1 Introduction and outline of this thesis

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1.1 Introduction

This thesis focuses on the early detection by the Dutch Preventives Child Healthcare (PCH) of children with psychosocial problems and examines in particular whether short questionnaires can improve early detection.

Most Dutch children are doing well. A recent study compared the well-being of children in 21 rich countries and concluded that children in the Netherlands were better off than those in other countries.\(^1\) The Health Behavior in School Children study also concluded that, on average, Dutch children did well and were more satisfied with their lives than children in other European countries.\(^2\) However, such global findings do not imply that all children are doing fine and that all children are doing well and are feeling happy. On the contrary, many studies have shown that a great number of children suffer from serious psychosocial problems. Brugman et al.\(^3\) studied the prevalence of emotional and behavioral problems in children aged five to fifteen years, using the Child Behavior Checklist (CBCL) and the Youth Self Report (YSR) and found prevalences ranging between 6 and 9\%. A more recent study by Zeil et al.\(^4\) studied the age group from 14 months to twelve years of age, using the CBCL and the Infant and Toddler Emotional Assessment Scale (ITSEA) and found prevalences ranging between 2\% (very young girls) and 8\% (boys aged five or six years).

These figures are based on studies using a cut-off point, which are, inevitably, to a certain extent arbitrary. However, there are also other indicators showing that many Dutch children and adolescents suffer from serious psychosocial problems, hampering normal, healthy development:\(^5\) in 2004 there were about 33,000 new admissions to the youth mental-healthcare services; 52,000 new voluntary admissions to Bureau Jeugdzorg (Youth Welfare Work, BJZ) and 7,000 new admissions to youth rehabilitation centers. The total number of children under the age of 19 receiving treatment in youth mental healthcare services was 84,000. An additional 57,000 youngsters were receiving treatment at centers for justitioal youth care. Furthermore, in that same year, more than 33,000 handicapped youngsters under the age of 25 were receiving a disability allowance because they were not fit to work (Wajong). Of all cases newly enrolling for this allowance, 39\% were doing so on the basis of some psychological – not intelligence related – handicap.

In short, psychosocial problems can seriously hamper children’s healthy development and are often a burden for parents and other family members. In many cases, these problems tend to be persistent and they do not disappear automatically,\(^6\) possibly because they may have been caused by physical and genetic factors or by experiences in very early childhood. They may have long-term negative consequences, like academic under-achievements, substance abuse, the need for referral to mental healthcare or professional counseling, problems at school and clashes with the law.\(^7,12\)

In the Netherlands PCH has, by law, the duty to identify children with psychosocial problems and, if necessary, to assure that they are given adequate care. This is an important aspect of its work as research has shown that many children with serious problems do not receive any form of help at all.\(^13\) This despite the fact that research has also shown that early detection of children with emotional and behavioral problems, if followed by adequate treatment, significantly improves their prognosis.\(^14,15\)
1.2 PCH in the Netherlands: a short description

Reijneveld et al. describe Dutch PCH as that part of the healthcare system that focuses on the promotion, protection and safeguarding of health, growth and physical and mental development. Its target group are all children, between zero and nineteen years of age. It distinguishes itself from other parts of the healthcare system in that it offers its services pro-actively, not waiting until the moment that a problem may arise. Traditionally PCH is offered by two different types of organizations: well-baby clinics, (Consultatiebureaus, CB), mostly a service offered by the ‘Home-Help Organizations’ (Thuiszorgorganisaties), targeting (parents of) children aged 0 to 4, and PCH from 4 to 19, a service offered by regional public health centers (Gewestelijke Gezondheidsdiensten, GGD). PCH offers both individual and collective services, in a variety of disciplines: specialized youth doctors, community and youth nurses, epidemiologists, dieticians, speech therapists, epidemiologists and sometimes psychologists. Children are invited for a standard health examination at specific intervals, 15 times between 0 and 4 years of age and 3 times when they are at primary and secondary schools.

The main services are defined in PCH’s Basic Working Package. Some of the services are a standard, uniform part of this working package and have to be provided systematically to all children involved, in a standardized way. The main services are:

1. Monitoring and identification of problems
2. Estimating the need for (extra) care
3. Screening and immunization
4. Health promotion, advice, instruction and support, aiming to improve health related behavior
5. Handling of health risk
6. Supporting the (mental) healthcare system

The identification of children with psychosocial problems is part of the service mentioned under 1 and belongs to the uniform part of PCH’s Basic Working Package. When a child is identified as having problems, PCH should, of course, carefully estimate the type of care needed in this child’s case. Identifying children with problems is, primarily, a service offered to individual parents and children. Additionally, it should contribute to the collectively offered monitoring service, in which PCH systematically tries to monitor the health of the population under its care and advises local and regional health authorities on the development of adequate healthcare policies.

1.3 The Term ‘Psychosocial Problems’

What does the term “psychosocial problems” mean? It is a common term in Dutch PCH, but its definition presents difficulties. In 1985 Vogels et al. contacted representatives of all kinds of services working with young people and asked them to indicate the most important psychosocial problems facing children and adolescents. The answers varied enormously: problems with parents or peers, homosexuality, fear of failure, unemployment, having no future perspective, divorce of the parents and so on.
Pubmed does not use the phrase as one of its standard keywords. The Pediatric Handbook Online (http://www.rch.org.au/paed_handbook/index.cfm?doc_id=1571, date May 16, 2007) has an entry titled “psychosocial problems” but does not offer a clear definition. Instead it lists a range of problems, varying from anxiety disorders, family relationships difficulties, psychosis, ADHD, sleep problems, learning difficulties, child abuse and neglect and – remarkably – death of a child.

In 1999 the study group ‘Monitoring Stations in Dutch PCH’ organized a meeting of experts to discuss prevention of psychosocial problems among children and adolescents by PCH. Leading experts in the field of PCH and child and adolescent psychiatry contributed to this meeting. One of the issues discussed was how to define the term psychosocial problems in this specific context. Those present agreed that a clear distinction should be made between factors contributing to or causing the development of psychosocial problems and psychosocial problems themselves. Furthermore they agreed that the early detection of psychosocial problems should focus on emotional and behavioral problems and on problems at school. This definition limits the term psychosocial problems to problems in the functioning of the child itself. The Association of Dutch Regional Health Services (GGD Nederland, GGD NL) and the Dutch Institute for Care and Wellbeing (Nederlands Instituut voor Zorg en Welzijn (NIZW)) adopted a similar approach: psychosocial problems are described as problems in psychosocial functioning; they may be emotional but are often also visible in the child’s behavior. This definition will also be used in this thesis.

1.4 Psychosocial problems and Dutch PCH

The early detection of children with psychosocial problems has been part of the uniform part of PCH’s Basic Working Package since 2002. Since its explicit inclusion, this part has attracted an increasing amount of attention, and a great deal of importance has been attached to it. This high profile was caused by several dramatic cases of child abuse and child neglect, which made it clear that Dutch institutions in mental and physical healthcare were insufficiently focused on the identification and management of children at risk. Nevertheless, the late inclusion (2002) of the early detection of psychosocial problems as a an essential part of PCH’s working package, does not mean that it was totally ignored before that date. Reijneveld et al. suggest that PCH always paid some attention to psychosocial problems, but that in the beginning other issues, like clean drinking water, healthy nutrition and hygiene were more relevant and urgent, simply because the main issue then was to safeguard health and improve survival rates. They see the beginning of the 1970s as the time when interest in psychosocial problems started to increase. In 1971 the Netherlands Institute for Preventive Medicine (Nederlands Instituut voor Praeventieve Geneeskunde, NIPG), now part of TNO Quality of Life, published a report on secondary school pupils’ complaints, concluding, amongst other findings, that the identification of these problems required better trained and more highly educated staff. Ter Haar Romeyny-Wachter and Wassen-Van Schraven published two articles
describing a roadmap to preventive mental healthcare, in which they formulated a clear role for well-baby clinics.  

It is difficult to assess what exactly happened in the PCH practice at that time. Vogels et al. studied the annual reports of all PCH departments in the Netherlands, for the years 1982, 1983, 1984 and 1985. This was done in preparation of a study on PCH for older adolescents. Psychosocial problems or mental health were rarely mentioned in those reports; far fewer references were found, for example, to the number of children with head lice. Yet, at the same time the interest in psychosocial problems was clearly growing in the field. The department for PCH in South-East Drenthe asked the NIPG to carry out a large-scale study on the prevalence of psychosocial problems. This study focused on pupils in secondary vocational schools but was also to include youngsters who had already left school. Other regional healthcare centers took similar initiatives. Using the well validated CBCL, PCH in South-East Limburg did a study aiming to establish differences in the prevalence of psychosocial problems between regions in their catchment area and between individual schools. This was done with the explicit aim of developing a differentiated program of care. The PCH in Apeldoorn also did a study to determine the prevalence of psychosocial problems in the population falling within their catchment area. By then, several centers had also introduced consultation hours where pupils and parents could seek advice, mainly focusing on psychosocial problems. Some centers decided it was worthwhile hiring people with specific expertise: psychologists or a nurse certified as a welfare worker.

All the projects mentioned above were local initiatives, focusing on different groups and or problems, using different measuring instruments and methodologies, and lacking any form of standardization. However, at a national level, interest in psychosocial problems was growing too. In 1983, the Netherlands Association for Preventive Child Healthcare (Nederlandse Vereniging voor Jeugdgezondheidszorg, NVJG) instituted a commission whose remit was to formulate guidelines for the care for adolescents. In its final report this commission stated that in this age group more attention should be paid to psychosocial problems than to problems connected with physical development. This report resulted in the foundation of the Netherlands Association for Care for Adolescents (Nederlandse Vereniging voor Adolescentenzorg, NVAZ). This association started to publish a quarterly, almost exclusively directed at psychosocial development. The recommendations of the commission’s report, however, were never implemented at a national level.

At governmental level interest in psychosocial problems was growing, too. In 1985 a chain of suicides in one school in the North of the Netherlands received a lot of media coverage. The regional PCH center was criticized severely for taking too few initiatives to prevent this chain of suicides. The Inspector for PCH, then part of the Health Department, took the initiative to institute a Working group on PCH and Prevention of Suicide, whose remit was to formulate guidelines for PCH which would actively contribute to the prevention of suicide in adolescents. Some of the recommendations of this commission, especially those on reinforcing the chain of care, seem very modern, but they were never actually implemented.

So, for quite a while, the amount of interest shown in psychosocial problems and the action taken by local PCH departments was determined mainly by local priorities and
individual interests. At the end of the nineties, this changed, partly because the decision was taken to formulate the PCH Basic Working Package and partly, too, because PCH departments were becoming more experienced in dealing with questionnaires on psychosocial problems.

1.5 Questionnaires on psychosocial problems in Dutch Preventive Child Healthcare

By the mid-eighties nearly all departments already used short questionnaires as part of the care package offered to individual children and parents. Each PCH department used its own questionnaire which were all different, measuring different concepts, and using different items. Mostly they were about one page long, but they focused on a wide range of aspects, covering physical health, life style, and psychosocial problems. Most of these questionnaires were never validated. The questionnaires were used mainly to help parents prepare for the standard health examination: they were intended as a kind of checklist for subjects that needed attention during that examination.

Some PCH departments, however, went further and considered using questionnaires to select those children that needed to be examined in a face to face examination, especially with regard to adolescents. This led to fierce debates. Verhoeven Tjan, for example, reported on a study comparing the findings based on an unvalidated questionnaire on psychosocial problems with findings based on the consultation during a standard health examination. She found considerable discrepancies between the two methods and concluded that questionnaires, therefore, could not replace the traditional standard health examination.30 Other studies addressed similar questions.31,32 Baecke reported about one of the first attempts to develop a standardized and validated questionnaire, focusing mainly on psychosocial problems.33 He intended this questionnaire to be used as a sort of screening questionnaire, distinguishing children with problems from those without. Its validation, however, was weak: he only reported significant differences on a personality test for children between pupils with extremely high and low scores on the questionnaire’s subscales. Although a number of other PCH departments did use this questionnaire, it was never adopted universally. One of the likely reasons for this is that in the beginning of the 1990s the volume of PCH services for adolescents gradually started to decrease, as financial cutbacks and changing systems of financing led many PCH centers to focus on younger age groups. Other PCH centers started to experiment with published questionnaires, e.g. the Delft Questionnaire (Delftse Vragenlijst34) used for some time by the PCH center in South East Limburg.

A turning point in this confusing development was the inauguration in the late nineties of the working group on the identification of psychosocial problems. It was instituted by GGD NL and officially called the National Working Group on the Identification of Psychosocial Problems in Youth (Landelijke Werkgroep Signalerings van Psychosociale Problematiek bij Jongeren’, LSPPJ). This working group consisted of epidemiological and sociological researchers and of school doctors working at regional PCH centers. They developed the National Checklist for Indicating Psychosocial Problems in Five-Year-Olds (Landelijke Signaleringslijst voor Psychosociale Problematiek bij Kleuters,
LSPPJ). They tested its internal consistency, scale structure and validity, i.e. the extent to which it could distinguish between those receiving treatment and those not. Similarly, they developed the Short Indicative Questionnaire for Psychosocial Problems among Adolescents (Korte Indicatieve Vragenlijst voor Psychosociale Problematiek bij Adolescenten, KIVPA). These instruments were intended as tools to be used in the standard health examination, not as a replacement for it and not as a screening device as such. The aim was to give PCH professionals an indication of existing problems and help them focus the consultation with the parents on these problems. Having developed these questionnaires, the LSPPJ supported the implementation on a national scale: they wrote manuals, developed scoring forms and introduced methods for optical data entry so that the data collected could be used, not only in the context of individual care, but also for epidemiological purposes. Furthermore, they co-operated wholeheartedly in critical evaluations of these instruments and used the results of these studies to improve the questionnaires. Later on they developed a questionnaire for psychosocial problems affecting primary school children (vragenlijst voor Psychosociale Problematiek in de Bovenbouw van het Basisonderwijs, PSYBOBA) and decided to participate in the evaluation of this instrument in comparison with two other instruments.

By doing so, the LSPPJ has contributed enormously towards an evidence-based system of detecting psychosocial problems in Dutch PCH and towards a reduction of the uncontrolled proliferation of unvalidated methods and instruments. Their efforts have also led to a consensus on the criteria which must be met by questionnaires to be used by PCH. First of all of course, questionnaires must be valid and reliable indicators of the phenomenon to be assessed, in this case: the likelihood of psychosocial problems being present. Also, questionnaires need to have added value: they should improve the chances of identification compared to identification based on other methods, like using information about risk indicators or carrying out an interview during the standard health examination. However, the specific PCH context demands the fulfillment of two extra criteria: PCH professionals have only a limited amount of time to spend on each individual standard health examination, which means that (paper and pencil) questionnaires have to be short, and that PCH professionals can easily work out the scores. Also, such questionnaires have to be suitable for children or parents from different backgrounds, including all socio-economic classes and all ethnic minorities. That means – again – that they cannot be very long, but also that they must be very easy to understand and that their phrasing and content must be acceptable for people from different backgrounds. Finally and preferably, the questionnaire must help prepare the respondents (parent and/or child) for the standard health examination. This being the case, the questionnaire can be used to structure the conversation between parent/child and PCH professional.

1.6 Early detection of psychosocial problems by Preventive Child Healthcare

What PCH has to do, essentially, is to determine which children are in need of special attention as a result of psychosocial problems. This sounds very much like screening
and many of the methods used in this thesis are also often used in the evaluation of screening procedures. The criteria for questionnaires that must be met, for example, correspond to those discussed by Wilson and Junger. Yet, a closer inspection of the concept of screening shows that early detection of psychosocial problems cannot be viewed as a proper form of screening. Wilson and Jungner define screening as ‘the presumptive identification of unrecognized disease or defect by the application of tests, examinations or other procedures which can be applied rapidly’. They discussed three criteria for the evaluation of screening tests (validity, reliability and ‘yield’ (i.e. the number of newly detected cases)) and formulated ten principles that must be born in mind when planning screenings:

1. The condition sought should be an important health problem
2. There should be an accepted treatment for patients with recognized disease
3. Facilities for diagnosis and treatment should be available
4. There should be a recognizable latent or early symptomatic stage
5. There should be a suitable test or examination
6. The test should be acceptable to the population
7. The natural history of the condition, including development from latent to declared disease should be adequately understood
8. There should be an agreed policy on whom to treat as patients
9. The cost of case-finding should be economically balanced in relation to possible expenditure on medical care as a whole
10. Case-finding should be a continuing process

In time, these principles have grown to be accepted as criteria that must be met for a screening program to be acceptable. Recently, they were adapted and updated. Clearly, this definition is not suitable for the identification of children with psychosocial problems. The main reason for this is that psychosocial problems, although they may be related to psychiatric disorders, cannot be seen as defined diseases or defects. Furthermore, although there is evidence that high-quality early detection of psychosocial problems improves the prognosis, there is not always an accepted treatment, there is no clear latent stage and much remains unknown about the natural history of – the diversity of – psychosocial problems.

Nevertheless, the identification of children with psychosocial problems is part of the Dutch PCH’s Basic Working Package, because PCH’s overall aim is to monitor and safeguard the healthy development of all children in the Netherlands. If this aim is to be realized, the identification of psychosocial problems is essential, because psychosocial problems may be indicators of the existence of psychiatric disorders needing professional care and because psychosocial problems by themselves can be a risk factor for a healthy development, for example when parents are lacking in the skills needed to cope with those problems, in which case the interaction between parents and child may deteriorate. Another possibility is that such problems may be the underlying cause of physical problems, such as headaches, repeated infections, abdominal pains et cetera.

The early identification by PCH of children with psychosocial problems is a first step, that identifies those children who need more attention because of the likely existence of psychosocial problems. In other words, it is a procedure which switches on an alarm, thus calling for attention. After this signal, PCH professionals have to assess by means
of other procedures a) whether any psychosocial problem is indeed present, b) what the nature of the problem is, c) how serious the problem is, and d) whether parent and/or child are in need of support. Therefore, early detection needs to be supplemented with some form of assessment that enables PCH professionals to determine whether child and/or parent need extra care, and if so, what kind of care.

Several studies have shown that PCH identifies many children as having psychosocial problems. Reijneveld et al. for example found that PCH, using only information on file and the consultation during the standard health examination, identifies about 9% of children aged 14 months to 4 years of age as having problems. In older age groups this percentage is considerably higher. Brugman et al. reported that among children aged 5 to 15, 25% had been identified as having at least one problem. Zeijl et al. reported percentages varying from 11% among 11-months old children to 28% among children aged five to six years. The same studies, however, also strongly suggest that the identification of problems by PCH is far from perfect. When comparing the identification by PCH with the CBCL-score of the children involved, Brugman et al. reported that the identification of problems was 6 times more likely in children with a clinical CBCL Total Problem Score. However, PCH identified no psychosocial problems in 43% of the children with a clinical CBCL. Also, PCH suspected that such problems existed among a large number of children, even though CBCL data suggested few or no problems. Reijneveld et al. and Zeijl et al. have reported similar discrepancies.

This in itself does not mean that PCH problem identification is wrong. CBCL scores are based on behaviors, moods and problems perceived and reported by parents. PCH may see different aspects of the child’s functioning and research has shown that different informers’ perceptions should be considered as supplementary and worthwhile information, both in their own right and in combination. Yet, both the concurrent and the predictive validity of the CBCL and the YSR as instruments to detect emotional and behavioral problems has been proven over and over again. This means that a clinical CBCL or YSR score should be taken seriously and that the discrepancies between PCH findings and CBCL indications are strong signals that identification by PCH may be in need of improvement.

There are several ways in which this improvement might be achieved. Wiefferink et al. studied the effectiveness of using a detailed protocol, in combination with a specific training. Clearly, time may be a critical factor for a high-quality identification of psychosocial problems to be achieved. Another method, tried in the past but never explicitly evaluated, is adding specific expertise to that already present in PCH, for example introducing clinical psychologists and/or social workers. In PCH for younger children, a number of rather intensive methods are being introduced, involving protocol-based home visitation (Samen Starten, Project Oké). Several studies have given a strong indication that these approaches are effective, improving both identification and offering easy opportunities for interventions. Durlak & Walls studied the effectiveness of interventions in the field of mental health. One critical factor they identified for the effectivity of interventions was the use of validated questionnaires to identify the children to which those interventions should be directed. This method is clearly in line with standard methods used by Dutch PCH in the past. The extent to which
questionnaires can improve the identification of children with psychosocial problems is the main focus of this thesis.

1.7 Research questions and outline of this thesis

The following questions will be answered in this thesis:

1. Can differences in the number of children identified as having psychosocial problems by individual health professionals be explained by differences in the prevalence of problems or background characteristics in the groups of children they examine?

2. What are the psychometric qualities of a number of short questionnaires PCH could use to identify children with psychosocial problems, and could they improve the identification by PCH?

3. Is it possible to develop a Computerized Adaptive Test using items from questionnaires on psychosocial problems, in order to achieve a short, yet accurate assessment of the likelihood of psychosocial problems being present?

Data from several studies have shown not only discrepancies between problem identification and validated indicators of psychosocial problems, but also large differences between individual PCH professionals in the percentage of children they identify as having problems. In Chapter 2 we will assess whether these differences are larger than may be expected on the basis of random variation and whether these differences may be explained by differences in the prevalence of problems or risk factors in the subsamples examined by individual professionals.

In Chapter 3 the psychometric properties of the KIVPA, intended to be used in PCH for adolescents, will be evaluated. The scale structure and validity – in terms of sensitivity and specificity – are evaluated. Also, it will be determined whether using this questionnaire offers added value, compared to identifying children based on information about potential risk indicators.

Chapter 4 will assess the psychometric properties of one of the questionnaires developed by the LSPPJ, the LSPPK. The LSPPK is intended to be used in PCH for 5 and 6 years old. The methods used in this chapter are comparable to those used in Chapter 3.

The PSC, the Pediatric Symptom Checklist, is widely used in the USA for the detection of children with problems in all kinds of settings. Several studies have shown strong psychometric properties. Chapter 5 describes a study evaluating the psychometric properties and its added value for Dutch PCH for children in the second phase of primary education. In this chapter the concept of added value is extended, compared to the definition used in the previous two chapters. We will not only determine whether the PSC allows for a better identification than potential risk indicators, but also whether it improves the identification based on the clinical judgement of the PCH professional, after having examined the child.

In Chapter 6 a randomized comparison of three questionnaires is described, the SDQ, the PSC and the PSYBOBA, developed by the LSPPJ. The aim of this study is to determine which of these questionnaires would be most suitable for the identification of
children with problems in the 7 to 12 age group. The questionnaires will be compared in terms of scale structure, validity and the extended added value they may offer to PCH. Also, their suitability, both for parents and PCH professionals, will be compared.

The Strengths and Difficulties Questionnaire (SDQ) was developed in the United Kingdom.\textsuperscript{49,50} The quality of the instrument has been proven in different countries and cultures. There is evidence that the quality of the Dutch version is high, too.\textsuperscript{51,52} Chapter 7 presents a detailed evaluation of four different SDQ-based classification methods, comparing their validity and added value for the identification of children with problems in the second phase of primary education by PCH professionals.

Questionnaires to be used by PCH must, of course, offer valid and reliable indicators for the existence of psychosocial problems. Due to the strong time limitations within which PCH has to work, they must meet another criterion: they have to be short and easy to score. Short questionnaires are, however, inherently less reliable than longer questionnaires.\textsuperscript{53} A lack of reliability means, by definition, a greater chance of misidentification. Item Response Theory (IRT) provides a way out of this dilemma, offering a method with which assessment using only a few items can result in a highly accurate measurement. Chapter 8 will describe a study assessing whether the items from four questionnaires may be used for an IRT-based computerized adaptive test.

In Chapter 9 the main findings of this thesis are summarized and discussed.

References


