

Identification of child mental health problems in primary care: an interdisciplinary approach
Koning, N.R.

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# **Chapter 1**

**General introduction** 

#### General introduction

Mental health problems (MHPs) have a substantial impact on the global burden of disease. In 2010, MHPs accounted for 7.4% of all disability-adjusted life years(1). On average one in five adults experienced an MHP within the previous 12 months worldwide and 29.2% of adults experience one or more mental health disorders across their lifetime(2). Roughly half of all lifetime MHPs occur by the age of 14 years and three-quarters of MHPs are present at the age of 24 years(3, 4). Adult mental illness may be prevented through early intervention in childhood and adolescence(4). Early identification of MHPs in children is thus important in order to provide adequate treatment strategies and enable prevention of adverse outcomes in later life(5). Or, as Kieling et al. stated: 'Action is imperative to reduce the burden of MHPs in future generations and to allow for the full development of vulnerable children and adolescents worldwide'(6).

General practitioners (GPs) are the gatekeepers of the Dutch healthcare system and are, together with preventive youth healthcare professionals, in a well-placed position to identify child MHPs(7). Approximately 80% of Dutch children and adolescents with MHPs visited their GP within the preceding year(8). However, these children were often visiting for physical rather than psychological reasons and were often not recognised by their GP as having MHPs(8). In this introduction, the case of Tess is presented to illustrate the difficulties GPs can face when identifying child MHPs.

# The story of Tess, 14 years old

Julia is a GP in a group practice of three. This morning she saw Tess (14 years old), together with her mother. Tess and her mother have been patients in the practice for six years, since they moved from a neighbouring village. The reason for the visit is that her mother is worried because Tess has not been herself for a long time, is constantly tired and is not eating well.

After some hesitation, Tess tells Julia that she is somehow not happy anymore. A lot appears to have happened in the past few years. Tess's parents divorced 3 years ago, her father had lost his job and had some mental issues. Tess still finds this difficult and has had some difficulties with making friends at her new school. Lately, she hasn't been able to concentrate that well and her grades are declining. Julia decides to refer Tess to secondary mental healthcare because of Tess's depressive feelings.

After the consultation, Julia asks herself if she could have seen this coming? The medical history of Tess shows visits for a viral upper tract infection, a broken wrist due to a roller skating accident and several visits with different colleagues for constipation in the past couple of years, which was treated with dietary advice and temporary laxatives.

# Child mental health problems

To help Julia, this thesis aims to improve the early identification of child MHPs in general practice. First, a general background with regard to child MHPs and the Dutch healthcare system for children will be provided. The current state of research regarding the identification of child MHPs in primary care will be described, before concluding with the objective and outline of this thesis, and the used patient cohort.

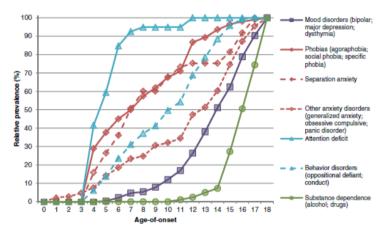
#### **Definition**

Psychosocial problems can be described as any behavioural/externalizing problems (e.g. hyperactivity or aggressive behaviour), emotional/internalizing problems (e.g. depressive feelings or anxiety) or social problems (difficulties to make contact with or keep contact with others)(9-11). In general, different terminology and definitions are used to refer to a similar concept. The World Health Organization (WHO) describes mental and behavioural disorders as a set of disorders which are generally characterized by some combination of abnormal thoughts, emotions, behaviour and relationships with others; however, symptoms may vary substantially(12).

This thesis aims to improve the early identification of child MHPs in primary care, including general practice and preventive youth healthcare (PYH). In light of early identification, we include any problems in psychosocial functioning, ranging from problems with mild to severe impairment.

#### Prevalence and risk factors

MHPs are common in children and adolescents. Depending on age, setting and definition, reported prevalence rates vary from 10 to 20 and sometimes 25%(6, 10, 13, 14). A meta-analytic review found that worldwide almost one in seven children under 18 years meet diagnostic criteria for a mental health disorder(15). The occurrence of MHPs differs per problem type, but also across age and gender (figure 1)(13). In primary school for instance, externalizing problems become more apparent in boys. Internalizing problems such as depressive feelings and anxiety occur more frequently among girls in adolescence(13, 14, 16).



**Figure 1.** Standardized cumulative prevalence curves for Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IC) disorders, Ormel et al(13). The figure shows the relative percentage of children with a specific MHP according to age. For example, from the children aged 18 years with substance dependency, 50% already had this dependency at age 16 years.

Multiple risk factors play a role in the origin of MHPs(10). Individual attributes (e.g. genetic background, a child's temperament), social circumstances (e.g. family composition) and the environment in which people live (e.g. neighbourhood, socioeconomic status, culture) all have an impact on one's mental health and well-being(10, 17).

The different risk factors associated with a child's mental health can occur at any stage in life. The life-cycle approach provides a model that maps relevant risk factors of child MHPs and shows how risk exposures in the formative stages of life, including substance use in pregnancy, insecure attachment in infancy or family violence in childhood, can affect mental well-being or predispose towards MHPs many years later (figure 2)(6, 17).

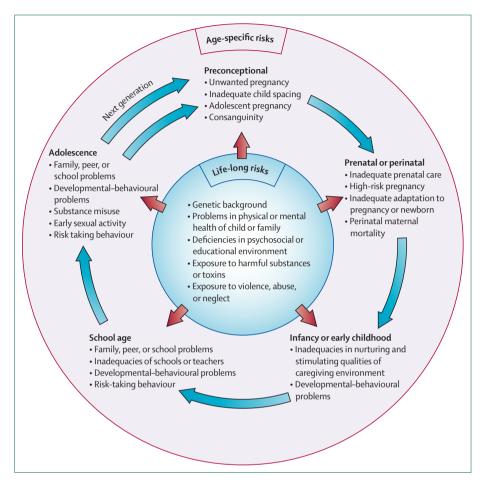


Figure 2. The lifecycle approach to risk factors for MHPs, Kieling et al(6)

# Impact of child mental health problems

Child MHPs often have a negative effect on a child's everyday functioning and wellbeing(10). In children and young adults aged 10 to 29 years old, MHPs accounted for the highest proportion of total disability-adjusted life years(1). It is known that child MHPs influence a child's healthy development and frequently have long lasting effects, resulting in, for instance, a higher risk of impediment due to a DSM-diagnosis later in life and a poorer performance at school and/or on the job market(3, 4, 10, 18, 19). Disturbances to an individual's mental well-being can also lead to broader welfare losses at the family/household and societal level(12, 20). The burden on

families ranges from economic difficulties to emotional reactions to MHPs, the stress of coping with disturbed behaviour, the disruption of household routine and the restriction of social activities(12, 20, 21). The economic costs of MHPs are large. A study performed in the United States estimated the lost family income due to childhood MHPs to be approximately \$10,000 yearly(20).

# Primary healthcare for children in the Netherlands

General practitioners (GPs) and preventive youth healthcare professionals (PYHPs) are the key professional groups involved in the Dutch primary healthcare for children. Almost every Dutch citizen is enlisted with a general practice and general practice is the formal point of entry into secondary healthcare, including mental healthcare(22). In addition, PYHPs provide regular check-ups to children and adolescents with the aim to prevent disease, promote health and allow early detection of health risks, disease, and developmental problems in the physical, psychological, social and cognitive domains(7). Due to structured call schedules linked to the municipal basic administration, approximately 80-90% of all children aged 0 to 19 years are regularly seen in preventive youth healthcare (PYH)(23). Around 15 preventive check-ups are provided during the first four years of a child's life. During primary and secondary school, PYH offers four contact moments(7). PYHPs use several validated screening tools to aid MHP recognition. Examples of these screening tools are the Strengths and Difficulties Questionnaire (SDQ) and the short indicative questionnaire for psychosocial problems among adolescents (KIVPA), two questionnaires which are filled out by parents or children themselves depending on age(10).

All in all, GPs and PYHPs each have their own specific knowledge and tasks within the Dutch healthcare system. They each have different information on the (mental) health and illnesses of children and their families, and gather this information at different times and for different reasons. This means that their roles can potentially be complementary(24). Sharing relevant information between general practice and PYH could facilitate early identification of child MHPs and such collaboration is promoted by several professional associations including the Dutch College of GPs (Nederlands Huisartsen Genootschap), the National Family Practice Association (Landelijke Huisartsen Vereniging) and Dutch Preventive Youth Healthcare Physicians (Artsen Jeugdgezondheidszorg Nederland)(25). However, collaboration and interdisciplinary communication between both domains still is not part of usual practice on either side. It is unknown how current collaboration between general practice and PYH is and how often they share information.

#### Identification of child mental health problems

With the current knowledge about risk factors for adverse child mental health outcomes and with both the GPs and the PYHPs regularly seeing a child during childhood and adolescence, one would expect that MHPs are adequately identified. However, a substantial number of children with MHPs will not be recognised as having MHPs by their GPs and PYHPs(8, 26). Children usually do not present with a recent-onset and well-defined single disorder. More commonly, children have a long history of several problems, distress and impairments below or above diagnostic thresholds(27, 28). In addition to the under-recognition of child MHPs, a between-professional variance in the identification of child MHPs has been reported(29). This between-professional variance in identification could not be explained by child characteristics and could only partly be explained by investigated professional or practice characteristics(29). Factors such as gender, past treatment for MHPs, type of visit, professional acquaintance with the child and professional training were found to be associated with the identification of child MHPs by primary care professionals in two systematic reviews published over a decade ago(30, 31).

# Risk prediction models based on routine healthcare data

A possible solution to improve the identification of child MHPs in an efficient way might be the use of a risk prediction model based on readily available routine healthcare data. Risk predictions facilitate the identification of groups of patients at high risk for e.g. developing a specific disease or responding to a provided treatment. Prediction models for anxiety and depression in (young) adults in primary care have been developed and have shown good discriminative properties, with only the study on depression in young adults solely based on readily available routine healthcare data(32-34). To our knowledge, models based on readily available routine healthcare data that help identifying MHPs in children and adolescents in primary care are not available yet. Such a model estimating the probability of a child developing an MHP in, for instance, the next year might help professionals to better recognise problems in daily practice, thereby improving timely recognition. In the case of Tess, a risk prediction model would have automatically calculated Tess's risk of developing an MHP based on the available data in Tess's electronic medical record. At the time Tess had visited Julia or one of her colleagues for constipation, there would have been a possibility for them to see Tess's risk of developing an MHP, and they might have taken the opportunity to approach the constipation differently, with more

attention to the context. As mentioned before, both GPs and PYHPs potentially have complementary information(24). This leads to the question of whether Julia could have better evaluated Tess's situation when relevant information was exchanged between PYH and GP.

# Objective and outline of this thesis

In order to improve the early identification of child MHPs, the main objective of this thesis was to develop a prediction model for child MHPs based on readily available information from electronic health records from general practice. In addition, we investigated whether combining electronic health record information from general practice and PYH resulted in better performing prediction models. Next to model development, we explored several contextual aspects of improving MHP identification in primary care such as the current collaboration between GPs and PYHPs and factors associated with identified MHPs by primary care professionals.

Chapter 2 provides an overview of the literature regarding factors associated with child MHP identification in primary care. The factors we found serve as a starting point for the development of a prediction model for child MHPs. In Chapter 3, we explore the development of a prediction model for a first recorded child MHP based on routine healthcare data from Dutch general practice. Different prediction models were developed for different age categories. Chapter 4 presents the results of the study investigating the usefulness of routine healthcare data from Dutch PYH for research purposes and specifically for the development of a prediction model regarding concerns for MHPs according to PYH.

Using the findings of chapter 3 and 4, we combine the routine healthcare data from general practice and PYH in Chapter 5. We examined the overlap between concerns for MHPs in PYH and MHPs according to GPs. In addition we investigated whether combining information from PYH and general practice is useful in the identification of child MHPs.

As not all children with MHPs need to be referred to mental healthcare, we link the general practice and PYH data to data regarding mental healthcare use from Statistics Netherlands in Chapter 6. We examined how MHP diagnosis occurs in primary care and in mental healthcare, the timeline of diagnosis and whether combining data from both general practice and PYH aids identification of children who use mental healthcare.

In chapter 7, we investigate the current collaboration between GPs and PYHPs in a qualitative study. In addition, we make an inventory of physicians' needs regarding collaboration and where they see room for improvement. Finally, in chapter 8 the findings of this thesis are summarised and discussed. Clinical implications, using the case of Tess as an example, are outlined, and methodological reflections and recommendations for future research are presented.

# Cohort study used in this thesis

This thesis presents the results of the Pippi-study, which stands for 'primary care integrated for the identification of psychosocial problems in children'. In the Pippistudy, patient data from both general practice and PYH was analysed. The populationbased cohort consisted of all children aged 19 years or younger on 31st December 2016 who were registered with a general practice that was affiliated with the ELAN primary care network (Extramural LUMC Academic Network) of the Leiden University Medical Centre (LUMC), in the Netherlands. The participating general practices were located in the greater Leiden area. The routine healthcare data of all included children were anonymously extracted from the electronic medical records by an external trusted third party (TTP). The TTP de-identified the general practice routine healthcare data of every child. In order to link the patient data from general practice with the data from PYH, the TTP provided both the Dutch citizen service number and the pseudo patient number from the children included in the Pippi-study to the PYH organisation from the Leiden region (Gemeentelijke Gezondheidsdienst Hollands Midden). The PYH organisation extracted all available data for these children and also deidentified their routine healthcare data with the same pseudo patient numbers. In this way, we received anonymous patient data from PYH and general practice for approximately 50,000 children, which we could combine on the individual patient level with the pseudo patient number.

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