In between looking and seeing: recognition, referral and assessment of children and adolescents' mental health problems at the interface of primary care and secondary mental healthcare

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“As for the future, your task is not to foresee it, but to enable it.”

Antoine de Saint Exupery

Chapter 1

General introduction

Box 1

Imagine a consultation with the general practitioner, Dr. Jan. A 13 years old girl, Hanne, visits with her mother for recurrent unexplained abdominal pain. Her mother mentions that Hanne also does not manage to complete full days at school. The physician focuses thoroughly on the abdominal symptoms and continues the physical examination.

When asked for, Hanne's mother explicates that the school attendance problems happened a few times in the last two months. She explains that she divorced Hanne's father over a year ago and wonders whether Hanne might be troubled by this big change at home. "However", she adds, "the problems at school are of a more recent date and seem not so much related". Hanne's adjustment to the divorce of her parents took some weeks after she moved to her mothers' house, but Hanne is now best friends with two other girls at school. This reassures the general practitioner.

The general practitioner decides not to ask further as there is no defined request for help with psychosocial problems and Hanne seems not to be off-balance. Hanne gets a prescription for a fiber solution to treat the presumed bowel problems, the mother expresses thanks for the consultation, and they leave.

Ideally, when minors' emotions persistently hinder wellbeing, an appropriate treatment or management plan should be made and followed through. In practice, however, many steps and challenges exist between the two ends of mental health needs and obtaining adequate support. A major and first challenge is recognizing minors' experiences or expressions that might point towards the existence of a mental health-need and evaluating their symptoms and strengths.[1 2] Not only do patients and their primary surrounding fail to recognize psychosocial needs, but also professionals fail to recognize and assess them sufficiently.[3-5] For example, in the above-described consultation, the general practitioner decided not to enquire further as the mental health related problems were not the primary focus of that consultation and the few explicated problems did not sound much worrisome to the professional (Box 1). The general practitioner underrecognized the likelihood that this might be an early case of school refusal, which is a major risk factor for problems to build up and persist.[6 7] If the general practitioner had perceived risks, they could enquire further and balance attention to both the likelihood that watchful waiting might be sufficient as well as

whether signposting to resources for prevention and health promotion might be adequate. Therewith the general practitioner could reach its potential in navigating minors towards 'the right service in the right place, at the right time delivered by the right person'– a meaningful Chinese proverb often used by authors from the field of healthcare.

In practice, it is not uncommon that a professional has no resources to recognize, assess, and react to the first signs of mental health problems.[8] This is also true for anxiety disorders which are highlighted in decades of research as the most common mental health problem amongst minors and adults.[9] We now more than ever have insight into the correlates and consequences of mental health disorders that are not outwardly visible but have major long-term consequences. Nonetheless, the treatment gap remains and efforts investigating practical steps between recognition and treatment are relatively scarce in the literature.

In this dissertation we present a series of studies on I) whether general practitioners even think about a probable anxiety disorder when presented with descriptions of psychosocial problems (chapter 2), II) what general practitioners write on their referral letters to child and adolescent mental healthcare (chapter 3), and III) what the predictive value of a feasible step-wise assessment method could be at the interface between primary healthcare and secondary mental healthcare (chapter 4). While values for common mental health disorders (e.g. depressive disorders and attention-deficit hyperactivity disorders) will be presented in each chapter, extra focus will be put on anxiety disorders as an example of a widespread yet overlooked and underserved mental health problem.

The results of the studies could inform clinicians on the status quo considering recognition and referral of minors with mental health problems, which are major healthcare topics in several countries including the Netherlands. Moreover, the findings could serve policy and curriculum makers, thereby improving evidence-based practices in child and adolescent mental healthcare.

Epidemiology of mental health in youth

Most of young people develop healthily and show resilience to stressful experiences. Notwithstanding, mental health problems are not uncommon. Each year about one in four minors meet the criteria of mental health disorders as they are hindered in their daily life by

emotional and behavioural problems.[10 11] The prevalence rates are not much different, if not higher amongst adults.[12] In fact, both retrospective and longitudinal studies suggest that a substantial amount of adult cases are formed by caseness from younger ages on.[9 13-15] It is found that about three-quarters of persons with a mental health disorder at some point in their life met the criteria of a psychiatric disorder already before the age of 24, and over half the lifetime cases had mental health problems before the age of 14.[9 13] Indeed, the age of onset distribution of most mental health problems shows an onset in childhood or adolescence (Figure 1[16]). In addition to that, it is not far-fetched to conclude that child mental health has to be highlighted when aiming for healthy functioning of individuals and society.

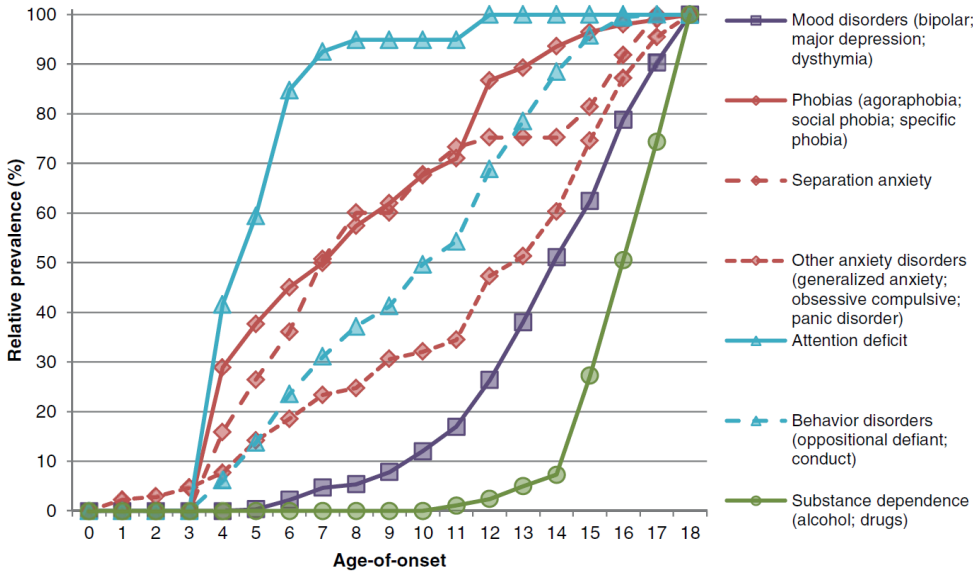

Figure 1. Standardized cumulative prevalence curves for mental health disorders, from Ormel et al. (2015). The plots track per age the relative prevalence of each index disorder.[16]

Mental health disorders account for a significant amount of disease burden worldwide; in literature this is also expressed as disability adjusted life years (DALYs). When grouped altogether, they form the fifth leading cause of DALYs over the life span.[17] Specific categories of mental health problems, such as depressive disorders and self-harm, account for three out of the ten leading causes of DALYs. In female adolescents in the age group 10 to 19 years

anxiety disorders on their selves are even amongst the top five leading causes of disease burden. The cost and cascade of problems triggered by mental health problems often build up over time as a result of their early age of onset. Therefore, as the World Health Organization formulates, “investments in minors might bring a triple dividend of benefits: now, for their future adult lives, and the next generation”.

Effective investments might help prevent a negative snowball effect in minors’ developmental trajectory. Access to mental health treatment is one such example of a valuable investment to prevent their developmental potential from being thwarted.[18 19] Nonetheless, there is a major gap between the occurrence and treatment of child mental health problems, also called a treatment gap. On average over two thirds of young people with a mental health-need do not access adequate support.[20 21] The numbers vary depending on the type of mental health problem with for instance an estimated 3.4% of people with social anxiety disorder making treatment contact within a year of onset, 33.6% of people with a panic disorder, and 37.4% for major depressive disorder.[21] Median delays in access to treatment are estimated as respectively 16 years, 10 years and 8 years after onset.[21]

Challenges in recognition and access to services

To facilitate timely access to services, minors’ mental health needs must be recognized. However, in reality, this is a rather challenging aim. Many steps exist between the two ends of a need for care and obtaining appropriate support and intervention. In their filter model Goldberg and Huxley[22] describe the pathway to mental healthcare by means of five levels of care and four major filters in between these levels (Figure 2[22 23]). They underline that primary care is the first and foremost point where decisions are made and at which most of the sub-filters are.[24] Examples of such filters are the illness behaviour of the patient, and other characteristics of both the doctor and patient.[22 24] A major challenge in mental health needs of children and adolescents is recognizing their experiences and expressions that might indicate a mental health problem and how to evaluate their symptoms and strengths. As children and adolescents are still developing, it is difficult to differentiate signs of problematic development from typical and temporary developmental challenges. Also, as they depend on their primary surrounding, another challenge is formed by problems that are

difficult to perceive outwardly by parents.[25-27] Hence others have expanded the filter-model and included filters such as the social context,[28] problem recognition by parents or important others in minors' lives,[29] or more specific stages of problem recognition, such as perceiving that there might be an issue, what the issue is, and subsequently the realization that there is a need for mental healthcare.

Mental health treatment seeking is not only a multistep process[27] as a result of the persons involved but also due to complexities in the health system. Even though the filter-model of Goldberg and Huxley implicates that after referral patients reach psychiatry, in the current era with various stakeholders and institutions, there are many more pathways – with each also various bottlenecks and hence relationships with the earlier filters. In the next paragraph, we describe the current landscape in child adolescent mental healthcare in the Netherlands, and tap into how the variety of pathways might help benefit from the pros of specialization, as well as increase risks in decision-making through increased ambiguity in responsibilities and opportunities.

The care landscape

The variety of pathways toward mental healthcare is a result of decades of reforms set up to meet increasing healthcare demands both in terms of quality and quantity. In developed countries, in the last decades, the reforms were dominated by the replacement of specialised services with low threshold services, also known as the dichotomization of primary and secondary care services. Primary care services were created in the 1950s, after recognition of their potential to improve monitoring and management of health-related problems in a low-threshold, local and low-cost framework. Since then, the healthcare system has undergone many reforms, and decades later, primary care is still at the center of reforms. Recently, in the Netherlands new reforms took place in child healthcare

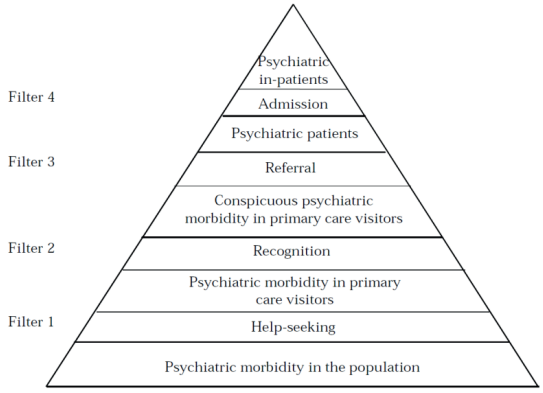

Figure 2. Goldberg and Houxley's Filter-model (1982) describing the process of help seeking for mental health problems, from Zwaanswijk (2005).[22 23]

legislation by the Youth Healthcare Act.[30 31] Before 2015 the care system for youth was financed and organized in different levels and the system with various stakeholders did not facilitate the provision of tailored and harmonious care. Starting from 2015, all authority, financing and responsibility were given to the municipalities to diminish the number of stakeholders and fragmentation in care. So-called inter-professional local youth teams were formed to intensify preventive care and function as a bridge between primary and specialised care services. With this decentralisation it was expected that better-tailored interventions could reach minors earlier and prevent their problems from worsening.[32] Nonetheless, seven years later, at the time of writing this introduction, the delivery of coherent, coordinated, timely and sustainable care for youth with various needs in the social and health domains is still a major topicality. Evaluations on how the youth act turned out report that working methods of local youth teams differ between municipalities and that integrated working approaches might lack even within municipalities.[33] Reports conclude that the matter might be to facilitate what works on the case level, independent of how the health system is organized.[34]

Assessment

In a care-model with various stages and specialisations, by definition, a chain of providers will be involved, and thus communication will form a challenge. Minors' strengths and challenges should be made explicit and assessed for adequate and cohesive care. This is also

highlighted in studies on integrated care. Such studies underline that next to clear clinical pathways, and collaboration between professionals, a broad assessment of problems and possibilities is needed to facilitate support that is tailored to the needs of children and families across life domains.[35-37] A broad assessment approach that is done timely might also contribute to the achievement of several aims that are also formulated with the new Youth Healthcare Act, including ameliorating the quality of care, reducing waiting time, and facilitating access to care.[33 34] But what is assessment? Assessment as part of evidence-based practice refers to "the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences" (Box 2). This definition underlines the importance of both clinicians' day-to-day evaluations as well as drawing from results of empirical research. Both are viewed as an indispensable part of high-quality care that starts with putting from both clinicians' expertise and more formal guidelines in order to explicate patients' "characteristics, culture, and preferences". In absolute terms one might even argue that without assessment no focused treatment can be initiated, as at least a form of hypothesis generating and testing has to precede before and during each treatment intervention.

Box 2. Definitions of evidence based practice and assessment

What is **evidence-based practice** in **medicine**, Sacket et al (1996)	Evidence-based practice, defined as "(…) the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. (…)".[38]
Definition and purposes of **assessment in psychiatry**, Mash & Hunsley (2005)	What is assessment: Assessment captures the assessment process (hypothesis generating and testing, decision-making) and the assessment methods (tests, observation, measures to gather data). What are the purposes of assessment: the six interrelated purposes of assessment are screening, diagnosis and case formulation, prognosis and prediction, treatment design and planning, treatment monitoring and treatment evaluation.[39]
Evidence-based assessment as defined by the **American Psychological Association**	Evidence-based assessment aims to "promote effective psychological practice and enhance public health by applying empirically supported principles of psychological assessment, case formulation, therapeutic relationship, and treatment".[40]

Assessment captures both the methods and the process to aid hypothesis generating (Box 2). In the clinical field, however, often with assessment, the use of structured assessment methods such as questionnaires is meant, partly as a result of the origin of structured assessment methods for scientific purposes. Structured assessment methods such as rating scales and questionnaires were initially used for scientific and epidemiological purposes as a reliable proxy for what cannot be directly observed in the diagnostic process – i.e. the information gathering to estimate the likelihood of various diagnostic possibilities. The persons experienced subjective inner feelings are than explicated, operationalised, through rating of items that form a proxy for these experiences including feelings, cognitions and sensations.[41 42] Assessment stimulates informants thinking about symptoms and signs that are typically less perceived, as in this way informants are prompted to evaluate daily behaviour and experiences that are less remarkable.[43 44] Later on, structured assessment instruments were included in the clinical field for individual patients to diminish the risk of tunnel vision and unaddressed problems at the side of the clinicians. In child and adolescent mental healthcare, the inclusion of multiple informants into the assessment procedure is emphasized given the still ongoing cognitive development and reliance of minors on their parents, differences in children's behaviour in various contexts including school, at home, and amongst friends, and differences in how various informants perceive children's behaviour.

Focusing on general practitioners

In the Netherlands, minors are invited for a structured mental health screening and health check twice during primary school and twice during high school. Between these preventive moments, the signaling role is up to the direct caregivers of youth and their teachers.[45] When parents and caregivers signal a need, there are several pathways to follow and professionals to visit. Reports on general practice consultations from around Europe show that over two thirds of youth visit a general practitioner at least once a year.[46 47] Recent studies on referral pathways from the Netherlands suggest that over a third of the youth support trajectories indicated between 2016 and 2019 were still indicated by general practitioners, despite the legal shift towards the newly created local youth teams within the Youth Healthcare Act.[48 49] Clearly, the general practitioner is first point of contact for many families in the case of health related problems including mental health.[34 50 51] Considering

the life time perspective of general practice, general practitioners are in a unique position to recognize and manage mental health problems. Last but not least, primary healthcare is approachable in its nature and could thereby have a major role in timely identification, and help disrupt the relation between socioeconomic status and the abovementioned alarming treatment rates. Therefore, in this dissertation, emphasis is placed on general practitioners as an example of an essential partner in facilitating minors reach for mental healthcare.

Focusing on anxiety disorders

Anxiety disorders form a typical example of a widespread yet overlooked mental health problem that starts early in life, and when not intervened, frequently persists or build-ups into adult life. Hence, the case of anxiety disorders portrays a clear image of the importance of tackling mental health problems in youth. Anxiety disorders have a median age of onset of 11 years and show similarities with typical development. Signs and symptoms of problematic anxiety often fly under the radar.[13] Those who do access treatment do mostly so after as much as 9 years after onset.[52] Median delays in receiving treatment range between 9 to 30 years depending on type of anxiety disorder whereas these median delays are estimated to be below 10 years for mood disorders and substance abuse disorders.[21] We know from the literature that these are the cases with the highest life hindrance and are only the tip of the iceberg.[20 52] It is estimated that more than half of the persons with anxiety disorders never receive professional support for their anxiety disorder.[53] Studies focusing on youth conclude similar, if not more alarming, treatment coverage rates.[54-56]

The benefits of a decrease in the treatment gap of anxiety disorders have been modeled by Chisholm and his colleagues.[57 58] In their conservative simulation study, they report an economic benefit-cost ratio of 5.3 (range 2.6 to 10.9) by a treatment gap reduction of about 16 to 25%. This suggests that a reduction of the number of untreated people by a quarter might result in a five-fold monetized short-term benefit relative to the cost of treatment. Nonetheless, studies amongst children in paediatric primary care reveal that only 31% of youth with clinical level anxiety disorders have received any form of intervention whereas, for instance, 75% of children with attention-deficit hyperactivity disorder and 40% of those with depressive disorder received a form of intervention.[54] In general, studies suggest that the so called internalizing disorders that are less expressed outwardly are recognized less or

perceived as not requiring care,[23] and within the group of internalizing disorders, anxiety disorder are recognized less than depressive disorders and receive treatment less frequently.

Besides the short-term economic burden, underdetection makes problems build up. Anxiety disorders are proposed as a risk factor for the onset of comorbidities, as persons with anxiety disorders are often the first to develop a series of problems including depression, substance use, academic difficulties, dropout and difficulties in familial functioning or at the workplace. Often it is only after the development of other issues that these persons seek or obtain help, still with chances that the treatment is not focused on the anxiety disorder.[59]

Objectives and research questions

With this dissertation we aimed to add to the knowledge gap in the referral-intake process for child and adolescent psychosocial problems, specifically anxiety disorders (Figure 3). First, we studied whether general practitioners even think about anxiety disorders when they are presented with cases at risk of anxiety disorders (chapter 2). Also we examined which treatment decisions general practitioners preferred when various mental health disorders are suspected. Next, we quantified what general practitioners write on referral letters about various mental health problems once the decision to refer is made (chapter 3). Here, we also explored which more general reasons, such as problems at school or family environment, were indicated. In the third study, we investigated the added value of a sequential assessment approach with potential for broader use at the interface between primary and secondary mental healthcare (chapter 4).

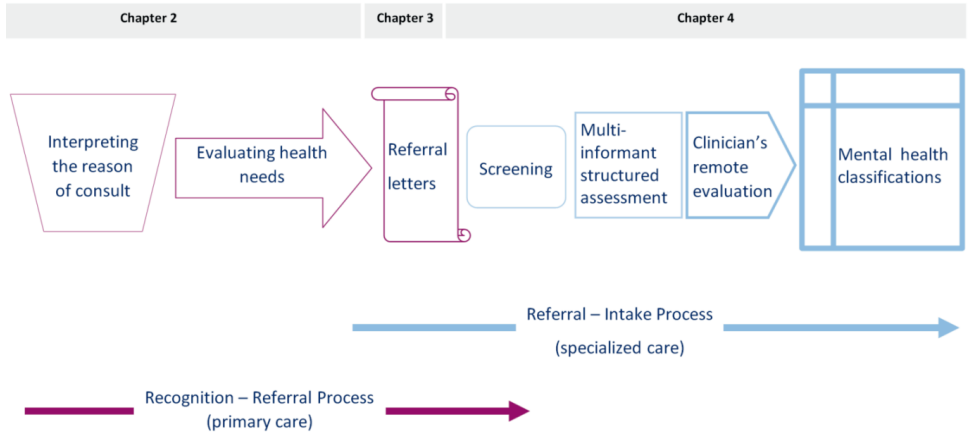

Figure 3. The scope of the studies presented in this dissertation

Study 1: Recognition of anxiety disorders in children: a cross-sectional vignette-based survey among general practitioners

Many studies have found that people with anxiety disorders in particular are infrequently recognized as such. Historically this has been related to many factors, including patient factors such as avoidance, practice- and professional based factors such as mental healthcare skills and knowledge. However, where in the diagnostic process professionals' underdetection starts is less known. We questioned whether the often shown underdetection starts already in the first diagnostic considerations and interpretations professionals make. Therefore, to gain insight into the detection and referral of child anxiety symptoms we presented general practitioners with hypothetical case descriptions, i.e., vignettes, reflecting mixed symptoms in which child anxiety may be manifested. The main question here was whether they attribute the symptoms to anxiety in their first interpretation of presented problems? We asked how they would diagnose and manage problems as described in the vignettes. To gain insight in their conscious management tendencies, general practitioners were also asked what they prefer to do in terms of referral when they assume the existence of the common mental health problems in children.

Study 2: Informative value of referral letters from general practice for child and adolescent mental healthcare

Referral letters are a central part of patients journey through healthcare institutions. Nonetheless there were little to no empirical studies on the informative value of referral letters. As a first step to address the lack of scientific knowledge in this area, we reviewed referral letters of youth that accessed specialised mental healthcare. Based on the available literature, discrepancies were expected, particularly regarding the prediction of anxiety disorders. Contrary to anxiety disorders, developmental and externalizing disorders were expected to show better symmetry between initial reason of referral and the final diagnosis. Thus, we expected that anxiety would not have been mentioned sufficiently often in referral letters of cases clinically identified with an anxiety disorders.

Study 3: The diagnostic process from primary care to child and adolescent mental healthcare services: the incremental value of information conveyed through referral letters, screening questionnaires and structured multi-informant assessment

The use of structured assessment methods is advised to improve early detection, objectify burden and sound decision-making considering the diagnosis and therapeutic progress. However, in many practices, structured assessment is not implemented sufficiently. Often clinicians report that these questionnaires and assessment instruments might limit patient satisfaction and the development of a healthy therapist-client relationship. Studies amongst patients however do not support these concerns.[8] What remains a relevant question for practices is whether the various instruments add to the clinical process. Although many instruments each with different purposes are developed, and well investigated as a standalone measure, studies on their incremental value have not been reported in the literature. As in clinical practice each following information overlaps with the previous, insight is needed in the unique predictive value of the instruments in the sequence. Therefore, in the third study, we present the added value of commonly available sources of information with potential for integrated use in and between primary and secondary mental healthcare: referral letters (RLs), the strength and difficulties questionnaire (SDQ) as a screening, and the development and well-being assessment (DAWBA) as a more elaborate assessment tool.

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