that moment, making it likely that diagnoses remained underreported. This finding stresses the high complexity of mental health in youth and the need to use an array of expertise within a YMH team as well as organisations outside direct mental health care.

The high number of Axis IV factors reported is understandable since this is the age where people usually attend school or study elsewhere. Moreover at this phase of life around puberty, individuals may encounter more relational problems with parents or family. An Australian study (Rickwood et al., 2014) found that a considerable number of patients accessing specialized mental health care, reported relationships (11.4%) or school/work (6%) as main reason for seeking help. The "Breaking the Cycle" report (Social Exclusion Unit, Office of the Deputy Prime Minister, 2004) also lists homelessness, problems regarding education or work, crime, and poor housing as typical problems youth face. It seems likely that psychological problems or disorders are linked to psychosocial and environmental problems where effects and interaction in both directions are probable. Therefore, cooperating with, for example, care services that aim to support youth in daily life is of great value as these services can directly target the two most common axis

IV factors in our study, namely educational problems and problems with a primary support group, each of which are seen in about two-thirds of the patients here.

Our findings show a relatively high percentage of low intellectual capacity, indicating the importance of awareness and screening of intellectual disability. While patients are usually screened for axis I and II disorders, intelligence is only tested after an indication or possibly stagnation of therapy. From previous research, it is well recognised that people with intellectual disability are more likely to suffer from mental health disorders compared to individuals with normal intellectual abilities and that those individuals with dual diagnoses may benefit from adapted treatment approaches (Hodapp et al., 2006).

Treatment effect

To explore the effectiveness of the YMH team, treatment effects were analysed for the whole group of patients as well as for the two sex groups separately. Our results indicate an overall positive and significant improvement of patient symptoms given their BSI score (rated by the patient) and improved functioning, as indicated by higher GAF scores (rated by the clinician) at the end of treatment compared to the beginning. Although the BSI scores are only available for 18 years onwards, it is encouraging that results of the GAF scores are in line with the results of the BSI scores, as GAF was also administered for those patients younger than 18 years. Thus, both patients and professionals experienced improvement after therapy and patients' BSI scores seem to reach a comparable level to the general population (Beurs, 2006). These are excellent results given the complexity of problems and they support the integrated, client-centred approach of the YMH team.

Analysis of the two sex groups separately, does not seem to call for an immediate need for a sex-specific approach. Our patient group consisted of 40% males versus 60% females, which is a common finding in clinical samples (Rickwood et al., 2014; Vessey & Howard, 1993). Our results indicate that males started out with lower clinical scores, reporting less severe self-reported symptoms, than females. An explanation for the gender difference in clinical scores at the start might be that males, although suffering from possibly strong symptoms, are less likely to disclose mental health problems related to social stigma in line with their stereotypical roles. Females are more willing to disclose

distressing information to others (Ward et al., 2007; World Health Organization, 2001) and ask for help. Even though the clinical scores initially differ, males and females show comparable improvement rates according to patients' own ratings and professionals' assessment.

Limitations

Our findings are limited by the lack of a comparison group. Superiority of the YMH team approach could be demonstrated by comparing patients of a specialized YMH team to patients of mental health institutions that do not offer a special service for this group and adhere to standard CAMHS and AMHS procedures. A follow up study measuring long-term effects would be further enlightening. Furthermore, continuity would be necessary not only for treatment but also for diagnostic instruments and outcome measures to ensure quality and effectiveness in youth mental health (Kwan & Rickwood, 2015).

In summary, our description of the working method of the innovative YMH team and the clinical characteristics of its population, support the importance of continuity of care around the critical age of 18 and demonstrates beneficial effects of the described client-centred approach.

Practical recommendations

This paper concludes by offering practical recommendations for YMH psychiatry in practice, based on the study results. Firstly, co-morbidities in patients are common and they and their interaction should be considered including all diagnoses and other areas of concern. This includes special attention for intellectual disability since this has implications for choice of treatment and its effect. Our results suggest that due to co-morbidities, a multidisciplinary and comprehensive approach addressing the multitude and combination of disorders and problems seems more appropriate for youth, than working with separate care paths with specialized teams for different disorders.

Secondly, results suggest that YMH should include particular attention to psychosocial and environmental problems as they are closely linked to each other and call for an integral approach to understand and treat them. This also applies

to educational problems, which are extremely frequent in this group and have far reaching consequences for the individual.

It is important that YMH programs with continuous care around the age of 18 receive more attention and become the standard rather than the exception. Clinical disorders in youth do not respect age- or diagnostic boundaries.

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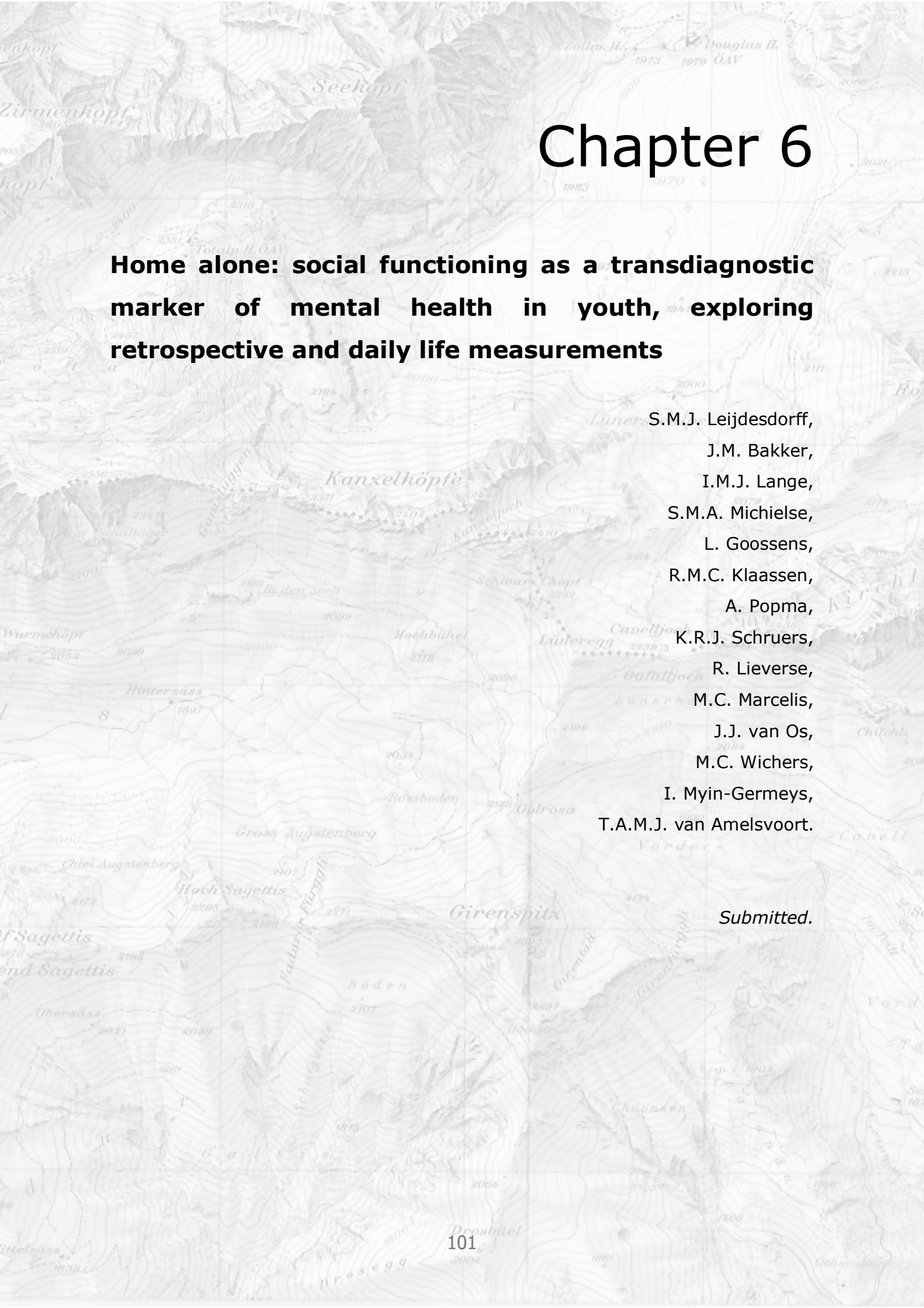
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A detailed topographic map of a mountainous region, likely in the Alps. The map features numerous peaks and valleys, with labels in German such as 'Seekopf', 'Zirmenköpf', 'Kanzelköpfe', 'Girensplatz', and 'Hochbühel'. Contour lines are drawn across the map to indicate elevation. The map is oriented with North at the top.

Chapter 6

Home alone: social functioning as a transdiagnostic marker of mental health in youth, exploring retrospective and daily life measurements

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Submitted.

Abstract

Purpose

Early detection and intervention of mental health problems in youth are topical given that mental disorders often start early in life. Young people with emerging mental disorders however, often present with non-specific, fluctuating symptoms. Recent reports indicate a decline in social functioning (SF) as an early sign of specific emerging mental disorders such as depression or anxiety, making SF a favourable transdiagnostic approach for earlier detection and intervention. Our aim was to investigate the value of SF in relation to transdiagnostic symptoms, and as a predictor of psychopathology over time, while exploring traditional retrospective versus innovative daily diary measurements of SF in youth.

Method

Participants (N=75) were 16-25 years of age and presented early stage psychiatric symptomatology. Psychiatric symptoms, including anxiety and depression, as well as SF -both in retrospect and in daily life- were assessed at two time points and analysed cross-sectionally and longitudinally.

Results

A significant and negative association between SF and all psychiatric symptoms was found, and SF was a significant predictor of change in general psychiatric symptoms over time. Results were only significant when SF was measured traditionally retrospective.

Conclusion

This study confirms a distinct relation between SF and transdiagnostic psychiatric symptoms in youth, even in a (sub)clinical population, and points towards SF as a predictor of transdiagnostic psychiatric symptoms. Further research is needed to learn more about the added value of daily life versus retrospective measurements.

Background

Three out of four mental disorders emerge before the age of 25 (Kessler et al., 2005). Treatment delays of mental disorders at a young age increase the risk of mental, social and vocational problems later in life (Patel et al., 2007; McGorry et al., 2007). Consequently, the mental healthcare sector is increasingly shifting attention to early detection and intervention programmes and hence searching for novel ways to improve identification of individuals who are at risk for developing mental disorders (Kwan & Rickwood, 2015; Campion et al., 2012). Since sub-clinical symptoms are one of the main risk factors for developing a full-blown disorder as defined by the Diagnostic and Statistical Manual of mental disorders (DSM-5, American Psychiatric Association, 2013), studies on early detection of mental disorders often focus on its sub-clinical-symptoms to detect an emerging disorder before its actual onset (Fusar-Poli et al., 2013; Van der Gaag et al., 2012; Campion et al., 2012). In youth, however, several symptoms including, low mood and anxiety often co-occur, sometimes with fluctuating severity (Yung et al., 1996), making it hard to detect a specific mental disorder early, according to current diagnostic criteria.

Therefore, there is a need for transdiagnostic approaches and corresponding outcome measurements, particularly in youth (van Amelsvoort, Klaassen & Van den Heuvel, 2018) to enable early intervention in this population. Social functioning (SF), could be such a transdiagnostic factor (Shah et al., 2020) facilitating working across diagnostic silos. SF is affected in several mental disorders; it has been shown to be impaired in people with established mental disorder and decreased SF is related to more severe psychopathology and worse treatment response (Kupferberg et al., 2016; Bellack et al., 1990). Even in at risk populations, it has been suggested that SF is impaired in people with subclinical psychiatric symptoms, and therefore may be an early sign of the disorder (Grove et al., 2016). Indeed, studies in youth at clinical high risk of psychosis show that their SF is worse compared to healthy controls and at a similar level as those with a first episode of psychosis (Chudleigh et al., 2011) or recurrent psychotic episodes (Addington et al., 2008), with higher risk of developing a psychotic episode in people with poorer social or general functioning (Fusar-Poli et al., 2015; Sullivan et al., 2013). More importantly, the relation between SF and psychiatric symptoms does not seem to be limited to disorder specific symptoms. When mood and anxiety were assessed in a sample

of youth at clinical high risk of psychosis, lower SF was associated with more depressive and social anxiety symptoms (Chudleigh et al., 2011). This relation between SF and transdiagnostic (sub)clinical psychiatric symptoms argues for the potential value of SF for identifying individuals at risk. Therefore, in the context of early-detection tools, focusing on SF instead of diagnosis-specific symptoms may be a useful approach, but more knowledge is needed about SF in relation to transdiagnostic subclinical psychiatric symptoms in youth. In addition, insight in the predictive validity of SF for symptoms change over time would give the opportunity to target specifically those youngsters with the highest risk of developing a mental disorder and thus most in need of early intervention.

Traditionally, SF is defined as the ability to fulfil a societal role, including engagement in vocational as well as social relationships (Bosc, 2000; Hirschfeld et al., 2000) and assessed with retrospective questionnaires, such as the Social Functioning Scale (SFS, Birchwood et al., 1990). However, these assessments have several disadvantages of which the recall bias might be most noteworthy (Last et al., 2001). In addition, when assessing a three-month period retrospectively, recent incidents may influence the overall score disproportionately. These obstacles might be mitigated in daily diary techniques such as the Experience Sampling Method (ESM, Myin-Germeys et al., 2018, Van Os et al., 2017; aan het Rot et al., 2012; Ebner-Priemer & Trull, 2009; Csikszentmihalyi & Larson, 1987). With ESM, it is possible to measure SF in daily life, by for example asking individuals several times a day what they are doing (providing information with regard to the ability to fulfil a societal role) and who they are with (presenting information with regard to engagement in relationships). By providing the possibility to collect multiple measurements over a period of time, and measuring someone's current thoughts and emotions in a real world rather than laboratory environment, ESM gets around some of the common biases of traditional measurements (Myin-Germeys & van Os, 2007). However, ESM has several disadvantages, as participants may experience answering the same questionnaire multiple times burdensome (Chen, 2006) or intrusive, and because of the repeated infiltration in participants daily life, ESM may influence behaviour and thereby study results (Koro-Ljungberg et al., 2008).

Even though both ESM and retrospective questionnaires come with certain (dis-)advantages, how they relate to each other (i.e., the ecological validity of the

SFS) in the context of SF has rarely been investigated. Schneider et al. (2017) were the first to make this comparison, combining SFS and ESM data in non-affective first episode psychosis patients and healthy controls, showing associations between SFS scores and ESM measures in the interpersonal domain in both groups. SFS scores and ESM measures, however, were inconsistent when examining the social activity domain, showing a ceiling effect in SFS scores in the healthy control group, which could signify that the SFS is less suitable for detecting more subtle differences in SF than ESM, which is what would be of interest from an early-detection point of view.

In sum, detection of individuals at risk for developing mental disorders is important for prevention of these disorders and subsequent reduction of both the individual and the societal burden of mental disorders (Campion et al., 2012). The current study aimed to firmer establish SF as a useful early detection marker by cross-sectionally investigating the relation between SF and transdiagnostic psychiatric symptoms in youngsters reporting sub-clinical psychiatric symptoms. In addition, SF as a predictor of symptoms change over time was examined longitudinally, using both retrospective SFS scores as well as daily life assessments with ESM.

We hypothesized higher SF scores in youngsters with fewer psychiatric symptoms and lower SF at baseline to predict an increase of psychiatric symptoms over time. The comparison between SFS scores and the ESM measure with regard to their relation with psychiatric symptoms had an exploratory nature.

Methods

Participants

Data were collected as part of a large randomized controlled trial investigating the effect of a psychological intervention on subclinical psychopathology in emerging adults, not in clinical care [inclusion period: September 2013 - January 2017] (Bakker et al., 2019; Bakker et al., 2017).

All participants were 16-25 years of age and were recruited by advertisements in public places and on social media. In the present study, only those participants were included who had a score of >123 (norm group II general population,

Arrindell & Ettema, 2005) corresponding with above average psychiatric symptomatology using the Symptom Checklist (SCL-90, Derogatis, 1977). The study was approved by the Medical Ethical Committee of Maastricht University Medical Centre (Dutch Trial Register nr.: NTR3808). All participants signed informed consent before the study onset after the procedure had been fully explained to them. For participants under the age of 18, additional consent was given by their parents.

Procedures and measures

Potential participants received information about the study protocol followed by a first screening by phone and two measurement meetings (T1 and T2, see figure 1).

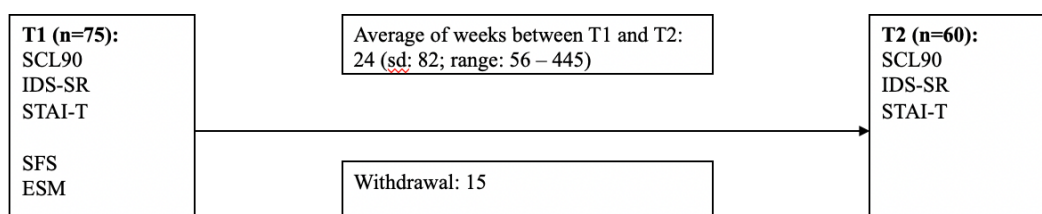


Figure 1. Measurements per measure moment

Average amount of weeks between the two measure moments, with standard deviation and range, and number of participants that dropped out of the study after the first measurement.

Note: SCL-90: Symptom Checklist. IDS-SR: Inventory of Depressive Symptomatology, Self-report. STAI-T: State-Trait Anxiety Inventory, Trait. SFS: Social Functioning Scale. ESM-SF: Experience Sampling Method Social Functioning measure.

Psychiatric symptoms

Anxiety, depressive and general psychiatric symptoms were assessed using, respectively, the State-Trait Anxiety Inventory, Trait (STAI-T, Spielberger, 1983), the Inventory of Depressive Symptomatology, Self-report (IDS-SR, Rush et al., 1996) and the SCL-90. All three measures were assessed both at T1 and T2.

Social functioning

SF was assessed both in retrospect, using the SFS, and prospectively in daily life, using ESM.

SFS. The SFS is a self-report questionnaire, measuring SF over the last three months and in general. The SFS contains 7 subscales, including Withdrawal (waking time, time spend alone), Interpersonal behaviour (having a partner, number of friends, the ability to engage in social conversations) and Pro-social activities (visiting family, museum and attend church activities). Subscales differ in their number of items, ranging from 4 to 22 items per subscale. All raw subscale scores were transformed into scaled scores (Addington & Addington, 1999), and a total SFS score was computed per person by calculating the mean of these standardised subscale scores (Birchwood et al., 1990).

ESM. ESM requires individuals to carry a device (PsyMate, www.psymate.eu) that beeps 10 times a day at semi random moments (within blocks of 90 minutes), inviting them to fill out a short questionnaire on their context, behaviour and mood at that specific moment. Participants were asked to use the PsyMate for 7 to 15 days in a row, depending on the specific protocol of the larger study. The ESM questionnaire contained an item questioning the current location; "Where am I?" (answer categories: at home, at family/friends, at work/school, public place, place for hobby/leisure activities, on the way, somewhere else), and an item addressing social situation; "Whom am I with?" (answer categories: partner, family, household members, out-home family, friends, colleagues/classmates, counsellors, acquaintances, strangers/others, nobody). Reflecting the earlier mentioned definition of SF (Bosc, 2000; Hirschfeld et al., 2000), ESM-SF was based on a combination of these two items, namely; lower levels of going out, defined as reports of being at home (tapping into the ability to fulfil a societal role), together with limited social contact, defined as reports of being alone (tapping into the ability to engage in relationships), resulting into a measure indicating the percentage of beeps participants reported being home-alone.

Statistical analysis

Analyses were done using Stata/SE version 13.1. All models included age, sex and educational level as covariates. Multiple linear regression analyses were performed to, cross-sectionally, investigate the associations between both traditional (SFS) as well as daily life (ESM-SF) measurements of SF and psychiatric symptoms, measured with the IDS-SR, SCL-90 and STAI-T. In order to examine whether change of symptoms over time could be predicted by either

SFS or ESM-SF scores, another set of multiple linear regression analyses was performed using SFS and ESM-SF scores at T1 in interaction with the number of days between T1 and T2 as predictors, and psychiatric symptoms at T2 as the outcome variable, controlling for T1 symptom scores. Results were considered significant at a $p < 0.05$ level. Sensitivity analyses were performed, using t tests and logistic regressions, to examine whether the results were influenced by the specific protocols within the larger study (i.e., different lengths of ESM data collection), and to examine whether characteristics (age, gender, symptoms, etc) differed between participants who dropped out between T1 and T2 versus those who completed the study.

Results

Demographics

A total of 75 youngsters were included (Table 1). 87% of all participants were students, of whom 78% bachelor students (either at university or applied science level), 8% master students, 11% high school students, and 3% was engaged in another form of education.

ESM-SF data of 7 participants were excluded from analyses because they did not fill in a minimum of 33% of all beeps. The average number of days participants used the PsyMate was 14 days (range: 4 - 25 days). The mean compliance rate, meaning the percentage of answered beeps while using the ESM application, was 61.14% (calculated as the percentage of filled in beeps during the days that participants actually used the PsyMate). For 1 participant the SFS score was missing at T1.

Table 1: demographic variables

Measure		N	Mean (sd) / %
Age		75	20.8(.26)
Sex	female	63	84.0%
	male	12	16.0%
Vocational	work	7	9.3%
	study	65	86.7%
	other	3	4.0%
Living situation	alone	10	13.3%
	student housing	32	42.7%
	parents/family	20	26.7%
	partner	13	17.3%
ESM-SF		68	33.2(2.05)
SFS		74	117.5(.61)
SCL-90		75	172.2(4.72)
IDS-SR		75	23.2(1.20)
STAI-T		75	49.0(1.20)

Note: *number and the percentage of participants within this category. Age in years. ESM-SF: the number of participants of whom the home-alone score was calculated (N), the percentage of moments of being at home alone (mean), and the standard deviation (sd). SFS: Social Functioning scale. SCL-90: Symptom Checklist. IDS-SR: Inventory of Depressive Symptomatology, Self-report. STAI-T: State-Trait Anxiety Inventory, Trait. SFS, SCL-90, IDS-SR, STAI-T: scores at baseline.

Social functioning and psychiatric symptoms cross-sectionally

As shown in table 2, were lower SF scores related to more severe depressive, anxiety and general psychiatric symptomatology at T1, measured with the SCL-90, the IDS-SR and the STAI-T. The percentage of explained variance per model varied between 20-24%. Of all covariates, only age showed a significant

contribution to the model when analysing the associations between SFS and STAI-T ($\beta = 1.08, p = .034$) and SFS and SCL-90 scores ($\beta = 4.36, p = .030$). The analyses of psychiatric symptoms and SF in daily life showed no significant relations.

Table 2: Social functioning and psychiatric symptoms at T1

Measure	Beta	p-value
SCL-90		
ESM-SF	.376	.254
SFS	-3.333	<.001**
IDS-SR		
ESM-SF	.105	.218
SFS	-.970	<.001**
STAI-T		
ESM-SF	.066	.427
SFS	-.774	.001**

Note: ESM-SF being the percentage of being at home alone. SFS: Social Functioning scale. SCL-90: Symptom Checklist. IDS-SR: Inventory of Depressive Symptomatology, Self-report. STAI-T: State-Trait Anxiety Inventory, Trait. * indicating significance at a $\alpha < .05$ level. ** indicating significance at a $\alpha < .01$ level.

Social functioning and psychiatric symptoms over time

Change in general psychiatric symptoms between T1 and T2, measured with the SCL-90, was significantly predicted by the SFS score at T1 ($\beta = -.020, p = .047$) (Table 3). Participants with lower SF at T1 show a stronger increase in psychiatric symptoms over time, compared to participants with higher SF at T1 and after correcting for T1 psychiatric symptoms. Furthermore, of all added covariates; age, sex, educational level and psychiatric symptoms at T1, only the last one contributed significantly to the model. This was the case for all three psychiatric questionnaires; the SCL-90 ($\beta = .516, p < .001$), the IDS-RS ($\beta = .419, p < .001$) and the STAI-T ($\beta = .744, p < .001$). The relations between SFS

at T1 and the IDS-SR and STAI-T at T2 however, were not significant, and neither were the associations between ESM-SF at T1 and SCL-90, IDS-SR and STAI-T scores at T2. These models explained 37 – 53% of variance.

Sensitivity analyses

A first sensitivity analysis was done to check whether the results differed between participants who were allocated to different conditions within the larger protocol, and no significant differences were found. A second analysis was done to compare study drop-outs to remainders with no significant differences.

Table 3: Social functioning at T1 and psychiatric symptoms at T2

	beta	p-value
SCL-90 (follow-up)		
ESM-SF x time	.001	.727
SFS x time	-.020	.047*
IDS-SR (follow-up)		
ESM-SF x time	<-.001	.642
SFS x time	-.003	.167
STAI-T (follow-up)		
ESM-SF x time	< -.001	.922
SFS x time	-.002	.539

Note: ESM-SF being the percentage of being at home alone. SFS: Social Functioning scale. SCL-90: Symptom Checklist. IDS-SR: Inventory of Depressive Symptomatology, Self-report. STAI-T: State-Trait Anxiety Inventory, Trait. * indicating significance at a $\alpha < .05$ level. ** indicating significance at a $\alpha < .01$ level.

Discussion

The aim of the current study was to investigate the value of SF in relation to transdiagnostic (sub)clinical symptoms in youth, cross-sectionally and over time, while using both traditional as well as daily life measurements of SF. Cross sectionally, a transdiagnostic relation between SF and psychiatric symptoms was confirmed, showing that poorer SF relates to more severe psychiatric symptoms,

including depressive, anxiety and general psychiatric symptoms in youth, even in a (sub)clinical population. Analysis of the predictive validity of SF showed lower SF at T1 as a predictor of an increase in general psychiatric symptoms over time. These effects were only significant when SF was measured with the traditional SFS.

Above mentioned results partly matched our expectations. First, it was our hypothesis that SF would correlate with psychiatric symptoms both when measured traditionally as well as in daily life, whereas our results only showed significant effects when SF was assessed traditionally, using a retrospective questionnaire. Second, as hypothesized, our results showed poorer SF as predictor of increased general psychiatric symptoms over time, but this effect was not seen for the depressive and anxiety questionnaires' scores.

The value of SF

The cross-sectional association between SF and psychiatric symptoms, as confirmed in the present study, is in line with previous research (Grove et al., 2016; Chudleigh et al., 2011). More interestingly is that, instead of focusing on a specific disease (Schneider et al., 2017), the present study allowed for a broad range of psychiatric symptoms below as well as above the diagnostic thresholds. Thereby, this study endorses the value of SF as transdiagnostic marker of (sub)clinical psychopathology in youth, demonstrating the potential of SF in early detection of mental ill health.

An advantage of SF as early indicator of psychiatric disorders might be that SF is easier assessable than diagnosis-specific symptoms, especially for people in the direct environment of youth. In youth psychiatry, there is a paradox in the need for care versus the use of care: the majority of mental disorders starts early in life (Kessler et al., 2005) but adolescents are least likely to seek help due to age specific barriers such as poor access and financial costs (Hetrick et al., 2017; Rickwood et al., 2007; Vyas et al., 2015). As a consequence, a minority of youngsters experiencing mental health problems actually receives professional help (Slade et al., 2009; De Graaf et al., 2010).

Functional decline has received attention also outside the field of (youth) mental health. Dementia research showed promising results for the assessment of functioning, as problems with activities in daily life are often first noticed by the patient and its environment and, in at risk populations, functional decline can be

a predictor of the progression to the actual disorder (Jutten et al., 2017, Sikkes et al., 2011). Moreover, the importance of SF for mental health is emphasized by the World Health Organization's (WHO) definition of SF: "mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community" (WHO, 2001).

Social functioning and psychiatric symptoms longitudinally

To be able to detect those at risk of developing a mental disorder as early as possible, the predictive validity of SF over time is particularly interesting. Our longitudinal results are promising, showing poorer SF in relation to an increase of psychiatric symptoms over time. Our results did not show a relation between SF and specific depressive and anxiety symptoms, which finding further emphasizes the relation between SF and psychiatric symptoms to be generic rather than disease specific (Chudleigh et al., 2011), which can be seen as an advantage of SF as transdiagnostic factor, especially in a population of young people where several symptoms often co-occur, sometimes with fluctuating severity (Yung et al., 1996). In addition, because of the need for early detection and intervention, the mental health sector tried to learn from other medical fields such as oncology. Following their example, a staging model was developed (Scott & Henry, 2017; McGorry et al., 2007) showing prodromal stages with non-specific symptoms and a disease specific presentation appearing later on in the development of a mental disorder. Even in full blown mental disorders, the clinical presentation can be diffuse including transdiagnostic symptoms, which might advocate for a more dimensional view on psychopathology rather than strict categorical diagnoses (Tan & van Os, 2014). In the light of these theoretical developments, focusing on SF would be a useful addition to diagnosis-based symptoms in assessing disease progression. Concerning our results, it must be stated that the predictive relation between SF and psychiatric symptoms over time must be interpreted with some cautiousness, because the significance level is just below the significance threshold. The possibility of a type 1 error must be considered, in which case the null hypothesis was unfairly rejected. Lowering the alfa level by strictly controlling for multiple testing, on the other hand, would increase the chance of a type 2 error, i.e. not rejecting an untrue hypothesis.

SFS versus ESM-SF

Since we did only find significant results when examining SF traditionally, the ESM-SF measure as transdiagnostic marker of SF can be questioned. In contrast to earlier research examining the relation between the SFS and ESM-SF in a population of non-affective first episode psychosis patients (Schneider et al., 2017), the present study focused on the transdiagnostic role of SF in a (sub)clinical population with a broad range of psychiatric symptoms. Because of the exploratory nature of the comparison between the two SF measures in the current study, no direct conclusions can be drawn, but still, some associations between ESM-SF and psychiatric symptoms might have been expected. A possible explanation for the lack of results using the ESM-SF measure in the present study is that the sample of the present study was quite homogeneous, consisting of mostly female, high educated university students, around the age of 19, with (sub)clinical general psychiatric symptoms. This homogeneity can be stated as a limitation of the present study. Furthermore, almost half of our study population stated to live in student housing, and a quarter lived with their parents or family members, which might lead to a smaller amount of possible time to spend alone, while at home than in non-student populations. In this case, being with other people does not necessarily lead to actual social engagement, while on the other hand, young people might be digitally social engaged while being at home alone. Therefore, in retrospection, the ESM-SF measure, defined as the time spend at home while being alone, might be less suitable for this specific population, whereas the SFS, might be less influenced by the living situation because this is only a minor part of its broad range of items. Another explanation is that we did not use the correct ESM items to tap into social functioning. Future studies could aim to examine the use of other ESM items that tap into impact of social contact on a person, a feeling of connectedness or satisfaction with social contact or being alone. A last explanation for our contradictory results regarding the SFS and ESM measures, may lie in the so-called method effect (Lance, Dawson, Birkelbach & Hoffman, 2010); the choice of measurement methods partly effects the results of a study, with higher correlations between measurements assessed with the same method. This method effect may explain a stronger association between the traditional SFS questionnaire and the psychiatric symptoms questionnaires, than between the ESM-SF measure and the psychiatric symptoms questionnaires in the present

study. Therefore, future research might explore the predictive validity of the ESM-SF measure for psychiatric symptoms that are measured with an ESM measure as well, instead of with a questionnaire. This would create the opportunity to not only compare overall ESM-SF with psychiatric symptoms, but to, in addition, examine the relation between ESM-SF and psychiatric symptoms during all beeps. In such a study design, a next possibility is to investigate whether psychiatric symptoms at a certain measure moment can be predicted by previous assessed levels of SF, using time-lagged analyses, or to examine whether change in social functioning can be an early sign of mental problems emerging.

Conclusion

To conclude, the findings of the present study confirmed our hypothesis regarding a cross-sectional association between SF and depressive, anxiety and general psychiatric symptoms. Furthermore, lower SF predicted an increase in general psychiatric symptoms over time. Thereby, this study demonstrates the value of SF as transdiagnostic marker of (sub)clinical psychopathology in youth. Further research is needed to learn more about the predictive validity of SF and any added value of daily life versus retrospective measurements of SF and psychiatric symptoms, focussing on a broad range of symptoms, in a heterogenous population of young people with the goal of facilitating prevention, early detection and intervention, even outside a clinical context.

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Prevalence of psychopathology in children of parents with mental illness and/or addiction: an up to date narrative review

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Abstract

Purpose of review

Children of parents with a mental illness and/or addiction are at high risk for developing a mental illness themselves. Parental mental illness is highly prevalent leading to a serious number of children at high risk. The aim of this review is to give an up-to-date overview of psychopathology in children of parents with various mental illnesses and/or addiction, based on recent literature.

Recent findings

Worldwide, 15 to 23% of children live with a parent with a mental illness. These children have up to 50% chance of developing a mental illness. Parental anxiety disorder sets children at a more specific risk for developing anxiety disorder themselves, where children of parents with other mental illnesses are at high risk of a large variety of mental illnesses. Although preventive interventions in children of mentally ill parents may decrease the risk of problem development by 40%, currently, these children are not automatically identified and offered help.

Summary

This knowledge should encourage mental health services to address the needs of these children which requires strong collaboration between Child and Adolescent Mental Health Services and Adult Mental Health Services. Directions for further research would be to include both parents, allow for comorbidity and to look deeper into a broader variety of mental illnesses such as autism and personality disorder other than borderline.

Introduction

Three out of four adult mental illnesses arise before the age of 25 (Kessler et al., 2005). The onset of a mental illness before the age of 25 threatens critical age-specific, interpersonal and occupational and educational development. Longer duration of mental illness during adolescence is one of the strongest predictors for persistent adult disorder (Patton et al., 2014). Therefore, prevention, and early detection and intervention is a key solution to avoid enduring problems. Studies of people at increased risk for mental illness have, besides focusing on environmental factors, always been oriented at genetic factors as well (Yung & McGorry, 2007). Children of parents who suffer from a mental illness and/or addiction are, due to both genetic as well as environmental factors, particularly at risk for developing a mental illness themselves. Offspring of parents with a severe mental illness (SMI), mostly defined as schizophrenia, major depressive disorder, bipolar disorder, or severe borderline personality disorder, have a 50% chance of developing any mental illness, and 32% probability of developing a SMI. This is 2,5 times the risk compared to children of parents without mental illnesses (Rasic et al., 2014).

Parental mental illness is highly prevalent; 2.7 million parents (3.8%) in the US had a SMI in the past year and 12.8 million parents (18.2%) with children aged 18 or younger had any mental illness in the past year (Stambaugh et al., 2017). Maybery and Reupert (2005) estimated that there are between 21% and 23% of children living in Australian households where at least one parent has a mental illness, equating to just over a million children. In the Netherlands 577.000 children grow up with a parent with a mental illness and/or addiction. This number is calculated by only combining parental mood disorder, anxiety disorder, ADHD and addiction, therefore this number probably is a gross underestimation (Goossens & Van der Zanden, 2012). In Canada, 15.6% of all children are exposed to parental psychiatric disorders (Bassani et al., 2008). Thus, worldwide, there is a serious number of children at high risk for diverse adverse outcomes, leading to a high service demand and costs in the long-term. A large cohort study in Denmark showed that children of parents with mental illness or addiction are at high risk of a large variety of psychiatric illnesses, but specific illnesses were not concordant in parents and children (Dean et al., 2010). Van Santvoort et al. (2015) conducted a thorough systematic review into the specificity of the relation between parents with depressive disorder, bipolar

disorder, and anxiety disorder and their children's diagnoses showing that parental depressive and bipolar disorder indeed increases the risk for children to develop various mental illnesses, but parental anxiety disorder sets children at a more specific risk for developing anxiety disorders. So far, reviews focusing on a broader variety of mental illnesses in parents and their specific relations to psychopathology in their children are lacking.

Therefore, a comprehensive search of MEDLINE/PubMed and PsycINFO was conducted by February 2017 for articles, meta-analyses and reviews about psychopathology in children of parents with mental illness and/or addiction. Search terms for children were children and offspring. Search terms used for parents with mental illness and/or addiction were parents with mental illness, mental disorder, mental disease, depression, bipolar, schizophrenia, psychosis, anxiety disorder, personality disorder, ADHD, autism, ASD, addiction, substance abuse, impaired parents, high risk. Once an initial pool of articles was obtained, a lateral search was conducted from the reference section of every article.

The aim of this narrative review is to give an up-to-date overview of psychopathology in children of parents with various mental illnesses and/or addiction, based on recent literature.

Schizophrenia

Children of parents with schizophrenia are at increased risk to develop any mental illness compared to a control group of children of parents without mental illnesses (Hameed & Lewis, 2016). Of all mental illnesses, the risk is highest for schizophrenia in these children (Rasic et al., 2014), with a prevalence from 15% to 40% into adulthood (Hameed & Lewis, 2016). Furthermore, children of parents with schizophrenia have an increased risk of developing bipolar disorder or major depressive disorder (Rasic et al., 2014), anxiety disorder (Hameed & Lewis, 2016), ADHD (Reupert et al., 2013a; Sanchez-Gistau et al., 2015), and ASD (Fairthorne et al., 2016). Furthermore, for children with a mother with SMI very poor spelling at the age of 12 may be an elevated indicator of risk for developing a psychotic disorder later in life (Lin et al., 2016).

Major depressive disorder

Depression is one of the most common mental illnesses with a life-time prevalence of 16.6% (Kessler et al., 2005). When one parent is depressed, a

child has a 40% chance of developing depression at the age of 18 and at the age of 25 this percentage rises up to 60% (Beardslee et al., 1993). Offspring of parents with a major depressive disorder are four times more likely to develop an affective disorder (Lavoie & Hodgins, 1994) and twice as likely to develop any mental illness compared to children of parents with no mental illness (Olfson et al., 2003). A meta-analysis of 193 studies showed a variety of internalizing and externalizing problems and general psychopathology (Goodman et al., 2011) in offspring of a parent with a depressive disorder, including substance use and anxiety disorders (Havinga et al., 2017; Hirshfeld-Becker et al., 2012; Lieb et al., 2002), even at 20-year follow-up (Weissman et al., 2006).

Maternal postpartum depressive disorder elevates the risk for anxiety disorder in adolescents. Children whose mother experienced a postpartum depression are also at increased risk for depressive disorder, but only in case of recurrent depressive episodes in their mothers (Halligan et al., 2007). This elevated risk of depression is strongest when the mother experiences at least 17 months of depressive disorder subsequent to the postpartum period before their child is 16 years old (Murray et al., 2011). Also, maternal antenatal depressive disorder is a risk factor for the development of both internalizing and externalizing disorders in children (Stein et al., 2014).

Finally, children of depressed mothers are more likely to have suicidal thoughts or behavior than children of healthy mothers (Klimes-Dougan et al., 1999), with a positive correlation between mother's and child's suicidality.

Bipolar disorder

Children of a parent with bipolar disorder have a serious increased risk 52% of developing any mental illness (Rasic et al., 2014; Lapalme et al., 1997). The risk ratio for children of parents with bipolar disorder is highest for bipolar disorder and increased for developing mania (Axelson et al., 2015), schizophrenia, major depressive disorder (Axelson et al., 2015; Sanchez-Gistau et al., 2015; Rasic et al., 2014), substance use, ADHD (Sanchez-Gistau et al., 2015; Axelson et al., 2015; Reupert et al., 2013a), and anxiety disorder (Axelson et al., 2015).

Borderline Personality disorder

A recent systematic review into offspring of mothers with borderline personality disorder (BPD) shows that these children have an increased risk for

psychopathology, including BPD, depressive disorder, externalizing problems such as aggression or attention problems, and emotional problems (Eyden et al., 2016). Children of parents with BPD are at higher risk of mental health difficulties compared to children of parents with axis I mental illnesses or other personality disorders (Petfield et al., 2015). More severe BPD symptoms in mothers are a predictor of more severe BPD in their children, and co-morbid depressive disorder increases this risk even more (Barnow et al., 2013). A study into female adolescent inpatients showed that high levels of depression and psychosocial stress in fathers was associated with BPD in their daughters (Infurna et al., 2016).

Addiction

In general, consistently higher and clinically significant internalizing and externalizing problems are seen in children of parents with addiction. These children are at increased risk of addiction, depressive disorder, and post-traumatic stress disorder (PTSD) themselves (Staton-Tindall et al., 2013). Also, mothers with addiction are more than twice as likely to have a child with ASD than mothers without addiction (Fairthorne et al., 2016).

With respect to alcohol, Rossow et al. (2016) conducted a thorough systematic review to address adverse child outcomes of parental alcohol abuse. Two thirds of their large quantity of articles from 1980 until 2013 have adolescent drinking as outcome measure, and another outcome measure than substance abuse is rare. Parental alcohol abuse increases the risk of developing alcoholism in children, but study results are contradictory on whether there is a specific risk for either paternal or maternal alcohol abuse.

Parental alcoholism is shown to be a risk factor for co-morbid alcoholism, depression, and antisocial personality disorder in a study into opioid addicts (mean age 27 years old). Furthermore, the alcohol abuse problems were more severe among opioid addicts with parental alcoholism compared to opioid addicts without parental alcoholism (Kosten et al., 1985).

Concerning cannabis misuse, adolescents with parents with cannabis use disorder (CUD) have an increased risk of developing CUD, especially in daughters of mothers with CUD. Parental hard drug use disorder and antisocial personality disorder are also risk factors for onset of CUD in adolescents (Kosty et al., 2015).

School-aged children of opiate- and/or cocaine-addicted mothers have high rates of any psychiatric disorder (60%), major depressive disorder (20%), oppositional defiant disorder (ODD) (18%), conduct disorder (17%), ADHD (13%), and substance abuse (5%) (Weissman et al., 1999). Comparing offspring gender, male offspring is at higher risk of developing ADHD where female offspring had a higher risk of developing depressive disorder (idem). Children of parents with opioid or methamphetamine addiction are at higher risk for ADHD, major depressive disorder, and anxiety disorder (Parvaresh et al., 2015).

Anxiety disorders

Children with a parent with anxiety disorder have a two-fold risk of developing anxiety disorder themselves (Reupert et al., 2013b). Parental panic disorder is a predictor for the development of multiple anxiety disorders including panic disorder, agoraphobia, social phobia and obsessive-compulsive disorder (OCD) in their children. When parents suffer from both panic disorder and depressive disorder, their children are at an increased risk of developing specific phobia and major depressive disorder (Hirshfeld-Becker et al., 2012). Offspring of parents with OCD have an increased risk of developing ASD (Meier et al., 2015). Compared to children of parents with mood disorders, children of parents with an anxiety disorder are at a more specific risk to develop anxiety disorders themselves (Van Santvoort et al., 2015).

Apart from parental diagnosis, parental early onset, having two affected parents instead of one, female gender (Havenga et al., 2017), chronic and recurrent parental mental illness, and comorbidity are factors that increase the risk for depressive and anxiety disorder in offspring (Hosman et al., 2009).

ADHD

ADHD is a highly heritable disorder (Faraone et al., 2005). Up to 43% of children with a parent with ADHD develop ADHD themselves and they are also at higher risk of developing psychopathology in general compared to children of parents without ADHD (Minde et al., 2003). Parents with ADHD are often suffering from comorbid mental illnesses, especially anxiety disorders (idem), which increases the risk for psychopathology in their children even more. ADHD in children is most persistent over time when their mother is diagnosed (Breau et al., 2017). A remarkable finding is that within the group of children with a parent with

ADHD, there is no significant difference between the risk factor in children of parents with remitted versus persistent ADHD. Being exposed to a parent with ADHD however, increases the risk of family conflicts and lesser levels of family cohesion (Biederman et al., 2002).

Autism

Children of parents diagnosed with ASD are at an increased risk of developing ASD. Twin studies show a concordance for ASD of 92% in monozygotic pairs versus 10% in dizygotic pairs (Baily et al., 1995), pointing out a strong genetic component. The risk of developing ASD is nine-folded compared to children of parents with another mental illness like OCD (Meier et al., 2015).

Conclusion and discussion

Children of parents with a mental illness and/or addiction are at high risk of developing a mental illness (Rasic et al., 2014). Parental anxiety disorder sets children at a more specific risk for developing anxiety disorder themselves, where children of parents with other mental illnesses are at high risk of a large variety of mental illnesses. Because of the high prevalence of parental mental illnesses (Stambaugh et al., 2017) there is a large number of children at high risk. Currently, these children are not automatically identified and offered help. Preventive interventions in children of mentally ill parents decreased the risk of problem development by 40% (Siegenthaler et al., 2012). This knowledge should encourage Adult Mental Health Services to commit itself to not only focus on the mentally ill adult, but to also address parenting skills and their children's wellbeing. Furthermore, it should encourage Child and Adolescent Mental Health Services to be alert for parental mental illness, which requires strong collaboration between Child and Adolescent Mental Health Services and Adult Mental Health Services which is currently often insufficient (Maziade, 2017; Hovish et al., 2012; Singh et al., 2008; Leverton, 2003). Pfeifferberger et al. (Pfeifferberger et al., 2016) conducted a study to investigate how mental health services addressed child well-being in New Zealand. Their results showed that in less than half of the records of parents with a mental illness there was information about their children, and only in 6% there was a specific plan for action. To improve services for children of mentally ill parents, since 2010 Norway altered their health legislation into making it mandatory to assess

whether mentally ill patients have children. In the first three years since this alteration, significantly more children were identified as being at risk, but follow-up in terms of support for these children did not significantly increase (Lauritzen et al., 2014).

Identification of children at risk for developing mental illness is the first step. To decrease the risk of problem development, different types of interventions are developed, mostly focusing on informing the children about their parent's illness and supporting both children and parents (Van Santvoort et al., 2014; Reupert et al., 2013b; Siegenthaler et al., 2012). In addition to these interventions, children of parents with mental illness ask for recognition, information about their parent's disease, and to be part of decisions made about their family (Bilsborrow, 2015).

Some limitations in research into children of parents with mental illness and/or addiction, as described by Leverton in 2003 (Leverton, 2003), still exists.

Research often focuses on both parents or mothers, and less often on the role of the fathers (Van Santvoort et al., 2015). Most studies are based on persons with a single diagnosis, whereas in real life there is often more than one disorder (comorbidity) and diagnoses are not always clear or they change over time. Furthermore, a paucity of literature into mental illnesses other than affective disorder, anxiety disorder, psychosis, or BPD remained.

Key points

1. Children of parents who suffer from a mental illness and/or addiction are at high risk for developing a mental illness themselves.
2. Parental mental illness is highly prevalent leading to a serious number of children at high risk.
3. Parental anxiety disorder sets children at a more specific risk for developing anxiety disorder themselves, where children of parents with other mental illnesses are at high risk of a large variety of mental illnesses.
4. This knowledge should encourage mental health services to address the needs of these children which requires strong collaboration between Child and Adolescent Mental Health Services and Adult Mental Health Services.
5. Directions for further research would be to include both parents, allow for comorbidity and to look deeper into other mental illnesses such as autism and personality disorder other than borderline.

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Chapter 8

General discussion

Purpose of this dissertation

The overall aim of this dissertation was to explore novel ways to enhance mental health of young people by investigating service accessibility, service reform and early detection of mental health problems. Similar to other countries, the Netherlands shows a gap between the number of young people with mental health problems and those who receive appropriate care (Hendrickx et al., 2020; De Graaf et al., 2010). The gap between Child and Adolescent Mental Healthcare (CAMHS) and Adult Mental Healthcare (AMHS) forms one of the major barriers for continuity of care around the age of 18. Furthermore, complex and fluctuating symptoms of mental health problems in youth make it sometimes hard to diagnose a specific mental disorder, while a diagnosis is traditionally required to receive treatment. As a response, and in the footsteps of initiatives abroad, Dutch youth walk-in centres were developed to bridge this gap. Enabled by an innovation grant in 2016, a model tailor-made to the Dutch situation was developed in 2017, resulting in multiple @ease walk-in centres since 2018. These centres are youth-friendly and easily accessible, allowing young people aged 12 to 25 to discuss their mental health as well as physical, sexual, financial, vocational and social problems. Relatively new was the involvement of peer volunteers in these centres. In addition to these walk-in centres, a specialised Youth Mental Health team was established within a large mental healthcare facility, aiming at bridging the gap between CAMHS and AMHS, and working transdiagnostically.

To improve youth mental health, a better apprehension of these innovative youth mental health services was needed, as well as the characteristics of the young people visiting these services, their associated burden and up-to-date knowledge about barriers and facilitators on their pathways to care. In addition, to enhance prevention and early detection, identification of individuals at increased risk and daily life markers of mental health problems were investigated.

Main findings and conclusions

Conclusions that can be drawn from this dissertation, regarding the main research themes were as follows.

1. Barriers and facilitators

As described in chapter 2, a first barrier to mental health care was formed by negative attitudes towards mental health problems. Remarkable was the assumption that mental health problems develop with an older age: a strong contrast to the abundance of evidence advocating for mental health problems as (chronic) disorders of young people (Insel, 2009). This leads to late recognition and acceptance of mental health problems amongst young people. As a result, young people seek help only when problems begin to escalate. Obvious suggestions for improvement involve increasing awareness of youth mental health problems and clear information about possible treatment options. When investing in awareness around mental disorders, our findings stress the importance to particularly emphasise their existence in youth. Ways to increase awareness are through school curricula and by governmental campaigns including young influencers opening up about their mental health problems and challenges. Informative examples are the Irish Social, Personal and Health Education course (Gabhainn et al., 2010), the Heads Together foundation, directed by the British princes Harry and William, aimed at tackling stigma around mental health problems (www.headstogether.org.uk) and 'Stichting Durf Te Vragen' by professional YouTuber Dylan Haegens (www.stichtingdtv.nl). Young people should be involved in the development of these programs to make sure that their message will reach the target group. A second remarkable barrier to receiving care can be summarised as care related costs. Given the well-organised healthcare system in the Netherlands, costs itself did not form the major barrier, but young people felt worried and uncertain concerning these costs: they were frightened to develop debts. This anxiety prevented them from seeking help. A facilitating role could be played by healthcare insurance companies, making information more youth-friendly and easier accessible. Last, an extension of walk-in options would facilitate entrance to care as these were experienced as being easily accessible. Introducing walk-in options might benefit both young people and (mental) healthcare providers as no-show rates and waiting lists significantly threaten the efficiency of the organisation of healthcare (Edbrooke-Childs & Deighton, 2020; Van Dieren et al., 2013). Walk-in options may be a starting point to bridge the gap between waiting lists and no-shows.

2. Easy access walk-in youth centres

From the start of @ease, scientific research and innovative practice were intertwined, resulting in a successful development of the @ease centres and valuable information guiding further improvement of youth mental health services, both within and outside of the Netherlands. One of the missions of @ease was to increase resilience and consequently the chance of a positive development of young people, aged 12 to 25 (chapter 3). This mission translated into the working method of the @ease centres, where volunteers, including experts by experience, provided peer-to-peer counselling, anonymous and free of charge. All volunteers were trained in listening, motivational interviewing, solution focused strategies and suicide prevention. A diverse group of health care professionals supervised the volunteers. This group of professionals continuously invested in building bridges within the @ease regional contexts, enabling to offer the support needed to continue daily activities and intervention only when necessary.

Our data showed that mental health problems in youth consulting @ease had a considerable impact on their quality of life and an economic impact on society, yet almost 75% did not receive any care. One third reported having a parent with a mental disorder (COPMI, chapter 7), resulting in an increased chance to develop mental health problems themselves. Therefore, they form an important group for preventive interventions but are often not identified and offered help. @ease at least partly matched their needs. In addition to peer-to-peer counselling, COPMI groups were organised at @ease, offered by prevention professionals from a local mental healthcare organisation. Further research is essential to enhance identification, prevention and early interventions for this vulnerable group.

In general, visitors were satisfied to very satisfied with services provided by @ease. Our results show the necessity and feasibility of @ease as a youth-driven, professionally supported organisation and argue for a broader implementation of such initiatives. Important in this process of scaling up is to keep the balance between model fidelity and continuously matching young persons' needs. The development of the first @ease centres was based on scientific research and wishes of Dutch stakeholders such as young people, (mental) health care professionals, national and local authorities. Mission, working method and safety were carefully worked out. A next challenge will be

the combination of making use of this existing knowledge (top-down) without ignoring the needs of the young people and the offer of existing services at each particular new setting (bottom-up).

3. Adjusting existing mental health services to young persons' needs

Knowledge about accessibility and youth-friendly care is not only relevant for innovative initiatives, but also transferrable into traditional mental health services. After entering the healthcare system, not all young people receive appropriate care (chapter 2). Several changes of therapists or prematurely stopped treatments threaten the continuity of care whilst this is essential for youth. Recognising the importance of the continuity of care around the age of 18, a Youth Mental Health (YMH) team was introduced within a large Dutch mental healthcare organisation (chapter 5). Treatments were performed by a multidisciplinary team of professionals from both CAMHS and AMHS to ensure a client-centred approach and continuity of care for this patient group with a high diversity and complexity of problems. Key elements were working transcending diagnoses, flexibility and collaboration with other care providers. As a result, continuity of care was met when patients turned 18 and treatments were successfully performed. These results argue for a broader implementation of YMH-teams, aiming at a better match between traditional mental health services and the needs of their young patients. To do so, mental health services have to overcome ideological, structural, functional, cultural, financial and organisational differences between CAMHS and AMHS (Tuomainen et al., 2018; McLaren et al., 2013; Singh, 2009). Specifically, organisations should facilitate professionals who are used to working in separate specialised teams, to work together multidisciplinary in YMH-teams. In addition, mental health services have to start invoicing healthcare insurance companies instead of municipalities when patients turn 18. It takes extra effort for these services to organise this shift behind the scenes, but an increasing amount of Dutch mental healthcare organisations are succeeding which is promising.

4. Early detection

It could be questioned whether early detection is the responsibility of the mental healthcare sector alone. Markers of daily life functioning could facilitate parents, teachers or GP's to examine the mental health of young people outside the

clinical context. One third of young people aged 10-18 years old, experienced high performance pressure and asked for an elevated attention for personal development instead of focusing on school performances (Trimbos-Instituut, 2020). The intention to lower daily life pressure and increase resilience in youth, resonates as one of the four main goals of the National Healthcare Policy (Ministry of Health, Welfare and Sport, 2020). This policy argues for cooperation across domains to answer complex needs and prevent burden of disease. It also argues for extra attention for vulnerable groups such as COPMI, to maximise the beneficial effects of preventive and early interventions. An example of such an intervention is the STORM program (www.stormaanpak.nl, Gijzen et al., 2018), in which a youth-centred framework including schools and a diversity of health care professionals cooperate to increase resilience and prevent suicide amongst young people.

Social functioning could be a marker enhancing early detection of mental health problems, outside the clinical context. Chapter 3 shows an impaired social functioning in youth visiting @ease and the study in chapter 6 confirmed a distinct relation between social functioning and transdiagnostic psychiatric symptoms in youth, even in a (sub)clinical population. This relation is interesting as a characteristic of youth is that symptoms often fluctuate in severity, sometimes at a subthreshold level (Jones, 2013; Kessler et al., 2007; Yung et al., 1996). This poses a challenge in diagnosing a specific mental disorder, thereby preventing early intervention. Transdiagnostic markers such as social functioning would present the opportunity to assess the burden of mental health problems independently from specific psychiatric symptoms or disorders.

Therefore, a broader apprehension of the predictive value of social functioning and the added value of daily life versus retrospective measurements is required. In addition, in the light of early detection and intervention, the group of children of parents with a mental disorder pre-eminently deserves extra attention (chapter 7). Due to the high prevalence of mental disorders, the COPMI group encompasses a serious number of young people worldwide at increased risk for developing a mental disorder. Although preventive interventions in children of mentally ill parents may decrease the risk of problem development by 40% (Siegenthaler et al., 2012); currently, these children are not automatically identified and offered help. One of the reasons might be an often insufficient collaboration between CAMHS and AMHS (Leverton, 2003; Hovish et al., 2012;

Singh et al., 2008; Maziade, 2017). Another explanation is that adult mental health professionals do not want to risk the therapeutic relationship with their patients by questioning the mental health of their children, and thereby their parenting skills, or that they simply do not have enough time. A positive development is the establishment of the Child check in the Netherlands (Augeo, 2014; Staatsblad, 2013); a tool obliged for professionals working with adult patients, assessing whether a patient has children and if they are safe. However, the Child check directs towards further steps only in cases of serious risk of harm for the children. Thereby, the Child check is a good start to raise awareness for COPMI, but again forms a situation in which help is only offered when problems escalate. To improve early detection, all professionals working with adult patients should be motivated to provide their patients' children with some information about their parents' disorders. In addition, these children should know that they are not alone in their situation and where help could be found if needed. Further research should investigate the needs and wishes of young people in the COPMI group to better reach these individuals at risk for developing mental health problems.

Future research

This dissertation emphasises the need for innovative youth mental health initiatives aiming at improving access to care. It also shows the feasibility of accessible youth mental health services in practice. Discussing these results, it remains challenging to investigate the effectiveness of those initiatives in terms of increased wellbeing and the amount of prevented burden of disease. Effectiveness is often studied by randomised controlled trials, assigning part of the study population to a control, placebo or waiting group. Aiming at improving access, assigning half of the group of young people seeking help to a waiting condition, would have the opposite effect. The decreased quality of life, (partial) school dropout (chapter 4), impaired social functioning, psychosocial distress and suicidality (chapter 3) in our study population, further argue against such an approach. Further research should, therefore, focus on novel study designs to explore the effectiveness without denying participants access. At @ease, follow-up data is being collected at all visits, as well as at 3, 6 and 12 months following the last visit. To study effectiveness, it would be interesting to compare this follow-up data to mental health and well-being data from the general population

and/or patient groups. Another possibility is to use a stepped method while implementing new youth mental health services in different cities. The time difference between the establishment of individual centres can be used to already start including young people who are interested in the service, and compare their data to data collected at sites with fully operational centres. This way, sites that are in the preparation phase can serve as a control group to the data gathered amongst service users. Still, it remains challenging to attribute any differences between those groups completely to the effectiveness of the service. There might be other contextual factors that play a role at each individual site as well.

Most designs in mental health research are aimed at minimising noise, intending to produce a pure look at the research object. This approach fits the natural sciences, working from a paradigm of realism; the truth exists independently from the viewer, who tries to unveil it. We should however value other scientific paradigms as well. As noise is an inevitable part of life, we should search for ways to embrace instead of fight it. Studying mental health from a paradigm of social constructivism, research outcomes can be seen as a result of interaction between the study object and the observer. Collecting data, in the form of interviewing participants, or letting them fill in questionnaires about their wellbeing, might be perceived as some sort of intervention on its own. It is unknown whether the interest in our participants' wellbeing changed their state of mind. It can therefore be argued that mental health research should shift a bit from the natural sciences towards the social sciences and benefit from their study designs.

Regarding methodology, qualitative research designs, in which experiences and motives are studied, form a valuable addition to quantitative research designs. Quantitative research can be perceived as a flight with an airplane, looking at research objects from a distance, searching for patterns. In this analogy, qualitative research adds beautifully to this overview by being on the ground, feeling the temperature, smelling the scents and tasting the local cuisine. At a prudent pace, these designs are more and more combined in the field of mental health which can be seen as a great asset.

Returning to the discussion about measuring effectiveness of youth mental health services leads to not only the question how to analyse this effectiveness, but also how effectiveness is defined. From a health care perspective, it is

natural to investigate measures of psychopathology. However, it might be the case that other measurements better answer our questions. It would be interesting to focus more on social functioning, as it provides insight in the impact of mental health problems at important areas of life. Following the positive health movement (Huber et al., 2011), health is not the absence of disease, but the ability to adapt and self-manage. It would be particularly interesting to investigate a self-management intervention in the COPMI group, aiming at decreasing their risk for mental disorders and better matching their needs. Qualitative research could provide a better understanding of key features of such interventions to match the needs of young people in the COPMI group. Seeing service users as experts on their own lives, their satisfaction with the service provides considerable information as well as the extent to which their goals were reached. An interesting example is MyLifeTracker, a brief mental health outcome measure designed for young people, targeting areas of general well-being, day-to-day activities, relationships with friends, relationships with family and general coping (Kwan et al., 2018). Further research is needed to define better outcome measures for youth mental health services, including measuring the impact of mental health problems in daily life.

Future practice

These results of this dissertation argue for a broader implementation of easily accessible youth mental health services, in and outside the clinical context. Besides, governmental bodies should invest in mental health awareness amongst young people and clear information about treatment options. Healthcare insurers could play a facilitating role by making information about care related costs more youth-friendly and easier accessible. Mental and other healthcare organisations should invest in informal settings with walk-in options, personalised care, working transdiagnostically and meeting continuity of care over the age of 18. Future development of the Dutch youth mental health services could concentrate on being even more easily accessible by offering further online possibilities. @ease provides an online chat possibility, similar to other services such as JouwGGD by the Dutch public health organisation (www.jouwggd.nl) and the MindYoung online platform (www.mindyoung.nl) all particularly developed for, and with help from, young people. Promising is the development of @ease Online (www.facebook.com/ENYOY-112612060581152); an online platform offering

eHealth to improve resilience, based on eHeadspace (www.headspace.org.au/eheadspace). In particular, focus should be on reaching more young people under the age of 18, children of parents with mental disorders and people with lower intellectual capacities as people with intellectual disability are more likely to suffer from mental health disorders compared to individuals with normal intellectual abilities (Hodapp et al., 2006). Last, there are a variety of mental health initiatives, especially online, sometimes overwhelming young people and making it hard to find appropriate help. It remains a challenge to cooperate with other initiatives, to bridge gaps instead of creating more confusion.

Strengths and limitations

The interconnectedness of scientific research and innovative practice can be considered a strength of this dissertation. Our research received continuous input from its end-users, and the scientific data provided a constant feedback loop for the service development of @ease. Furthermore, gathering data for research projects can be challenging, especially in a target group of young people with mental health problems outside the context of mental healthcare. The set-up of our project enabled investigation of this unknown group of young people, their wellbeing, experiences, needs and wishes. In addition, this project brought together a variety of stakeholders in the field of youth mental healthcare, including young people, mental health care professionals from both CAMHS and AMHS, schools and municipalities. Moreover, a large group of skilled, experienced and highly motivated (young) volunteers empowered this project. Social functioning showed to be a promising early detection marker for mental health problems in youth, even with transdiagnostic (sub)clinical symptoms. A strength was the use of a daily life measurement, although the use of this method and the predictive value of social functioning should be further studied. It can be considered a limitation that people surrounding the young people such as teachers, parents and close friends were not involved in this research. Further research including these groups could provide helpful information for early detection of problems and to further increase resilience by using the social safety nets of young people. Another limitation can be seen in the fact that a large proportion of the total population visiting @ease were students at universities (of applied sciences). Therefore, it can be argued that not all vulnerable groups have

been reached yet. Future development of youth mental health services could focus on reaching a larger amount of young people within these vulnerable groups. As described above, further research should investigate the effectiveness and long term-effects of youth mental health initiatives such as @ease. Computing the burden of disease of mental health problems amongst young people can be seen as a strength of this dissertation. However, our calculation was limited to current quality of life and costs of illness. Further research could investigate the long-term burden of mental health problems on an individual as well as societal level. Thereafter, possible long-term reduction in societal costs and individual burden could be calculated.

Conclusion

To conclude, this dissertation shows the necessity of easier accessible youth mental health services as the burden of mental health problems amongst young people is high and numerous barriers prevent them from receiving the care they require. Even when they are in the healthcare system, care is not always appropriate. In addition to the necessity, this dissertation showed the feasibility of easier accessible youth-friendly mental health services in the Netherlands, within and outside of traditional mental health facilities. Therefore, the growing attention for, and development of, innovative youth mental health services can be considered both encouraging as well as crucial. The results of this dissertation argue for a broader implementation of accessible mental health services for young people, bridging organisational gaps and the involvement of young people as experts on their own lives; aiming at better understanding and matching their needs.

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A detailed topographic map of a mountainous region, likely in the Swiss Alps. The map features numerous peaks and valleys, with labels in German and Italian. Key peaks include Zirmenkopf (2805m), Felsenkopf (2835m), Seekopf (2698m), Kanzelköpfe (2402m), and Girenspitz (2303m). The map also shows various valleys and passes, such as the Tödlalpe and the Gross Augstenberg. The map is overlaid with a grid of latitude and longitude lines.

Addendum

Summary

Samenvatting

Impact paragraph

Curriculum vitae & list of publications

Dankwoord

SUMMARY

The starting point of this dissertation was the need for early detection and intervention of mental health problems amongst young people. The main theme of this PhD project has been accessibility of care for youth, in order to improve their wellbeing and social functioning.

The majority of mental disorders starts early in life, threatening critical emotional, cognitive and social development. However, amongst young people, there is a gap between need for care and use of care. In other words, the people who need it most, are least likely to receive appropriate care. This discrepancy emphasised the need for improved access to care for young people (**chapter 1**). As a response, worldwide, youth mental health initiatives emerged to match young persons' needs. In 2018, @ease walk-in centres were founded in the Netherlands. These centres are youth-friendly and easily accessible, allowing youth aged 12 to 25 to discuss their mental health as well as physical, sexual, financial, vocational and social problems.

To improve youth mental health, a deeper understanding of these innovative youth mental health services and the young people visiting these services was needed. Who are they? How are they doing, now and over time? What brings them to seek help or withholds them from it when needed? And how can we facilitate them in receiving appropriate help if needed? These questions led to an exploration of ways to enhance mental health, wellbeing and productivity of young people by investigating service accessibility, service reform and early detection in youth mental health.

Barriers and facilitators

The first step was to gain in-depth and up-to-date insight in the perceived barriers and facilitators by young people aged 12 to 25 years old in the process of access to care. **Chapter 2** shows that negative attitudes towards mental health problems lead to late recognition and acceptance of mental health problems amongst young people, making them seek help only when problems begin to escalate. Suggestions for improvement involve an increase in awareness of youth mental health problems and clear information about possible treatment options. When investing in awareness around mental disorders, our findings

stress the importance to particularly accentuate their existence in a person's younger years. A facilitating role could be played by healthcare insurers by making information about care related costs more youth-friendly and easier accessible. Other facilitators for entrance to care are: an extension of walk-in options and informing people on the length of waiting lists and alternative options. Informal settings with personalised care and a maximum amount of therapists would facilitate access to appropriate care after entering the system. On the one hand, our study results can be seen as a validation of the shared approach in improving youth mental health services worldwide. On the other hand, they show that further innovation in youth mental healthcare is still very topical in realising easily accessible care.

@ease walk-in youth centres

A next step was to gain a better understanding of key elements of the @ease walk-in youth centres, its visitors and the burden of their mental health problems. **Chapter 3** shows both the necessity and the feasibility of @ease as a youth driven, professionally supported organisation in the Netherlands.

Volunteers, including experts by experience, are supervised by a diverse group of healthcare professionals and provide peer-to-peer counselling. All staff is trained in listening, motivational interviewing, solution focused strategies and suicide prevention. **Chapter 4** demonstrates that mental health problems in youth consulting @ease have a considerable impact on their quality of life when compared to the general population of Dutch young people. In addition, their problems have an economic impact on society, yet almost 75% is not receiving the required care. One third of @ease visitors falls within the increased risk group of children of parents with mental disorders (COPMI). A lack of interventions during this critical period in life may have major lifelong consequences. This knowledge about the burden of (sub-threshold) mental health problems in the critical group of young people who are in need for help, especially those without any form of professional care, underlines the importance of the problem. This should stimulate putting easily accessible youth mental health care high on policy and research agendas.

Adjusting existing mental health services to young persons' needs

Even after entering the mental health care system, young people do not always

receive appropriate help. Therefore, solely improving accessibility is not enough; existing mental health care should better match young persons' needs as well. Accordingly, a specialised Youth Mental Health (YMH) team, presented in **chapter 5**, was set up within a large mental health care institution, providing Youth Mental Health Care by a team consisting of professionals from both Child and Adolescent as well as Adult Mental Healthcare services. The YMH-team incorporated suggestions of earlier research into a client-centred treatment. Key elements were multidisciplinary meetings, working transcending diagnoses, flexibility and collaboration with other care providers. The group of emerging adults accessing the YMH-team showed a high diversity and complexity of disorders and problems. Using a client-centred approach, continuity of care was met when patients turned 18, allowing treatments to be successfully performed by the same team of professionals.

Early detection

In addition to youth-friendly and accessible mental health care, detection of individuals at risk for developing mental disorders is important to prevent these disorders and their associated individual and societal burden. Social functioning was recently reported as a possible early transdiagnostic marker for emerging mental disorders. Transdiagnostic markers would give the opportunity to assess the severity of mental health problems independently from specific psychiatric symptoms or disorders, also outside the clinical context. To be able to study social functioning in daily life, the Experience Sampling Method (ESM) was used in addition to a traditional retrospective measurement. As described in **chapter 6**, a distinct relation between social functioning and psychiatric symptoms was confirmed, even in a (sub)clinical population of young people with transdiagnostic symptoms. There was a trend towards social functioning as a predictor of change in these psychiatric symptoms over time. Further research is needed to learn more about the predictive value of social functioning and the added value of daily life versus retrospective measurements.

When discussing early detection and individuals at risk for emerging mental disorders, young people with parents with mental disorders deserve special attention (**chapter 7**). Because of both genetic as well as environmental factors, this group is considered particularly at risk for developing a mental disorder themselves. Worldwide, 15–23% of children live with a parent with a mental

disorder. These children have up to 50% chance of developing a mental disorder. Although preventive interventions in children of parents with mental disorders may decrease the risk of problem development by 40%; currently, these children are not automatically identified and offered help. This knowledge should encourage mental health services to address the needs of these children which requires strong collaboration between Child and Adolescent Mental Health Services and Adult Mental Health Services.

Chapter 8 forms the General Discussion of this dissertation. In sum, the feasibility as well as necessity of innovative youth-friendly initiatives was shown, within and outside the context of traditional mental health services. Yet, distinct barriers to care still exist, leading to a high burden of mental health problems in the group of young people seeking help, even when this help is meant to be easily accessible for them.

Regarding our main findings, two major directions for further research stand out. First, it remains challenging to investigate the effectiveness of innovative youth mental health initiatives in terms of increased wellbeing and the amount of prevented societal burden. Effectiveness is often studied with randomised controlled designs, assigning part of the study population to a waiting or control group. Aiming at improving access, however, assigning half of the group of young people seeking help to a waiting condition would create the opposite effect. Further research could focus on novel study designs to explore the effectiveness without denying participants access. Secondly, due to the high prevalence of mental disorders, a serious number of young people worldwide has parents with mental disorders. In spite of the development of effective preventive interventions, only a minor part of these young people receives any form of prevention. In the light of early detection, further research should investigate the needs of this group to better match these needs as they are at increased risk for developing mental health problems.

To conclude, this dissertation shows the necessity of easier accessible youth mental health services as the burden of mental health problems amongst the youth is high, and numerous barriers prevent them from receiving the care they need. In addition to the necessity, this dissertation shows the feasibility of easier accessible youth-friendly mental health services in the Netherlands, within and

outside of traditional mental health facilities. The results of this dissertation argue for a broader implementation of accessible mental health services for young people, involvement of young people as experts on their own lives; aiming at a better understanding and matching their needs.

SAMENVATTING

Ain't no mountain high enough: hoe kan het zorgaanbod beter aansluiten bij jongeren met psychische problemen?

Het merendeel van de psychiatrische stoornissen ontstaat vroeg in het leven, voor de leeftijd van 25 jaar, en vormt daardoor een risico voor de emotionele, cognitieve en sociale ontwikkeling. Juist onder jongeren bestaat er echter een kloof tussen zorgbehoefte en de zorg die zij daadwerkelijk ontvangen. In andere woorden: zij die het het meest nodig hebben, hebben de minste kans op adequate hulp. Deze discrepantie benadrukt het belang van laagdrempelige hulp voor jongeren (**hoofdstuk 1**). Wereldwijd ontstonden de afgelopen jaren verschillende *youth mental health* initiatieven, met als doel het aanbod beter aan te laten sluiten op de vraag van jongeren. In 2018 werden de Nederlandse @ease inloopcentra opgericht. In deze centra vinden jongeren van 12 tot 25 jaar een luisterend oor bij vragen of zorgen over hun psychische of fysieke gezondheid of met financiën, seksualiteit, werk, opleiding of hun sociale situatie.

Om hulp zo toegankelijk mogelijk te maken voor jongeren was meer kennis nodig over deze *youth mental health* initiatieven zoals @ease. Welke jongeren maken gebruik van deze centra? Welke invloed hebben hun problemen op hun leven? Wat maakt dat ze hulp zoeken of hier juist vanaf zien? En hoe kunnen we adequate hulp faciliteren? Deze vragen vormden de basis voor het onderzoek naar jongeren-vriendelijke hulp, het verbeteren van bestaande zorg en vroege detectie; met als doel de psychische gezondheid, het welzijn en het functioneren van jongeren te verbeteren.

Drempels en helpende factoren

De eerste stap was het verkrijgen van inzicht in de drempels en helpende factoren die jongeren van 12 tot 25 jaar ervaren wanneer zij hulp nodig hebben.

Hoofdstuk 2 laat zien dat negatieve overtuigingen rondom psychische problemen, zoals schaamte en geen belasting willen vormen voor anderen, leiden tot late herkenning en acceptatie van psychische problemen onder jongeren. Dit zorgt ervoor dat jongeren pas hulp zoeken wanneer hun problemen escaleren. Als mogelijke oplossingen vragen jongeren om meer bekendheid over psychische

problemen in het algemeen en specifiek over psychische problemen bij jongeren, en betere informatie over mogelijkheden voor hulp. Daarnaast kunnen zorgverzekeraars een faciliterende rol spelen door informatie over zorgkosten duidelijker en toegankelijker te presenteren. Tot slot zouden meer transparantie en informatie over de duur van wachtlijsten en alternatieve opties voor hulp, zoals laagdrempelige inlooplocaties, helpen om de zorg toegankelijker te maken voor jongeren. Eenmaal in zorg vragen jongeren om gepersonaliseerde zorg, zo min mogelijk verschillende hulpverleners en een informele sfeer. Enerzijds bevestigen de resultaten uit **Hoofdstuk 2** het belang van de wereldwijde aanpak voor jongeren-vriendelijke zorg. Anderzijds laten zij zien dat verdere innovatie noodzakelijk is om laagdrempelige hulp voor jongeren te realiseren.

@ease inloopcentra

De volgende stap was meer kennis verzamelen over de belangrijkste elementen van de @ease centra, de bezoekers en hun ziektelast. Hoofdstuk 3 laat zowel de noodzaak als de haalbaarheid van de @ease centra zien. Vrijwilligers, onder wie ervaringsdeskundigen, bieden een luisterend oor aan leeftijdsgenoten. Een diverse groep professionals biedt supervisie en is aanwezig wanneer nodig / gewenst. Alle medewerkers zijn getraind in luistervaardigheden, motiverende gesprekstechnieken, oplossingsgericht werken en suïcidepreventie.

De jongeren die @ease bezoeken hebben een duidelijk verminderde kwaliteit van leven vergeleken met hun leeftijdsgenoten uit de algemene populatie (**hoofdstuk 4**). Daarnaast valt een derde van de @ease bezoekers in de risicogroep van kinderen van ouders met psychiatrische problemen (KOPP). Bovendien hebben hun problemen reeds een maatschappelijke economische impact, maar ontvangt 75% van hen niet de hulp die zij nodig hebben. Deze kennis over de ziektelast van (subklinische) psychische problemen in de groep van jongeren op zoek naar hulp, onderstreept het belang van laagdrempelige hulp voor jongeren. Uitblijven van hulp tijdens deze kwetsbare en kritieke levensfase kan levenslange consequenties hebben. Jongeren-vriendelijke hulp moet hoog op beleid- en onderzoeksagenda's staan.

Aanpassen van bestaande zorg

Ook wanneer jongeren reeds in zorg zijn ontvangen zij niet altijd adequate hulp. Enkel het verbeteren van de toegankelijkheid van zorg is niet voldoende; het

huidige hulpaanbod zou ook beter moeten aansluiten bij de behoeften van jongeren met psychische problemen. Met dit doel werd een gespecialiseerd transitieteam opgezet binnen een grote GGZ-instelling die zowel kind & jeugd als volwassenzorg aanbiedt (**hoofdstuk 5**). In de werkwijze van dit transitieteam staat de cliënt centraal en wordt multidisciplinair gewerkt, transdiagnostisch, flexibel en in nauwe samenwerking met collega-zorgorganisaties. De cliënten van dit transitieteam worden gekenmerkt door een grote diversiteit en complexiteit aan stoornissen en problemen. Door de werkwijze van het transitieteam, waarin de cliënt centraal staat, kon continuïteit van zorg door een vast team van professionals gewaarborgd blijven, ook over de leeftijd van 18 jaar heen. Behandelingen werden succesvol afgesloten.

Vroege detectie

Naast toegankelijke en jongeren-vriendelijke hulp, is het belangrijk om mensen met een verhoogd risico op psychische problemen vroeg te detecteren. Door middel van vroege detectie en interventie kan de ontwikkeling van een deel van de psychiatrische stoornissen voorkomen worden, evenals verminderde kwaliteit van leven en bijbehorende maatschappelijke impact. Sociaal functioneren werd onlangs aangemerkt als mogelijke vroege transdiagnostische marker voor beginnende psychische problemen. Een transdiagnostische marker zou het mogelijk maken om de ernst van psychische problemen in te schatten, onafhankelijk van specifieke psychiatrische stoornissen, ook buiten de klinische context. Om sociaal functioneren in het dagelijks leven te meten werd in dit proefschrift, in aanvulling op een traditionele retrospectieve vragenlijst, gebruik gemaakt van de Experience Sampling Method (ESM). Bij ESM krijgen deelnemers gedurende de dag 10 keer een melding op hun smartphone om een aantal korte vragen in te vullen over hun welzijn en functioneren op dat moment. Zoals beschreven in **hoofdstuk 6** werd een duidelijke relatie tussen sociaal functioneren, enkel wanneer gemeten met de traditionele vragenlijst, en psychische problemen aangetoond, ook in een (sub)klinische populatie van jongeren met transdiagnostische symptomen. Er was een trend zichtbaar van sociaal functioneren als voorspeller van verandering in psychiatrische symptomen over tijd. Verder onderzoek is nodig om meer te weten te komen over de voorspellende waarde van sociaal functioneren en de toegevoegde waarde van ESM.

In het kader van vroege detectie zijn kinderen van ouders met psychiatrische problemen de belangrijkste specifieke risicogroep (**hoofdstuk 7**). Door zowel een genetische kwetsbaarheid als een mogelijk verstoorde opvoedcontext hebben zij tot wel 50% kans om zelf ook een psychiatrische stoornis te ontwikkelen. Wereldwijd vallen 15–23% van de kinderen in deze risicogroep. Ondanks het bestaan van effectieve preventieve interventies worden deze kinderen momenteel niet automatisch geïdentificeerd en geholpen. Deze kennis zou GGZ-organisaties moeten aanmoedigen om (meer) preventie in te zetten voor deze groep. Daarbij is een goede samenwerking tussen kind & jeugd- en volwassenenzorg essentieel om kinderen van volwassen cliënten preventieve interventies aan te bieden.

Hoofdstuk 8 vormt de Algemene Discussie van dit proefschrift. Samenvattend toont dit proefschrift zowel de noodzaak als de haalbaarheid van jongeren-vriendelijke initiatieven, binnen en buiten de context van traditionele geestelijke gezondheidszorgorganisaties. Ondanks het meer en meer ontstaan van toegankelijke hulpverlening ervaren jongeren die hulp zoeken nog hoge drempels, leidend tot een relatief hoge individuele en maatschappelijke ziektelast. Voor vervolgonderzoek is ten eerste het in kaart brengen van de effectiviteit van *youth mental health* initiatieven een belangrijke uitdaging, zowel wat betreft welzijn als maatschappelijke kosten over de tijd. Effectiviteit wordt vaak onderzocht door middel van gerandomiseerde gecontroleerde trials waarbij een deel van de onderzoekspopulatie wordt toegewezen aan een controle- of wachtgroep. Wanneer toegankelijkheid echter het doel is, zou het een tegengesteld effect hebben om een deel van de hulpzoekende jongeren toe te wijzen aan een wachtgroep. Vervolgonderzoek moet focussen op vernieuwende studie designs om de effectiviteit te meten zonder daarbij toegang tot hulp te weigeren. Een tweede uitdaging voor toekomstig onderzoek is meer inzicht krijgen in de behoeftes van kinderen van ouders met psychiatrische problemen (KOPP), om hulp beter te kunnen laten aansluiten bij deze groep met een verhoogd risico op psychische problemen. Gezien de hoge prevalentie van psychiatrische stoornissen is de groep KOPP-kinderen groot. Vanuit het doel van vroege detectie en interventie is gerichte preventie bij deze groep essentieel. Ondanks het bestaan van effectieve interventies ontvangt echter slechts een klein deel een vorm van preventie.

Concluderend toont dit proefschrift de noodzaak van laagdrempelige hulp voor jongeren aan. De last van psychische problemen onder jongeren is hoog en zij ervaren verscheidene barrières wanneer zij hulp (willen) zoeken. Naast de noodzaak wordt ook de haalbaarheid van jongeren-vriendelijke hulp in Nederland belicht, zowel binnen als buiten de GGZ. De resultaten in dit proefschrift pleiten voor een bredere implementatie van laagdrempelige hulpinitiatieven voor jongeren. Hierbij is de betrokkenheid van jongeren als expert in hun eigen leven essentieel om inzicht te krijgen in, en tegemoet te komen aan hun behoeftes.

IMPACT PARAGRAPH

Aim and main conclusions

The overall aim of this dissertation was to explore novel ways to enhance mental health of young people by investigating service accessibility, service reform and early detection. The research described in this dissertation demonstrates the need for such an enhancement as the burden of (emerging) mental health problems amongst the youth is high and numerous barriers prevent them from receiving the care they require. Despite great effort and initiatives, it remains challenging to reach young people at risk for, or already confronted with, (emerging) mental disorders. Young people often present diverse symptoms, fluctuating in severity. This makes it hard to diagnose a specific mental disorder, while a diagnosis is traditionally required to receive treatment. Even when young people receive help from the health care system, the provided care is not always appropriate. Therefore, the growing attention for innovative youth mental health services and early detection strategies is encouraging as well as crucial. In addition to the urgency, this dissertation showed the feasibility of easier access and youth-friendly mental health services in the Netherlands as well as further possibilities for early detection of mental health problems.

Scientific and societal impact

A key characteristic of this dissertation is the interconnectedness of scientific research and innovative (clinical) practice. Knowledge from the international research community formed the basis to set up both the @ease youth walk-in centres (www.ease.nl, **chapter 3**) and the Youth Mental Health team (**chapter 5**). From the start, the development of these services was monitored and evaluated, providing insights for further improvement. A strength of this dissertation is the combination of expertise and methods from different fields, including medicine, psychology and health economics. A product of this cooperation is the burden of disease study, discussed in **chapter 4**.

Furthermore, this dissertation combines qualitative and quantitative research methodologies to zoom in on individual young people seeking help (**chapter 2**), whilst simultaneously zooming out to investigate groups at risk deserving extra attention (**chapter 3, 6, 7**). Moreover, traditional retrospective measurements were combined with daily diary techniques (Experience Sampling Method, **chapter 6**) to measure the impact of mental health problems on social

functioning in daily life. In addition, the development of @ease brought together a variety of stakeholders in the field of youth wellbeing, including young people, experts by experience, social and mental health care professionals, municipalities and schools. This resulted in (i) numerous presentations at symposia and service training sessions for a wide public of healthcare professionals in the Netherlands, Belgium, Germany and Australia, (ii) the working method and results continuously being discussed with municipalities, national governmental bodies and policy makers and (iii) the organisation of interactive workshops about mental health and wellbeing at schools.

@ease

@ease was successfully developed and has shown its added value by being youth driven, professionally supported and scientifically embedded. The mental health problems that young people who consulted @ease deal with, had a considerable impact on their quality of life and an economic impact on society, yet almost 75% was not receiving care. A lack of interventions in this critical period in life may have major lifelong consequences. The first results of the @ease service provided insight in the group of young people with mental health problems and their associated burden. However, besides being study participants, these young persons were offered actual help by @ease: 291 young persons received peer-to-peer counselling. This counselling was provided by volunteers, including experts by experience, who were supervised by a diverse group of healthcare professionals. All volunteers and staff members were trained in listening, motivational interviewing, solution focused strategies and suicide prevention. The societal aspect of the @ease-training may have a broader impact as the use of knowledge and skills within the setting of @ease is considered to be applicable to a variety of contexts. A significant part of the group of volunteers studied to become a health care professional. They might take their knowledge and experiences from @ease to future working environments and may apply it there as well. The @ease-training was regularly updated using the information from new research data, enabling interaction between research and practice. The high burden of mental health problems amongst young people combined with the experienced barriers preventing them from receiving the required care, demonstrates the need for accessible youth mental health services such as @ease. It also shows that the @ease model we developed overcomes several

help seeking barriers for this group of young people. It is particularly interesting to observe that one third of @ease visitors mentioned having at least one parent with a mental disorder, resulting in having up to 50% chance to develop mental health problems themselves. Therefore, they form an important group for preventive interventions but are however often not identified and offered help. @ease at least partly matched their needs but further research is needed to improve identification, prevention and early interventions for this vulnerable group.

Where most burden of disease studies focus on either young children or adults, often with full-blown mental disorders, our burden of disease study had scientific impact by investigating adolescents of whom most were not (yet) receiving care. However, our calculation was limited to the current quality of life and costs of illness. Further research could investigate the long-term burden of mental health problems amongst young people on both an individual as well as a societal level. Thereafter, possible long-term reduction in societal costs and individual burden could be investigated.

Youth Mental Health team

Knowledge about accessibility and youth-friendly care is not only relevant for innovative initiatives, but also transferrable into traditional mental health services. Recognising the importance of continuity of care around the age of 18, a specialised Youth Mental Health (YMH) team was set up within a large mental health facility, providing both Child & Adolescent as well as Adult Mental Healthcare (**chapter 5**). Treatments were performed by a multidisciplinary team of professionals. Key elements were working transcending diagnoses, flexibility and collaboration with other care providers. The group of emerging adults accessing the YMH-team presented a high diversity and complexity of problems and highly prevalent co-morbidities. Results showed that treatments were successfully performed and continuity of care was met when patients turned 18. This argues for a broader implementation of YMH-teams across the country, aiming for a better match between traditional mental health services and the needs of their young patients. A condition for this match seemed to be the transdiagnostic approach; the flexibility to meet the complex dynamics of psychopathology that young people with (emerging) mental disorders often present. A contributing factor of the YMH-team was the success to bridge the gap

between Child & Adolescent and Adult Mental Healthcare. In addition, this dissertation sets valuable steps towards an improved connection between initiatives outside as well as within the clinical context.

Dissemination of knowledge

Results of this dissertation were nationally shared at symposia and via workshops with colleagues in both the research and practical field, besides other stakeholders such as policymakers. A broader audience was reached via national and regional television and radio broadcasts, and through reports in Dutch newspapers and journals. Examples of Dutch television programs in which parts of this dissertation were discussed are: EenVandaag, NOS journaal, RTLZ Samen Sterk Tijdens Corona, Avondgasten and Limburg Centraal.

Internationally, the results of this dissertation were published in scientific journals and presented to colleagues at the International Association of Youth Mental Health (IAYMH) conference in 2019, Brisbane (Australia), the IAYMH conference in 2017, Dublin (Ireland), the Early Intervention in Mental Health conference in 2018, Boston (USA) and the DGPPN Kongress in 2018, Berlin (Germany). The working method and first results were deliberated on with international colleagues during work visits to headspace youth centres in Denmark and Australia, the University of Canberra and Orygen National Centre of Excellence in Youth Mental Health, Australia.

Future research

As described above, further research should investigate the effectiveness and long term-effects of youth mental health initiatives such as @ease. In addition, the inclusion of parents, teachers and friends of young people could provide helpful information for early detection and to further increase resilience. It would be interesting to learn about the experiences of volunteers involved and how staff members would describe the added value of @ease to their parent organisation. A deeper knowledge regarding the needs of young people in vulnerable groups including people with lower intellectual capacities and children of parents with mental disorders is essential as they are exposed to an increased risk of developing mental health problems. Last, transdiagnostic markers such as social functioning would provide the opportunity to assess the burden of mental health problems independently from specific psychiatric symptoms or disorders,

also outside the clinical context. Therefore, a further understanding regarding the predictive value of transdiagnostic markers and daily life measurements is required.

Suggestions for improvement

The results of this dissertation argue for a broader implementation of easily accessible youth mental health services. Young people should always be involved in the developments of these services, as they are experts on their own lives. Future development of youth mental health services should focus on reaching a wider extent of young people under the age of 18, including their parents and significant others, people with lower intellectual capacities and children of parents with mental disorders as increased risk groups. Mental health care organisations should invest in informal settings with walk-in options and personalised care, working transcending diagnoses and removing barriers at age 18, to facilitate access to appropriate care after entering the system. Healthcare insurers could play a facilitating role by making information about care related costs more youth-friendly and easier accessible. Governmental bodies should invest in mental health awareness amongst the youth and clear information about treatment options.

CURRICULUM VITAE

Sophie Leijdesdorff werd op 10 april 1990 geboren in Rotterdam. Na het afronden van het gymnasium aan het Rotterdams Montessori Lyceum studeerde zij van 2008 tot 2013 psychologie aan de Erasmus Universiteit Rotterdam. Zij behaalde de master Klinische Psychologie met keuzevakken in de wetenschapsfilosofie en studeerde af op een onderzoek naar werkgeheugentraining met dr. Elke Geraerts en dr. Sabine Wanmaker. Na haar afstuderen startte zij als fondsenwerver bij het Erasmus MC Alzheimercentrum. Ze combineerde fondsenwerving met het doen van wetenschappelijk onderzoek naar neuropsychologische profielen van erfelijke vormen van fronto-temporale dementie en, in samenwerking met het VUmc Alzheimercentrum, naar meten van invloed van dementie op het dagelijks functioneren. Voor dit onderzoek ontving zij diverse (reis)beurzen van het Erasmus Trustfonds, Alzheimer Nederland en het Alzheimer's Association International Conference committee. In januari 2017 verhuisde ze naar Maastricht voor haar promotieonderzoek aan Maastricht University, gesuperviseerd door prof. Therese van Amelsvoort, prof. Arne Popma en dr. Rianne Klaassen. Gedurende haar promotietraject was zij betrokken bij de opstart van @ease, met eerste vestigingen in Maastricht, Amsterdam, Heerlen, Rotterdam en Groningen, en was zij actief als trainer en supervisor van @ease-vrijwilligers. Daarnaast werkte zij als therapeut binnen het transitieteam van Virenze / Met GGZ, waarover zij tevens een wetenschappelijk artikel publiceerde. Zij presenteerde haar werk op nationale en internationale congressen en bracht deze kennis over op een breed publiek door media optredens bij onder andere EenVandaag, NOS op3 en Limburg Centraal. Sophie zet haar onderzoek voort als postdoctoraal onderzoeker aan Maastricht University.

Sophie Leijdesdorff was born in Rotterdam, The Netherlands, on April 10, 1990. She studied Psychology at Erasmus Universiteit Rotterdam from 2008 to 2013. She holds a master's in Clinical Psychology and graduated at a working memory training research project with dr. Elke Geraerts and dr. Sabine Wanmaker. After graduation, she started as fundraiser for the Erasmus MC Alzheimer's centre. She combined fundraising with doing scientific research into cognitive profiles to discriminate between genetic variants of behavioural frontotemporal dementia, and a research collaboration with the VUmc Alzheimer's centre around functional

decline in dementia. To present this work abroad, she received several travel grants from the Erasmus Trustfonds, Alzheimer Nederland and the Alzheimer's Association International Conference committee. In January 2017, Sophie moved to Maastricht to start her PhD research at Maastricht University, supervised by prof. Therese van Amelsvoort, prof. Arne Popma en dr. Rianne Klaassen. During her PhD research, Sophie was involved in starting up the first @ease centres in Maastricht, Amsterdam, Heerlen, Rotterdam and Groningen. Besides her research, she worked as a therapist within the transitional psychiatry team at Virenze / Met GGZ, and wrote a publication about this team as well. She presented her work at national and international conferences and to a broader audience by television interviews such as EenVandaag, NOS op3 and Limburg Centraal. Currently, Sophie continues her work on youth mental health research as a postdoctoral researcher at Maastricht University.

LIST OF PUBLICATIONS

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5. Jutten, R. J., Peeters, C. F., Leijdesdorff, S. M., Visser, P. J., Maier, A. B., Terwee, C. B., ... & Sikkes, S. A. (2017). Detecting functional decline from normal aging to dementia: development and validation of a short version of the Amsterdam IADL Questionnaire. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 8, 26-35.
6. Poos, J. M., Jiskoot, L. C., Leijdesdorff, S. M. J., Seelaar, H., Panman, J. L., van der Ende, E. L., ... & De Jong, F. J. (2020). Cognitive profiles discriminate between genetic variants of behavioral frontotemporal dementia. *Journal of neurology*, 1-10.

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