Personalizing preschool preventive child health care

Personalizing Preschool Preventive Child Health Care
The MOM study

Bernice M. Doove

The research presented in this thesis was conducted at the School for Public Health and Primary Care (CAPHRI), Department of Social Medicine, Maastricht University, the School for Mental Health and NeuroScience (MHeNS), Department of Psychiatry and Psychology, Maastricht University Medical Centre, and the Academic Collaborative Centre Public Health Limburg. CAPHRI participates in the Netherlands School of Primary Care Research (CaRe).

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Table of contents

List of abbreviations

AUROC - Area Under de Receiver Operating Characteristic;
CAP-J - Classificatiesysteem voor de Aard van Problematiek van Jeugd
CBCL - Child Behavior Checklist;
C-TRF - Caregiver-Teacher's Report Form;
DAZ - D-score-for-Age Z-scores
D-score – (Van Wiechen) Developmental score;
ICF-CY - International Classification of Functioning, Disability and Health -Children and Youth version;
METC - Medical Centre Medical Ethics Committee;
MOM - Monitoring Outcome Measurements of child development study;
NOSIK - Parenting Stress Index Short Form;
NPV- Negative Predictive Value;
PPV- Positive Predictive Value;
PCHC - Preventive Child Health Care;
PEDS - Parent's Evaluation of Developmental Status;
SDQ - Strengths and Difficulties Questionnaire;
SES - socioeconomic status;
SF-36 - Short-form survey on health and quality-of-life;
SNEL - language-screening instrument;
STATA - Statistical Software Package;
STEP - Standard Taxation of Severity of Problems;
VAS - visual analogue scale;
WHO -World Health Organization.

CHAPTER 1

1

Introduction Preventive Child Health Care, the MOM study and outline of the thesis

'No child left behind'

The present work describes the Monitoring Outcome Measurements of child development (MOM) study for Personalizing Preventive Child Health Care (PCHC) in the preschool period. At first the rationale, paradigm and methodology for Personalizing PCHC is delineated. Then the general outline and aims of the MOM study and this thesis are described.

Preventive Child Health Care, a Public Health endeavour

PCHC can be summarized as the public health endeavour to address and influence the early conditions that place children at risk for less than optimal health, development and successful social participation. PCHC is synonymous with Paediatric Preventive Primary Care. In many countries, PCHC provides ongoing monitoring for all children and their families to prevent adverse mental and physical health outcomes over the life course (1-3). Monitoring enables professionals to intervene in the earliest phase of emerging problems and disabling symptoms, even before formal criteria for diagnostic classifications are met (4, 5). The Dutch PCHC has been established to closely monitor the health and development of all children during routine medical assessments in well-child care clinics offered by PCHC professionals (6). The Dutch PCHC includes preventive health care nurses and doctors and has a high level of population compliance, all children are regularly invited to visit the PCHC. Dutch PCHC doctors are expected to be specialist in social medicine, the study of man in its total environment. Therefore, PCHC focuses on optimizing the interaction between the biological-genetic baseline of children on the one hand and their material and immaterial environment on the other, insofar as this is important for their health, growth and development (7). The pursuit of longitudinal continuity of care for children and adolescents determines the frequency and content of the contact moments within PCHC. Our changing society and system changes in the youth sector poses continuous challenges for PCHC to optimize the growth, health and development of children and, where necessary, reduce complex problems, together with parents and other partners in the care sector.

No child left behind

There is a large amount of knowledge about conditions and outcomes of child health and development. The more basic question is how development works for each unique child, that is, the complex process by which a particular child becomes the person who he or she is (8). Within this process, the quality of the social and educational environment, including interpersonal relationships, is key to children's healthy development and social participation (9, 10). In children's development is essential how children are seen and treated by their parents and other caregivers, beginning in the early years of life. For

children to thrive and become healthy adults, they need a quality of care from parents and other caregivers that is sensitive and responsive, with consistent routines, and a family that is surrounded by a solid network of support. To support child health and development and to make sure that 'no child is left behind', community must adapt to the needs of children's family and educational surrounding (8). Child health is more than the absence of disease. Health can be formulated as the ability to adapt and self-manage (11). The World Health Organization (WHO) equates -mental- health with 'well-being', mediating the ability to realize one's abilities, cope with the normal stresses of life, work productively, and to contribute to society.

Early identification of emerging problems at preschool age

Early identification of children at risk for developmental delay or related problems is essential for optimal early intervention and support in the social/educational domain. Then, the probability of re-aligning the trajectory of development and successful social participation is best and treatment, thus, is more cost-effective (8, 12-16). It has been suggested, however, that the sensitivity for detecting early problems is low (2, 17, 18). For many conditions in childhood where early support is likely to be of benefit – development, language, behaviour, family psychosocial issues – their very nature is such that there is not a suitable screening test to categorize into pass or fail (19).

Children and contexts will shape each other

Starting from an integrated bio-psycho-social-ecological paradigm, children and contexts will shape each other (13). A complex and dynamic interplay of biological and contextual factors is influencing develop-mental health and social participation across the life span (13, 20). Therefore, early recognition of mental health and behavioural problems is challenging, given that normal development in young children is highly variable and all growth and development takes place in interaction with the environment (21, 22). Especially with young children, the various developmental domains are inextricably linked. Development in one domain always influences another developmental domain, and therefore also social participation.

Emerging problems vs disorders

Children with symptoms of developmental health problems may have significant clinical needs, and are at risk of alterations in development, possibly altering school readiness (23).

Early recognition of symptoms, before onset of diagnosable disorders, prevents children at an early age experiencing stigma and, potentially, exclusion from an appropriate learning environment. In addition, overtreatment in the early phases of mental symptoms can cause inhibition of the capacity for resilience and coping.

The prevalence of children who do not meet DSM-5 criteria for a disorder but who have clinically significant impairment may be equal or twice as large as the group of children meeting formal diagnostic criteria for severe emotional disorder (1, 24, 25). These children represent an important group from a public health perspective (18, 26-28).

Personalizing PCHC

The ever-changing society and social demand for help is a challenge for PCHC. To construct models of well-being and disease that are both predictive and actionable, PCHC will need to transform a conventional approach ('find it and fix it') into a dynamic strategic approach aimed towards the future: 'predict it and personalize it' (29-32). Personalized PCHC is new, integrating predictive, preventive, participatory and personal (instead of 'a one-size-fits-all' approach) components of medicine from a Public Health perspective for balanced health policy on community and individual level (33). Balanced strategies prevent 'growing into deficit', maximize health benefits, minimize harms, and avoid unnecessary healthcare costs.

'Growing into deficit'

PCHC offers a unique framework to positively influence the clinical consequences of incipient problems, in particular problems that do not (yet) meet criteria for a diagnostic classification. When a biological vulnerability is present, a preclinical prodromal phase can develop in which no symptoms are yet observable. The interaction between genetically determined vulnerability (baseline risk) and stressors (environmental factors) in a continuum over time ultimately leads to a diagnostic entity on the basis of which an intervention is decided. Before that, processes of initiation and progression of symptoms take place. According to this concept, there is so-called 'growing into deficit' within a continuum. Whether 'growing into deficit' applies will be determined by the 'initiating events' and health determinants in the environmental contexts. Figure 1 shows an adaptation of Snyderman's curve representing the timelines of 'growing into deficit' (34) .

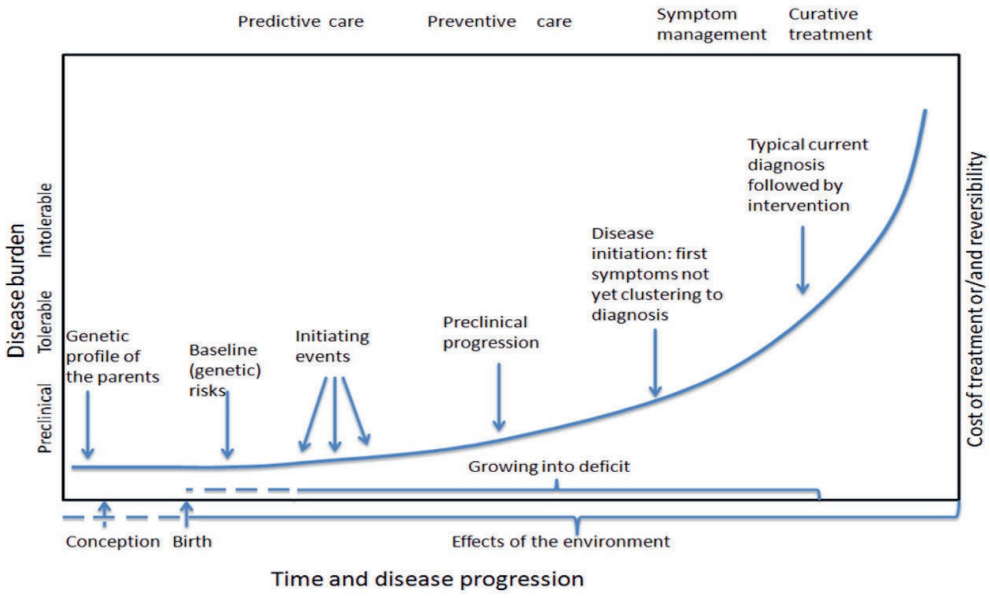

Figure 1. Adaptation of Snyderman's curve representing the timelines of growing into deficit and developing common complex diseases, adapted from Syurina et al, 2013, ref. 34.

Integrative research from a life course perspective

PCHC practice requires reliable and valid criteria for identifying emerging mental health and behavioural problems at a stage when symptoms do not yet cluster into to specific diagnostic entities as described in mental health classification systems (14, 35, 36).

Integrative research from an unified theory of development and a life course perspective is required to identify genetic baseline risks, initiating events and symptoms to prevent disease burden and enhance well-being (13, 37). These activities may be initiated by professionals but involve a partnership with parents and professionals in non-health care settings who come in contact with children and their families (19).

The MOM study. School readiness from the perspective of Personalized Child Health Care

In this chapter, the paradigm and methodology of the MOM study are described. Personalizing PCHC for early identification of preschool child health and developmental emerging problems is the rationale behind the MOM study. To prevent 'growing into deficit', the focus is on variation in dimensional measures of behavioural and developmental phenotypes that underlie preschool development, health and school readiness, which in turn is strongly associated with adult well-being (38, 39).

The main aim of the MOM study is to provide insight into developmental pathways impacting school readiness as an outcome of preschool healthy development, in order to nurture potential for all children from a live course perspective.

General research questions were (i) What is the predictive value of multi-informant perceived concerns in the preschool period at the age of 3 to 4 years in relation to preschool mental development and school readiness? (ii) What parental and environmental factors are most strongly associated with preschool mental development and school readiness at the age of 3 to 4 years? (iii) To what extent is the level of school readiness predicted by childhood developmental and environmental factors? (iv) Can the outcomes of the MOM study be translated to the practice of monitoring and multi-screening in PCHC?

School readiness as outcome

Optimal development during the preschool period enables children to master abilities essential for school readiness. School readiness can be seen as a transition between the home stage and the elementary stage, marked by the relation between shifts in the child and shifts in the context (13). It reflects the quality of the previous developmental period, and enables a person to become a successful participant in the process of mastering future developmental tasks (40). School readiness can be perceived as a dynamic outcome of preschool healthy development and resilience, predicting social participation, rather than as an exclusion criterion at the beginning of the formal educational experience (1, 4, 41, 42).

From a public health perspective, school readiness is a very useful construct, as it integrates multiple developmental pathways into a single 'hard' empirical outcome, which is associated with a range of adult mental health and social outcomes. Therefore, school readiness can be seen as an outcome as well as the starting point of a systemic multilevel investigation in order to characterize dimensional and multifaceted factors that shape

child healthy development and that sometimes may require intervention (14, 34, 40, 43-46). This is in accordance with the concept of 'mental capital', in addition to 'social capital', as a key domain of mental health promotion (47, 48). Mental capital refers to the totality of an individual's cognitive and emotional resources (49).

Multidimensional framework for health-related functioning

Multiple factors influencing developmental outcomes of children have to be described within a multidimensional perspective**:** health condition, body functions and body structures, activities of the person and participation of the person in society, and contextual factors such as environmental factors and personal factors (50). Regarding models of 'well-being' and Personalized PCHC, the components 'symptoms' and 'distress' needs special attention for early identification of 'growing into deficit'. The spectrum of symptoms along a continuum from normal variation to severe disorder has to be outlined into clinically meaningful gradations in relation to later adaptation and social participation (3, 51, 52). Different WHO-related or derived international classifications can be used in a complementary fashion in order to code and describe the different components (53).

The International Classification of Functioning (ICF) provides a framework of health-related functioning. This framework is based on a non-categorical approach to disability that describes the functioning of an individual in their current environment without the use of traditional disability categories or diagnoses (54, 55). The International Classification of Functioning, Disability and Health, Children and Youth version (ICF-CY) additionally includes learning and playing aspects and the developmental process. The expanded ICF–CY model as shown in figure 2 can be adapted for personalizing Preventive Public Mental Health and PCHC in relation to school readiness (54, 56, 57). Prevention of 'growing into deficit' requires attention to 'symptoms' and 'distress' in every component of this ICF-CY model.

Multi-axial Personalized PCHC profiles

The changes in functions, activities and participation of the child are reflecting different developmental domains. Each of the factors in these domains can be either a risk or a protective factor and subsequently predefine, evoke or maintain the variety of functional outcomes (44). Distinguishing these factors and indicators is of importance in making comprehensive multi axial health profiles for clinical decision support and symptom management. The perception of parents as well as kindergarten/day care providers, pre-school teachers (hereafter: professional caregivers) and PCHC professionals about

factors influencing child development play an important role (58-60). They are important perceivers with expert knowledge on child development from different perspectives (61). In addition, children's development and health are strongly influenced by how well their family functions. The transactional relation between regulation provided by the social context and self-regulation of the child is especially important in child mental health and 'growing into school readiness' (13). A strong and secure attachment bond with a primary caregiver is the core of developing resilience and a good health, and an important resource for successful social participation across the life span. (62-64). PCHC professionals and other healthcare professionals should be alert for parental health, and any imbalance between the parents' need for support and the support they actually receive (65).

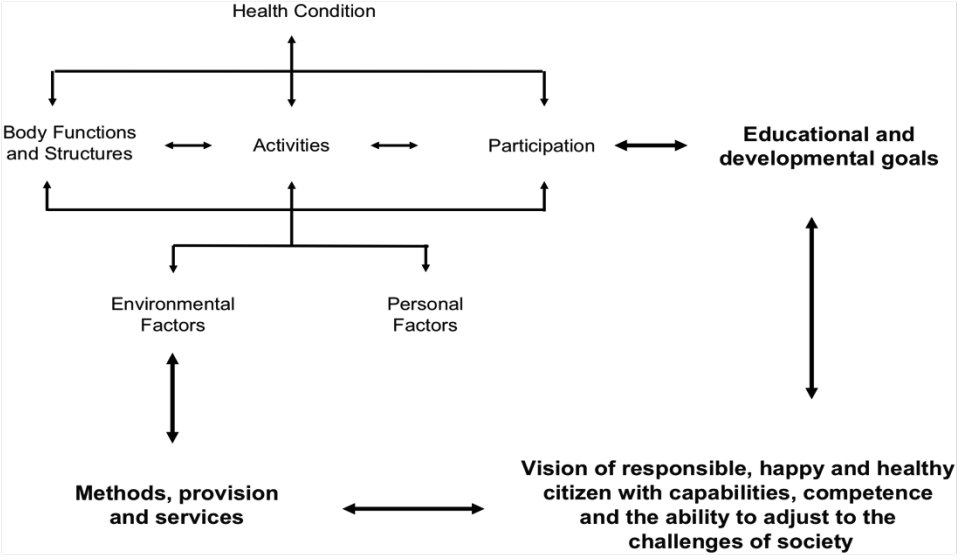

Figure 2. Expanded ICF model, adapted from Hollenweger, 2011, ref. 57.

The MOM study: outline of this thesis

PCHC toolkit for shared decision making

This thesis focuses in particular on the development and validation of a PHCH toolkit, with short tools assessing multiple constructs, to use as a first step in PCHC developmental health monitoring and shared decision making (11, 26, 66-71).

Like screening, the monitoring activities should adhere to the evidence-based principle that each such activity should lead to more benefit than harm (19). While the process of determining risk may for some issues resemble screening, it differs in that the response may be flexible or graded on a continuum. Service may be offered on the basis of risk alone; a diagnosable disorder does not need to be identified (19).

The integrated bio-psycho-socio-ecological approach as has been suggested by Sameroff fits with the philosophy of the field of child and youth care and provides an opportunity to utilize a variety of investigative tools that work together transactional (72). Selected variables and predictors in the MOM study influencing preschool mental health, school readiness and future mental health, have to be understood within interacting models of change and resilience across time: personal change, contextual change, regulation and representational change (21, 73, 74).

Prospective observational study

The MOM study was a prospective study within PCHC practice in Maastricht and surrounding area. A community-based sample of 346 children was systematically assessed with a comprehensive PCHC 'toolkit' of instruments using a multisource and cross-informant repeated measurement design to identify developmental pathways impacting school readiness. Children were aged three years at baseline and approximately four years at follow-up.

MOM obtained information from parents, professional caregivers and PCHC professionals on baseline risk and environmental factors to track predictive risk indicators influencing preschool mental health and subsequent school readiness. The MOM dataset also contains Developmental D-score data from 1602 children, measured on the Dutch Developmental Instrument (Van Wiechen) at consecutive visits at a well child centre.

Ethical standards

The MOM study has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All participating parents gave their informed consent prior to their inclusion in the study. The Maastricht University Medical Centre Medical Ethics Committee (METC) registration number of the MOM study is MEC 09-04-018/PL.

PHCH toolkit instruments

The MOM study PHCH toolkit instruments were chosen to facilitate personalizing PCHC for all children. These instruments should be appropriate to: (1) easily obtain information in the PCHC setting; (2) carry out dimensional assessment of symptoms and behaviour; (3) measure the progress of development of young children and their possible determinants of influence (18); (4) identify general signs and symptoms indicating a possible disruption or imbalance of the educational/parent-child system, not yet related to a specific diagnosis; (5) support communication between PCHC, parents and professional caregivers about their perceptions on health and development; (6) connect to the needs and demands of the child and the social system around the child; and promote shared decision making (18).

The intention is that MOM questionnaires become part of routine PCHC. So, instruments should be relatively short which is why Visual Analogue Scales (VAS) were developed. Not all instruments that were available have been validated before. Therefore, during the MOM study, the questionnaires included reference standards, to validate the MOM instruments. As shown in Fig. 3, the instruments in the MOM toolkit provided multi axial information about the attainment of the child's progress in the different outcome areas. The different instruments used in the MOM study are described in an appendix to this chapter.

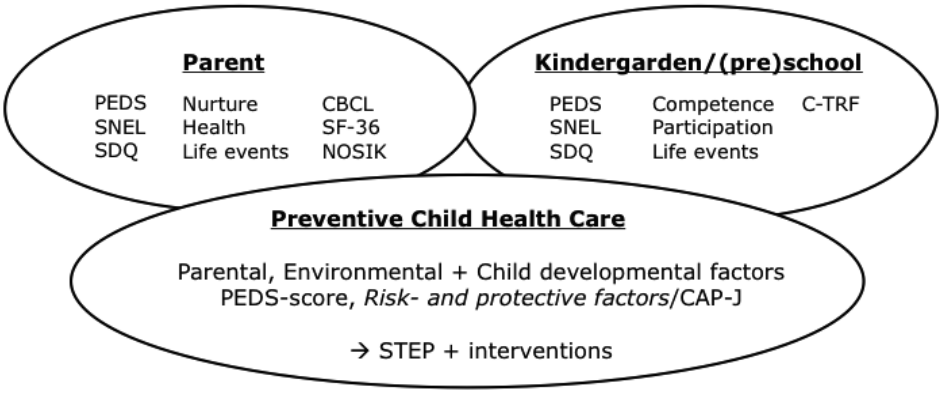

Figure 3. Mom study PCHC toolkit for multi-informant and multi- axial data collection

Key informants

At the age of 3 and 4 years, information was obtained from three different key informants: the parents/caregivers of the child, professional caregivers, and the PCHC professionals.

For each of the informants, individual comprehensive questionnaires were developed to collect information from child, environment, and their interaction and change over time. PCHC professionals were trained in communication and integrating information from multiple sources including observation, environmental input, and questionnaires and assessments tools. PCHC professionals completed a MOM questionnaire at age of 3 and 4 years, which contains information from the medical health record, PCHC assessments and the rating of the Parent's Evaluation of Developmental Status (PEDS). Information from birth till the age of 3 years was also retrospectively collected at baseline by the PCHC professional, including family-centered information (75, 76).

The key informants were able to participate through the cooperation and collaboration of various MOM study stakeholders. The different stakeholders are described and acknowledged in the section: Acknowledgement. 'It takes a village to raise a child'.

Outline of this thesis

Chapter 2 aims to define psychometric properties of the Dutch PEDS and three VAS about 'parenting', 'child behaviour' and 'child competence' at the age of 3 and 4 years. These instruments are a first step in validation of a potential future Dutch PCHC 'toolkit' with short instruments for multi axial and multi-informant screening and monitoring of general emerging problems and disabling symptoms.

Chapter 3 investigates 1) the validity of the Parents' Evaluation of Developmental Status (PEDS) to assess language development concerns; 2) the cross-sectional association of language development concerns with social participation; 3) the longitudinal association of language development concerns with social participation, and 4) the possible mediating effect of social competence on the association between language development and social participation at the ages of 3 and 4 years.

Chapter 4 examines the association between parental and professional caregivers' perception of early life stress (ELS) and social participation at preschool. In addition, the modifying effect of the risk factor 'parental health status' is assessed. In this study, social participation is operationalized using various instruments to assess factors underlying social participation: a child's general competence, attendance proportion and extra support (at day care, kindergarten and preschool), the impact of distress, concerns about child development and behaviour, and difficulties in child upbringing and parenting.

Chapter 5 explores early identification of a maladaptive system as a risk factor for child maltreatment. The association between different hypothesized parental risk factors and

social participation is assessed using 4 outcome measures: functioning of the child, quality of the environment, degree of care, and urgency of care. Two different risk factors are used: a cumulative risk factor and single risk factor. Various risk variables are included: parental concerns about parenting competency, child development and behaviour; parental health status; unstable parenting situation, and parental problems such as excessive amount of parental stress and parental traumatic experience. The cumulative risk factor is the total number of child and environmental risk factors present. Cross-sectional analyses are performed both with baseline data and with follow-up data. Similar findings at age 3 years and age 4 years could be interpreted both as a replication and as evidence that associations are similar at these ages.

Chapter 6 examines to what extent the Developmental score (D-Score) at the age of 2-2.5 years has added value as a brief monitoring tool in a comprehensive PCHC 'toolkit' of instruments as a short first step to identify emerging developmental problems impacting preschool social participation at the age of 4 years. In addition, various background characteristics (gender, parental educational status, age of the mother at birth of the child, hereafter maternal age) and risk factors in the family (parental health, parenting, early life stress, number of risk factors) are measured to determine the association with the D -score.

Chapter 7 summarizes and discuss the main research findings. Finally, benefits and future perspectives for personalized PCHC are discussed.

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Appendix.

MOM instruments

PEDS - Parents and professional caregivers completed the Parents' Evaluation of Developmental Status (PEDS), a 10-item standardized semi-structured questionnaire to elicit concerns regarding child development for children aged less than eight years in the general population and clinical samples (77). PEDS provides both open-ended questions and specific probes regarding concerns in various domains: expressive and receptive language, fine motor, gross motor, behaviour, socialization, self-care and learning. PCHC professionals categorized the parental PEDS-scores and the professional caregivers' PEDS-scores into various developmental domains using the PEDS Score Form. These developmental domains are: global/cognitive, expressive language and articulation, receptive language, fine-motor, gross motor, behaviour, social-emotional, self-help, school and health.

The PEDS is validated for clinical samples and general population samples aged between 0 and 8 years, and is available in multiple languages. In a validation US study the PEDS sensitivity was between 91-97% and specificity between 73-86% (78).

In collaboration with Frances Page Glascoe, the PEDS was translated into Dutch by a process of forward translation by a PCHC professional, rating by an expert team and backward translation by an independent English native speaker. Further adaptation was performed after a pilot in parents, which was followed by an interview. Subsequently, the PEDS was integrated into the parent and as well as the professional caregivers' questionnaire. These questionnaires were piloted to test the time to complete the questionnaires, to check for indistinct questions and to check whether the instructions were clear.

Parenting VAS - In order to quantify self-rated parental competencies, a 'parenting' Visual Analogue Scale (VAS) ranging from 0-100 was used; parents expressed the degree to which they felt competent, secure and happy with raising their child (0 = I do not manage to raise my child as I wish, 100 = raising my child is up to my expectations). A higher VAS score means parent judges 'parenting' more positive.

Child behaviour VAS - A 'child behaviour' VAS assessed how the parents evaluated their child's behaviour (0 = my child is difficult and badly behaved, 100 = my child is very obedient and easy to handle). A higher VAS score means parent judges 'child behaviour' more positive.

Parental Health Likert Scale - Parents were asked to judge their own physical and mental health as well as the physical and mental health of the other parent/caregiver, using a 5-point Likert Scale from 1 (bad) to 5 (excellent). Self-rated health status is a simple, yet widely used, measure with similar validity as more sophisticated health assessments; it is also a reliable predictor of mortality and health care use in adults (79). The four health variables were combined into one parental health variable, which was then dichotomized (fair and poor were recoded into 1 and excellent, very good and good were recoded into 0).

MOM included an extra data collection to assess reliability. The intra-rater test–retest reliability showed strong and significant correlations (Spearman correlation: parental and co-parental physical health = 0.92 and 0.99, respectively, $p<0.0001$; parental and co-parental mental health = 0.93 and 1.00, $p<0.0001$)

Furthermore, questions about how the parents judge their own physical and mental health are assessed using a 5-point Likert Scale from 1 (bad) to 5 (excellent).

Child competence VAS - To address the issue of the child's functional adaptation, professional caregivers were asked to score on a Visual Analogue Scales (VAS) the capability of the child in general (0= not competent, 100= very competent), as well as on three early child outcomes. These outcome measures are related to the qualities necessary for school readiness: 1) having positive social-emotional skills including social relationships (0= negative, 100=positive), 2) to acquire and use knowledge and skills, including early language/communication and early literacy (0= not at all, 100=optimal), 3) to use appropriate behaviours to meet their needs (0= not at all, 100=optimal). These overall functional outcomes emphasize the integration of skills and behaviours across developmental domains for meaningful action.

Attendance to school or preschool - To quantify participation, professional caregivers were asked about child attendance to school and/or day-care, and elementary school.

Extra support - Professional caregivers were asked if children receive extra support in one-way or the other, in- or outside preschool and school.

Early life stress- Parents and professional caregivers were asked an open-ended question about any major negative event in the child's life. Per life event described, the parents give an impact factor, ranging from 1 to 10, to quantify the impact the event had on their child (80, 81). To qualify the early life stress a child experienced, the 'Psychosocial and Environmental Stressor Checklist' of the DC:0-3R is used (82, 83). When multiple life

stressors are described, the life stressor with the highest impact factor is used to qualify and quantify the early life stress.

SNEL - The language-screening instrument SNEL (Spraak- en taal Normen Eerste Lijns gezondheidszorg) is a Dutch single, one-dimensional scale of 14 language milestones completed by parental as well as teacher report**.** It taps lexical, syntactic, and phonological skills, as well as both receptive and expressive language skills, and is well suited for mapping progress in language ability (84).

SDQ - The Strengths and Difficulties Questionnaire (SDQ) is used to assess children's behavior. The SDQ consists of 25 items relating to the child's strengths and difficulties, which are scored on a 3-point Likert scale (1 2 3) (85, 86).

Section two of the parent and professional caregiver questionnaires contained validated developmental screening tools to be used as reference standards: the Child Behavior Checklist (CBCL), the Caregiver-Teacher's Report Form (C-TRF), the 36-item Short Form health survey (SF-36) and the Parenting Stress Index Short Form. These instruments are well standardized and widely used in both clinical and research settings because of their demonstrated reliability and validity and their convenient applicability. Dutch versions were used.

CBCL - Parent reported behaviour problems of the children were assessed using the CBCL1½-5 (version 2001). It consists of 120 items on behaviour and emotional problems on a 3-point Likert scale (87, 88).

C-TRF - Professional caregivers reported behaviour problems were assessed using the C-TRF 1½ -5 (89). It consists of almost the same 120 items as the CBCL.

The Parenting Stress Index Short Form (in Dutch abbreviated as **NOSIK**) is a 25-item self-report instrument **to assess parental perceived difficulty in child raising.** Parental-stress-related statements are provided and parents can answer on a 5-point Likert scale ranging from 1 (totally disagree) to 5 (totally agree). The short form includes items with the best performance in the complete version of the Parenting Stress Index. The Crohnbach's alpha of the NOSIK total score is between 0.92 and 0.95 (90).

SF-36 - The SF-36 is a multi-purpose, short-form health survey for adults, so that **information on parental health and quality-of-life** can be obtained. It includes 36 questions and yields an 8-scale profile of functional health and well-being scores as well as psychometrically based physical and mental health summary measures and a preference-based health utility index. Each scale can be directly transformed into a 0-100 scale on

the assumption that each question carries equal weight. The eight sections are: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, and mental health. It is a generic measure, as opposed to one that targets a specific age, disease, or treatment group. The SF-36 has proven useful in surveys of general and specific populations, comparing the relative burden of diseases as well as in differentiating the health benefits produced by a wide range of different treatments (91).

Family history - Situations of problems in the biological family about multi-complex common disorders like asthma, diabetes, depression, developmental problems- as well as behavioural problems and learning disorders are collected (34, 92).

Examples of other **background factors** of the family and professional caregivers are: Parental age and nationality, Parental educational status, Parental profession and status of employment, Family status, Family language, professional caregivers' years of work experience.

Van Wiechen scheme and developmental D-score - MOM includes a quantitative Van Wiechen developmental score (D-score). The Van Wiechen scheme is a Dutch developmental instrument that is routinely used by all PCHC Centers in the Netherlands and Belgium to monitor the development of all children from birth to the age of four years. The scheme consists of a set of 57 developmental indicators. The basic assumption of the D-score is the existence of a common continuous scale for the development. Research shows that the quantitative D-score succeeds in representing outcomes of the instrument on a common interval scale. The definition of the D-scores is not specific to age, so the D-score of a measured person can be compared to the D-score of another person of a different age. Difference scores between sessions can be used to evaluate developmental velocity on the individual level (93).

Risk and protective factors - PCHC professionals were asked to notice risk and protective factors on multiple levels, including variable and fixed markers on biological, psychological, family, community, and cultural levels (94-96).

Severity - The PCHC doctor was trained to systematically rate the severity of the child's and environmental problems as well as the urgency of the intervention. Severity is defined as a comprehensive clinical judgment that communicates the relative urgency and seriousness of needs, above and beyond the child's disorder. Severity has four dimensions: symptoms, dysfunction, burden of suffering on the child/educational context, and risk/protective factors (51).

STEP - The Standard Taxation of Severity of Problems (Standaard Taxatie Ernst Problematiek, STEP) is used for taxation of the severity of the problems (97).

Interventions - PCHC professionals were asked to rate previous interventions, support and referrals to specialized (mental) health and community services.

CHAPTER 2

2

Validation of short instruments assessing parental and caregivers' perceptions on child health and development for personalized prevention.

Doove, B., Feron, J., Feron, F., Van Os, J. & Drukker, M. Validation of short instruments assessing parental and caregivers' perceptions on child health and development for personalized prevention. Clin Child Psychol Psychiatry, 2019: p. 1359104518822673.

Systematically exploring parental as well as other caregivers' concerns is a main component in Preventive Child Health Care (PCHC) for family centred practice and personalized health care. To facilitate communication and early identification of emerging mental health problems, a PCHC toolkit based on short instruments was developed. This paper investigates the reliability and validity of 1) two Visual Analogue Scales (VAS) to assess parent-reported 'parenting' and 'child behaviour'; 2) a professional caregiver-reported VAS to assess 'child competence'; and 3) the Parents' Evaluation of Developmental Status (PEDS) in Dutch PCHC. Parents as well as childcare, kindergarten and preschool teachers completed instruments in a community-based sample of children (n=346) aged 3 years at baseline. The 3 VAS and PEDS were associated with standardised questionnaires assessing the same constructs. Overall predictive accuracy showed: good to excellent for 'parenting' VAS, fair to good for 'child behaviour' VAS and poor for 'child competence' VAS. The PEDS, 'parenting' VAS and 'child behaviour' VAS, demonstrated high sensitivity at various cut-off points of index test and reference standard. At follow-up, approximately one year later, results were similar. Although the 'child competence' VAS scored lower on one aspect of validity, the PEDS and the different VAS are reliable, valid and useful as brief monitoring tools in daily Dutch PCHC practice.

Abstract

Introduction

Delayed or disrupted childhood development may lead to vulnerabilities and mental disorders during life, with a social and economic impact on society (1-3). Early identification of developmental problems can break the vicious circle of disadvantage. Supporting healthy development and successful social participation is also more cost-effective than treating disorders later (4-6).

From a public mental health perspective, children with symptoms of mental problems below the threshold of a full-blown disorder represent an important group. These children may have significant clinical needs and are at risk of arrested development, not achieving their potential and capabilities (7). The group of children with symptoms of mental problems may be twice as large as the group of children meeting formal diagnostic criteria for a mental disorder (8, 9).

The Dutch system for Preventive Child Health Care (PCHC) has been established to closely monitor the physical and mental development of all children during routine medical assessments in well-child care clinics offered by PCHC professionals (e.g. doctors, nurses) (10). Monitoring enables professionals to intervene in the earliest phase of emerging problems and disabling symptoms, even before formal criteria for diagnostic classifications are met (8, 11-13). It has been suggested, however, that the sensitivity for detecting early mental health problems and symptoms is low (2, 14-16).

From a dynamic transactional developmental perspective, health can be seen as the ability to adapt and self- manage in presence of social, physical, and emotional challenges (17, 18). The individual's social and educational environment including interpersonal relationships is hypothesized to be key to PCHC professionals aiming to provide personalized prevention. Parents are a key determinant of influence on their young children's health. Next to PCHC physical examination, periodic eliciting and addressing parental as well as other caregivers' perception and concerns is a main component in a family centred practice (19-21). Considering the fact that parents know their child best, an optimal communication between child health care providers, parents and other caregivers is essential for indicating the child's health, development and behaviour (22). Thus, Dutch PCHC has a Public Health task to address and influence school readiness before children enter school (23). From a dynamic transactional developmental perspective, school readiness can be seen as an outcome measure for preschool child health (24).

To improve early identification of health problems, PCHC needs to focus on 'predict it and personalize it' instead of 'find it and fix it'. Signals and problems meeting formal criteria for disorders represent the late stage of a dynamic process that can be identified in a much

earlier phase when treatment plasticity is still considerable (24-27). A screening toolkit including short instruments assessing multiple constructs was developed to use as a short first step in PCHC mental health screening and shared decision making (2, 26, 28-30).

The present paper aims to validate the Dutch version of the Parents' Evaluation of Developmental Status (PEDS). Research has shown that parent-completed screening tools are highly accurate in detecting true problems, are relatively inexpensive, and promote a dialogue about concerns, needs and demands between parents and other caregivers (31-33). In addition, visual analogue scales (VAS) were developed as short instruments on child upbringing (hereafter: parenting), child behaviour and child competence.

In a PCHC setting, screening tests with a high sensitivity are important to identify children in the earliest phase of emerging problems and disabling symptoms to prevent 'growing into deficit' (30). A high negative predictive value is preferable, it ensures that most children who pass the screening are truly healthy. Over-referrals in a first stage PCHC screening are no problem, they can benefit from additional preventive monitoring (34). Furthermore, PCHC screening and monitoring instruments should: 1) easily obtain information in every day PCHC setting; 2) carry out dimensional assessment of symptoms and behaviour; 3) measure the progress of development of young children and their possible determinants of influence; 4) identify general signals and symptoms indicating a possible disruption or imbalance of the educational /parent-child system, not yet related to a specific diagnosis; 5) support communication between PCHC, parents and teachers/employees from childcare, kindergarten, preschool or primary school (hereafter: professional caregivers) about their perceptions on health and development; 6) connect to needs and demands of the child and social system around the child, and; 7) promote shared decision making (30, 35).

Among the available validated parent-completed screening tools, the PEDS is designed to elicit concerns and facilitate communication between professionals and parents in addressing developmental and behavioural problems in children (36). Parents as well as professional caregivers can complete the questionnaire. Ten questions explore several concerns and answers are multiple-choice: "no", "a little", "yes". Subsequently, an open-ended field provides more information. PCHC professionals can use the PEDS in two ways: 1) as an informal means to elicit and to respond to parental concerns; 2) as a developmental screening test. It needs clinical judgement but takes only 5 minutes to categorize the parental or other caregivers' concerns in different developmental domains on the 'PEDS score sheet': global/cognitive, expressive language and articulation, receptive language, fine-motor, gross motor, behaviour, social-emotional, self-help, school and health. The 'PEDS Score Form' enables PCHC professionals to make decisions about high, moderate or low risk using the 'PEDS Interpretation Form'. The original PEDS as a screening tool has

a sensitivity of 91-97% and a specificity of 73-86% for accuracy of parental concerns in detecting children at high and/or moderate developmental risk (37). The PEDS is less time-consuming than other instruments, emphasis is on parental and other professional caregivers' opinions, it is validated for clinical samples and general population samples aged between 0 and 8 years, and is available in multiple languages. This suggests that the PEDS is an accurate tool for use as an initial screening and monitoring tool in Dutch PCHC, where professionals have to deal with the time constraints of daily practice (38).

Furthermore, in order to obtain more insight into risk and protective factors for developmental arrest, assessment of parental perception on 'parenting' and 'child behaviour', and professional caregivers' perception on 'child competence' is crucial (18, 39). It is known that short instruments like VAS can support communication between health providers and patients about their perceptions on health (40). The authors therefore developed 3 different VAS as possible PCHC 'toolkit' short instruments. Original questions were in Dutch. Each VAS is a single-item and continuous scale consisting of a horizontal line 100 millimetres (mm) in length anchored by two verbal descriptors, one for each symptom extreme. The respondent is asked to place a line perpendicular to the VAS line at the point that represents the intensity of the symptom. Using a ruler, the score is determined by measuring the distance (mm) on the 100 mm line between the symptoms extremes, providing a range of scores between 0-100 mm.

The 'parenting' VAS gives parents the opportunity to express the degree to which they feel competent, secure and happy with raising their child ranging from 0-100 (parenting VAS: 0 = I do not manage to raise my child as I wish, 100 = raising my child is up to my expectations). On the 'child behaviour' VAS, parents can evaluate their child's behaviour (child behaviour VAS: 0 = my child is difficult and badly behaved, 100 = my child is very obedient and easy to handle). To address the issue of the child's general functional adaptation to social, physical, and emotional challenges, professional caregivers can indicate on the 'child competence' VAS the degree of competence of the child in general (child competence VAS; 0 = not competent, 100 = very competent). The 'child competence' VAS is related to school readiness and 3 child outcomes: children have positive social relationships, children acquire and use knowledge and skills, and children take appropriate action to meet their needs. These outcomes are based on the assumptions that children of different ages demonstrate these outcomes in different ways with many pathways leading to competence.

Because these VAS were new, validation was required. In addition, the PEDS needed validation after translation into Dutch by the authors (see Methods).

In this paper, it is hypothesized that the total amount of parental and professional caregiver concerns is a valid signal for early detection of health problems. To detect problems and signals below the threshold of a full-blown disorder, continuous total problem score of the reference standard was used rather than the frequently used dichotomous clinical-borderline outcomes. To facilitate interpretability of the PEDS and the different VAS in daily PCHC practice, diverse cut-off points of both index test and reference standard were used to calculate different negative predictive values (NPV) and Receiver Operating Characteristic (ROC) curves. Eventually, the choice of an appropriate range along horizontal (false positives, 1-specificity) or vertical (sensitivity) axis depends upon the clinical setting. The different VAS cut-off points were set at 10th, 25th, and 50th percentile. Higher VAS scores means less perceived difficulties. Parental and professional caregiver PEDS cut-off points were 1, 2 or 3 and more concerns. All values above cut-off point were coded as high-perceived difficulty. Total amount and dichotomous 'parental concerns' and 'professional caregivers concerns' variables (any concern yes/no) and a 'PCHC professional decision about developmental risk' variable (high, moderate and low/no developmental risks) were constructed for use in the analyses as well.

The aim of this study is to define psychometric properties of the Dutch PEDS and three VAS about 'parenting', 'child behaviour' and 'child competence' at the age of 3 and 4 years, as a first step in validation of a potential future Dutch PCHC 'toolkit' with parent and other caregiver completed short instruments for multi axial and multi-informant screening and monitoring of general emerging problems and disabling symptoms.

Methods

Population and procedure

The present study was performed as part of the Monitoring Outcome Measurements of child development (MOM) study, a prospective observational study within PCHC practice. A community-based sample of children is systematically assessed using multisource and cross-informant repeated measurements designed to identify developmental pathways impacting school readiness as an outcome of social participation. Children were aged 3 years at baseline. MOM obtained information from parents, professional caregivers and PCHC professionals on baseline risk and environmental factors to track predictive risk indicators for making multiaxial health profiles.

The Maastricht University Medical Centre Medical Ethics Committee approved the MOM-study protocol under registration number MEC 09-04-018/PL. All persons involved provided written informed consent.

Parents of children born in the fourth quarter of 2006, 2007 and 2008 and living in Maastricht and surrounding municipalities were asked to participate in the MOM study. They received written information about the MOM study. A 'parent questionnaire' was included so that parents could see the questions that would be asked. After parents returned the signed consent form and the completed parent questionnaire, the professional caregiver of the participating child received a 'professional caregiver questionnaire' including the name of the participating child. The PCHC doctor of the participating child was then informed and asked to complete 1) a 'PCHC questionnaire' based on the information from the PCHC file and PCHC consultations, and 2) the 'PEDS score sheet' and 'PEDS interpretation form'.

Before including participants, managing boards of all PCHC, preschool and day-care organisations in Maastricht and the various surrounding municipalities were contacted, informed, and asked for their consent to participate the MOM study. All organisations and their professionals received written information. In total 46 day-care and 58 preschool classes agree to participate if parents were willing to participate the MOM study.

The PEDS was translated into Dutch in collaboration with the original author F. P. Glascoe, by a process of forward translation by a PCHC professional and backward translation by an independent English native speaker (36). Content validity and cultural appropriateness of the PEDS were discussed in both parents and professional caregivers. To prevent wording problems, further adaptation of the Dutch PEDS was performed after a pilot with parents and professional caregivers. Ten parents were asked to comment and discuss the different VAS, and the usefulness and feasibility of the Dutch PEDS after translation in Dutch. Thirty-six professional caregivers from 18 different day -care and preschool locations participated in a pilot to investigate the usefulness and feasibility of the MOM study questionnaire including the Dutch PEDS and the different VAS. All PCHC doctors received further training on the PEDS methodology and other instruments and in how to complete the 'PCHC questionnaire'.

Reference standards

To study various types of validity, different validated screening tools for emerging problems and disabling symptoms at the age of 3 and 4 years were included in the parental and professional caregivers MOM questionnaires, to be used as reference standard: CBCL total score for the child behaviour VAS and parental PEDS concerns, C-TRF total score for the child competence VAS and professional caregiver PEDS concerns, and NOSIK for the parenting VAS. For all index tests, the parental and professional caregivers SDQ were used as a reference standard for perceived impact of distress.

To screen children's behavioural, emotional and social functioning, the Child Behavior Checklist (CBCL), Dutch version 1½-5, 2001 (41), consists of 100 parent-reported problem

items. Based on the behaviour of the child in the preceding two months, each item is scored on a 3-point Likert scale: 0=not true, 1=somewhat true and 2=certainly true (42-44). The total problem score is computed by adding the sum of all 0-1-2 scores. Syndrome scales are part of the Internalizing and Externalizing broadband scales. The Internalizing scale consists of four scales: Emotionally Reactive (e.g. 'rapid shifts between sadness and excitement', 'disturbed by any change in routine'), Anxious/Depressed (e.g. 'Looks unhappy without good reason', 'nervous, high strung or tense'), Somatic Complaints (e.g. 'headaches', 'nausea, feels sick') and Withdrawn (e.g. 'refuses to play active games', 'seems unresponsive to affection'). The Externalizing scale contains two scales: Attention Problems (e.g. 'can't concentrate', 'wanders away') and Aggressive Behaviour (e.g. 'angry moods', 'defiant'). Good reliability and validity have been reported for the CBCL/1.5-5, also in the Netherlands (45).

The Caregiver-Teacher's Report Form (C-TRF) Dutch version1½ -5 (46) is used for professional caregivers-reported children's behavioural, emotional and social functioning. It is the professional caregiver version of the CBCL and consists of almost the same 100 items.

CBCL and C-TRF cut -off points differ between populations: between countries as well as within countries and age groups (47). If the clinical and borderline total score cut off points are set to high, a substantial part of the MOM study children would not be identified as 'at risk' children, suggesting an underestimation. Therefore, in this study, CBCL and C-TRF continuous total problem scores were used and total score cut off points were set at 10th, 25th and 50th percentile of the MOM study reference standard scores. To replace the clinical cut-off points, the percentile numbers are based on the current sample and were chosen arbitrary to cover a range.

The NOSIK is a 25-item self-report instrument to assess parental perceived difficulty in child rearing. Parental-stress-related statements are provided and parents can answer on a 5-point Likert scale ranging from 1 (totally disagree) to 5 (totally agree). The short form includes items with the best performance in the complete version of the Parenting Stress Index. The Cronbach's alpha of the NOSIK total score is between 0.92 and 0.95 (48). The NOSIK total score was obtained by adding the sum of all 1-5 scores, with a scoring range of 25-150. In this paper, NOSIK continuous total problem score was used and total problem score cut -off points were set at 7th, 12th and 31th percentile. Scores were calculated using non clinical cut-offs scores for the NOSIK: 74 (high –very high), 62 (above average) and 43 (average and below)(48).

The Dutch version of the extended Strengths and Difficulties Questionnaire (SDQ) was included to assess the child's behaviour and the impact of distress (49, 50). It is a brief

behavioural screening questionnaire for children aged 3-16 years with 25 items on strengths and difficulties. These 25 items are divided in 5 scales: 1) emotional symptoms; 2) conduct problems; 3) hyperactivity/inattention; 4) peer relationship problems; and 5) prosocial behaviour. The SDQ total difficulties sumscore is generated using the items of all subscales except prosocial behaviour. The extended SDQ includes an SDQ Impact of distress supplement with eight questions to identify the impact of the behavioural problems of the child. The first question asks whether the informant thinks the child has a problem, the remaining questions asses chronicity, distress, social impairment, and burden for others. From the SDQ, three dimensions can be inferred: perceived difficulties (is there a problem), impact score (distress and social incapacity on the child) and burden rating (do symptoms impose a burden). The SDQ is considered acceptable as a research instrument in community samples (51). Multi-informant SDQ's (parents, professional caregivers) at the age of 5 -17 years have a specificity of 80% and a sensitivity of 85% for the detection of child mental disorders (52). A more recent study in including parent SDQ only showed a lower but still acceptable validity (sensitivity of 0.76 at a cut-off point with specificity of 0.90) in a Dutch community population of children at the age of 3-4 years (31). In this study, the parental and the professional caregiver SDQ continuous total problem score, SDQ total score, SDQ conduct score and SDQ impact score are used. Parental SDQ total score cut off points were set at 12 (10th percentile) and 9 (21th percentile), professional caregiver SDQ total score at 15 (11th percentile) and 11 (23th percentile). These norm scores were determined from a sample of Dutch native children, representative for the Dutch population (53). The 'SDQ-impact score' refers to the impairment supplement and the 'probe question' refers to the first dimension: perceived difficulties (is there a problem). If any of the parents or professional caregivers scored 'yes' on the impact probe question in this study the dichotomous overall distress variable was set at 'yes'.

Statistical analysis

For this paper, data of parents, professional caregivers and PCHC professionals were analysed at the age of 3 years and at the next follow-up almost a year later. Data analysis was performed using Stata 13 (54). Background characteristics and mean scores of used instruments were calculated. In order to test representativeness, parental education of a random sample of 40% non-responders was manually collected from the medical PCHC files.

Validation of the Dutch PEDS and different VAS was performed based on criteria of the 'Consensus-based Standards for the selection of health Measurements INstruments (COSMIN) criteria for evidence (55).

Test–retest reliability of the three VAS and parental PEDS was examined in a separate data set. Seventeen parents and 20 professional caregivers completed the measurement twice within a period that no real change had occurred between sessions (6-7 days). The intraclass correlation coefficient (ICC) and 95% CI was calculated using the continuous variables (oneway random effect model, individual measurements)(56). In addition, Kappa was calculated using various cut –off points (57).

Parental concerns and professional caregivers' concerns were cross tabulated and a chi-square statistic was calculated to assess agreement and disagreement between informants**.**

Internal consistency of the PEDS items was tested as a measure of reliability by computing Cronbach Alpha coefficients. In addition, factor analysis assessed whether items load on the same factor.

Validity of the different VAS and PEDS, with respect to children's mental health, behaviour and parental perceived difficulty in child rearing, were examined.

For construct validity (whether instrument has associations with other constructs as expected), Spearman correlations between these instruments and validated instruments were calculated. In addition, associations between the different VAS and PEDS on the one hand, and the SDQ, CBCL, C-TRF and the NOSIK on the other hand, were analysed using linear (continuous outcomes) and logistic (dichotomous outcomes) regression analysis, in separate regression models. Results of linear regression analysis were standardised, i.e. all continuous variables were converted to variables with standard deviation of one. Normal distribution of the residuals and heteroscedasticity were checked after all linear regression analyses. Assumptions were violated, however violations were minor. Because regression analysis is relatively robust, results are assumed valid.

To compare the index instruments with well-established instruments assessing the same construct, criterion validity (sensitivity and specificity) and convergent validity (correlation between the two continuous variables) were assessed. Each of the VAS had a different reference standard: the NOSIK for the parenting VAS, the CBCL total score for the child behaviour VAS, and the C-TRF total score for the child competence VAS. Concerning general emerging problems and disabling symptoms, reference standards of the parental and professional caregiver PEDS were the CBCL respectively the C-TRF. Sensitivity, specificity and NPV of all index instruments were assessed and ROC curves were generated. Subsequently, the area under the ROC curve (AUROC) was calculated for the different VAS. To examine convergent and construct validity, each variable was entered in a separate regression model to measure the association between each index/

test measures and reference standards. It was hypothesized that there would be a stronger association between the reference standard and the index test and also an association between the index tests and other validated instruments, but not as strong.

Finally, external responsiveness of the different VAS was tested by comparing changes in VAS score between age 3 years and age 4 years with changes in their reference standard score, to detect change over time in the construct to be measured. Changes in the PEDS were related to changes in the SDQ, NOSIK, CBCL and C-TRF total score.

Results

Descriptives of the study sample

At baseline, questionnaires of 346 children were completed, 166 (48%) boys and 180 (52%) girls. In over 85% of the children, both parent and professional caregiver filled in the questionnaire. The mean age of the children at baseline was 3.0 (SD ± 0.2, Table 1). More than half of the parents had received higher education (63%). At baseline, parents scored on average 70.3 on the parenting VAS and 66.3 on the child behaviour VAS. Professional caregivers scored on average 63.7 on the child competence VAS. Parents of 147 children (43%) and professional caregivers of 162 children (54%) indicated any PEDS concern. Based on the PCHC 'PEDS interpretation form', 33 of 325 children (10%) were scored at 'high risk' at the age of 3 years, another 100 children (31%), were scored at "moderate risk'. The follow-up was approximately 10 months later (mean age 3.8; SD ± 0.2, Table 1).

Reliability and validity

The test–retest reliability of the different VAS showed a strong and significant correlation between two consecutive assessments (ICC: Parenting VAS=0.8, 95% CI 0.6-0.9; Child behaviour VAS=0.9, 95% CI 0.8-1.0; Child competence VAS = 0.9, 95% CI 0.8-1.0). The test–retest reliability of the parental PEDS was strong as well (ICC: 0.8, 95% CI 0.5-0.9). Various cut-off points of the different VAS and PEDS showed different Kappa's (Table 2).

Table 1. Descriptive statistics at base line (T1) and follow-up (T2)

Variable	N		Mean (S.D.)		Range			
	T1	T2	T1	T2	T1	T2		
Age in years	346	293	3.0 (0.2)	3.8 (0.2)	1.8-3.5	3.5-4.8		
Parenting VAS[1]	327	281	70.3 (18.8)	72.5 (16.5)	6-100	14-99		
Child's behaviour VAS[2]	329	279	66.3 (17.8)	67.8 (16.5)	1-97	11-100		
Child competence VAS[3]	290	251	63.7 (19.7)	69.7 (16.3)	4-100	10-99		
SDQ (parents)	338	293	6.8 (4.9)	6.1 (4.2)	0-28	0-27		
SDQ (prof.[4])	294	256	6.1 (5.0)	5.0 (5.0)	0-27	0-29		
NOSIK	336	289	41.4 (18.7)	38.9 (17.0)	25-140	25-134		
CBCL	331	285	21.3 (19.2)	17.8 (15.2)	0-117	0-109		
C-TRF	289	257	13.2 (17.1)	13.2 (15.7)	0-92	0-98		
			No concerns		**Concerns**			
PEDS (parents)	339	293	192 (57%)	167 (57%)	147(43%)	126 (43%)		
PEDS (prof.[4])	300	257	138 (46%)	144 (56%)	162 (54%)	113 (44%)		
	T1	T2	T1	T2	T1	T2	T1	T2
			Low risk		**Moderate risk**		**High risk**	
PEDS (PCHC)	325	312	192 (59%)	206 (66%)	100 (31%)	84 (27%)	33 (10%)	22 (7%)
			Normal		**Borderline**		**Abnormal**	
SDQ impact (parents)	340	292	307 (90%)	271 (93%)	6 (2%)	8 (3%)	27 (8%)	13 (4%)
SDQ impact (prof.[4])	292	254	248 (85%)	223 (88%)	0	0	44 (15%)	31 (12%)

VAS: visual analogue scale; SDQ: Strengths and Difficulties Questionnaire; NOSIK: Parenting Stress Index Short Form; CBCL: Child Behavior Checklist; C-TRF: Caregiver-Teacher's Report Form; PEDS: Parent's Evaluation of Developmental Status; PCHC: Preventive Child Health Care; [1] A higher VAS score means parent judges parenting more positive; [2] A higher VAS score means parent judges child behaviour more positive; [3] A higher VAS score means professional caregiver judges child competence more positive; [4] Professional caregivers.

Table 2. Test–retest reliability: Kappa at different cut off points different VAS and parental PEDS

	Parenting VAS			Child behaviour VAS			Child competence VAS			Parental PEDS concerns		
Cut off point[1]	42[$]	64	74	44	55	69	39	50	67	3	2	1
Kappa		0.42	0.75	0.43	0.82	0.85	0.47	1.00	0.52	0.64	0.82	0.64

VAS: visual analogue scale; PEDS: Parent's Evaluation of Developmental Status;
Kappa: 0-0.20 = 'slight'; 0.21-0.40 = 'fair'; 0.41-0.60 = 'moderate'; 0.61-0.80 = 'substantial'; above 0.81 = 'almost perfect'
[1] When dichotomising the different VAS cut-off point and amount of PEDS concerns, all values below are coded as high perceived difficulty; [$] No Kappa available.

There was a statistically significant association between parental concerns and professional caregivers' PEDS concerns both at baseline and at follow-up (Chi-square =34.8; df =1, p<0.001 and 8.1; df=1, p=0.004, respectively).

Internal consistency of the PEDS was tested and factor analysis revealed that all parental PEDS items loaded on one factor. Professional caregiver PEDS items loaded on 2 factors,

but the second factor provided no added value. In both parental PEDS and professional caregivers' PEDS, loadings of individual items were not strong (loadings between 0.33 and 0.70 and between 0.09 and 0.64, respectively). Cronbach's alpha of the PEDS was 0.7 in parents and 0.6 in professional caregivers.

For construct validity, the three VAS were correlated with the SDQ total score, the SDQ conduct subscale, the CBCL, the C-TRF and the NOSIK. Higher VAS scores means less perceived difficulties on parenting, child behaviour or child competence, therefore the higher the VAS, the lower the scores on these validated instruments. Table 3 presents correlations including those between the different VAS and their reference standard at the age of three years and replicated with data collected approximately a year later (Spearman correlation: Parenting VAS - NOSIK = -0.57 and -0.48, $p<0.001$; Child behaviour VAS - CBCL = -0.56 and -0.57, $p<0.001$; Child competence VAS –C-TRF = -0.40 and -0.32, $p<0.001$; Table 3).

Linear regression analyses showed associations between the VAS, PEDS and various validated outcomes (Table 4). For example, parents who indicated more parenting difficulties also showed significantly higher problem scores on the NOSIK ($\beta= -0.7$, $p<0.001$) and the SDQ parents total score (parents $\beta = -0.5$, $p<0.001$). The association between child behaviour VAS and professional caregivers SDQ showed a small effect size according to Cohen (58, 59), but the association was statistically significant ($p<0.001$). The association between the competence VAS and outcomes assessed by the parents was also small, but significant. All other associations between continuous variables (first 3 rows of Table 4) showed intermediate or large effect sizes. In addition, logistic regression showed strong associations between all three VAS and the dichotomous SDQ impact variables. The linear and logistic regression analyses showed strong associations as well between parental PEDS concerns, professional caregivers PEDS concerns and PCHC PEDS interpretation and various validated instruments (Table 4). When analyses were repeated in the follow-up data, results were similar. Some associations were weaker but remained significant, with one exception. There was no significant association between professional caregiver PEDS concerns and the NOSIK.

Table 3. Spearman rho correlations between three VAS scales and validated instruments at base line (T1) and follow-up (T2)

		Parents						Professional caregivers			
		Parenting VAS [1]	Child's behaviour VAS [2]	NOSIK Total score	SDQ total score	SDQ conduct	CBCL total score	Child competence VAS [3]	SDQ total score	SDQ conduct	C-TRF total score
Parents											
Parenting VAS[1]		1									
Child's behaviour VAS[2]	T1	0.64†	1								
	T2	0.63†									
NOSIK total score	T1	-0.57†	-0.43†	1							
	T2	-0.48†	-0.46†								
SDQ total score	T1	-0.47†	-0.46†	0.49†	1						
	T2	-0.45†	-0.49†	0.45†							
SDQ conduct	T1	-0.49†	-0.54†	0.43†	0.59†	1					
	T2	-0.44†	-0.56†	0.37†	0.58†						
CBCL total score	T1	-0.57†	-0.56†	0.68†	0.69†	0.54†	1				
	T2	-0.51†	-0.57†	0.62†	0.71†	0.46†					
Professional caregivers											
Child competence VAS[3]	T1	0.11	0.17**	-0.12	-0.29†	-0.13*	-0.21†	1			
	T2	0.15	0.11	-0.01	-0.21**	-0.09	-0.16*				
SDQ total score	T1	-0.14*	-0.20**	0.23†	0.35†	0.19**	0.32†	-0.47†	1		
	T2	-0.23†	-0.19**	0.16*	0.31†	0.25†	0.31†	-0.32†			
SDQ conduct	T1	-0.18**	-0.20**	0.20**	0.18**	0.25†	0.24†	-0.17**	0.60†		
	T2	-0.22†	-0.25†	0.16*	0.19**	0.28†	0.22**	-0.07	0.60†	1	
C-TRF total score	T1	-0.24†	-0.33†	0.25†	0.29†	0.21†	0.31†	-0.40†	0.65†	0.46†	1
	T2	-0.26†	-0.21**	0.22**	0.27†	0.29†	0.32†	-0.32†	0.73†	0.51†	

VAS: visual analogue scale; NOSIK: Parenting Stress Index Short Form; SDQ: Strengths and Difficulties Questionnaire; CBCL: Child Behavior Checklist; C-TRF: Caregiver-Teacher's Report Form;
* $p<0.05$; ** $p<0.01$; † $p<0.001$;
[1] A higher VAS score means parent judges parenting more positive;
[2] A higher VAS score means parent judges child behaviour more positive;
[3] A higher VAS score means professional caregiver judges child competence more positive.

Table 4. Linear regression analysis and logistic regression analyses to analyse the association between 3 VAS-scales and PEDS (in separate regression models) and various validated outcomes (such as NOSIK, SDQ, CBCL, C-TRF) at base line (T1) and follow-up (T2)

		Parents			Professional caregivers	
Total score		**SDQ**	**CBCL**	**NOSIK**	**SDQ**	**C-TRF**
		β (95% CI)	**β (95% CI)**	**β (95% CI)**	**β (95% CI)**	**β (95% CI)**
Parenting VAS (parents)[1]	T1	-0.5 (-0.6; -0.4)†	-0.6 (-0.7; -0.5)†	-0.7 (-0.7; -0.6)†	-0.2 (-0.3; -0.8)**	-0.3 (-0.4; -0.2)†
	T2	-0.5 (-0.6; -0.4)†	-0.6 (-0.7; -0.5)†	-0.5 (-0.6; -0.4)†	-0.4 (-0.5; -0.3)†	-0.4 (-0.5; -0.2)†
Child behaviour VAS (parents)[2]	T1	-0.5 (-0.6; -0.4)†	-0.5 (-0.6; -0.5)†	-0.5 (-0.6; -0.4)†	-0.2 (-0.3; -0.1)†	-0.4 (-0.5; -0.3)†
	T2	-0.5 (-0.6; -0.4)†	-0.5 (-0.6; -0.4)†	-0.5 (-0.6; -0.4)†	-0.2 (-0.4; -0.1)†	-0.2 (-0.4; -0.1)†
Child competence VAS (prof.[4])[3]	T1	-0.3 (-0.4; -0.2)†	-0.3 (-0.4; -0.2)†	-0.3 (-0.4; -0.1)†	-0.6 (-0.7; -0.5)†	-0.6 (-0.7; -0.5)†
	T2	-0.3 (-0.4; -0.2)†	-0.3 (-0.4; -0.2)†	-0.2 (-0.3; -0.1)**	-0.5 (-0.6; -0.4)†	-0.4 (-0.5; -0.3)†
PEDS concerns yes/no (parents)	T1	0.5 (0.4; 0.7)†	0.6 (0.5; 0.8)†	0.5 (0.4; 0.7)†	0.3 (0.1; 0.4)†	0.3 (0.2; 0.5)†
	T2	0.6 (0.4; 0.9)†	0.8 (0.6; 1.0)†	0.7 (0.4; 0.9)†	0.5 (0.3; 0.8)†	0.5 (0.3; 0.8)†
PEDS concerns yes/no (prof.[4])	T1	0.5 (0.3; 0.7)†	0.5 (0.3; 0.7)†	0.4 (0.2; 0.7)†	0.9 (0.7; 1.0)†	0.6 (0.5; 0.8)†
	T2	0.4 (0.2; 0.7)**	0.4 (0.2; 0.7)**	0.1 (-0.1; 0.4)	1.0 (0.7; 1.1)†	0.8 (0.6; 1.0)†
PEDS interpretation High-moderate / Low risk (PCHC)	T1	0.7 (0.4; 0.9)†	0.7 (0.5; 0.9)†	0.6 (0.3; 0.8)†	0.7 (0.5; 0.9)†	0.6 (0.4; 0.8)†
	T2	0.5 (0.2; 0.7)†	0.4 (0.2; 0.7)**	0.3 (0.1; 0.6)**	0.5 (0.3; 0.8)†	0.5 (0.3; 0.8)†

		SDQ impact (parents)	SDQ impact (prof. [4])
		OR (95% CI)	**OR (95% CI)**
Parenting VAS (parents)[1]	T1	0.3 (0.2; 0.4)†	0.6 (0.5; 0.8)**
	T2	0.3 (0.2; 0.5)†	0.5 (0.4; 0.8)**
Child behaviour VAS (parents)[2]	T1	0.4 (0.2; 0.5)†	0.6 (0.4; 0.8)**
	T2	0.4 (0.3; 0.6)†	0.7 (0.5; 1.0)
Child competence VAS (prof.[4])[3]	T1	0.4 (0.3; 0.6)†	0.2 (0.1; 0.3)†
	T2	0.4 (0.3; 0.7)†	0.2 (0.1; 0.3)†
PEDS concerns yes/no (parents)	T1	24.8 (5.8; 106)†	4.7 (2.2; 9.8)†
	T2	14.8 (3.4; 64.8)†	3.9 (1.6; 9.8)**
PEDS concerns yes/no (prof.[4])	T1	14.5 (3.4; 62.3)†	52.2 (7.1; 385)†
	T2	3.2 (1.2; 8.7)*	25.4 (5.9; 109)†
PEDS interpretation High-moderate /Low risk (PCHC)	T1	5.2 (2.3; 12.0)†	5.1 (2.5; 10.7)†
	T2	3.4 (1.3; 8.4)*	2.5 (1.2; 5.4)*

NOSIK: Parenting Stress Index Short Form; SDQ: Strengths and Difficulties Questionnaire; CBCL: Child Behavior Checklist; C-TRF: Caregiver-Teacher's Report Form; VAS: visual analogue scale; PEDS: Parent's Evaluation of Developmental Status; PCHC: Preventive Child Health Care; CI: confidence interval; OR: odds ratio (obtained from logistic regression); Cells in grey present analysis with an index test and the reference standard of that specific index test; β=standardised regression coefficient.

[1] A higher VAS score means parent judges parenting more positive;

[2] A higher VAS score means parent judges child behaviour more positive;

[3] A higher VAS score means professional caregiver judges child competence more positive;

[4] Professional caregivers.

*p <0.05; **p <0.01; †p <0 .001;

In relation to criterion validity: diagnostic accuracy of the Parenting VAS, including AUROC, sensitivity, specificity and NPV is shown in table 5A and figure 1. At baseline, when dichotomising the reference standard cut-off point and all values above are codes as high-perceived difficulty, the different VAS are performing excellent to poor. Different AUROC's are: Parenting VAS – NOSIK 94.0, 87.8, 79.8; Child behaviour VAS – CBCL 84.4, 80.8, 76.9; Child competence VAS –C-TRF 89.5, 72.8, 66.2 (Table 5 to 7). At the follow up moment almost a year later, results were similar. Table 8 and 9, figure 2 and 3 show the diagnostic accuracy of the parental and professional caregiver PEDS, depending on various cut-of points of the CBCL and C-TRF as reference standard and the PEDS at baseline. At the follow up moment almost a year later, results were similar. (Other figures are available on request).

Table 5. Parenting VAS with different AUROC and a variation of sensitivity, specificity and negative predictive values (NPVs) as a result of different VAS and reference standard cut-off points, at base line (T1) and follow-up (T2)

Various cut-off points of the NOSIK[1] (Perceived difficulties)	AUROC (%) (CI 95%)		Various cut-off points of the Parenting VAS[2]		Sensitivity/ specificity (%)		NPV (%)	
	T1	T2	T1	T2	T1	T2	T1	T2
74 (High –very high)	94.0 (90.1; 97.8)	87.8 (76.1; 99.5)	< 42	< 49	77.3 / 95.0	62.5 / 92.4	98.3	97.6
			< 64	< 66	90.9 / 78.4	87.5 / 75.2	99.2	99.0
			< 74	< 75	100 / 52.5	93.8 / 51.9	100	99.3
62 (Above average)	87.8 (81.5; 94.2)	85.9 (76.2; 95.5)	< 42	< 49	55.0 / 96.5	52.4 / 92.6	93.8	96.0
			< 64	< 66	77.5 / 80.9	81.0 / 75.9	96.2	98.0
			< 74	< 75	90.0 / 54.1	90.5 / 52.5	97.5	98.5
43 (Average and below)	79.8 (74.6; 85.0)	80.7 (75.9; 86.6)	< 42	< 49	26.5 / 97.7	31.3 / 95.7	74.2	81.5
			< 64	< 66	54.9 / 86.9	62.7 / 82.5	80.7	87.4
			< 74	< 75	81.4 / 62.4	82.1 / 59.2	87.9	91.2

VAS: visual analogue scale; AUROC: area under the receiver operating characteristic curve; NPV: negative predictive value; CI: confidence interval. AUROC: > 90% = excellent; 80-90% = good; 70-80% = fair; 60-70% = poor;

[1] When dichotomising the reference standard cut-off point all values above are coded as difficult parenting from the perspective of the parent;

[2] A higher VAS score means parent judges parenting more positive; the different VAS cut-off points were set at 10%, 25% and 50%.

Table 6. Child behaviour VAS with different AUROC and a variation of sensitivity, specificity and negative predictive values (NPVs) as a result of different VAS and reference standard cut-off points, at base line (T1) and follow-up (T2)

Various cut-off points of the CBCL[1,2]		AUROC (%) (CI 95%)		Various cut-off points of the Child behaviour VAS[3]		Sensitivity/ specificity (%)		NPV (%)	
T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
43+>	36+>	84.4 (76.6; 92.3)	82.0 (73.2; 90.7)	< 44	< 47	60.0 / 94.8	44.4 / 93.1	95.1	93.8
				< 55	< 60	71.4 / 80.8	70.4 / 78.8	95.9	96.0
				< 69	< 69	88.6 / 51.8	88.9 / 51.8	97.4	97.7
28+>	23+>	80.8 (75.4; 86.3)	79.8 (74.1; 85.5)	< 44	< 47	35.4 / 97.1	27.5 / 95.1	81.4	79.4
				< 55	< 60	57.3 / 86.2	53.6 / 83.3	85.5	84.1
				< 69	< 69	82.9 / 57.7	81.2 / 57.6	90.8	90.0
16+>	14+>	76.9 (71.8; 82.0)	75.5 (69.7; 81.2)	< 44	< 47	20.5 / 98.1	19.6 / 99.2	55.1	52.7
				< 55	< 60	41.6 / 91.9	39.2 / 88.4	60.1	56.7
				< 69	< 69	71.4 / 66.3	70.6 / 68.2	69.7	67.7

VAS: visual analogue scale; AUROC: area under the receiver operating characteristic curve; NPV: negative predictive value; CI: confidence interval. CBCL; Child Behavior Checklist.
AUROC: > 90% = excellent; 80-90% = good; 70-80% = fair; 60-70% = poor;
[1] When dichotomising the reference standard cut-off point all values above are coded as bad child behaviour from the perspective of the parent;
[2] The different CBCL cut-off points were set at 10%, 25% and 50%; the higher the score the more perceived problems;
[3] A higher VAS score means parent judges child behaviour more positive; the different VAS cut-off points were set at 10%, 25% and 50%.

Table 7. Child competence VAS with different AUROC and a variation of sensitivity, specificity and negative predictive values (NPVs) as a result of different VAS and reference standard cut-off points, at base line (T1) and follow-up (T2)

Various cut-off points of the C-TRF[1,2]		AUROC (%) (CI 95%)		Various cut-off points of the Child competence VAS[3]		Sensitivity/ specificity (%)		NPV (%)	
T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
31+>	28+>	89.5 (82.0; 97.0)	76.4 (65.7; 87.1)	< 39	< 48	58.6 / 96.4	44.8 / 92.8	95.3	92.8
				< 50	< 61	82.8 / 82.8	62.1 / 77.9	97.6	94.0
				< 67	< 71	93.1 / 54.4	79.3 / 53.6	98.6	95.2
16+>	14+>	72.8 (65.3; 80.3)	65.5 (57.8; 73.2)	< 39	< 48	28.8 / 97.6	27.0 / 94.9	79.5	75.5
				< 50	< 61	49.3 / 85.0	41.9 / 79.7	82.6	76.6
				< 67	< 71	74.0 / 57.8	60.8 / 54.2	86.2	76.8
7+>	6+>	66.2 (59.8; 72.5)	63.4 (56.3; 70.4)	< 39	< 48	17.5 / 100	15.7 / 95.7	51.4	39.6
				< 50	< 61	34.9 / 88.5	32.7 / 83.7	54.3	41.8
				< 67	< 71	60.4 / 60.8	56.0 / 59.8	57.3	44.0

VAS: visual analogue scale; AUROC: area under the receiver operating characteristic curve; NPV: negative predictive value; C-TRF: Caregiver-Teacher's Report Form; CI: confidence interval.
AUROC: > 90% = excellent; 80-90% = good; 70-80% = fair; 60-70% = poor;
[1] When dichotomising the reference standard cut-off point all values above are coded as low competence from the perspective of the professional caregiver;
[2] The different C-TRF cut-off points were set at 10%, 25% and 50%; the higher the score the more perceived problems;
[3] A higher VAS score means professional caregiver judges child competence more positive; the different VAS cut-off points were set at 10%, 25% and 50%.

Table 8. Parental PEDS concerns with a variation of sensitivity, specificity and negative predictive values (NPVs) as a result of different amount of PEDS concerns and reference standard cut-off points, at base line (T1) and follow-up (T2)

Various cut-off points of the CBCL[1,2]		Various cut-off points amount of Parental PEDS concerns		Sensitivity/ specificity (%)		NPV (%)	
T1	T2	T1	T2	T1	T2	T1	T2
43+>	36+>	3+>	3+>	94.4 / 63.5	89.7 / 62.9	98.9	98.2
		2+>	2+>	80.6 / 80.2	72.4 / 82.8	97.1	96.4
		1+>	1+>	58.3 / 90.4	58.6/ 93.8	94.6	95.2
28+>	23+>	3+>	3+>	79.8 / 69.8	75.0 / 68.5	91.0	89.0
		2+>	2+>	59.5 / 84.9	50.0 / 86.4	86.0	83.6
		1+>	1+>	41.7 / 94.3	31.9/ 95.3	82.5	80.5
16+>	14+>	3+>	3+>	64.5 / 79.1	56.6 / 73.7	68.6	59.8
		2+>	2+>	43.4 / 90.8	34.9 / 91.0	61.2	55.0
		1+>	1+>	26.0 / 96.3	18.4 / 96.2	56.1	50.8

PEDS: Parent's Evaluation of Developmental Status; NPV: negative predictive value; CBCL: Child Behavior Checklist;
[1] When dichotomising the reference standard cut-off point all values above are coded as high-perceived difficulties;
[2] The different CBCL cut-off points were set at 10%, 25% and 50%; the higher the score the more perceived problems.

Table 9. Professional caregiver PEDS concerns with a variation of sensitivity, specificity and negative predictive values (NPVs) as a result of different amount of PEDS concerns and reference standard cut-off points, at base line (T1) and follow-up (T2)

Various cut-off points of the C-TRF[1,2]		Various cut-off points amount of Professional caregiver PEDS concerns		Sensitivity/ specificity (%)		NPV (%)	
T1	T2	T1	T2	T1	T2	T1	T2
31+>	28+>	3+>	3+>	100 / 51.9	93.5 / 62.8	100	98.6
		2+>	2+>	100 / 72.9	87.1 / 80.1	100	97.8
		1+>	1+>	96.6 / 83.1	71.0 / 89.4	99.5	95.7
16+>	14+>	3+>	3+>	89.5 / 59.6	73.7 / 68.5	94.1	86.1
		2+>	2+>	77.6 / 79.8	61.8 / 86.2	90.9	84.3
		1+>	1+>	64.5 / 89.2	44.7 / 93.4	87.5	80.1
7+>	6+>	3+>	3+>	78.1 / 75.4	55.2 / 75.5	74.8	49.3
		2+>	2+>	56.8 / 89.6	38.7 / 90.4	64.2	45.9
		1+>	1+>	43.2 / 96.3	26.4/ 96.8	59.4	43.1

PEDS: Parent's Evaluation of Developmental Status; NPV: negative predictive value; TRF: Caregiver-Teacher's Report Form

[1] When dichotomising the reference standard cut-off point all values above are coded as high-perceived difficulties;

[2] The different C-TRF cut-off points were set at 10%, 25% and 50%; the higher the score the more perceived problems.

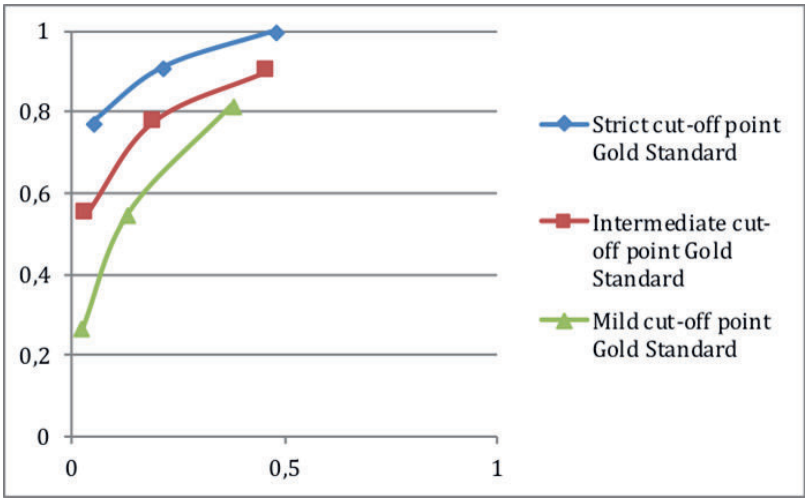

Fig. 1 Different cut –off points Parenting VAS and NOSIK: strict-intermediate and mild, at baseline (T1)

NOSIK: Parenting Stress Index Short Form; VAS: visual analogue scale.

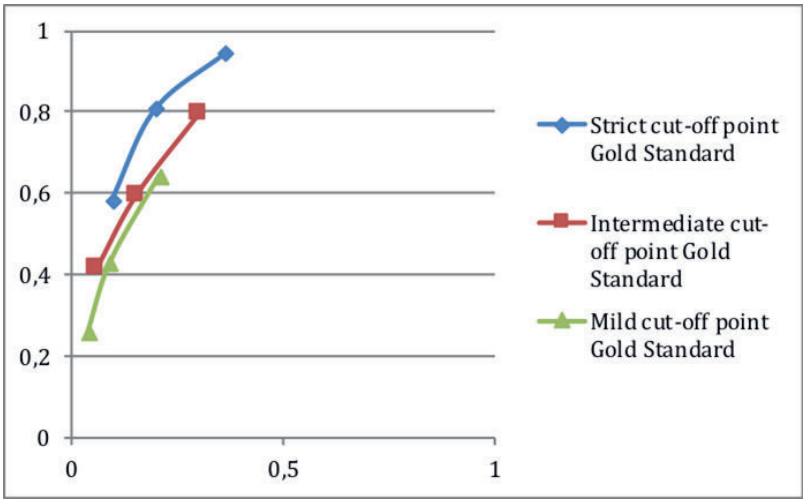

Fig. 2 Different cut –off points PEDS parent and CBCL: strict-intermediate and mild, at baseline (T1)

CBCL: Child Behavior Checklist; PEDS: Parent's Evaluation of Developmental Status.

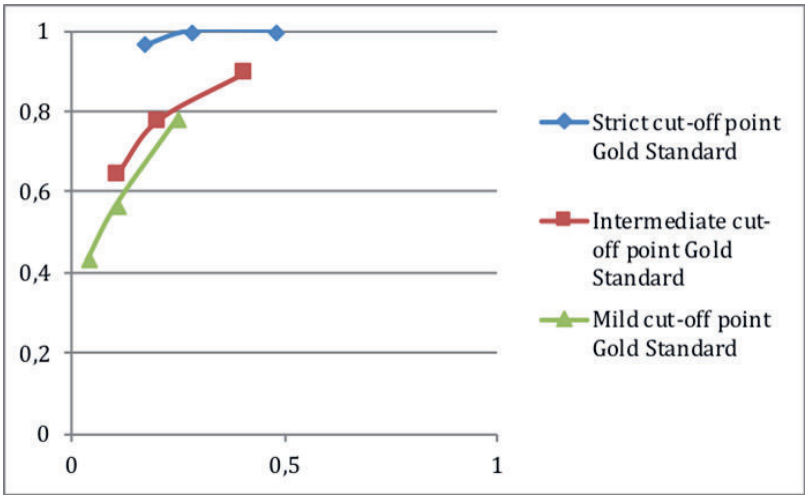

Fig. 3 Different cut –off points PEDS professional caregiver and C-TRF: strict-intermediate and mild, at baseline (T1)

C-TRF: Caregiver-Teacher's Report Form; PEDS: Parent's Evaluation of Developmental Status.

Changes in VAS were associated with changes in reference standard, but correlations were relatively low (Table 10, external responsiveness). Potential outliers were checked

manually and twice a parent reversed the VAS scoring which was corrected. Changes in parental and professional caregiver PEDS concerns were associated with changes in SDQ impact scores.

Table 10. Spearman correlations between change scores in VAS-scales and PEDS and changes in their reference standard (external responsiveness)

Changes between baseline and follow-up in VAS and PEDS:	Changes in reference standard	Spearman correlation
Parenting VAS (parents)[2]	NOSIK	-0.35†
Child behaviour VAS (parents)[3]	SDQ (parents)	-0.13*
Child behaviour VAS (parents)[3]	CBCL	-0.38†
Child competence VAS (prof [1])[4]	SDQ (prof[1])	-0.36†
Child competence VAS (prof [1])[4]	C-TRF	-0.26†
PEDS concerns yes/no (parents)	Impact SDQ (parents)	0.26†
PEDS concerns yes/no (prof [1])	Impact SDQ (prof[1])	0.27†

NOSIK: Parenting Stress Index Short Form; SDQ: Strengths and Difficulties Questionnaire; CBCL: Child Behavior Checklist; C-TRF: Caregiver-Teacher's Report Form; VAS: visual analogue scale; PEDS: Parent's Evaluation of Developmental Status.
[1] Professional caregivers.
[2] A higher VAS score means parent judges parenting more positive;
[3] A higher VAS score means parent judges child behaviour more positive;
[4] A higher VAS score means professional care giver judges child competence more positive;
* $p<0.05$; ** $p<0.01$; † $p<0.001$;

Discussion

Thus, the Dutch PEDS, a 'child behaviour' VAS, a 'parenting' VAS, and a 'child competence' VAS, at the age of 3 and 4 years demonstrate good psychometric properties.

Test-retest reliability

This study showed a good test-retest reliability of the different VAS and PEDS. Internal consistency on the PEDS was weak. This was expected because of the characteristics of the PEDS with the underlying factor structure and results in previous studies (37); answers to each PEDS questions contribute uniquely to the overall result.

Both versions of the PEDS concerns were strongly associated but overlap was far from 100%, indicating important contextual effects. This supports the usefulness of the multi-informant procedure as applied in the MOM study.

Construct validity

All three VAS as well as the PEDS were also moderately but significantly correlated with the NOSIK as well as with the SDQ, CBCL, and C-TRF in the expected direction. Standardised

effect sizes showed a relatively strong association between the parenting VAS and the NOSIK, the child behaviour VAS and the CBCL, and the child competence VAS and the C-TRF.

Criterion and convergent validity

Table 4 shows the associations between index test and different validated instruments. The parenting VAS and the child behaviour VAS were moderately but significantly correlated with their reference standards and other parental validated instruments. There was a significant but less strong correlation between the parental VAS and the professional caregiver outcomes. The same was true for the child competence VAS, a stronger correlation with the professional caregiver outcomes SDQ and C-TRF but less stronger correlations with the parental outcomes. As a global indicator of the diagnostic performance of the index test, the diverse AUROC of the different VAS were good, especially with strict and intermediate reference standard cut-off points. In addition, at various cut-off points of the reference standard, both parenting VAS and behaviour VAS show a high sensitivity and NPV at cut-off points of <74 respectively <69, with similar results almost a year later (Table 5 and 6). Table 5 to 9 are an example of an overview to support PCHC professionals to make a choice of an appropriate combination of sensitivity, specificity, NPV in relation to cut-off points of the index test. For the PCHC professional, e.g. a specific parental VAS cut-off point in daily practice can be reason to ask more about the parental representation of parenting. Figure 1 shows that there is more between a 'strict clinical' cut-off point and 'no concerns'. The child competence VAS showed moderate but significant correlation with the C-TRF (Table 3). Only with two VAS cut-off points (<50 and <67) related with a strict cut-off point of the reference standard, the competence VAS showed a high sensitivity/specificity and NPV (Table 7). Thus, these results suggest that for early identification of emerging concerns and disabling symptoms, both parental and child behaviour VAS are sufficiently valid and the child competence VAS is less valid.

Furthermore, both parental and professional caregivers' PEDS concerns as well as PCHC PEDS interpretation were strongly associated with their reference standard. Depending on various cut-off points of the reference standard, three or more PEDS concerns showed a high sensitivity and NPV for high-perceived mental health problems. Figure 2 and 3 show the diversity of sensitivity between a 'strict clinical' cut-off point and 'no concerns'.

It is noteworthy that associations and regression coefficients testing convergent validity (association with reference standard) are not stronger than associations and regression coefficients testing construct validity (association with a similar but non-identical construct). No obvious explanation is available, yet. The difference between parental and professional caregivers' outcomes as seen in Table 4 emphasizes the contextual influences.

PEDS in previous research

In the present study, 10 % and 7% of the children were indicated as high developmental risk at 3 years, respectively 4 years of age, and 31% and 27% were associated with moderate risk. A review study identified a prevalence of parental concerns on the PEDS indicating 13.8% (95% CI=10.9-16.8%) high-risk children and 19.8% (95% CI=16.7-22.9%) moderate-risk children. The high amount of children at moderate-risk in this study is possibly related with the research population of children aged 3 and 4 years of age with relatively highly educated parents. Studies parental PEDS concerns conducted in high-income countries reported a significantly higher rate of moderate-risk concerns (37).

Thus, the PEDS may also be valid for use in routine Dutch PCHC practice. The PEDS reveals questions and subjects that parents and professional caregivers want to discuss which are not yet related to changes in the SDQ, NOSIK, CBCL and C-TRF total score. The PEDS facilitates communication concerning parental and professional caregivers concerns about and across different child developmental domains. The answers always need to be checked in case parents do not use screening instruments properly for example because of literacy and language barriers or in case parents do not raise concerns when they should. In addition to these short instruments, other PCHC developmental instruments, like e.g. the Van Wiechen Developmental screen, Family Centred Method, Spark**,** ASQ and SDQ can be used to assess and monitor parental and child mental health, their interactions, family history, risk and resilience factors, and developmental milestones (9, 31, 60, 61).

Methodological issues

This study has some limitations. A rather high proportion of parents did not give consent to participation. The response ratio was 20%. In all, parents of 1702 children were asked to participate the MOM study. These children were within the caseload of the PCHC professionals participating in the MOM study. However, not all PCHC professionals participated in MOM. Consequently, parents of non-participating PCHC doctors were asked to participate by another PCHC doctor (BD), who did not know these families. During the baseline inclusion, the number of participating PCHC professionals increased. Response from one PCHC doctor who participated from the beginning (BD) was 70%. In order to test representativeness, 40% of non-responders were randomly sampled to manually collect data on parental education from the medical files. The distribution in non-responders was minimally different from distribution in responders (responders baseline 63%, 27%, 10%, follow up 64%, 26%, 10% and non-responders 55%, 33%, 12% having high, intermediate and low parental education, respectively). The overrepresentation of parents with a high level of education suggests the presence of selection and the possibility of limited representativeness. Findings suggest that there is a tendency to meaningful differences in effect sizes between different levels of parental education (Tables available on request).

Further research is required with a greater numbers of participants with lower parental educational status.

Because response in participating doctors was relatively high and because distribution in socio-economic status was comparable, results presented in the current paper can be considered approximately representative for the general population. If the PEDS and different VAS are implemented in general PCHC practice, a response rate higher than 70% is expected, because a possible barrier for parents to participate in MOM was the number of questions added for research purposes (e.g. additional instruments for the purpose of validation of PEDS and VAS). Usually, short form questionnaires collected in PCHC have response rates between 80 and 90% (62).

Additionally, although in only two occasions a parent reversed the VAS scoring, instructions for use of the VAS has to be improved to prevent mistakes in scoring.

Another limitation is the reference standard which should ideally be an established measure accurately measuring the same construct as the index test should measure. In this paper, the same kind of reference tests, CBCL and C-TRF, are used to establish the validity of two different index tests, the parenting VAS and the competence VAS. Notwithstanding, parental CBCL and professional caregiver's C-TRF are the true reference standards for parenting VAS and competence VAS, respectively. These reference tests were the best available and applicable validated instruments for routine preventive child health assessments to measure signs and symptoms of early distress and impairment in a general population of children.

Furthermore, it is recommended to repeat the test-retest with at least 50 participants and to validate other aspects of the Dutch PEDS. The PEDS includes separate domains such as language and motor skills and these constructs also have a reference standard. Although each type of parental concern can be associated with validated tests on the same developmental domain, studies about the validity of the PEDS showed that parents often have concerns in seemingly unrelated domains, i.e. parents often reflect on not just the apparent problem but also its impact on other aspects of development (63). However, assessing the validity of the language and motor developmental domains of the Dutch PEDS is beyond the scope of the present paper. The focus of the current paper is on obtaining early signals to facilitate a dialogue on overall concerns across several developmental domains like behavioural, social-emotional and mental health.

Conclusion

One of the most basic activities in PCHC is the focus on early identification of developmental and behavioural problems. In this respect, PCHC professionals have to deal with emerging problems and symptoms at a stage where signs and symptoms do not yet meet diagnostic criteria, but already give rise to early impairment and distress for both the children and their families. In order to screen emerging problems, short but valid monitoring tools are required. The PEDS as well as the parenting VAS and the child behaviour VAS have shown to be valid in Dutch PCHC standard practice. The child competence VAS is less valid. Further research is needed. The experiences in the context of the present study stress the challenge to use a multi-informant approach with a PCHC 'toolkit' of short validated instruments for multiaxial information. It can improve communication and 'shared decision making' for personalized PCHC (64, 65).

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CHAPTER 3

3

Preschool communication: early identification of concerns about preschool language development and social participation.

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Background

Adverse communication development in preschool children is a risk factor influencing child health and wellbeing with a negative impact on social participation. Language and social skills develop and maintain human adaptability over the life course. However, the accuracy of detecting language problems in asymptomatic children in primary care needs to be improved. Therefore, it is important to identify concerns about language development as a risk factor for child health. The association between parental and professional caregivers' concerns about language development and the level of preschool social participation was assessed, as well as the possible mediating/moderating effect of the perception of social competence. In addition, validity and predictive value of parental and professional caregivers' concerns about language development were tested.

Methods

To identify emerging concerns about development and social participation, a community sample of 341 preschool children was systematically assessed with a comprehensive preventive child health care 'toolkit' of instruments, including parent-completed tools like the Parents' Evaluation of Developmental Status (PEDS) and child competence Visual Analogue Scales (VAS). At baseline, children were aged 3 years and at follow-up approximately 4 years

Results

There was a statistically significant association between parental and professional caregivers' concerns about language development and the level of preschool social participation, with a mediating effect of child social competence at the age of 3 years as well as 4 years. Negative predictive value of parental and professional caregiver language concerns at the age of 3 and 4 years were 99% and 97%, respectively. Furthermore, this article showed that while some preschool children grow out of language problems, others may develop them.

Conclusion

Short but valid paediatric primary care tools like the PEDS and child competence VAS can support monitoring and early identification of concerns about language development and social competence as a risk factor for preschool social participation. Personalized health care requires continued communication between parents, professional caregivers and preventive child health care about parental and professional caregiver perceptions concerning preschool language development as well as the perception of a child's social competence.

Abstract

Introduction

Poor communication is a risk factor influencing child health and wellbeing with adverse consequences for behaviour, literacy, learning, mental health, future employment, parenting, the next generation and social inequalities (1, 2).

Effective communication is fundamental to the initiation and maintenance of successful peer relations (3, 4). The ability to interact with others and to establish relationships is of great influence on learning and development, and successful social adaptation and participation. From a dynamic perspective, health can be seen as the ability to adapt and self-manage in the face of social, physical, and emotional challenges (5). For this, language and social skills are needed; they develop and maintain human adaptability over the life course (6, 7).

From a public health perspective, preschool children represent an important group (8, 9). The preschool period is a sensitive period in language development (7, 10). Developmental growth in language skills is an important parameter of overall communication development (11). Language problems are often the first presenting symptoms of delay in the development of multiple basic functions including socialization and communication (3, 12). Early expressive and receptive language problems and behavioural problems may have long-term consequences (13). In particular, early receptive language problems are a significant risk factor for adult mental health (1).

However, the accuracy of detecting language problems in asymptomatic children in primary care is inadequate (14). Early recognition of adverse language development is challenging, given that normal development in young children is highly variable and all growth and development takes place in interaction with the environment (15-17). Differentiating between speech language delays and disorders is complicated, children with concerns about language development are a heterogeneous group with different individual and environmental characteristics. On the other hand, many children whose language development is delayed may catch up over the next few years and do not require interventions (18). Prevalence of language problems varies widely (2-25%) due to a lack of consistent definitions, the nature of the population, the diagnostic method that is utilized, and whether data were collected in a clinical sample or in the general population (19-21).

From a personalized health care 'growing into deficit' model (Fig.1), prevention of language developmental problems requires a focus on concerns, emerging problems and symptoms at an early stage where signs and symptoms do not yet meet diagnostic criteria for a disorder (13, 22, 23). For early identification of language needs, it is important to understand the pervasive nature of language development (8, 13, 19). It is assumed that

differences in young children's language development reflect differences in experience and in creating interactive routines, next to their biologically mediated genetic potential (24). If needed, early intervention has to be personalized; standard intervention programs have limited added value (25).

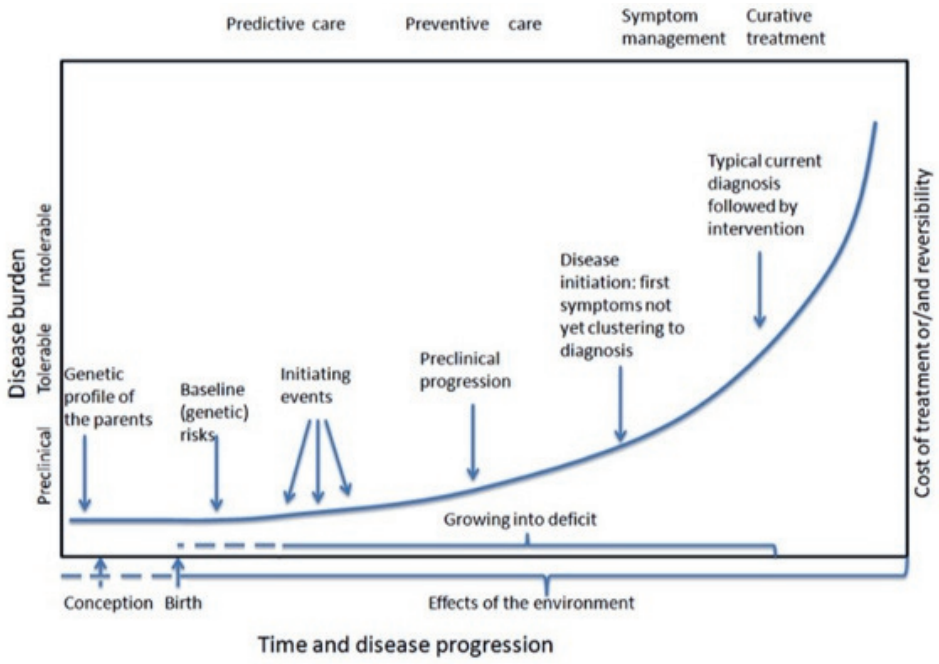

Figure 1. Modification to Syurina's adaptation of Snyderman's curve representing the timelines of 'growing into deficit'and developing common complex diseases, ref. 23.

Previous research has shown that there is an association between language difficulties, behavioural difficulties and social participation (26, 27). Language impairment in childhood may be related to problems with activities and social participation as defined by the International Classification of Functioning Disability and Health – Children and Youth (ICF-CY) (19, 28). Social participation is a broad concept including the objective state and the subjective experience of involvement in society. This concept has to be understood in the light of social roles (6). For young children, play is an important social activity.

Social competence development is linked with both language development and social participation. Social competence is affected when abilities or skills that are required to engage in socio-cognitive processes and to display social behaviours are limited (7). For example, not only expressive and receptive language, but also the ability to grasp non-linguistic signals is important for optimal social interaction and participation. Toddler's

play has been associated with their language proficiency (4). However, this same study also showed that the child's functioning in play was better explained by their social competence than by their language skills. From a dynamic transactional developmental perspective (29), it is hypothesized that language development is mediated by social competence and social participation, and vice versa. Language development, social competence and social participation are seen as dynamic skills simultaneously developing during the preschool period, suggesting a reciprocal model (30).

A community-based approach with a focus on personalized health care requires cooperation and communication within a public health framework (8, 22). According to a bio ecological model of development-in-context, it is important to obtain child context-specific information (20). Teachers, employees from childcare, kindergarten, preschool or primary school (hereafter: professional caregivers) as well as parents and Preventive Child Health Care (PCHC) professionals are important perceivers with expert knowledge on child development from different perspectives.

PCHC is synonymous with Paediatric Preventive Primary Care. All children in the area are regularly invited to visit the PCHC. Dutch PCHC system includes preventive health care doctors and has a high level of population compliance. It is a public health endeavour to provide ongoing monitoring up to the age of 18 years (31, 32). This way, the early conditions that place children at risk for less than optimal development and successful social participation can be improved (33-36). To deal with emerging problems and symptoms at an early stage where signs and symptoms do not yet meet diagnostic criteria for a disorder, systematically exploring parental as well as other caregivers' concerns is a main component in PCHC for family-centred practice and personalized health care. Knowledge and understanding of the true epidemiology of genetic and environmental risk and protective factors and their early phenotypes can help in prevention of 'growing into deficit' (23, 37).

In order to document children's development over time, monitoring development at multiple time points, across informants, instruments and contexts, is more valid and accurate than a single assessment(16, 38-41). For early identification of developmental problems, special attention should be given to the validity of instruments about the perceived impact of concerns as concurrent and long-term predictors, and outcome domains such as health, wellbeing and social participation (42). In a PCHC setting, monitoring instruments should: 1) easily obtain information in every day PCHC setting; 2) carry out dimensional assessment of symptoms and behaviour; 3) measure the progress of development of young children and their possible determinants of influence; 4) identify general signals and symptoms indicating a possible disruption or imbalance of the educational /parent-child system, not yet related to a specific diagnosis; 5) support

communication between PCHC, parents and professional caregivers about their perceptions on health and development; 6) connect to needs and demands of the child and the social system around the child; and 7) promote shared decision making (43, 44). Short instruments with a high negative predictive value are preferred; it ensures that most children who pass the developmental assessment are truly healthy. Follow-up consultations are no problem, these children can benefit from additional preventive monitoring (45).

Research has shown that parent-completed tools are highly accurate in detecting true problems, are relatively inexpensive, and promote a dialogue about concerns, needs and demands between parents and other caregivers (46-48). Therefore, incorporating tools utilizing a parent-and professional caregivers-report assessment like the Parents' Evaluation of Developmental Status (PEDS), child competence Visual Analogue Scales (VAS) and the Strengths and Difficulties Questionnaire (SDQ) into a routine child monitoring toolkit could improve the rate of early identification of concerns about language development, social competence and social participation (43, 49). In this article, the concept social participation was operationalized using instruments to assess early emerging concerns about factors underlying preschool competence and social participation: a child's general competence at day care, kindergarten and preschool, the impact of distress and the total amount of concerns about child development and behaviour

This article investigates 1) the validity of the Parents' Evaluation of Developmental Status (PEDS) to assess language development concerns; 2) the cross-sectional association of language development concerns with social participation; 3) the longitudinal association of language development concerns with social participation, and 4) the possible mediating effect of social competence on the association between language development and social participation at the ages of 3 and 4 years.

Methods

The present study was performed as part of the Monitoring Outcome Measurements of child development (MOM) study, a prospective observational study within PCHC practice. A community-based sample of 346 children was systematically assessed with a comprehensive PCHC 'toolkit' of instruments using a multisource and cross-informant repeated measures design to identify developmental pathways impacting school readiness as an outcome of social participation. Children were aged 3 years at baseline and 4 years at follow up.

The Maastricht University Medical Centre Medical Ethics Committee approved the MOM-study protocol under registration number MEC 09-04-018/P. Therefore, this study has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All participating parents gave their informed consent prior to their inclusion in the study.

Data collection and instruments

For this article, data of parents, professional caregivers and PCHC professionals of 341 children were analysed. At baseline, children were aged 3 years and at follow-up approximately 4 years. To assess emerging problems, signs and symptoms, perceptions, demands and concerns about development and social participation, various short instruments like the Parents' Evaluation of Developmental Status (PEDS), the Strengths and Difficulties Questionnaire (SDQ) and child competence Visual Analogue Scales (VAS) were included in this study. PCHC professionals provided information about, for example, background factors, family history, child health and development and interventions.

Language concerns

Parents as well as professional caregivers completed the PEDS, a 10-item standardized semi-structured questionnaire to elicit concerns regarding child development for children aged less than 8 years in the general population and clinical samples (40). Ten questions explore concerns in various domains: expressive and receptive language, fine motor, gross motor, behaviour, socialization, self-care and learning. The PEDS question could be answered on a trichotomized scale: "no", "a little", "yes". Subsequently, an open-ended field provides more information. The PEDS is validated for clinical samples and general population samples aged between 0 and 8 years, and is available in multiple languages. In recent validation studies from the USA for the accuracy of parental concerns in detecting children at high and/or moderate developmental risk, the PEDS has a sensitivity of 91-97% and specificity of 73-86% (50). The PEDS is less time-consuming than other instruments, emphasis is on parental and other professional caregivers' opinions, and has reasonable test characteristics for developmental screening in primary care settings (51). Furthermore, the PEDS has shown to be reliable, valid and useful as brief monitoring tools in daily Dutch PCHC practice (43, 51).This suggests that the PEDS is an accurate tool for use as an initial screening and monitoring tool in Dutch PCHC, where professionals have to deal with the time constraints of daily practice.

For the current paper, dichotomous 'parental concerns' and 'professional caregiver concerns' variables about expressive and/or receptive language (any concern yes/no) were constructed for use in the analyses, if any of the parents or professional caregivers scored 'yes' or 'a little', the answer was set as 'yes'.

Child competence

To address the issue of the child's functional adaptation, professional caregivers were asked to indicate on 2 VAS, the degree of the child's general competence and the child's social competence (0= not competent, 100= very competent).

Participation

The child's general competence as described above is one of the instruments to assess the broad construct of participation. Other instruments are SDQ total score and SDQ impact.

The Dutch version of the SDQ was completed by parents as well as by professional caregivers to assess the child's behaviour (46, 52-54). The SDQ is a brief behavioural screening questionnaire for children aged 3-16 years. It also includes items that identify the impact of the behavioural problems of the child. The SDQ is considered valid and reliable as a research instrument in community samples (49). For this article, the 'SDQ total sum score' and the 'SDQ impact of distress score' of both parents and professional caregivers were used. If any of the parents or professional caregivers scored 'yes' on the impact probe question, the dichotomous overall distress variable was set at 'yes'.

Van Wiechen developmental test

In addition to the validation of the overall PEDS, validity of the PEDS language items was assessed, using the Van Wiechen developmental test as reference standard (43, 55-57). This Dutch instrument is a modification of the Gesell test and is routinely used by all PCHC Centres in the Netherlands and Belgium to monitor the development of all children from birth to the age of four years. It consists of a set of 57 developmental indicators to assess motor behaviour, speech, communication, and social skills based on physicians' observations and interviewing the parents. A total of 23 indicators cover language development and communication and are called language milestones. All PCHC professionals are trained to asses and register mile stones in the PCHC system according to a uniform protocol. For this paper, the Van Wiechen communication and language items were used. In a large community-based sample of Dutch children, test characteristics of the Van Wiechen language items for the age group 36-48 months showed an Area Under the Curve (AUC) of 0.83%, with an average sensitivity of 66.1%, specificity of 87.5%, positive predictive value (PPV) of 29.2%, and a negative predictive value (NPV) of 98.8 % (58).

In a study in Australia, agreement between ratings of parental PEDS language concerns and clinical assessment was high (86-90%); agreement between teacher PEDS language concerns and clinical assessment was lower and more varied (63-80%) (59). In this study, parental and professional caregiver PEDS language concerns were combined to provide complementary information and capture all possible language concerns of a specific child. Subsequently this combined concerns variable was validated; reference standard was the

Van Wiechen developmental test, communication and language items (see above)(60, 61). For this study, the PCHC professionals were asked to judge the Van Wiechen language and communication items as 'sufficient' or 'not sufficient', at the age of 3 years and a year later.

Other variables

As an indicator of socioeconomic status, the level of maternal and paternal education was assessed across 3 categories: low (primary education, junior vocational education), middle (general secondary education, senior vocational education) and high (preparatory university education and university education). The parent with the highest level of education determined parental educational level.

Statistical analyses

All analyses were performed using Stata Statistical Software, version 15 (62). First, to assess the validity of the PEDS language items, positive predictive value (PPV) and negative predictive value (NPV) were obtained at the age of 3 years and at the age of 4 years. PPV and NPV were then assessed as measures of predictive validity of language concerns at the age of 3 years, using the Van Wiechen developmental test at age 4 years as reference standard. Second, logistic and linear regression analyses were performed. In the cross-sectional analyses at both ages 3 and 4 years and in the longitudinal analyses, the independent variable (X) was concerns about language development. The dichotomous dependent variable (Y) to index social participation, used in the logistic regression analyses, was SDQ impact of distress score. Continuous dependent variables (Y) to index social participation, used in the linear regression analyses, were: SDQ total score, the child's general competence VAS and the child's social competence VAS. Analyses were adjusted a priori for age, sex and parental educational status.

Finally, to analyse the fourth research question, the child's social competence was included as a mediator (M) in the association between independent (X) and dependent (Y) variable. Mediation was assessed by analysing a regression model with and without the mediator. The question was whether the association between X and Y after including the mediator is zero or substantially smaller than the direct association between X and Y. This is visualized in Figure 2. The arrows a, b, c and c' present regression coefficients or odds ratios: a represents the association between independent variable (X) and mediator (M); b represents the association between the mediator (M) and the dependent variable (Y); c represents the crude association between independent variable (X) and dependent variable (Y); and c' represents the association between X and Y after including the mediator (M) in the regression model. When the hypothesis that there can be mediation is plausible and c shows an association while c' is smaller or close to zero, there is evidence for partial or full mediation, respectively.

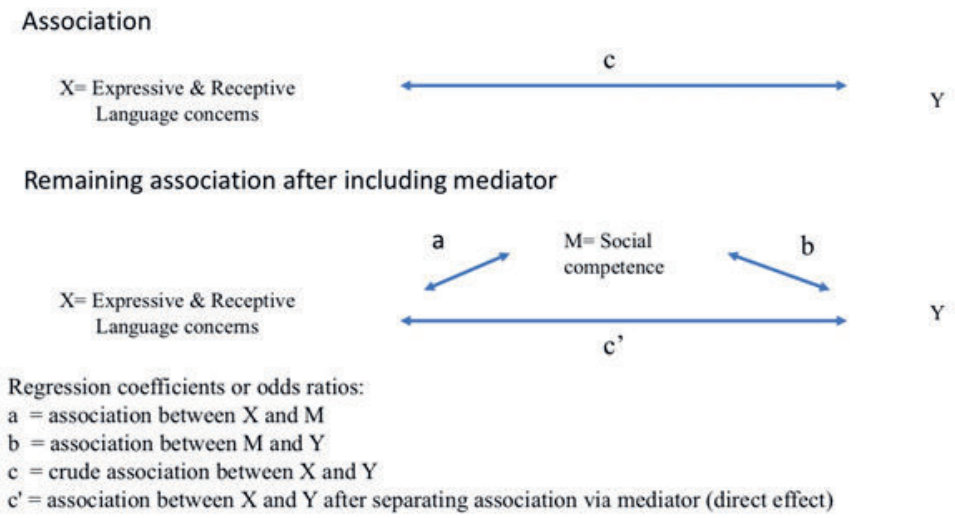

Figure 2. Theoretical figure to explain analysis of mediation

Results

Parents of 346 children agreed to participate in the MOM study. At baseline, parents of 341 children and professional caregivers of 301 children completed the questionnaires. The mean age of the children was 3.0 years (SD 0.2, Table 1). For 296 of these children (86%), information from both informants was available. In the follow up, at the age of approximately 4 years (mean age 3.8; SD 0.2, Table 1), information of both informants was available for 236 children (68%). For 32 children (9%) there was no information available from parents or professional caregivers because they did not return the questionnaire. At baseline, the total sample of children consisted of 166 boys (48%) and 180 girls (52%). Of the participating children, 60% (n=207) were resident in the municipality of Maastricht, while 40% (n=139) lived in the surrounding areas. At baseline, parents and/or professional caregivers of 108 (32%) of 334 children had concerns about expressive and/or receptive language development (12 missings on the PEDS). In the follow up, at the age of 4 years, the total number of children with concerns about language development was 81 (26%) of 313 children (Table 1).

Table 1. Descriptive statistics at baseline (T1) and follow-up (T2)

Variable	N		Mean (S.D.)		Range	
	T1	T2	T1	T2	T1	T2
Age in years	346	293	3.0 (0.2)	3.8 (0.2)	1.8-3.5	3.5-4.8
Child general competence VAS[1]	290	251	63.7 (19.7)	69.7 (16.3)	4-100	10-99
Child social competence VAS[1]	297	254	62.9 (23.4)	68.9 (20.1)	3-100	9-99
SDQ (parents)	338	293	6.8 (4.9)	6.1 (4.2)	0-28	0-27
SDQ (prof.[2])	294	256	6.1 (5.0)	5.0 (5.0)	0-27	0-29
			Normal		Atypical	
PEDS concerns about language[3]	334	313	226 (68%)	232 (74%)	108 (32%)	81 (26%)
Van Wiechen developmental test [4]	331	319	304 (92%)	298 (93%)	27 (8%)	21 (7%)
SDQ impact (parents)	340	292	307 (90%)	271 (93%)	33 (10%)	21 (7%)
SDQ impact (prof.[2])	292	254	248 (85%)	223 (88%)	44 (15%)	31 (12%)

[1] A higher Visual Analogue Scale (VAS) score means professional caregiver judges child competence more positive
[2] Professional caregivers
[3] Parental and/or professional caregiver's concerns about expressive and/or receptive language development
[4] Speech, language and communication items

In order to test representativeness, 40% of non-responders were randomly sampled to manually collect data on parental education from the medical files. The distribution in non-responders was minimally different from distribution in responders (responders 63%, 27%, 10% and non-responders 55%, 33%, 12% having high, intermediate and low parental education, respectively).

Validity of the PEDS language items

The prevalence of PCHC language concerns was 8% at the age of 3 and 7% one year later (Table 2). At the age of 3 years, PEDS language concerns had a PPV of 23% and NPV of 99%. At the age of 4, the PPV and NPV of PEDS language concerns were 19% and 97% respectively (Table 2). Table 3 shows the stability of language developmental concerns at the age of 3 and 4 years. The predictive validity of the PEDS at the age of 3 years was: PPV of 14% and NPV of 97% (Table 4).

Table 2. Prevalence, positive and negative predictive value of PEDS concerns about language development at the age of 3 and 4 years

Expressive language and/or receptive language		T1 reference standard[2]		
T1PEDS concerns[1]		Yes	No	Total
	Yes	24	82	106
	No	3	222	225
	Total	27	304	331

Expressive language and/or receptive language		T2 reference standard[2]		
T2 PEDS concerns[1]		Yes	No	Total
	Yes	15	65	80
	No	6	225	231
	Total	21	290	311

T1 Prevalence 8.2%; Specificity 73%; Sensitivity 88.9%; PPV 22.6%; NPV 98.7%
T2 Prevalence 6.8%; Specificity 77.6%; Sensitivity 71.4%; PPV 18.8%; NPV 97.4%
[1] Parental and/or professional caregiver's concerns about language development
[2] Van Wiechen developmental test, speech, language and communication items

Table 3. Stability of PEDS concerns about language development at the age of 3 and 4 years

Expressive and/or receptive language		T2 PEDS concerns[1]		
T1 PEDS concerns[1]		Yes	No	Total
	Yes	55 (18%)	45 (14%)	100 (32%)
	No	26 (8%)	186 (60%)	212 (68%)
	Total	81 (26%)	231 (74%)	312(100%)

Prevalence 26.0%; Specificity 80.5%; Sensitivity 68.0%; PPV 55.0%; NPV 87.7%;
[1] Parental and/or professional caregiver's concerns about language development

Table 4. The predictive validity of PEDS concerns about language development at the age of 3 years

Expressive and/or receptive language		T2 reference standard[2]		
T1 PEDS concerns[1]		Yes	No	Total
	Yes	14	89	103
	No	7	209	216
	Total	21	298	319

Prevalence 6.6%; Specificity 70.1 %; Sensitivity 66.7%; PPV 13.6 %; NPV 96.8 %
[1] Parental and/or professional caregiver's concerns about language development
[2] Van Wiechen developmental test, speech, language and communication items

Association between language development concerns and preschool social participation

When assessing parental SDQ impact at the age of 3 years, children with receptive language concerns had an OR of 7.3 and children with expressive language concerns had an OR of 2.4. However, confidence intervals were overlapping (Table 5).

According to professional caregivers, the association between receptive language concerns and outcomes was stronger than the association between expressive language and outcomes (e.g. general competence VAS: B=-21.3, p<0.001; Table 6). In addition, both professional caregivers and parents reported more behavioural problems when there were receptive language concerns (SDQ total score B=4.5, p<0.001; B=4.5, p<0.001, respectively). A year later, the association between language concerns, competence and behaviour was less strong but still significant, except for PEDS expressive language concerns and the parental perception of child behaviour (Table 6).

Table 5. Logistic regression analysis (significant interaction with one or both risk factors): association between PEDS concerns about expressive and receptive language development and SDQ impact according to parents and professional caregivers at the age of 3 and 4 years; odds ratios (OR) and 95% confidence intervals (CI).

	SDQ impact (Parents)		SDQ impact (prof.[2])	
	T1	T2	T1	T2
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
PEDS concerns[1] Expressive language	2.4 (1.2; 5.1) *	2.5 (1.0; 6.3) *	3.0 (1.5; 5.8) **	2.3 (1.1; 5.0) **
PEDS concerns[1] Receptive language	7.3 (3.1; 17.3) †	5.3(1.7; 16.3) **	10.5 (4.6; 24.1) †	2.6 (0.8; 8.6)

*p <0.05; **p <0.01; †p <0 .001; 95% CI=95% confidence interval; OR=odds ratio (obtained from logistic regression)

[1] Parental and/or professional caregiver's concerns about language development

[2] Professional caregivers

Table 6. Linear regression analysis: association between PEDS concerns about expressive and receptive language development and child general competence, child social competence, and total score SDQ according to parents and professional caregivers at the age of 3 and 4 years; b- coefficient (B) and 95% confidence intervals (CI)

	Child general competence VAS[2] (prof.[3])		Child social competence VAS[2] (prof.[3])		Total score SDQ (Parents)		Total score SDQ (prof.[3])	
	T1	T2	T1	T2	T1	T2	T1	T2
	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
PEDS concerns[1] Expressive language	-11.4 (-16.4 -6.8) †	-10.7 (-15.1; -6.2) †	-12.1 (-17.9; -6.4) †	-10.3 (-15.9; -4.7) †	2.6 (1.5; 3.7) †	1.1 (-0.0; 2.3)	2.8 (1.5; 4.0) †	2.2 (0.8; 3.6) **
PEDS concerns[1] Receptive language	-21.3 (-28.7; -13.9) †	-13.3 (-21.7; -4.9) **	-19.1 (-27.8; -10.4) †	-16.1 (-26.5; -5.7) **	4.5 (2.7; 6.3) †	4.2 (2.3; 6.0) †	4.5 (2.7; 6.3) †	3.2 (0.8; 5.7) **

*p <0.05; **p <0.01; †p <0 .001; 95% CI=95% confidence interval; b- coefficient (B) (obtained from linear regression)
[1] Parental and/or professional caregiver's concerns about language development
[2] A higher VAS score means professional caregiver judges child competence more positive
[3] Professional caregivers

Mediating effect of social competence

At baseline and at follow up a year later, there was a significant association between social competence and social participation, but also a direct association between concerns about expressive and/or receptive language development and social competence. For example, according to the professional caregiver, at age 3 years there was a significant association between language concerns and social participation (SDQ impact B= 4.3, p<0.001; SDQ total score B= 3.0, p<0.001) and a significant association between social competence and social participation (SDQ impact B= 0.9, p<0.001; SDQ total score B=-0.1, p<0.001) (Tables 7, 8). There was a mediating effect of social competence: after inclusion of social competence in the regression model, the remaining association between language concerns and social participation was less strong (SDQ impact B= 2.8, p=0.014; SDQ total score B=1.2, p=0.016). A year later, at the age of 4 years, the mediating effect of social competence was even stronger with non-significant regression coefficients (B=1.1, p=0.884 and B=0.8, p=0.198, respectively). When tested separately, the mediating effect was found both for expressive and receptive language concerns (data not shown). Mediating effects of social competence were also found between language concerns and general competence (data not shown).

Table 7. Mediating effect of social competence on the association of PEDS concerns about language development with SDQ impact score at T1 and T2

			Odd ratios			
		Path	T1		T2	
			Parent	Prof.[2]	Parent	Prof.[2]
PEDS concerns[1] language (X)	Social competence (M)	a	-13,5†[3]	-13,5†[3]	-10.8†[3]	-10.8†[3]
Social competence (M)	SDQ Impact score (Y)	b	1.0**	0.9†	1.0†	0.9†
PEDS concerns[1] language (X)	SDQ Impact score (Y)	c	4.2†	4.3†	2.8*	2.4*
PEDS concerns[1] language (X)	SDQ Impact score (Y)	c'	3.0**	2.8*	0.9	1.1

* p<0.05; ** p<0.01; † p<0.00;
[1] Parental and/or professional caregiver's concerns about expressive and/or receptive language development
[2] Professional caregivers
[3] B regression coefficients

Odd ratios unless otherwise indicated:
a = association between X and M
b = association between M and Y
c = crude association between X and Y
c' = association between X and Y after separating association via mediator (direct effect)

Table 8. Mediating effect of social competence on the association of PEDS concerns about language development with SDQ total score at T1 and T2

			B regression coefficient			
		Path	T1		T2	
			Parent	Prof.[2]	Parent	Prof.[2]
PEDS concerns[1] language (X)	Social competence (M)	a	-13,5†	-13,5†	-10.8†	-10.8†
Social competence (M)	SDQ total score (Y)	b	-0.0†	-0.1†	-0.1†	-0.1†
PEDS concerns[1] language (X)	SDQ total score (Y)	c	3.2†	3.0†	1.5**	2.4**
PEDS concerns[1] language (X)	SDQ total score (Y)	c′	2.1†	1.2*	0.1	0.8

* p<0.05; ** p<0.01; † p<0.001
[1] Parental and/or professional caregiver's concerns about expressive and/or receptive language development
[2] Professional caregivers

B regression coefficients:
a = association between X and M
b = association between M and Y
c = crude association between X and Y
c′ = association between X and Y after separating association via mediator (direct effect)

Discussion

The results in this paper suggest concurrent and predictive validity of the PEDS to assess parental and professional caregivers' language development concerns, as well as the mediating effect of professional caregivers' perception of the child's social competence in the association between these concerns and social participation at the age of 3 years as well as the age of 4 years.

Validity of preschool language development concerns

Prevalence of language delay (7-8%) in the present study is within the international reported range of prevalence of atypical language delay (7-15%) (20, 21, 38). In addition, the association between parental and professional caregiver concerns on the one hand, and not meeting the expected milestones for language on the other, was statistically significant. These results are in line with other studies where parental concerns were consistently associated with preschool language development (40, 58, 63). Moreover, this confirms the value of including parents' and professional caregivers' expert knowledge in the assessment and clinical decision-making process for personalized support (28, 59). The high NPV of parental and professional caregiver language concerns validate a strategy of exclusion of children without concerns from extra monitoring. The PEDS language screening items appear to be very good in identifying children who do not have any language delay. Current assessment tools are still not sufficiently specific to discriminate between delayed language that will resolve naturally and delayed speech or language that will develop into persistent problems. The relatively low PPV in the present study implies a high percentage of false positives. Earlier research has shown that children

with false positive screening results differ from children with true negative scores. These children had more risk factors and their performance on diagnostic measures was less (45). As confirmed by other population studies (17, 18, 26, 64), this article showed that while some preschool children grow out of language problems, others may develop them (Table 3). From a classical screening point of view, children crossing back and forth over the threshold would impact sensitivity and specificity. However, PCHC repeated monitoring concerns of language development and if necessary, extra follow up can make a distinction between children 'growing into or out of deficit'.

So, PCHC monitors the true positives as well as the false positives and refers when needed, even if the child did not score on the reference standard. Language tests may not capture important aspects of everyday communication. In addition, a language problem may not always look like a language problem: underlying comprehension impairment can present as poor academic attainment, impaired social interaction, or behavioural difficulties (12, 65). Furthermore, due to the variation in the cut-off points of different 'reference standard' measures in research, interpretation of parents' and professional caregivers' information is complicated. In addition, there is no agreement on different definitions of language disorders and what proportion of the population should be considered cases that need intervention (65).

Prediction of preschool social participation: mind the communication

Parental and professional caregiver concerns were associated with altered social participation at home as well as in preschool. This association was seen both in cross-sectional and in longitudinal analyses.

Language concerns seem to be predictive for altered social participation as early as in preschool. Earlier research showed that especially children who experienced language impairment that persisted into the school years are at risk for adult mental health problems and substandard social participation (66). The strongest association was seen between receptive language delay concerns and behavioural problems. Odds ratio confidence intervals of children with receptive and expressive language concerns were overlapping, thus were not statistically significant, except for the association with parental SDQ total score at the age of 4 years (Table 5). From PCHC practice it is recognizable that receptive and expressive language development are closely linked, with more problems in social participation because of language comprehension problems. This confirms the observation that needs of children with receptive language problems are complex and call for extra monitoring of the child's developmental pathway (1). Listening to parental and professional caregivers' concerns with avoidance of diagnostic labels is an important aspect of PCHC clinical judgement and pre-screening. It may identify other developmental problems without potential stigmatization (23, 37). Avoidance of diagnostic labels is not

the same as denying any role of biological risk factors in causing health problems; children vary in their biological as well in their social backgrounds and life events (65).

Mediating effect of social competence

Language delay in itself may not be a risk factor for later behavioural and emotional disturbances (67). The present results showed that concerns about language development may reflect the effect of other developmental problems (68). There was a mediating effect of child social competence on the association between receptive and expressive language concerns and social participation at the age of 3 and 4. While at age 3 years social competence was a partial mediator, at age 4 it was a full mediator. So, at age 4, social competence seems to play a more important role in the association between concerns and participation. After inclusion of social competence score, language concerns seem to lose their predictive value but these factors might be related to each other.

The expansion of this mediating effect between ages 3 and 4 years emphasizes once again that all children with language concerns can benefit from additional monitoring to prevent 'growing into deficit', especially concerning interpersonal relationships. There is a role for enhanced monitoring in which the primary care professional responds to parental concerns about language development and social skills (3, 6, 23). The group of children with symptoms of mental problems may be twice as large as the group of children meeting formal diagnostic criteria for a mental disorder (69-77). Inefficiency can arise if educational and medical support is restricted to those who meet arbitrary cut-offs as a result of discrepancy in criteria used for diagnostic labels (65). Therefore, a PCHC 'toolkit' with short instruments for regular short parental and professional caregivers' reports can serve as a first step in PCHC monitoring procedures to select children who require further support in the form of a 'watch and wait' strategy, assessment of other developmental domains, or referral to a specialist. Professional support can then be tailored to the needs, conform the child's development.

PCHC professionals have to deal with emerging problems and symptoms at a stage where signs and symptoms do not yet meet diagnostic criteria, but already give rise to early impairment and distress for both the children and their context, at home or/and in preschool. Both parental and professional caregiver concerns are relevant for early detection of problems, because they both know the child and their perception is from a different perspective (41). The PEDS: 1) facilitates monitoring of parental and professional caregivers concerns; 2) identify general signals and symptoms not yet related to a specific diagnosis; 3) support communication between PCHC, parents and professional caregivers about their perceptions on health and development; and 4) promote shared decision making (23, 44).

Methodological issues

Strength of the study is that a community sample of preschool children was systematically assessed using a comprehensive PCHC 'toolkit' of instruments designed for the purpose of monitoring in a public health setting. The study was integrated in real life practice. No children were excluded for not meeting inclusion criteria. In addition, the child's development and participation was evaluated across different settings with cross-sectional and longitudinal information from different instruments and multiple informants. With emphasis on their perception, information was obtained through hetero-anamnesis of parents and professional caregivers (78). PCHC professionals provided data as well; with exception of the Van Wiechen developmental test, these data were not used in the present paper. Furthermore, the Van Wiechen language milestones were collected in a uniform manner by trained professionals.

The present paper has some limitations. First, response rates were difficult to establish. In the MOM region over the study period, 1692 children were born and, therefore, were within the caseload of the PCHC professionals participating in the MOM study. However, not all PCHC professionals participated in MOM. Consequently, parents of non-participating PCHC doctors were asked to participate by another PCHC doctor (BD), who did not know these families. During the baseline inclusion, the number of participating PCHC professionals increased. Response from one PCHC doctor who participated from the beginning (BD) was 70%. Because response in participating doctors was relatively high and because distribution in socio-economic status was comparable, results presented in this article can be considered approximately representative for the general population. If the PEDS and different VAS are implemented in general PCHC practice, a response rate higher than 70% is expected, because a possible barrier for parents to participate in MOM was the number of questions added for research purposes (e.g. additional instruments for the purpose of validation of VAS). Usually, short form questionnaires collected in PCHC have response rates between 80 and 90% (79).

Second, the MOM data are limited to the city of Maastricht and surrounding areas. This part of the Netherlands is quite similar to the rest of the country. However, there are some differences. In Maastricht, the proportion of non-European inhabitants (about 10 %) is less than in the larger cities in the north west of the country (about 30%) (80). In addition, the proportion of highly educated parents participating the MOM is quite large (63%). For this reason, the MOM study findings may not necessarily be valid for large cities with ethnically mixed populations and areas with a larger proportion of low educated parents.

Third, assessment tools were general in nature and did not reveal specific information to assist with remediation of deficits. The measures find general delay and it is not necessarily clear that the delays are clinically significant. PCHC professionals must remain aware

they have to deal with emerging problems and symptoms at a stage where signs and symptoms do not yet meet diagnostic criteria. Although each type of parental concern can be associated with validated tests on the same developmental domain, studies about the validity of the PEDS showed that parents often have concerns in seemingly unrelated domains, i.e. parents often reflect on not just the apparent problem but also its impact on other aspects of development (40). Revelation of parental and professional caregivers' concerns are a first step in PCHC monitoring procedures to select children who require further assessment of other developmental domains, or referral to a specialist.

Fourth, social competence was included as a mediator because this measure was the best available assessing this construct. The professional caregiver assessed social competence, but if a similar instrument was available from the parents, we would expect to find similar mediating effects.

Finally, because of the small sample size, analyses were not adjusted for risk factors e.g. family history of language or literacy problems, health or developmental problems.

Conclusions

The individual's social and educational environment, including interpersonal relationships, is hypothesized to be instrumental for PCHC professionals wishing to provide personalized preventive public health care for successful participation for all children (31). In order to identify emerging problems at an early stage where signs and symptoms do not yet meet diagnostic criteria for a disorder, short but valid PCHC monitoring tools like the PEDS and different VAS are required (43). Within this PCHC 'toolkit', parental and professional caregivers' perception and concerns about language development take an important position. Language development can be seen as the outcome of the mental processes set in motion when the child meets the social and linguistic world (24, 81). The analyses presented here uncovered significant associations between parental and professional caregiver concerns about language development, the child's social competence and the level of preschool social participation. Therefore, paediatric primary care professionals may productively use parental and professional caregiver perceptions concerning preschool language development in clinical practice. Equally important is the perception of a child's social competence. In children not meeting the expected milestones for language development, a comprehensive developmental evaluation and additional monitoring of child development may be required, particularly concerning interpersonal relationships. Consequently, personalized health care requires cooperation within the public health frame. Monitoring of language and social competence development in preschool children

can profit from continued communication between parents, professional caregivers and preventive child health care.

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CHAPTER 4

4

Preschool social participation, the impact of early life stress and parental health.

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Abstract

In this article, the association between parental and professional caregivers' perceptions of early life stress (ELS) and the level of preschool social participation was examined, as was the possible moderating effect of parental health. In a community-based study, both parents and professional caregivers of 346 children aged 3 years provided information about child and environmental factors. Results showed that children with ELS more often experienced distress (OR 1.3, $p < 0.001$), had more peer problems (SDQ: B=0.1, $p<0.01$), and more often received extra support according to professional caregivers (OR 1.3, $p<0.01$). Parents more often reported concerns (OR=1.3, $p<0.001$), a greater number of concerns (B=0.3, $p<0.001$), and perceived more difficulties in parenting ('parenting' VAS: B=-2.5, $p<0.001$). Associations were stronger for children of parents with 'poor health'. For personalized family-centred health care, Preventive Child Health Care should systematically explore caregivers' perceptions and concerns of ELS, parental health and child social participation.

Introduction

Early life stress (ELS) is a risk indicator influencing child health and wellbeing. Stress can be positive, tolerable or toxic, depending on the nature of the adversity, the individual's stress reactivity and the level of social emotional support (1). Whether someone experiences stress as negative, depends on the extent to which an individual has control over the given stressor and whether the person has coping resources (2-7).

Toxic stress in childhood links adversity with poor health and health disparities (8, 9). In particular, adverse preschool childhood experiences may have a long-lasting impact on brain development (10, 11). Prevention of adverse childhood experiences and supporting resilience is required to improve Public Health(12). However, trauma exposure is not consistently investigated as a possible factor in aetiology of psychological and behavioural problems of young children (13).

Early identification of toxic stress is essential for optimal early intervention and support of the social/educational context, when the probability of re-aligning the trajectory of development and successful social participation is best and treatment, therefore, is more cost-effective (14-18). Early intervention can break the cycle of disadvantage (18, 19). Successful social participation is recognized as an important outcome in young children. When children participate well, they acquire skills and competencies, connect with others and with the community, and find purpose and meaning in life (20-22).

Preventive Child Health Care (PCHC) is the public health endeavour to provide on-going monitoring up to the age of 18 years (23, 24). PCHC is synonymous with Paediatric Preventive Primary Care. The Dutch PCHC system includes preventive health care doctors and has a high level of population compliance (25). Monitoring development with knowledge and understanding of genetic and environmental risk and protective factors and their early phenotypes, can help in prevention of 'growing into deficit' (26, 27) (Fig. 1).

PCHC needs to adopt methodologies that incorporate structured assessments for the range of traumatic stressors that are common in infancy and early childhood (28). To deal with emerging problems and symptoms at a stage where signs and symptoms do not yet meet diagnostic criteria, systematically exploring parental as well as other caregivers' concerns is a main component in PCHC for family-centred practice. This offers PCHC a great opportunity to provide personalized health care (29). Parents, teachers/employees from childcare, kindergarten, preschool or primary school (hereafter: professional caregivers) and PCHC professionals are important informants with expert knowledge on child development from different perspectives. The individual's social and educational environment including interpersonal relationships is hypothesized to be key to provide personalized preventive public health care for successful social participation of all children.

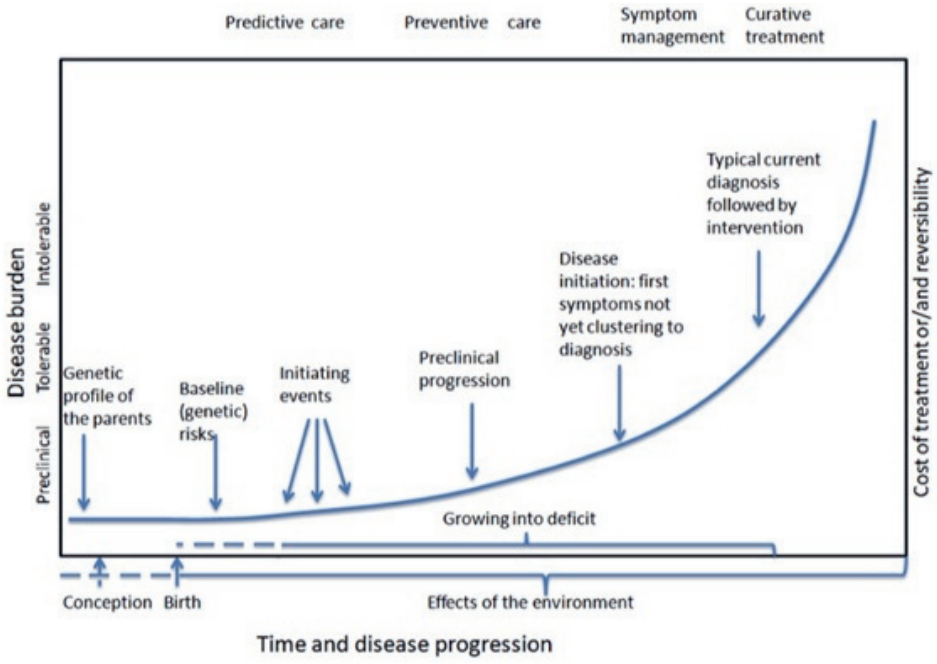

Figure 1. Modification to Syurina's adaptation of Snyderman's curve representing the timelines of 'growing into deficit' and developing common complex diseases, ref. 26.

It is known that the 'goodness of fit' of the transactional relationship between the social context and the child is of importance, in particular for genetically vulnerable individuals (30-33). Social emotional experiences can nurture and build resistance. Non-nurturing environments can generate additional vulnerabilities (8). In particular in the preschool period, strong social emotional support stimulates effective interactions and promotes emotional regulation in the face of adversities, thereby building resilience (34, 35).

Parental problems such as depressive symptoms, posttraumatic stress and adult insecure attachment can undermine a parent's ability to provide adaptive coping guidance to their children to prevent allostatic overload (6, 36). The child's self-regulation results from patterns of arousal and affect modulation repeatedly experienced in early relationships with their caregivers (37-39). Parental depression has been identified as a psychosocial risk factor associated with reduced positive parenting behaviour, negative perceptions, behavioural problems, poor health and delayed cognitive development of the child (40-44). Moreover, parental depression increases the child's risk of a diagnosis of a mental disorder at the age of four years (45). Furthermore, parental stress can counteract the effectiveness of early teaching interventions (46). High levels of parenting stress are related to adolescent depressive symptoms (47). Therefore, parental health might impact

the association between ELS and social participation. It is hypothesized that if a parent has health problems, this can influence the way the parent acts in times of stress, which in turn can modify the association between ELS and social participation in the child.

Social participation is a broad concept including the objective state and the subjective experience of involvement in society. This concept has to be understood in the light of social roles at home, daycare and preschool (48). For example, for young children, play is an important social activity. Social participation can be viewed as meaningful engagement with others. Such engagement can work both positively and negatively in social contexts. Meaningful engagement as an outcome cannot directly be measured. Variables of influence on (development of) meaningful engagement with others can be measured as a proxy outcome measurement of social participation. These variables include child competence and child behaviour such as pro-social behaviour, behavioral problems, emotional problems, hyperactivity / attention problems and peer problems. Peer engagement, problem-solving and prosocial skills are part of child general competence, a variable related to school readiness and future social participation (49). They are based on the assumption that children of different ages demonstrate these outcomes in different ways with many pathways leading to competence.

This article examines the association between parental and professional caregivers' perception of ELS and social participation at preschool. In addition, the modifying effect of the risk factor 'parental health status' was assessed. In this study, social participation is operationalized using various instruments to assess factors underlying social participation: a child's general competence, attendance proportion and extra support (at day care, kindergarten and preschool), the impact of distress, concerns about child development and behaviour, and difficulties in child upbringing and parenting.

Methods

Design and participants

For the present study, baseline data of 346 children participating the Monitoring Outcome Measurements of child development (MOM) study were used. The MOM study is a prospective cohort study that started in July 2009 and is carried out in the province of Limburg, the Netherlands. General population children were aged 3 years at baseline. The MOM study aims to identify developmental pathways impacting social participation and to guide personalized child health care. MOM is performed in the context of the Dutch PCHC. The study obtains information from parents (n=346), professional caregivers (n=103) like teachers/employees from childcare, kindergarten, preschool or primary school, as well as PCHC professionals (n=33), on baseline risk and environmental factors

to track predictive risk indicators for making multiaxial health profiles. Preschool children from a community sample were systematically assessed with a comprehensive preventive child mental health care 'toolkit' of instruments.

Parents were asked to participate in the MOM study. Inclusion criterion was age 3 years, there were no exclusion criteria, and 346 children born between October 1, 2006 and January 1, 2009 were included. Baseline data were collected between July 2009 and October 2011. In this article, baseline information of all 346 participating children provided by parents and professional caregivers was used.

Ethics statement

The Maastricht University Medical Centre Medical Ethics Committee approved the MOM-study protocol under registration number MEC 09-04-018/PL. In accordance with the Declaration of Helsinki, all subjects gave written informed consent after detailed explanation of the study.

Assessments

Early Life Stress (ELS) and ELS Impact factor. To assess early life stress (ELS), parents as well as professional caregivers provided information on life events and the impact of an event in the child's life in 3 domains: in the family, at school and elsewhere (i.e. life event not in the family or at school) (50, 51). Per domain, an open-ended question enquired about the life event with most impact. Because professional caregiver and parent answered the questions independently, they have provided either the same life event or a different one (within the three categories). Consequently, parents and professional caregivers were asked to rate the impact of this event in the child's life on Visual Analogue Scales (VAS) ranging from 1 to 10 (50, 51). It is possible that the parent and professional care giver judged another life-event as having most impact. In the current analyses, these VAS provided by the parents and the professional caregivers were used separately, as well as in combination (highest of the two). In addition, to categorize the open ended answers, the 'Psychosocial and Environmental Stressor Checklist' of the Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood: Revised Edition (DC:0-3R) was used to code the open ended answers by two authors independently (BD and BS) (52, 53). Disagreements about categorizing were resolved through consensus and discussion with a third author (FF). Categories included amongst others challenges to child's primary support group, social environment, educational/child care, health of a child, health-care access, finances, housing, occupational, and legal/criminal justice

Strengths and Difficulties Questionnaire (SDQ). The Dutch version of the Strengths and Difficulties Questionnaire (SDQ) was used by parents as well as by professional caregivers to assess the child's behaviour (54, 55). The SDQ is a brief behavioural screening questionnaire for children aged 3-16 years. It consists of 25 items relating to the child's strengths and difficulties, which are scored on a 3-point Likert scale. The total problem score (0-40) is the sum of the first four subscales: 'emotional symptoms', 'conduct problems', 'hyperactivity/inattention', 'peer relationship problems'. Higher scores indicate more problems. The subscale 'prosocial behaviour' is not included in the total problem score. Each subscale consists of 5 items. The SDQ is considered valid and reliable as a research instrument in community samples (56). Recent research shows a parent SDQ sensitivity of 0.76 at a cut-off point with 0.90 specificity in a community population of children at the age of 3-4 years (57). Both parents and professional caregivers completed in the SDQ. For the present paper, the SDQ sum score was used, as well as the subscores peer problems and pro social behaviour. The SDQ includes items that identify the impact of the behavioural problems of the child, the SDQ impact of distress. Although, parental SDQ was included in the analysis, the SDQ impact was generated using information from both parents and professional care givers in order to gain as much insight as possible into emerging problems and symptoms. If any of the parents or professional caregivers scored 'yes' on the impact probe question, in this study the dichotomous overall distress variable was set at 'yes'.

Child Behaviour Checklist (CBCL). Parent-reported behaviour problems of the children were assessed using the Child Behaviour Checklist (CBCL), Dutch version 1½-5, 2001 (58). It consists of 120 items on behaviour and emotional problems, rated on a 3-point Likert scale (59-61). Good reliability and validity have been reported for the CBCL/1.5-5, also in the Netherlands (62).

Caregiver-Teacher's Report Form (C-TRF). Professional caregivers reported behaviour problems using the Caregiver-Teacher's Report Form (C-TRF) Dutch version1½ -5 (63). It consists of almost the same 120 items as the CBCL.

In the present study, the continuous total problem score of the CBCL and the C-TRF were used. Both the CBCL and C-TRF sum scores included the first 100 items.

Attendance in class. To objectively quantify participation, attendance proportion at day-care, kindergarten and preschool was estimated by asking professional caregivers how many periods (mornings, afternoons) per week the child was supposed to be present, and how many periods the child was actually there on average.

Child competence VAS. To address the issue of the child's functional adaptation, professional caregivers were asked to indicate, on a VAS, the degree of competence of the child in general (0= not competent, 100= very competent).

Extra support. In addition, professional caregivers were asked to report whether children received extra support, in- or outside school.

Parenting VAS. In order to quantify self-rated parental competencies, a VAS ranging from 0-100 was used; parents expressed the degree to which they felt competent, secure and happy with raising their child (0 = I do not manage to raise my child as I wish, 100 = raising my child is up to my expectations).

Child behaviour VAS. Another VAS assessed how the parents evaluated their child's behaviour (0 = my child is difficult and badly behaved, 100 = my child is very obedient and easy to handle).

Parents' Evaluation of Developmental Status (PEDS). The PEDS is a 10-item parent as well as professional caregivers completed standardized semi-structured questionnaire to elicit concerns and facilitate communication between professionals and parents in addressing developmental problems in children aged less than 8 years, in the general population and clinical samples (64). PEDS questions include items on expressive and receptive language, fine motor, gross motor, behaviour, socialization, self-care and learning. A dichotomous parental concerns variable (any concern yes/no) was constructed for use in the analyses.

In a previous article, the 3 VAS to assess 'child competence', 'parenting' and 'child behaviour', as well as the parental and professional caregivers PEDS were validated for use in daily Dutch PCHC practice (65). All five instruments were strongly associated with various validated constructs. In addition, reliability was good. Finally, criterion validity was assessed using 'reference standard' instruments: the CTR-F was the reference standard for the 'child competence' VAS, the CBCL was the reference standard for the 'child behaviour' VAS and the Parenting Stress Index Short Form (in Dutch abbreviated as NOSIK) (66) was the reference standard for the 'parenting' VAS. Reference standard of the parental and professional caregiver PEDS were the CBCL respectively the C-TRF. Although the 'child competence' VAS scored lower on one aspect of validity, results suggest that the PEDS and the different VAS are reliable, valid and useful as brief monitoring tools in every day Dutch PCHC practice.

Parental Health. Parents were asked to judge their own physical and mental health as well as the physical and mental health of the other parent/caregiver, using a 5-point Likert Scale from 1 (bad) to 5 (excellent). Self-rated health status is a simple, yet widely used,

measure with similar validity as more sophisticated health assessments; it is also a reliable predictor of mortality and health care use in adults (67). As described earlier (65), MOM included an extra data collection to assess reliability. The intra-rater test–retest reliability showed strong and significant correlations (Spearman correlation: parental and co-parental physical health = 0.92 and 0.99, respectively, $p<0.0001$; parental and co-parental mental health = 0.93 and 1.00, $p<0.0001$ available upon request/unpublished results) The four health variables were combined into one parental health variable, which was then dichotomized (fair and poor were recoded into 1 and excellent, very good and good were recoded into 0).

Socioeconomic status. As an indicator of socioeconomic status, the level of maternal and paternal education was assessed in 3 categories: low (primary education, junior vocational education), middle (general secondary education, senior vocational education) and high (preparatory university education and university education). The individual with the highest level of education determined parental educational level.

Statistical analyses

All analyses were performed using Stata (Statistical Software Package), version 15 (68). Logistic and linear regression analyses of baseline data were performed. In all analyses, the independent variable was ELS. Dependent variables were social participation operationalised in various ways. Logistic regression was performed to analyse presence of PEDS concerns, SDQ impact of distress, attendance in class and presence of extra support. Linear regression analysis was performed to analyse number of PEDS concerns, SDQ total score, the SDQ subscales 'peer problems' and 'pro-social behaviour', CBCL total score, C-TRF total score, 'child behaviour' VAS, 'child competence' VAS, and 'parenting' VAS. Analyses were adjusted for age, sex and educational status of the parents.

Furthermore, the interaction term between ELS on the one hand and 'parental health status' on the other was included in the models analysing all outcomes. When the interaction term was non-significant, it was removed from the models. When there was significant interaction between 'parental health status' and ELS, the Stata post estimation command lincom was used to calculate stratified results.

Results

Parents of 346 children agreed to participate in the MOM study. In the caseload of participating doctors, response was 50-70%, but not all doctors participated (see discussion). Parents of 341 children and professional caregivers of 300 children completed the questionnaires. For 291 of these children (84%), information from both informants

was available. Of the participating children, 60% (n=207) were resident in the municipality of Maastricht, while 40% (n=139) lived in the surrounding area. Table 1 shows the background characteristics of the study respondents' sample at baseline. For one child there was no information whether the child experienced life events. ELS in the areas of challenges to the child's primary support group (60 %), education/child care (22%) and health (12%) were reported most frequently. Descriptive of the outcomes used to index 'Social participation' are shown in table 2.

Parental health status was associated with various variables used to index social participation (presence of PEDS concerns, SDQ impact of distress, number of PEDS concerns, child competence, parenting, child behaviour, SDQ sum score, CBCL sum score, C-TRF sum score (data not shown).

Table 1. Background characteristics of the study respondents' sample at baseline

	N		Number (%)	
Gender	346	Girls	180 (52%)	
		Boys	166 (48%)	
Parental Health status	341	Poor health [2]	48 (14%)	
Parental educational status	335	High	212 (63%)	
		Medium	92 (28%)	
		Low	31 (9%)	
Early Life Stress (ELS)	345	Presence of ELS (Parents or prof.[1])	115 (33%)	
			Mean (SD)	Range
Age children	346	Parents	3.0 (0.2)	1.8-3.9
	301	Prof.[1]	3.1 (0.2)	1.8-3.8
Impact factor ELS[3]	91	Parents	3.8 (2.6)	1-10
	42	Prof.[1]	3.7 (2.4)	1-9
	107	Parents or prof.[1]	4.0 (2.5)	1-10

[1] Professional caregivers
[2] Combined physical and/or mental health: poor or fair
[3] Only scored when ELS is present

Table 2: Descriptive of the outcomes used to index 'Social participation' (N=346)

	N	Number (%)	
Presence PEDS concerns (parents)	339	147 (43%)	
Extra support children receive (prof.[1])	293	22 (8%)	
SDQ –impact of distress (parents and prof.[1])	295	62 (21%)	
		Mean (SD)	Range
Number of reported PEDS concerns (parents)	339	1.0 (1.6)	0-10
Number of reported PEDS concerns (parents) if present	147	2.4 (1.7)	1-10
SDQ-total-score (parents)	338	6.8 (4.9)	0-28
SDQ-score peer problems (parents)	338	1.3 (1.5)	0-8
SDQ-score pro social behavior (parents)	339	8.0 (1.7)	1-10
CBCL-total-score (parents)	331	21.3 (19.2)	0-117
C-TRF-total score (prof.[1])	289	13.2 (17.1)	0-92
Child behavior (parents) [2]	329	66.3 (17.8)	1-97
Child competence (prof.[1]) [3]	290	63.6 (19.7)	4-100
Parenting (parents) [4]	327	70.3 (18.8)	6-100
Child's % of attendance in class [5]	282	98.6 (6.7)	50-100

[1] Professional caregivers
[2] A higher VAS score means parent judges child behavior more positive
[3] A higher VAS score means professional caregiver judges child competence more positive
[4] A higher VAS score means parent judges parenting more positive
[5] This is presence in class (quantitative participation) and was measured as a % of hours of enrolment per individual child. In 5% (n=13) of the children attendance was not 100%

Association between ELS and various outcomes

Children with ELS more often received extra support (OR=1.3, p=0.001) and more often experienced distress (OR=1.3, p<0.001), while their parents reported PEDS concerns more often (OR=1.3, p<0.001, Table 3). The number of concerns was also higher (B=0.3, p<0.001). Furthermore, parents of children with ELS perceived more difficulties in child upbringing ('parenting' VAS: B=-2.5, p<0.001) and peer problems (SDQ B=0.1 p<0.01, Table 4). None of these associations was moderated by 'parental health status'. Parental health status interacted with ELS in the model of SDQ total sum score (F=8.6, df=1,3, p=0.0036) and CBCL total sum score (F=9.7, df=1,3, p=0.0021). Thus, the association between ELS and SDQ total sum score was stronger in children with parents with poor health than in children with parents with fair health (B=1.2, p<0.001 and B=0.4, p=0.002, respectively, Table 5). A similar moderating effect was observed for the outcomes of CBCL and C-TRF.

Table 3. Logistic regression analysis: the association between ELS and dichotomous variables indicating quality of social participation (i.e. need for extra support, concerns, attendance); odds ratios (OR) and 95% confidence intervals (CI), according to parents (n=341), professional caregivers (n=300) or both (n=345)

Controlled for confounders (age, gender, parental educational status) The interaction terms parental health status X ELS were not statistically significant

	OR	CI
Extra support children receive (prof.[1])	1.3 **	1.1; 1.5
Presence PEDS concerns (parents)	1.3 †	1.1; 1.4
Attendance in class (prof.[1])	1.0	0.8; 1.3
SDQ -Impact of distress (parents and prof.[1])	1.3 †	1.2; 1.5

*p <0.05; **p <0.01; †p <0 .001
[1] Professional caregivers

Table 4. Linear regression analysis: the association between ELS and quality of social participation (number of concerns, child competence and parenting); B's and 95% confidence intervals (CI), according to parents (n=341), professional caregivers (n=300) or both (n=345) Controlled for confounders (age, gender, parental educational status)

The interaction term 'parental health status' X ELS was not statistically significant

	F	p	df	B	CI
Number of PEDS concerns (parents)	15.3	< 0.0001	4, 319	0.3 †	0.2; 0.3
Child competence (prof.[1])[2]	7.9	< 0.0001	4, 272	-0.8	-1.8; 0.2
Parenting (parents)[3]	12.3	< 0.0001	4, 307	-2.5 †	-3.4; -1.6
SDQ- peer problems (parents)	3.9	0.0045	4, 318	0.1 **	0.0; 0.2
SDQ -prosocial behaviour (parents)	3.9	0.0040	4, 319	-0.0	-0.1; 0.0
Child behaviour (parents)[4]	6.1	0.0001	4, 309	-1.8 †	-2.6; -0.9

*p <0.05; **p <0.01; †p <0 .001
[1] Professional caregivers
[2] A higher VAS score means professional caregiver judges child competence more positive
[3] A higher VAS score means parent judges parenting more positive
[4] A higher VAS score means parent judges child behaviour more positive

Table 5. Linear regression analysis (significant interaction with one or both risk factors): association between ELS and quality of social participation; B's and 95% confidence intervals (CI), according to parents (n=341), professional caregivers (n=300) or both (n=345)

Controlled for confounders (age, gender, parental educational status)

	Interaction term (F-test)[1]			Parental health B (CI)	
	F	p	df	Fair	Poor
SDQ sum score	8.6	0.0036	1, 316	0.4 ** (0.2; 0.7)	1.2 † (0.7; 1.7)
CBCL sum score	9.7	0.0021	1, 311	2.4 † (1.5; 3.4)	5.4 † (3.7; 7.0)
C-TRF	6.3	0.0125	1, 269	0.5 (-0.5; 1.5)	3.3 ** (1.4; 5.2)

p <0.05; **p <0.01; †p <0 .001
[1] Regression coefficient of interaction term parental health status X ELS

Discussion

Results of this study showed that ELS is associated with reduced quality of social participation in three-year olds as assessed using child's general competence, attendance proportion and extra support (at day care, kindergarten and preschool), the impact of distress, child development and behaviour concerns, and difficulties in child upbringing and parenting. When parental health was low the association between ELS and several dimensions of social participation (SDQ total, CBCL and C-TRF) was stronger.

The association between ELS and reduced quality of social participation is in line with a recent study showing an association between ELS and behavioural problems and poorer psychosocial functioning in pre-schoolers (69). Other research showed associations between ELS, reduced social participation and adverse consequences such as mental problems, learning disabilities, early school dropout, underachievement, unemployment, low socioeconomic status, poverty, antisocial behaviour and substance abuse (70-72). These associations emphasizes the importance of early identification of the impact of ELS.

While ELS is common (9, 73-75), it is important to know the prevalence and incidence of various types of ELS, rather than limiting attention to one specific type (12). Identifying less significant forms of ELS is a challenge, as these can have significant impact (13, 76). With this knowledge early identification is possible and therefore early intervention when signs and symptoms do not yet meet diagnostic criteria.

The interaction with parental health could have been expected as well, because other studies showed that both familial (genetic and non-genetic) and non-familial environmental factors may moderate ELS effects (1, 9, 10, 16, 77). In addition, parental health can impact the child's health indirectly via the pathway of emotional neglect (78). This interaction shows the importance of systematically asking the parent about perceptions of parenting and parental health.

Methodological issues

General population preschool children were systematically assessed using a comprehensive PCHC 'toolkit' of instruments. The baseline results presented in the current paper are cross-sectional, but in future, children can be followed over time.

Strength of the present study is that the child's participation is evaluated in different situations with information from multiple informants. ELS in 3-year-old children was obtained through hetero-anamnesis of parents and professional caregivers (79). Data provided by the PCHC professionals are not included in the present paper, but will be

reported separately. In addition, this study is based on real life practice. No children were excluded for not meeting inclusion criteria.

The present paper also has some limitations. First, a power calculation for the present research question showed that the number of subjects is sufficiently large to show medium effect sizes (Cohen's D=0.5), but underpowered to show smaller effect sizes. Any future replication of the current results will require a larger sample size. Nevertheless, respondents are representative for the South Limburg population (65). In addition, the distribution of parental education in non-responders was only slightly different from distribution in responders (responders 63%, 28%, 9% and non-responders 55%, 33%, 12% having high, intermediate and low parental education, respectively, chi-square=5.0, p=0.08) (65).

Secondly, since the MOM data are limited to Maastricht and surrounding area the findings of this study may not necessarily be valid for PCHC settings in other parts of the Netherlands and abroad. This part of the Netherlands is quite similar to the rest of the country. However, there are some differences. In Maastricht, the proportion of non-European inhabitants (about 10 %) is less than in the larger cities in the north west of the country (about 30%) (80). For this reason, the MOM study findings may not necessarily be valid for large cities with ethnically mixed populations

Moreover, the primary support network of a child and its family is relevant. Social support reduces stress. Another source of resilience is language and cognitive skills. It supplies a child with the necessary support to cope with stress and leads to resilience (adaptive behaviour) in the light of stressful life events (8, 81-83). No information with respect to the child's social support network (other than parents) was included in the present study. In future studies this should also be included.

Finally, an illness in a parent ('parental health status') can be a life event. Therefore, a sensitivity analysis was performed excluding the children whose ELS consisted of deceased or unhealthy parents (n=3). All results were similar to the original results (data not shown).

Recommendations and conclusions

To effectively address the health and well-being of children, PCHC must consider the educational context and not just the child (84). The process of development and social participation evolves as a 'dynamic cascade' of risk and protective factors that exist not in isolation but are continuously shaping one another (37). Children's development and health are strongly influenced by how well their family functions. Health care professionals

should be alert for parental health, and any imbalance between the parents' need for support and the support they actually receive (85). For children to be able to flourish and cope with stress, the quality of parental support and the educational context represent an important resource for successful social participation across the life span (38, 86, 87). For early identification of children at risk for developmental delay, PCHC professionals should acknowledge current constraints of families and may examine the presence and impact of ELS in the lives of children and the health of their parents (13). Therefore, PCHC workers have the important task to move beyond the disease classifications and to characterize the full palette of phenotypes of developmental profiles of children with multiaxial information (26).

This study confirms that parental and professional caregivers' perceptions and concerns are to be taken seriously (88, 89). In addition, PCHC is capable of adopting methodologies that incorporate structured assessments for the range of traumatic stressors that are common in infancy and early childhood. Short validated instruments with information from parents and professional caregivers do support ongoing communication on social participation, emerging problems and 'shared decision making' (90).

The design of the MOM study illustrates a paradigm shift from the curative approach towards personalized preventive, predictive and participatory public health care (29).

Important are preventive interventions aimed at easing the transition to parenthood, to support parenting self-efficacy and to control toxic stress. Being a parent is not just about parenting, it is a transition process that affects different aspects of a person's life such as relationships, work, finance, housing. Family Foundations is an example of a brief, universal, transition-to-parenthood intervention for couples to strengthen their cooperative relationship (91). This prevention program benefits all families, particularly families at elevated prenatal risk.

Furthermore, personalized health care requires optimal collaboration between parents, practice, policy and research, for cross-domain knowledge transfer and exchange to address the health of the child as well as the needs of the family (84). Then, personalized PCHC can be offered to support the capacity of parents and other caregivers and stimulate their health literacy in order to lower toxic stress and develop strong responsive early relationships with their children.

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CHAPTER 5

5

Parental perceptions and Personalized Health Care to prevent child maltreatment

B. Doove, B. Cuppen, M. Drukker, J. van Os, F. Feron. Parental perceptions and Personalized Health Care to prevent child maltreatment.
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Abstract

Background

The individual's social and educational environment including interpersonal relationships is hypothesized to be key to provide Personalized Health Care, to prevent child maltreatment. This article focuses on associations of child maltreatment risks with 4 outcome measures: functioning of the child, quality of the environment, degree of care, and urgency of care.

Subjects and Method

In a prospective observational study within PCHC practice, a community-based sample of 346 preschool children was systematically assessed with a comprehensive preventive child health care (PCHC) 'toolkit' of short validated instruments such as the Parents' Evaluation of Developmental Status (PEDS) and different Visual Analogue Scales (VAS). Cross-sectional linear regression analyses were performed, using baseline data (age three years). Dependent variables were: functioning of the child, quality of the environment, degree of care, and urgency of care. Independent variables used in the linear regression analyses were: parental concerns about parenting competency (parenting VAS) and child development and behaviour (child's behaviour VAS, number of parental PEDS concerns), parental health status, total number of risk factors, and specific risk factors: unstable parenting situation, excessive amount of parental stress, and parental traumatic experience. Analyses were adjusted for sex and parental educational status. To replicate the results, all analyses were repeated using follow-up data (age four years).

Results

Parental perceptions of parenting difficulties and bad child behaviour, three or more parental concerns, parents rating themselves as unhealthy, existence of seven or more risk factors, excessive amount of parental stress, and an unstable parental situation were associated with the four above-mentioned outcomes. At follow-up approximately 10 months later (mean age 3.9; SD ± 0.2), results were similar.

Conclusion

To improve early identification of children at high risk of child maltreatment, PCHC has to assess parent's health perception, the number of parental concerns and cumulative risk factors in the child's educational context.

Background

Child maltreatment causes significant risk for psychopathology during life course due to a cascade of developmental failures across various domains of neurobiological, socio emotional and cognitive development. These developmental failures can cause various problems in emotion recognition, emotion regulation, school functioning, and even intergenerational transmission of maltreatment (1). According to the World Health Organization, child maltreatment is defined as 'all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power' (2-4).

Beyond the fact that all children have the right to grow up in a safe environment (5), prevention of child maltreatment is important to diminish the continuity of burden and costs for society (6-8). Society has a moral and legal responsibility to protect children. With a yearly estimated childhood maltreatment prevalence of 33.8 cases per 1000 children aged between 0-17 years the Netherlands is no exception in this respect (9-11). Since not all cases of child maltreatment are reported these numbers are an underestimation. The prevalence of child maltreatment based on high school student's self-report is even higher, 99.4 per 1000 adolescents (12).

The Dutch Preventive Child Health Care (PCHC) has been established to closely monitor the health of all children during routine medical assessments in well-child care clinics offered by PCHC professionals (e.g. doctors, nurses). It is a free public service that is currently used by over 90% of all children in the country (13, 14). Monitoring child health enables PCHC professionals to intervene in the earliest phase of emerging problems and disabling symptoms, even before formal criteria for diagnostic classifications are met (15-18). This offers PCHC a great opportunity to provide personalized, predictive, preventive and participatory care: Personalized Health Care (19).

As in developmental disorders, the onset of child maltreatment is in most cases multifactorial. The genetic baseline risk of a person combined with its exposure to environmental factors is what causes a person to show signs and symptoms, within a developmental continuum over time. (1, 20). From an organizational perspective of development, child maltreatment represents a pathogenic relational environment and a severe hazard to children's adaptive and healthy development (7, 21). In particular, adverse preschool childhood experiences may have a long-lasting impact on brain development and health (22). Research shows diversity in process and outcome of developmental pathways (7, 23). Either resilient functioning or maladaptive functioning

may be achieved during transactional sensitive periods across the life cycle. Resilience is a developmental process that is not fixed or immutable. It can be defined as the capacity of a dynamic system to adapt successfully to disturbances that threaten function or development (24). Consequently, the individual's social and educational environment, including interpersonal relationships, is hypothesized to be key to PCHC to prevent child maltreatment.

Although the preschool period is known as a sensitive period for biological embedding, age and developmental phase relevant tasks from infancy to adulthood remain important for successful social participation during life course. Social participation is a broad concept describing the objective state and subjective experience of involvement with others in society. Social involvement has to be understood in the light of social roles. A clear definition does not yet exist (25). In this article, the concept social participation is operationalized using factors underlying social participation: functioning of the child, quality of the environment, degree of care and urgency of care.

To provide Personalized Health Care from a Public Health perspective, it is a daily challenge for PCHC to make a risk assessment for each child at the junction of the different symptom dimensions and diagnostic entities. Signs of alarm and reassurance have to be taken in consideration within this risk assessment. Research showed that instinct in general practice is based on the dialogue between patient and doctor, with a continuous interaction between analytical and non-analytical diagnostic reasoning (26). Next to PCHC physical examination, periodic eliciting and addressing parental as well as other caregivers' representations and concerns is a main component in a family centred practice (27-30). In this article, it is hypothesized that a PCHC 'toolkit' with short instruments for regular short parental and other caregivers report can serve as a first step in PCHC screening and monitoring procedures to select children who require further support. By measuring the degree of parental perception and concerns about parental health, parenting, child behaviour and child development, these instruments can signal a possible maladaptive system as a risk factor for child maltreatment (21).

The clinical reasoning of a PCHC professional, in which an evaluation is made of the severity and urgency of the problems, is difficult to translate into an instrument. However, various short instruments are available to support clinical judgement. Previous research showed that accumulation of risk factors is more essential in predicting child abuse potential than the presence of particular risk factors (31). Another issue is determining the severity or seriousness of the problems. Various descriptions and models have been developed to make clear what exactly is meant by the severity or seriousness of the problems (32). Practice shows us that different interpretations are given to the concept of 'seriousness'. Besides, there is a continuum of parenting practises and appropriate behaviour, and the

threshold for being judged as inappropriate behaviour depends on social norms. For this article, different supportive tools were used to facilitate analytical processing of available information and knowledge of the PCHC professional, to reassure or alert that there is something wrong and action is required.

The Monitoring Outcome Measurements of child development (MOM) study is a prospective observational study with data collection at age 3 years and at age 4 years. The present paper aims to analyse data at age 3 years and at age 4 years, cross-sectionally to study associations.

For early identification of a maladaptive system as a risk factor for child maltreatment, the present article examined the association between different hypothesized parental risk factors and social participation as assessed using 4 outcome measures: functioning of the child, quality of the environment, degree of care, and urgency of care. Two different risk measure types were used: a cumulative risk measure and single risk item measures. Various risk variables were included: parental concerns about parenting competency, child development and behaviour; parental health status; unstable parenting situation, and parental problems such as excessive amount of parental stress and parental traumatic experience. The cumulative risk factor was the total number of child and environmental risk factors present. Cross-sectional analyses were performed both with baseline data and with follow-up data. Similar findings at age 3 years and age 4 years could be interpreted both as a replication and as evidence that associations are similar at these ages.

Subjects and Method

Study design

The present study was performed as part of the Monitoring Outcome Measurements of child development (MOM) study, a prospective observational study within PCHC practice in Maastricht and surrounding area. A community-based sample of children was systematically assessed with a comprehensive PCHC 'toolkit' of instruments using a multisource and cross-informant repeated measures design to identify developmental pathways impacting school readiness as an outcome of social participation. Children were aged three years at baseline and approximately four years at follow-up. To assess perceptions, demands and concerns of parents and professional caregivers about development and social participation, various short instruments such as the Parents' Evaluation of Developmental Status (PEDS) and Visual Analogue Scales (VAS) were included in the MOM study. PCHC professionals provided information about child health, development, risk and protective factors, and interventions.

Population and sample

All 1692 children from a community birth cohort of were asked to participate. No children were excluded. Forty percent of non-responders were randomly sampled to manually collect data on parental education from the medical files. The distribution in non-responders was only slightly different from distribution in responders (responders 63%, 28%, 9% and non-responders 55%, 33%, 12% having high, intermediate and low parental education, respectively, chi-square=5.0, p=0.08). Thus, one may consider the community-based sample as representative (33).

Study variables

For this article the dependent study variables were: functioning of the child, quality of the environment, degree of care, and urgency of care. As independent variables were included: parental concerns about parenting competency, child development and behaviour; parental health status; unstable parenting situation, and parental problems such as excessive amount of parental stress and parental traumatic experience. Independent variable for cumulative risk factor was: total number of child and environmental risk factors present. Background factor variables were: gender and parental educational status.

Data collection and instruments

Data of parents and PCHC professionals were collected at the age of three years and the follow-up approximately a year later.

Parents completed the PEDS, a 10-item standardised semi-structured questionnaire to elicit concerns regarding child development for children aged less than eight years in the general population and clinical samples (34). PEDS provides both open-ended questions and specific probes regarding concerns in various domains: expressive and receptive language, fine motor, gross motor, behaviour, socialisation, self-care and learning. For the current article, the number of 'parental concerns' was used in the analyses.

In order to quantify self-rated parental competencies, a 'parenting' VAS ranging from 0-100 was used; parents expressed the degree to which they felt competent, secure and happy with raising their child (0 = I do not manage to raise my child as I wish, 100 = raising my child is up to my expectations). Another 'child behaviour' VAS assessed how the parents evaluated their child's behaviour (0 = my child is difficult and badly behaved, 100 = my child is very obedient and easy to handle). Good reliability and validity have been reported for the PEDS, 'parenting' VAS and 'child behaviour' VAS (33). Thus, PEDS and the different VAS were useful as brief monitoring tools in PCHC practice. In this article, specific VAS cut-off points (Table 3) were used to categorise the VAS variable (33).

The parents that completed the MOM-questionnaire scored their physical and mental health as well as the physical and mental health of the other parent/caregiver, using a 5-point Likert Scale from 1 (bad) to 5 (excellent). Self-rated health status is a simple, yet widely used, measure with similar validity as more sophisticated health assessments. It is a reliable predictor of mortality and health care use in adults (35). The MOM study included an extra data collection to assess reliability. The intra-rater test–retest reliability showed strong and significant correlations (Spearman correlation: parental and co-parental physical health = 0.92 and 0.99, respectively, $p<0.0001$; parental and co-parental mental health = 0.93 and 1.00, $p<0.0001$, available upon request/unpublished results). The four health variables were combined into one parental health variable, which was then dichotomised (fair and poor were recoded into 1 and excellent, very good and good were recoded into 0).

As an indicator of socioeconomic status, the level of maternal and paternal education was assessed. Three categories were defined: low (primary education, junior vocational education), middle (general secondary education, senior vocational education) and high (preparatory university education and university education). The parent with the highest level of education determined parental educational level.

One instrument to facilitate clinical judgement is the Standard Taxation of Severity of Problems (Standaard Taxatie Ernst Problematiek, STEP) to be assessed by the PCHC professional. In this article, the four scales of the STEP are the primary outcomes: 1) Functioning of the child: this scale includes questions about personal functioning, the duration of the problems, the extent to which a child is upset and the extent to which functioning impedes daily life and is a burden on others; 2) Quality of the environment: this scale includes questions about the quality of the primary educational environment, the other environment such as nursery, school and neighbourhood, the duration of the problems and the social support; 3) Degree of care: this scale includes questions about the type of care that you consider to be the right one in the coming period, the duration and the intensity of care; 4) Urgency of care: this scale consists of one question: how do you estimate the urgency of care, is the help needed acute or non-acute? Before completing the STEP, the PCHC doctor has inventoried all concerns, signals, problems, static and dynamic risks and protective factors of each child on the following five levels: 1) Child psychosocial functioning, 2) Child physical health and body-bound functioning, 3) Child skills and cognitive development, 4) Family and upbringing, and 5) Child and environment. This inventory tool for the MOM study was developed with the aid of a Dutch guideline on prevention of child abuse and risk assessment instruments such as the Dutch Child Abuse Risk Evaluation (CARE-NL) and the CAP-J, a Dutch instrument for classification of the nature of problems of the child (36-38).

For the MOM study, all participating PCHC doctors were trained to classify the signals, risk and protective factors and to estimate the severity of the problems.

Statistical analysis

Statistical analyses were carried out using Stata, version 15 (39). First, baseline descriptive statistics were provided. Subsequently, linear regression analyses were performed using baseline data (age three years). Dependent variables were the four domains of the STEP: functioning of the child, quality of the environment, degree of care, and urgency of care. In order to compare the scales of these four domains with each other, regression coefficients were standardized. Independent variables used in the linear regression analyses were: parental concerns about parenting competency (parenting VAS) and child development and behaviour (child's behaviour VAS, number of parental PEDS concerns), parental health status, total number of risk factors, and specific risk factors: unstable parenting situation, excessive amount of parental stress, and parental traumatic experience. Analyses were adjusted for sex and parental educational status. Third, all analyses were repeated using follow-up data (age four years).

Human subjects approval

Research ethical issues including informed consent, anonymity, and confidentiality, were addressed carefully during the study process. The Maastricht University Medical Centre Medical Ethics Committee approved the MOM-study protocol under registration number MEC 09-04-018/PL.

Results

Parents of 346 children agreed to participate in the MOM study. From the caseload of participating doctors, response was 50-70%, but not all doctors participated (see discussion). Parents of 341 children and professional caregivers of 300 children completed the questionnaires. For 291 of these children (84%), information from parent, professional caregiver as well as PCHC doctor was available. Of the participating children, 60% (n=207) were resident in the municipality of Maastricht, while 40% (n=139) lived in the surrounding area. The total sample of children consisted of 166 boys (48%) and 180 girls (52%), (Table 1).

The mean age at baseline the PCHC professionals provided information was 3.2 years (Table 2). More than half of the parents received high education (63%). At baseline, parents of 43% of the children indicated any PEDS concerns (Table 1) with a median number of concerns of 0 (range 0-10) (Table 2). One or both parents of 14% of the children mentioned poor parental health. Regarding other risk factors, 14% of the parent's experienced an

excessive amount of parental stress, 11% parental traumatic experience. In 11% of the cases there was an unstable parenting situation (Table1).

The median amount of risk factors was 3 (range 0-32). Furthermore, parents scored on average 70.3 on the parenting VAS and 66.3 on the child behaviour VAS (Table 2). Table 2 shows mean, standard deviation and range of the four domains of the STEP: functioning of the child (8.7; SD 4.2), quality of the environment (6.3; SD 2.9), degree of care (4.4; SD 3.2) and urgency of care (1.3; SD 0.7). Follow-up was approximately 10 months later (mean age 3.9; SD ± 0.2, Table 2) and showed similar results (Table 1and 2).

Table 1. Background characteristics of the study sample at baseline (T1) and follow up (T2), provided by PCHC professional (PCHC) and parents (parents).

	T1		T2	
	N	Number (%)	N	Number (%)
Gender	346			
Girls		180 (52)		
Boys		166 (48)		
Parental educational status	335		316	
High		212 (63)		201 (64)
Medium		92 (28)		84 (26)
Low		31 (9)		31 (10)
Presence PEDS concerns (parent)	339	147 (43)	293	126 (43)
Poor parental health (parents)	341	48 (14)	293	30 (10)
Excessive amount of parental stress (PCHC)	331	46 (14)	321	42 (13)
Parental Traumatic experience (PCHC)	331	35 (11)	321	30 (9)
Unstable parenting situation (PCHC)	333	35 (11)	321	33 (10)

Table 2. Descriptive statistics at baseline (T1) and follow up (T2), provided by PCHC professional (PCHC) and parents (parents).

Variable	T1			T2		
	N	Mean (S.D.)	Range	N	Mean (S.D.)	Range
Age in years [1]	331	3.2 (0.2)	2.5-4.8	321	3.9 (0.2)	3.1-4.8
Age mother	330	34.2 (4.6)	21-44	319	35.3 (4.4)	23-45
Age mother at first birth	327	28.8 (4.7)	15-41			
Age father	321	38.0 (6.1)	22-72	309	39 (6.0)	24-73
Age father at first birth	316	32.9 (5.8)	18-69			
Parenting VAS [2] (parents)	327	70.3 (18.8)	6-100	281	72.5 (16.5)	14-99
Child's behaviour VAS [3] (parents)	329	66.3 (17.8)	1-97	279	67.8 (16.5)	11-100
Functioning of the child (PCHC)	332	8.7 (4.2)	6-24	319	9.0 (3.9)	6-22
Quality of the environment (PCHC)	332	6.3 (2.9)	5-19	320	6.2 (2.7)	5-16
Degree of care (PCHC)	332	4.4 (3.2)	3-19	320	4.2 (2.9)	3-17
Urgency of care (PCHC)	331	1.3 (0.7)	1-5	320	1.3 (0.7)	1-5
	N	Median	Range	N	Median	Range
PEDS concerns (parents)	339	0	0-10	293	0	0-9
Risk factors (PCHC)	333	3	0-32	321	3	0-23

[1] Age of child the PCHC professional provided information
[2] A higher VAS score means parent judges parenting more positive
[3] a higher VAS score means parent judges child behaviour more positive

Associations with the four STEP subscales

Linear regression analyses showed associations between different variables and the four standardized STEP scales at baseline and follow-up (Table 3). For example, at baseline there was a statistically significant association between parenting difficulties (parenting VAS 0-41) and lower functioning of the child (B=1.2, CI 0.9; 1.5), less quality of the environment (B=0.6, CI 0.3; 1.0), higher degree of care (B=1.3, CI 1.0; 1.6) and greater urgency of care (B=1.2, SD 0.9; 1.6). Similar significant associations were seen between other variables and the four STEP scales: parental perceptions of bad child behaviour (child behaviour

VAS 0-43), three or more parental concerns (parental PEDS), parents rating themselves as unhealthy, and PCHC professionals mentioning the existence of seven or more risk factors, excessive amount of parental stress, or an unstable parental situation (Table 3a, b, c, d). Linear regression analyses almost a year later showed similar results.

Table 3a. Linear regression analysis at baseline (T1) and follow up (T2): association between different independent variables and dependent standardized STEP variable: Functioning of the child, according to parents (parents) and PCHC professionals (PCHC); b- coefficient (B) and 95% confidence intervals (CI). Controlled for confounders (gender, parental educational status)

Functioning of the child (PCHC)						
	T1			**T2**		
	B	95% CI	*p*	B	95% CI	*p*
Parenting VAS: T1/T2 (parents)						
1: 74-100 (ref)/75-100 (ref) in mm	0			0		
2: 64-73/66-74	-0.0	-0.3; 0.2	0.691	0.1	-0.2; 0.3	0.654
3: 42-63/49-65	**0.3**	**0.0; 0.6**	**0.041***	**0.5**	**0.2; 0.9**	**0.001****
4: 0-41/0-48	**1.2**	**0.9; 1.5**	**<0.001†**	**1.3**	**1.0; 1.7**	**<0.001†**
Child behaviour VAS: T1/T2 (parents)						
1: 69-100 (ref)/69-100 (ref) in mm	0			0		
2: 55-68/60-68	0.1	-0.1; 0.4	0.328	**0.3**	**0.0; 0.5**	**0.048***
3: 44-54/47-59	**0.3**	**0.0; 0.6**	**0.028***	**0.3**	**0.0; 0.6**	**0.045***
4: 0-43/0-46	**1.0**	**0.6; 1.3**	**<0.001†**	**1.2**	**0.8; 1.6**	**<0.001†**
Number of PEDS concerns (parents)						
0 (ref)	0			0		
1-2	**0.4**	**0.2; 0.6**	**0.001****	**0.4**	**0.2; 0.7**	**<0.001†**
≥ 3	**1.4**	**1.2; 1.7**	**<0.001†**	**1.5**	**1.2; 1.8**	**<0.001†**
Poor parental health status (parents)	**0.6**	**0.3; 0.9**	**<0.001†**	**0.5**	**0.1; 0.9**	**0.011****
Number of risk factors (PCHC)						
0-2 (ref)	0			0		
3-6	**0.4**	**0.2; 0.6**	**<0.001†**	**0.5**	**0.3; 0.8**	**<0.001†**
≥ 7	**1.4**	**1.1; 1.7**	**<0.001†**	**1.6**	**1.3; 1.9**	**<0.001†**
Excessive amount of parental stress (PCHC)	**0.9**	**0.6; 1.2**	**<0.001†**	**1.1**	**0.8; 1.4**	**<0.001†**
Parental traumatic experience (PCHC)	0.3	-0.1; 0.6	0.101	0.4	-0.0; 0.8	0.067
Unstable parenting situation (PCHC)	**0.8**	**0.5; 1.2**	**<0.001†**	**0.8**	**0.4; 1.1**	**<0.001†**

*p <0.05; **p <0.01; †p <0.001, 95% CI=95% confidence interval
Statistically significant results are in bold

Table 3b. Linear regression analysis at baseline (T1) and follow up (T2): association between different independent variables and dependent standardized variable: Quality of the environment, according to parents (parents) and PCHC professionals (PCHC); b- coefficient (B) and 95% confidence intervals (CI). Controlled for confounders (gender, parental educational status)

Quality of the environment (PCHC)						
	T1			T2		
	B	95% CI	*p*	B	95% CI	*p*
Parenting VAS: T1/T2 (parents)						
1: 74-100 (ref)/75-100 (ref) in mm	0			0		
2: 64-73/66-74	-0.0	-0.3; 0.2	0.825	0.1	-0.2; 0.3	0.486
3: 42-63/49-65	0.2	-0.1; 0.5	0.125	0.3	-0.0; 0.6	0.097
4: 0-41/0-48	**0.6**	**0.3; 1.0**	**<0.001†**	**0.6**	**0.3; 1.0**	**<0.001†**
Child behaviour VAS: T1/T2 (parents)						
1: 69-100 (ref)/69-100 (ref) in mm	0			0		
2: 55-68/60-68	0.1	-0.2; 0.3	0.588	0.2	-0.0; 0.5	0.106
3: 44-54/47-59	-0.1	-0.4; 0.2	0.355	0.1	-0.2; 0.4	0.355
4: 0-43/0-46	**0.7**	**0.3; 1.0**	**<0.001†**	0.1	-0.2; 0.6	0.220
Number of PEDS concerns (parents)						
0 (ref)	0			0		
1-2	0.2	-0.1; 0.4	0.134	0.0	-0.2; 0.2	0.891
≥ 3	**0.7**	**0.4; 1.0**	**<0.001†**	**0.6**	**0.3; 0.9**	**<0.001†**
Poor parental health status (parents)	**1.0**	**0.7; 1.2**	**<0.001†**	**0.6**	**0.3; 0.9**	**0.001****
Number of risk factors (PCHC)						
0-2 (ref)	0			0		
3-6	0.2	-0.0; 0.4	0.065	**0.3**	**0.1; 0.5**	**0.002****
≥ 7	**1.3**	**1.0; 1.6**	**<0.001†**	**1.5**	**1.2; 1.9**	**<0.001†**
Excessive amount of parental stress (PCHC)	**1.4**	**1.1; 1.7**	**<0.001†**	**1.4**	**1.1; 1.7**	**<0.001†**
Parental traumatic experience (PCHC)	**0.9**	**0.6; 1.3**	**<0.001†**	**1.1**	**0.7; 1.4**	**<0.001†**
Unstable parenting situation (PCHC)	**1.9**	**1.7; 2.2**	**<0.001†**	**1.7**	**1.4; 2.0**	**<0.001†**

*p <0.05; **p <0.01; †p <0.001, 95% CI=95% confidence interval
Statistically significant results are in bold

Table 3c. Linear regression analysis at baseline (T1) and follow up (T2): association between different independent variables and dependent standardized STEP variable: Degree of care, according to parents (parents) and PCHC professionals (PCHC); b- coefficient (B) and 95% confidence intervals (CI). Controlled for confounders (gender, parental educational status)

Degree of care (PCHC)						
	T1			T2		
	B	95% CI	*p*	B	95% CI	*p*
Parenting VAS: T1/T2 (parents)						
1: 74-100 (ref)/75-100 (ref) in mm	0			0		
2: 64-73/66-74	0.1	-0.2; 0.3	0.540	0.0	-0.2; 0.3	0.883
3: 42-63/49-65	0.2	-0.1; 0.5	0.169	**0.3**	**0.0; 0.6**	**0.024***
4: 0-41/0-48	**1.3**	**1.0; 1.6**	**<0.001†**	**1.1**	**0.8; 1.5**	**<0.001†**
Child behaviour VAS: T1/T2 (parents)						
1: 69-100 (ref)/69-100 (ref) in mm	0			0		
2: 55-68/60-68	0.1	-0.1; 0.3	0.218	0.2	-0.0; 0.5	0.115
3: 44-54/47-59	0.1	-0.2; 0.4	0.493	0.2	-0.1; 0.5	0.104
4: 0-43/0-46	**1.3**	**1.0; 1.7**	**<0.001†**	**0.9**	**0.5; 1.3**	**<0.001†**
Number of PEDS concerns (parents)						
0 (ref)	0			0		
1-2	0.1	-0.1; 0.3	0.245	0.2	-0.0; 0.4	0.107
≥ 3	**1.2**	**1.0; 1.5**	**<0.001†**	**1.2**	**0.9; 1.5**	**<0.001†**
Poor parental health status (parents)	**0.6**	**0.3; 0.9**	**<0.001†**	0.3	-0.0; 0.7	0.081
Number of risk factors (PCHC)						
0-2 (ref)	0			0		
3-6	**0.2**	**0.0; 0.4**	**0.029***	0.2	-0.0; 0.4	0.110
≥ 7	**1.5**	**1.2; 1.8**	**<0.001†**	**1.4**	**1.1; 1.7**	**<0.001†**
Excessive amount of parental stress (PCHC)	**1.1**	**0.8; 1.4**	**<0.001†**	**1.2**	**0.9; 1.5**	**<0.001†**
Parental traumatic experience (PCHC)	**0.7**	**0.4; 1.1**	**<0.001†**	**0.6**	**0.3; 1.0**	**0.001****
Unstable parenting situation (PCHC)	**1.2**	**0.8; 1.5**	**<0.001†**	**0.8**	**0.5; 1.2**	**<0.001†**

*p <0.05; **p <0.01; †p <0.001, 95% CI=95% confidence interval
Statistically significant results are in bold

Table 3d. Linear regression analysis at baseline (T1) and follow up (T2): association between different independent variables and dependent standardized STEP variable: Urgency of care, according to parents (parents) and PCHC professionals (PCHC); b- coefficient (B) and 95% confidence intervals (CI). Controlled for confounders (gender, parental educational status)

Urgency of care (PCHC)						
	T1			T2		
	B	95% CI	*p*	B	95% CI	*p*
Parenting VAS: T1/T2 (parents)						
1: 74-100 (ref)/75-100 (ref) in mm	0			0		
2: 64-73/66-74	0.0	-0.2; 0.2	0.927	-0.0	-0.3; 0.3	0.924
3: 42-63/49-65	0.3	-0.0; 0.5	0.051	**0.4**	**0.1; 0.7**	**0.016***
4: 0-41/0-48	**1.2**	**0.9; 1.6**	**<0.001†**	**0.8**	**0.5; 1.2**	**<0.001†**
Child behaviour VAS: T1/T2 (parents)						
1: 69-100 (ref)/69-100 (ref) in mm	0			0		
2: 55-68/60-68	0.1	-0.1; 0.3	0.453	0.2	-0.1; 0.5	0.136
3: 44-54/47-59	0.1	-0.2; 0.4	0.466	0.1	-0.2; 0.4	0.636
4: 0-43/0-46	**1.2**	**0.8; 1.4**	**<0.001†**	**0.9**	**0.5; 1.3**	**<0.001†**
Number of PEDS concerns (parents)						
0 (ref)	0			0		
1-2	0.1	-0.1; 0.3	0.487	0.1	-0.1; 0.3	0.291
≥ 3	**1.2**	**1.0; 1.5**	**<0.001†**	**1.3**	**0.9; 1.6**	**<0.001†**
Poor parental health status (parents)	**0.5**	**0.2; 0.8**	**0.001****	**0.5**	**0.1; 0.8**	**0.013***
Number of risk factors (PCHC)						
0-2 (ref)	0			0		
3-6	**0.3**	**0.0; 0.5**	**0.016***	**0.3**	**0.0; 0.5**	**0.029***
≥ 7	**1.4**	**1.1; 1.7**	**<0.001†**	**1.1**	**0.8; 1.4**	**<0.001†**
Excessive amount of parental stress (PCHC)	**1.0**	**0.7; 1.4**	**<0.001†**	**1.1**	**0.8; 1.4**	**<0.001†**
Parental traumatic experience (PCHC)	**0.7**	**0.3; 1.0**	**<0.001†**	**0.6**	**0.2; 0.9**	**0.005****
Unstable parenting situation (PCHC)	**1.3**	**1.0; 1.6**	**<0.001†**	**1.0**	**0.7; 1.4**	**<0.001†**

*p <0.05; **p <0.01; †p <0.001, 95% CI=95% confidence interval
Statistically significant results are in bold

Discussion

This article shows significant and strong associations between functioning of the child, quality of the environment, degree of care, and urgency of care, as measured with the STEP, and various variables: low parenting VAS score, low child behaviour VAS score, three or more PEDS concerns, seven or more risk factors, excessive amount of parental stress, and an unstable parenting situation. These results suggest that the above-mentioned parental perceptions can be risk factors as well as prodromal signals for a maladaptive system as a risk factor for child maltreatment.

Earlier research showed that the majority of the children reported for child maltreatment by informants are mistreated by a biological parent (11). To address underlying factors that increase the likelihood that the child will become a victim of child maltreatment, PCHC has to talk with all parents and other caregivers about signs of alarm. Furthermore, in order to obtain more insight into risk and protective factors for developmental arrest, assessment of parental well-being and parental competence in child raising is crucial (21, 23, 40). The quality of parenting represents an important resource for successful social participation across the life span. A strong and secure attachment bond with a primary caregiver is the core of developing resilience and a good health (41-43).

In addition, the results of this article emphasize the importance of adding the amount and degree of parental perceptions and concerns to the cumulative risk model. As noted earlier, previous research showed that an accumulation of risk factors is predictive for child abuse potential (31).

Child maltreatment should not be seen as a diagnosis, but rather as a serious symptom of a sick child's environment including interpersonal relationships. The weighted information about health and development of each specific child can foster a dialogue between parents and professionals about senses of reassurance or alarm that there is something wrong and action and further monitoring is required, even though there is no certainty on the presence of child maltreatment (26). The results of this article indicate that parental issues can be predictive of early onset of a maladaptive system. This stresses the importance of monitoring all children, more targeted preventive approaches, and the delivery of more precise, personalized healthcare, to improve population health (21). Further research is needed to refine assessment procedures of early identification of maladaptive systems. The using of integrated population-based data can be part of a 'practical strategy' for better understanding dynamic risk and protective factors for child maltreatment. Linked administrative data can provide, relatively low-cost, longitudinal and prospective information for tailored prevention strategies (44, 45).

Understanding how determinants influence health is key to prevention strategies (46, 47). Assessment and monitoring the health of communities and populations at risk is one of the core functions of public health. Public health prevention strategies can be categorized into three levels: primary, secondary and tertiary. Prevention of child maltreatment needs primary prevention strategies. The aim of primary prevention is to prevent it from happening and reduce the incidence of related diseases in the population. This is done largely through elimination of risk factors. In the context of the present results, a fourth category of prevention is important as well (48). After identifying and protecting the vulnerable individuals, it is important to keep in mind that interventions can do more harm than good, for example in case of out of home placement. Parents play an irreplaceable role in the lives of their children. Personalized health care can support this fourth type of prevention and reduce harm by means of parental participation and shared decision making in monitoring early signs of child and parental health and social participation concerns (49). Then, in collaboration with parents and other caregivers, effective targeted preventive programs can support parents and teach them positive parenting skills in order to bring about positive outcomes (8, 50).

This study has some strengths and limitations. Strength of the MOM study is the repeated measure multi source information from a community-based sample of children within PCHC practice including parental perception using short validated instruments and balanced information from PCHC professionals based on risk factors and signals as described in national guidelines (37, 38).

Another strength was that the data collection was not compiled to study child maltreatment but focused on signs and symptoms of early onset of a maladaptive system in a general population of preschool children. The MOM sample did not consist of children at high-risk for child maltreatment. Thus, the sample was not representative for high-risk children. Even in this general population sample results showed the importance of early identification of child maltreatment risks.

The present paper also has some limitations. First, response rates were difficult to assess. In the study region in the study period, 1692 children were born and, therefore, were within the caseload of the PCHC professionals participating in the study. However, not all PCHC professionals participated. Consequently, parents of non-participating PCHC doctors were asked to participate by another PCHC doctor, who did not know these families. During the baseline inclusion, the number of participating PCHC professionals increased. Response from one PCHC doctor that participated from the beginning was 70%. Because the caseload of participating PCHC doctors was similar to the caseload of non-participating PCHC doctors, it is likely that respondents are representative for the general population. Forty percent of non-responders were randomly sampled to manually collect

data on parental education from the medical files. The distribution in non-responders was only slightly different from distribution in responders (see study design). Thus, one may consider these results as representative (33).

Second, regression models included one main independent variable per model, because of limited power. In a sensitivity analysis, regression models including all main independent variables were analysed. Results were similar: associations were strong and statistically significant, especially regarding the variables three or more PEDS concerns and seven or more risk factors (data not shown).

Third, parents are not the only target population and partner in prevention of child maltreatment (51). For this article, available MOM study information from professional caregivers like teachers, employees from childcare, kindergarten, preschool or primary school was not used.

The most effective way to diminish child maltreatment is to prevent it from happening. Dutch PCHC can be seen as part of a sustainable Personalized Paediatric Health Care continuum, embedded in a national framework. To promote health and prevent child maltreatment, PCHC professionals need to be aware of specific risk factors and/or key signs and symptoms of all children. This research confirms the importance of asking all parents about their personal wellbeing and their perception of parenting and child development. The PCHC also needs to be aware of the number of parental concerns and the cumulative risk factors in the child's educational context. Moreover, one size does not fit all. Clinical reasoning and weighing all available information remain 'specialists' work to provide personalized predictive, preventive and participatory health care. Children and parents should be always at the centre of this care continuum with emphasis on empowerment and participation. The effect and outcome of preventive measures can only be improved if they meet the needs of parents and their children.

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CHAPTER 6

6

The Developmental Score as a brief tool for Preventive Child Health Care to identify emerging preschool developmental problems impacting school readiness.

Developmental Score: a tool for school readiness?

Bernice M. Doove, Frans J.M. Feron, Jim van Os, Marjan Drukker.
Under revision

Abstract

Objective

This article examines whether a Developmental Score (D-Score) at the age of 2-2.5 years has an added value as a brief monitoring tool in daily Preventive Child Health Care (PCHC) practice to identify emerging developmental problems impacting preschool social participation and school readiness.

Study design

The D-score-for-age z-scores (DAZ) of 311 children pertaining to a community-based sample was calculated on the basis of developmental characteristics measured at age 2-2.5 years. During the follow-up, social participation of the child at age 4 years was determined, using multi-informant information to assess factors underlying social participation. In addition, background characteristics and risk factors in the family were measured.

Results

After controlling for gender, parental educational status and age of the mother at birth, there were relatively strong and statistically significant associations between DAZ and factors underlying social participation at the age of 4 years. A low DAZ appeared to be a risk factor for e.g. professional caregiver perception of child's psychosocial wellbeing, presence of parental concerns, poor functioning of the child, and high urgency of care. In addition, there was a strong association between DAZ and early life stress, and an accumulation of risk factors in the family.

Conclusion

Multiple relatively strong and statistically significant associations suggest that the D-score has an added value as a brief monitoring tool in daily PCHC practice to identify emerging developmental problems impacting preschool social participation and school readiness. However, the use of the D-score does not replace the appraisal of PCHC professionals.

Introduction

Critical building blocks for adult health and successful social participation are established early in life. Early identification of developmental problems can break the vicious circle of disadvantage and is more cost effective than treating preventable disorders during life course (1, 2). Optimizing the accuracy of early individual developmental monitoring is particularly important for the identification of subtle developmental delays and mild impairments that may result in more intrusive conditions at school age. Monitoring enables professionals to intervene in the earliest phase of emerging problems and disabling symptoms, even before formal criteria for diagnostic classifications are met (3, 4). Prevention of this 'growing into deficit' and supporting preschool successful participation empowers children to master abilities essential for school readiness (5-8) (Figure1). School readiness can be perceived as a dynamic outcome of preschool healthy development and resilience, predicting health and social participation across the life course (5, 9, 10).

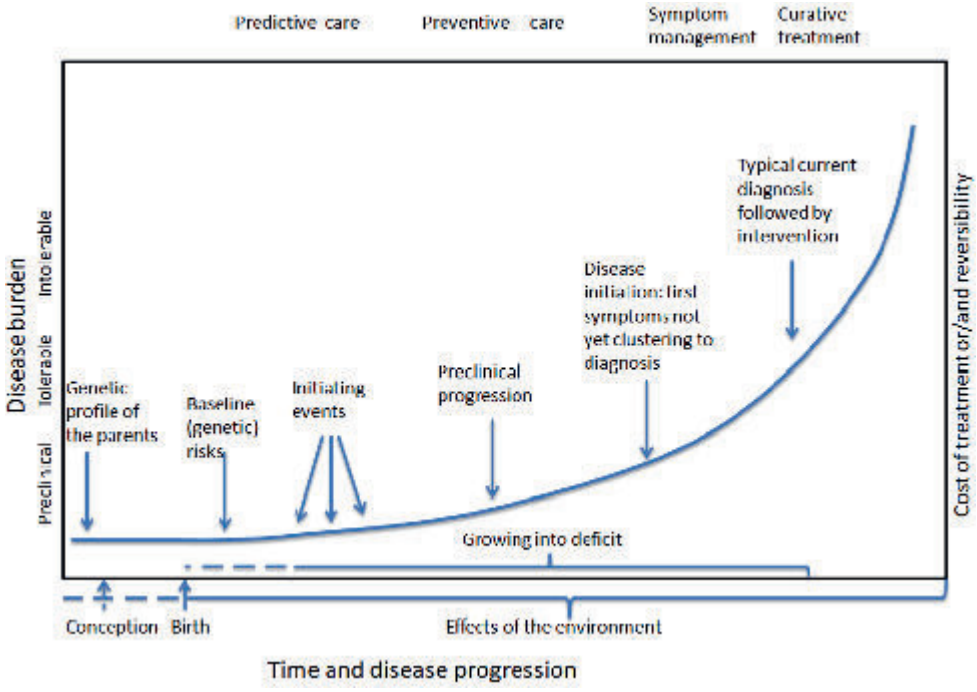

Figure 1. Modification to Syurina's adaptation of Snyderman's curve representing the timelines of 'growing into deficit' and developing common complex diseases, ref. 8.

The Dutch preventive Child Health Care (PCHC), synonymous with Preventive Pediatric Primary Care, has a Public Health task to closely monitor the health and development of all children during routine medical assessments in child health care centers offered by PCHC professionals (e.g. doctors, nurses) (11). From a transactional developmental perspective, development is a complex and dynamic process (10). Evaluating development during infancy and childhood is more difficult than the evaluation of growth, which depends on continuous anthropometric quantities. Development is typically classified in phases and stages and the quantitative methodology for stage measurement is less well developed than for quantitative measures (12). To identify developmental pathways impacting school readiness and social participation, PCHC needs a multi-informant approach with a monitoring 'toolkit' including short instruments assessing multi-axial information about child health and environmental factors (13-16). A Developmental Score (D-score) is an instrument that has the potential to provide additional input as a PCHC monitoring tool for early identification of emerging developmental problems.

Developmental Score (D-score)

Recently, Van Buuren et al. developed growth charts of development which assume the existence of a continuous latent variable on which the 'true' developmental score of a person can be related (12, 17). These estimates of a person's ability are called Developmental scores, or D-scores. The D-score facilitates interpretation of children's abilities across different ages (just as centimeters are used for height). In general, the more milestones the infant passes, the higher his or her D-score. Figure 2 is the reference diagram of the D-score of Dutch infants (12). The area between the + 2SD and -2SD lines delineates the D-score expected if development is normal. A validation study showed that D-scores were relatively constant across countries and progressed in a predictable order (18).

The social context

The quality of the social and educational environment, including interpersonal relationships, is key to children's healthy development and social participation (19, 20). To gain more insight in risk and protective factors for developmental arrest, assessment of parental well-being and parental competence in child raising is crucial (10, 20). Optimal interplay of parent and child characteristics is known to produce beneficial child outcomes, in particular for genetically vulnerable individuals (9, 21, 22). Strong social emotional support stimulates effective interactions and promotes emotional regulation in the face of adversities, thereby building resilience (23). Adversities can cause toxic early life stress, depending on the nature of the adversity, the individual's stress reactivity and the level of social emotional support and other protective factors (24). Furthermore, previous research showed that accumulation of risk factors can have more risk potential

than the presence of particular risk factors (25). For personalized health care, counselling in dialogue and the appraisal of the PCHC doctor is of importance (26).

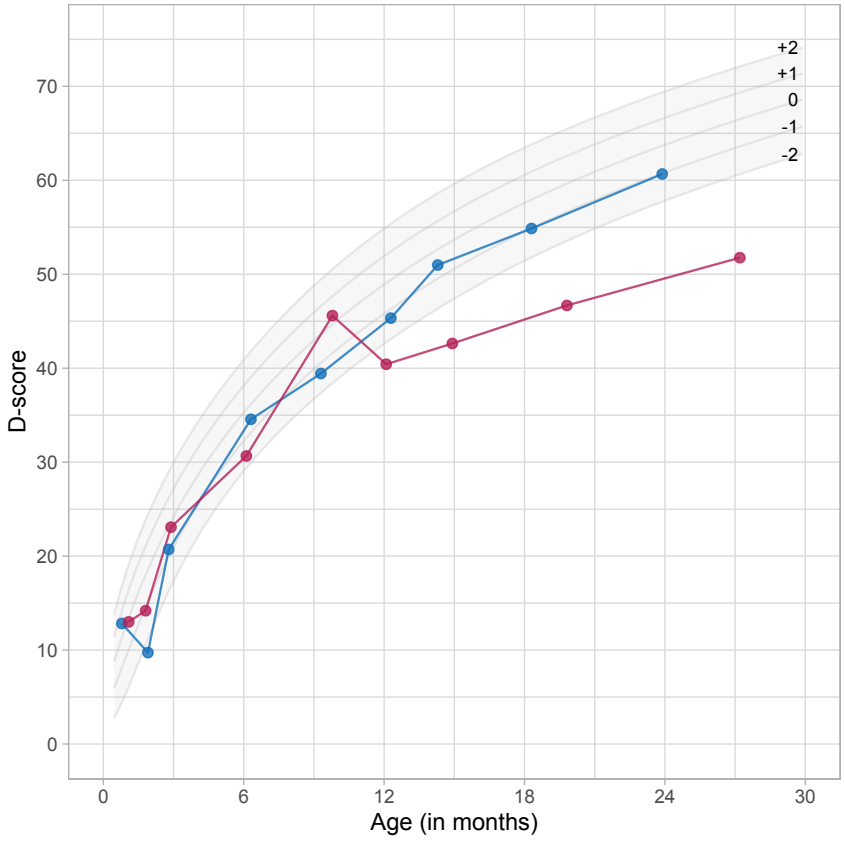

Figure 2. D-score reference chart, 0-30 months, with SD curves -2SD, -1SD, 0SD (median), +1SD and +2SD. Two child trajectories are superposed. The infant with the blue curve has a normal development around -1SD. Maturation of the infant with the red curve is severely delayed from the age of 12 months onwards (12).

Social participation

Social participation is recognized as an important outcome in young children. When children participate well, they acquire skills and competencies, connect with others and with the community, and find purpose and meaning in life (27). Social participation is a broad concept including the objective state and the subjective experience of involvement in society. This concept has to be understood in the light of social roles (28). Because participation is a complex and multidimensional phenomenon (27), social participation could be operationalized using multi-informant information to assess factors underlying social participation. Thus, the construct of participation includes various assessments:

i.e. difficulties with upbringing, behaviour, strengths and difficulties, impact of stress, concerns, the degree of functioning of the child, quality of the environment, degree of care, and level of urgency. Using a wide variety of instruments, the perception of the parent, the perception of childcare, kindergarten and preschool teachers (hereafter professional caregivers) as well as the overall clinical appraisal of the PCHC doctor can be included.

Aim

This article examines to what extent the D-Score at the age of 2-2.5 years has added value as a brief monitoring tool in a comprehensive PCHC 'toolkit' of instruments as a short first step to identify emerging developmental problems impacting preschool social participation at the age of 4 years. In addition, various background characteristics (gender, parental educational status, age of the mother at birth of the child, hereafter maternal age) and risk factors in the family (parental health, parenting, early life stress, number of risk factors) are measured to determine the relation with the D -score.

Methods

The present study was performed as part of the Monitoring Outcome Measurements of child development (MOM) study, a prospective observational study within PCHC practice in Maastricht and surrounding area. A community-based sample of children was systematically assessed with a comprehensive PCHC 'toolkit' of instruments using a multisource and cross-informant repeated measures design to identify developmental pathways impacting school readiness as an outcome of social participation. Children were aged three years at baseline and approximately four years at follow-up. This toolkit, including short tools assessing multiple constructs, was developed and validated to use as a first step in PCHC developmental health monitoring and shared decision making (7, 12-17).

Human subjects' approval

The Maastricht University Medical Centre Medical Ethics Committee approved the MOM study protocol under registration number MEC 09-04-018/PL.

Data collection and instruments

D-scores, collected at the age of 2-2.5 years, were merged with data collection at the age of 3 and 4 years and included: background characteristics (gender, parental educational status, maternal age), risk factors in the family (parental health, parenting, early life

stress, number of risk factors), and factors underlying social participation (parental and professional caregivers' perception of child development, behavior and the impact of stress, and the overall clinical judgement of the PCHC doctor about functioning of the child, quality of the environment, degree of care, and level of urgency). To assess perceptions, demands and concerns of parents as well as professional caregivers about development and social participation, various short instruments were included in the MOM study (see below). PCHC professionals provided information about child health, development, risk and protective factors, and interventions.

Parents' Evaluation of Developmental Status (PEDS). Parents and professional caregivers completed the Parents' Evaluation of Developmental Status (PEDS), a 10-item standardized semi-structured questionnaire to elicit concerns regarding child development for children aged less than eight years in the general population and clinical samples (29). PEDS provides both open-ended questions and specific probes regarding concerns in various domains: expressive and receptive language, fine motor, gross motor, behavior, socialization, self-care and learning. The PEDS is validated for clinical samples and general population samples aged between 0 and 8 years, and is available in multiple languages. In a validation US study the PEDS sensitivity was between 91-97% and specificity between 73-86% (30). Furthermore, the PEDS has shown to be reliable, valid and useful as brief monitoring tools in daily Dutch PCHC practice (16, 31).
For the current article, the number of 'parental concerns' and 'professional caregivers' concerns' was used in the analyses.

Parenting VAS and child behaviour VAS. In order to quantify self-rated parental competencies, a 'parenting' Visual Analogue Scale (VAS) ranging from 0-100 was used; parents expressed the degree to which they felt competent, secure and happy with raising their child (0 = I do not manage to raise my child as I wish, 100 = raising my child is up to my expectations). Another 'child behaviour' VAS assessed how the parents evaluated their child's behaviour (0 = my child is difficult and badly behaved, 100 = my child is very obedient and easy to handle). A higher VAS score means parent judges 'child behaviour' and 'parenting' more positive.
In a previous article, the two VAS to assess 'parenting' and 'child behaviour', as well as the parental and professional caregivers PEDS were validated for use in daily Dutch PCHC practice (16). In this article, continues VAS scales were used.

Early Life Stress VAS. To assess early life stress, parents as well as professional caregivers provided information on the impact of an event in the child's life in 3 domains: home, school and other (32). Per domain, an open-ended question enquired about the life event with most impact. Consequently, parents and professional caregivers were asked to rate the impact of this event in the child's life on VAS ranging from 1 to 10 (32).

In this article, the early life stress VAS provided by the parents and the professional caregivers were used in combination. If any of the parents or professional caregivers rated the early life stress VAS, the dichotomous early life stress variable was set at 'yes'.

Strengths and Difficulties Questionnaire (SDQ). The Dutch version of the Strengths and Difficulties Questionnaire (SDQ) was used by parents as well as by professional caregivers to assess the child's behaviour (33, 34). The SDQ is considered a valid and reliable research instrument in community samples (35). Research shows a parent SDQ sensitivity of 0.76 at a cut-off point with 0.90 specificity in a community population of children at the age of 3-4 years (36). Both parents and professional caregivers completed the SDQ. For the present paper, the SDQ sum score of the parents and professional caregivers was used. The SDQ includes items that identify the impact of the behavioural problems of the child, the SDQ impact of distress. If any of the parents or professional caregivers scored 'yes' on the impact probe question, in this study the dichotomous overall distress variable was set at 'yes'.

Parental health Likert Scale. The parent that completed the MOM questionnaire scored the individual physical and mental health as well as the physical and mental health of the other parent/caregiver, using a 5-point Likert Scale from 1 (bad) to 5 (excellent). Self-rated health status is a simple, yet widely used, measure with similar validity as more sophisticated health assessments (37). The MOM study included an extra data collection to assess reliability. The intra-rater test–retest reliability showed strong and significant correlations (Spearman correlation: parental and co-parental physical health = 0.92 and 0.99, respectively, $p<0.0001$; parental and co-parental mental health = 0.93 and 1.00, $p<0.0001$, available upon request/unpublished results). The four health variables were combined into one parental health variable, which was then dichotomized (fair and poor were recoded into 1 and excellent, very good and good were recoded into 0).

Parental educational level. As an indicator of socioeconomic status, the level of maternal and paternal education was assessed. Three categories were defined: low (primary education, junior vocational education), middle (general secondary education, senior vocational education) and high (preparatory university education and university education). The parent with the highest level of education determined parental educational level.

D-scores. In Dutch PCHC, at each routine medical assessment between the ages of 1-month and 4 years, a trained PCHC professional (e.g. doctor, nurse) assesses whether a child can fulfil a set of developmental behaviors and tasks, and assigns a pass/fail score to each child for each indicator. This set of 75 indicators is known as the Van Wiechen Developmental Scheme. This Dutch instrument is a modification of the Gesell test and

is routinely used by all PCHC Centres in the Netherlands and Belgium to monitor the development of all children from birth to the age of four years (38, 39). The Van Wiechen Developmental scheme can be administered rapidly, taking approximately 3 minutes (40). A fail score is a signal of a potential delayed development, and a reason for the PCHC doctor to consider further investigation of the child (17, 39). PCHC professionals assessed D-scores 11 times between birth and the age of 4 years. In the present analysis, the D-score when the child was aged closest to 2½ years was selected. D-score-for-age z-scores (DAZ) were used (12, 18). Children at the 50th percentile have a z-score of 0; children at the 15th and 85th percentile have a z-score of +1.0 and -1.0, respectively.

Standard Taxation of Severity of Problems (STEP). The Standard Taxation of Severity of Problems (Standaard Taxatie Ernst Problematiek, STEP) is an instrument to facilitate clinical judgement and is assessed by the PCHC professional. The four outcome scales of the STEP are: 1) Functioning of the child: personal functioning, the duration of the problems, the extent to which a child is upset and the extent to which functioning impedes daily life and is a burden on others; 2) Quality of the environment: quality of the primary educational environment, the other environment such as nursery, school and neighborhood, the duration of the problems and the social support; 3) Degree of care: type of care considered to be the right one in the coming period, the duration and the intensity of care; 4) Urgency of care: estimation of the level of urgency, acute or non-acute.

Risk factors. Before completing the STEP, the PCHC doctor made up an inventory of all concerns, signals, problems, static and dynamic risks and protective factors of each child on the following five dimensions: 1) Child psychosocial functioning, 2) Child physical health and bodily functioning, 3) Child skills and cognitive development, 4) Family and upbringing, and 5) Child and environment. This inventory tool for the MOM study was developed with the aid of a Dutch guideline on prevention of child abuse and risk assessment instruments such as the Dutch Child Abuse Risk Evaluation (CARE-NL) and the CAP-J, a Dutch instrument for classification of the nature of problems of the child (41, 42). For the MOM study, all participating PCHC doctors were trained to classify the signals, risk and protective factors and to estimate the severity of the problems. In this article, the amount of risk factors was dichotomized in 0-6, and 7 or more risk factors.

Statistical analysis

Statistical analyses were carried out using Stata, version 15 (43). First, descriptive statistics of various variables of 311 children at the age of 4 years were provided and t-tests and other univariate tests were performed to assess differences in DAZ between categories of the variables. Second, the association between DAZ (independent variable) and various dependent variables at the age of 4 years were analysed. Other independent variables included in the models were: background characteristics (gender, parental educational

status, maternal age) and risk factors in the family (parental health, parenting, early life stress, number of risk factors). Dependent variables were factors underlying social participation. The outcome was the overall clinical judgement of the PCHC doctor about functioning of the child, quality of the environment, degree of care, and level of urgency (STEP). Other outcomes were parental and professional caregivers' concerns, perception of child development, child behaviour and the impact of stress.

As a replication, data of the same children aged 3 years was analyzed.

Results

DAZ scores were available for 163 (52%) girls and 148 (48%) boys (Table 1). The mean DAZ at 2-2.5 years of 311 children was 0.4 (SD= 1.0, Table 1). At the time they gave birth to the indexed child, 19% of the mothers were older than 35 years. More than half of the parents had received higher education (64%). At the time the children were 4 years of age, 30 (11%) parents experienced their health as poor. Parents of 119 children (42%) and professional caregivers of 84 children (34%) indicated any PEDS concerns. According to parents and professional caregivers, 145 (47%) children experienced early life stress. According to the PCHC professional, in 20% of the families 7 or more risk factors were present (Table 1). In addition, PCHC professionals reported that 25% of the children were malfunctioning and 15% of the children lived in a low-quality environment. A high level of degree of care was needed in 10% of the participants and for 16% of the children the urgency of care was high.

In the univariate analyses, statistically significant differences in DAZ were seen between children with and without presence of PEDS concerns (Table 1).

In addition, the difference in DAZ was also statistically significant in categories of SDQ impact, early life stress, number of risk factors, functioning of the child, degree of needed care, and level of urgency. Table 2 shows DAZ means, standard deviations and range of various continuous variables: parenting VAS, child behavior VAS, and the SDQ sum score.

Table 1. Descriptive statistics (with outlier), relation between D-score (DAZ) at 2-2.5 years of age (N= 311) and different variables at age 4 years.

Variable	N (%)	Mean (SD)	Range	Difference Mean (95% CI)	t-test
DAZ (2-2.5 years of age)	311	0.4 (1.0)	-4.6 - 3.2		
Girls	163 (52%)	0.5 (0.9)	-2.4 - 3.2	-0.2	t= -1.4; df= 309
Boys	148 (48%)	0.3 (1.0)	-4.6 - 2.9	(-0.4; 0.1)	*p*= 0.15
Parental educational status	308				
High	198 (64%)	0.4 (1.0)	-4.6 - 3.2		
Medium	82 (27%)	0.4 (0.9)	-2.4 - 2.1		
Low	28 (9%)	0.2 (0.9)	-2.4 - 1.6		
Maternal age	309				
17-35 years	249 (80%)	0.4 (0.9)	-2.4 - 3.2	0.2	t= 1.1; df= 307
36-44 years	60 (20%)	0.3 (1.1)	-4.6 - 2.6	(-0.1; 0.4)	*p*= 0.26
	281				
PEDS concerns (parents)	119 (42%)	0.2 (1.1)	-4.6 - 2.9	0.3	t= 2.8; df= 279
No presence PEDS concerns	162 (58%)	0.5 (0.9)	-2.2 - 3.2	(0.1; 0.6)	***p*= 0.0048****
	248				
PEDS concerns (prof. caregiver)	84 (34%)	0.2 (1.0)	-4.6 - 2.0	0.3	t= 2.2; df= 246
No presence PEDS concerns	164 (66%)	0.5 (1.0)	-2.4 - 3.1	(0.0; 0.6)	***p*= 0.03***
	280				
SDQ impact (parents)	21 (8%)	-0.1 (1.3)	-4.6 - 1.4)	0.6	t= 2.5; df= 278
No SDQ impact	259 (92%)	0.4 (0.9)	-2.4 - 3.2	(0.1; 1.0)	***p*= 0.01***
	245				
SDQ impact (prof. caregiver)	31 (13%)	-0.1 (1.2)	-4.6 - 1.6	0.6	t= 3.0; df= 243
No SDQ impact	214 (87%)	0.5 (0.9)	-2.2 - 3.2	(0.2; 0.9)	***p*= 0.0026****
	233				
SDQ impact (parent and/or prof. caregiver)	41 (18%)	-0.1 (1.1)	-4.6 - 1.6	0.6	t= 3.4; df= 231
No SDQ impact	192 (82%)	0.5 (0.9)	-2.2 - 3.2	(0.2; 0.9)	***p*= 0.0009**†
Early life stress (parent and/or prof.	311				
caregiver)	145 (47%)	0.3 (1.0)	-4.6 - 2.9	0.2	t= 2.4; df= 309
No early life stress	166 (53%)	0.5 (0.9)	-2.2 - 3.2	(0.0; 0.5)	***p*= 0.0162***
	281				
Poor parental health (parents)	30 (11%)	0.3 (0.8)	-1.3 - 1.6	0.1	t= 0.4; df= 279
Fair parental health	251 (89%)	0.4 (1.0)	-4.6 - 3.2	(-0.3; 0.5)	*p*= 0.68
Number of risk factors (PCHC)	311				
0-6	249 (80%)	0.5 (0.9)	-2.2 - 3.2	0.3	t= 2.2; df= 309
≥ 7	62 (20%)	0.2 (1.1)	-4.6 - 1.6	(0.0; 0.6)	***p*= 0.0277***
STEP domains (PCHC)					
Functioning of the child	309				
Adequate	232 (75%)	0.5 (0.9)	-2.2 - 3.2	0.3	t= 2.5; df= 307
Poor	77 (25%)	0.2 (1.1)	-4.6 - 2.3	(0.1; 0.6)	***p*= 0.0115***
Quality of the environment	310				
Good	263 (85%)	0.4 (1.0)	-4.6 - 3.2	0.2	t= 1.1; df= 308
Low	47 (15%)	0.3 (0.9)	-1.7 - 1.6	(-0.1; 0.5)	*p*= 0.28
Degree of care	310				
Low	278 (90%)	0.5 (0.9)	-2.4 - 3.2	0.5	t= 2.9; df= 308
High	32 (10%)	-0.1 (1.2)	-4.6 - 1.3	(0.2; 0.9)	***p*= 0.0038****
Need for care	310				
Low	260 (84%)	0.5 (0.9)	-2.4 - 3.2	0.4	t= 2.5; df= 308
High	50 (16%)	0.1 (1.1)	-4.6 - 1.5	(0.1; 0.7)	***p*= 0.0125***

*p <0.05; **p <0.01; †p <0.001, 95% CI=95% confidence interval

[1]Age of child the PCHC professional provided information

[2] A higher VAS score means parent judges parenting more positive

[3] A higher VAS score means parent judges child behaviour more positive

Table 2. Descriptive continuous variables (with outlier), D-score (DAZ) at 2-2.5 years of age (N= 311) and different variables at age 4 years.

Continues variables	N	Mean (SD)	Range
DAZ (2-2.5 years of age)	311	0.4 (1.0)	-4.6 - 3.2
Parenting VAS (parents)	276	72.6 (16.5)	14-99
Child behaviour VAS (parents)	274	67.9 (16.6)	11-100
SDQ sum score (parents)	288	6.0 (4.2)	0-27
SDQ sum score (prof. caregiver)	254	5.0 (5.0)	0-29

In linear regression analysis, a statistically significant and a relatively strong association was seen between DAZ and maternal age (B= -0.6, $p < 0.05$, Table 3). Controlling for gender, parental educational status, and maternal age, there was a relatively strong and statistically significant association between DAZ and professional caregiver SDQ sum score (B= -0.7, $p < 0.05$, Table 3).

Table 3. Linear regression analysis: association between D-score at the age of 2-2.5 years and different variables, b- coefficient (B) and 95% confidence intervals (CI) at age 4 years. Controlled for confounders (gender, parental educational status, maternal age). D-score is independent variable.

	D-score-for-age z-score (DAZ)
	B (95% CI)
Maternal age [1]	**-0.6 (-1.1; -0.1)** *
Parenting VAS (parents) [2]	1.3 (-0.8; 3.4)
Child behaviour VAS (parents) [2]	0.3 (-1.7; 2.4)
SDQ sum score (parents)	-0.5 (-1.0; 0.0)
SDQ sum score (prof. caregiver)	**-0.7 (-1.4; 0.0)** *

*p <0.05; **p <0.01, 95% CI=95% confidence interval
[1]Controlled for confounders (gender, parental educational status)
[2] A higher VAS score means parent judges 'child behaviour' and 'parenting' more positive

Logistic regression analyses showed a relatively strong and statistically significant association between DAZ and various dichotomized variables (Table 4), e.g. presence of PEDS concerns (OR= 0.7, $p < 0.05$), 7 or more risk factors in the family (OR= 0.7, $p < 0.05$), poor functioning of the child (OR= 0.7, $p < 0.05$), and high level of urgency of care (OR= 0.7, $p < 0.05$). There was a strong association between DAZ and early life stress (OR 0.8, $p <$ 0.01). Results were similar when analyses were repeated using data of the children when aged 3 years (result not presented).

Table 4. Logistic regression analysis: association between D-score at the age of 2-2.5 years and different variables at age 4 years. Controlled for confounders (gender, parental educational status, maternal age). D-score is independent variable.

	D-score-for-age z-score (DAZ) OR (95% CI)
Presence PEDS concerns (parents)	**0.7 (0.6; 1.0)** *
Presence PEDS concerns (prof. caregiver)	**0.7 (0.6; 1.0)** *
SDQ impact (parents)	**0.6 (0.4; 0.9)** *
SDQ impact (prof. caregiver)	**0.6 (0.4; 0.8)** **
SDQ impact (parent and/or prof. caregiver)	**0.6 (0.4; 0.9)** **
Early life stress	**0.8 (0.6; 1.0)** **
Poor parental health (parents)	1.0 (0.7; 1.5)
Number of risk factors (PCHC) ≥ 7	**0.7 (0.5; 1.0)** *
STEP domains (PCHC)	
Functioning of the child	**0.7 (0.6; 1.0)** *
Quality of the environment	0.9 (0.6; 1.3)
Degree of care	**0.6 (0.4; 1.0)** *
Need for care	**0.7 (0.5; 1.0)** *

*p <0.05; **p <0.01, 95% CI=95% confidence interval

Discussion

The present study showed a relatively strong association between the D-score at the age of 2-2,5 years and factors underlying social participation at the age of 4 years. These results suggest the added value of using the D-score for early identification of emerging developmental problems and stagnating school readiness. That early life stress and risk factors in the family were also associated with the D-score, further supports the relevance of the D-score in PCHC practice. Development is a complex and dynamic process (10). Early identification of emerging developmental problems in relation with social participation is complex as well. To deal with emerging problems in the preschool period, PCHC professionals need to monitor both the developmental process and various educational context variables, especially in children with a lower D-score.

The present findings are in line with earlier research showing the contribution of the D-score at the age of 2-2.5 years in detecting children with below average intelligence level at the age of 5 (44). Second, the present results showed a relatively strong association between the D-score and presence of parental concerns about child development, presence of parental and professional caregiver 'concerns about child behaviour' and impact of behavioural problems of the child. In addition, earlier research emphasizes the importance of adding the number and degree of parental perceptions and concerns to the cumulative risk model (45). Third, the present study showed a strong association between 7 or more of risk factors in the family and D-score. This is in line with previous

research showing that an accumulation of risk factors is predictive for child abuse potential (25). Children with developmental delays are at increased risk for child maltreatment (46). Furthermore, a strong significant association was seen between early life stress and D-score. Earlier research showed associations between early life stress, reduced social participation and adverse developmental problems during life course (47-49). These associations emphasize the importance of early identification of the impact of early life stress. To prevent toxic early life stress (24), PCHC professionals should regularly ask about live events and the impact of an event in the child's life. Finally, child and family environment features are also important to consider. Results of this study showed a statistically significant association between a higher maternal age and a lower D-score. In contrast, Duncan and colleagues mentioned the potential pay–offs of maternal age over 25 years at birth of the first child (50). However, their study suggested an alternative thesis that the relationship between maternal age and child development demonstrates an inversed U shape and thus turns negative at advanced maternal ages. The present result is in agreement with that. Earlier research analysing the association between maternal age and educational outcome showed that older maternal age was associated with an increased risk for special education (51).

To support successful preschool social participation and school readiness, PCHC has to gain good insight in early signals and risk factors as well as protective factors from different perspectives (5, 14,). The provision of personalized health care requires specific knowledge and skills to identify meaningful relationships between unique individuals and their environment. Discrete and differential genes vs environmental interactions may not be captured in simple association studies (52). Considering the differential susceptibility hypothesis (53), it is emphasized to go beyond the one-size-fits-all approach in prevention. The concept of differential susceptibility is rooted in the assumptions that optimal parental characteristics depend on child characteristics. In particular, child characteristics in the context of a positive child-rearing environment may produce favourable outcomes, whereas the same characteristics in the context of an adverse rearing environment may lead to negative outcomes (22). Consequently, optimal PHCH characteristics depend on child and family characteristics.

Methodological issues

Strength of the MOM study is that the data collection was not primarily targeted on studying children with a deviant D-score but focused on signs and symptoms of early onset of a maladaptive system in a general population of preschool children. Another strength of this study is the repeated measure multi source information from a community-based sample of children within PCHC practice. Short validated instruments were used to assess perceptions including parental perception. The balanced information from PCHC professionals was based on risk factors and signals as described in national guidelines

(41, 42). Furthermore, the MOM study children are a representative sample of birth cohort Netherlands 2, part of the Global Scale of Early Development (GSED) project to construct two new instruments to support data collection necessary to establish global standards for early childhood development (18). In the MOM study, the DAZ showed a normal distribution with one outlier. The outlier turned out not to be a mistake but was based on an actual case. For that reason, the outlier has been included in the analyses. Data were not substantially affected by this outlier except for the range of the DAZ.

For the D-score, GSED-DAZ and Dutch-DAZ were available. Dutch-DAZ is based on van Wiechen developmental scheme data of the birth cohort Netherlands 1 and 2 as mentioned in Weber et al. Sensitivity analyses showed a negligible difference between GSED-DAZ and Dutch-DAZ. To compare the results of this article with future research on the van Wiechen developmental scheme, it was chosen to show results with the Dutch-DAZ. The MOM study has some limitations. First, rather than analysing social participation at age 4 years and age 3 years, separately, we intended to analyse all data simultaneously using mixed regression analysis. However, this analysis proved impossible due to small numbers of children in this study. Second, reference values and standard deviation scores of development beyond the age of 30 months are not yet available for the Van Wiechen developmental scheme (18). An update of the Van Wiechen developmental scheme, and more research with a bigger number of children is needed, to develop reference values and standard deviation scores of development beyond the age of 30 months. Finally, the D-score represents a sum score of several domains of motor, language, cognitive and personal development, a high score on one developmental domain can equal out a low score on another domain. A possible next step in research is developing D-scores for each developmental domain.

Conclusions and implications

To improve early identification of health problems, PCHC should focus on 'predict it and personalize it' instead of 'find it and fix it'. Signals and problems meeting formal criteria for disorders represent the late stage of a dynamic developmental process that can be identified in a much earlier phase when treatment plasticity is still considerable. The results of this article suggest that the D-score at the age of 2-2.5 years can provide additional input for early identification of developmental problems impacting preschool social participation and school readiness.

Applying the D-score does not replace the appraisal of the PCHC professional. Like all other variables, the D-score of an individual child has to be seen in the context of all unique developmental process variables. In the overall assessment, the PCHC doctor will

not only consider the information from the developmental examination, but also from the developmental context of the child to select children who require further support in the form of a 'watch and wait' strategy, assessment of other developmental domains, or referral to a specialist. Therefore, the D-score is considered to be a monitoring tool and not a screening instrument.

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CHAPTER 7

7

General Discussion

'What's in it for the child?'

Main MOM study research results

The Monitoring Outcome Measurements of child development study (MOM study) focusses on a new paradigm of personalizing Preventive Child Health Care (PCHC) from a Public Health perspective for balanced health policy on community and individual level. Personalized PCHC is an overarching framework to coordinate care with the primary aim to promote and to protect children's health and development, and to prevent disease in children. It unifies predictive tools, physical examination and developmental assessment with the unique child and its engaged parents/caregivers. As such, personalized PCHC focusses on tailoring the management and delivery of preventive health care to the unique individual characteristics of each child.

The MOM study was designed to realize a paradigm shift from the curative approach 'find it and fix it', towards 'predict it and personalize it'(1). The MOM study developed and combined tools to integrate predictive, preventive, participatory and personal components of medicine (instead of 'a one-size-fits-all' approach) (2). A community-based sample of preschool children was systematically assessed using a multi- and cross-informant repeated measurements design. Linked to the routine consultation, various instruments were completed by parents, teachers/employees from child care, kindergarten, preschool or primary school (hereafter: professional caregivers) and PCHC professionals, including reference instruments to validate the MOM PCHC monitoring instruments.

Among the available validated parent-completed monitoring tools, the Parents' Evaluation of Developmental Status (PEDS) was put in a key position in the MOM study. The PEDS is designed by Glascoe to elicit concerns and facilitate communication between professionals and parents in addressing developmental and behavioural problems in children(3)

MOM study results suggest that Personalized PCHC is a useful and essential paradigm to improve early identification of emerging preschool problems and symptoms at a stage where signs and symptoms do not yet meet diagnostic criteria, but already give rise to early impairment and distress for both the children and their context, at home as well as in preschool (4-6).

In **Chapter 2, 'Validation of short instruments assessing parental and caregivers' perceptions on child health and development for personalized prevention',** the central issues are the psychometric properties of the Dutch Parent's Evaluation of Developmental Status (PEDS), a 'child behaviour' Visual Analogue Scale (VAS), a 'parenting' VAS and a 'child competence' VAS, at the age of 3 and 4 years. The PEDS, 'parenting' VAS and 'child competence' VAS are reliable, valid and useful as brief parent-reported monitoring

tools in daily Dutch PCHC practice. The professional caregiver-reported 'child competence' VAS scored lower on one aspect of validity. Overall predictive accuracy of the PCHC toolkit instruments showed: good to excellent for 'parenting' VAS, fair to good for 'child behaviour' VAS and poor for 'child competence' VAS. The PEDS, 'parenting' VAS and 'child behaviour' VAS, demonstrated high sensitivity at various cut-off points of index test and reference standard. The high negative predictive values (NPV) are eligible as well, they ensure that most children who pass the 'screening' are truly healthy. Over-referrals in a first-stage PCHC screening are no problem, they can benefit from additional preventive monitoring (7). The PEDS revealed questions, subjects and concerns about and across different child developmental domains that parents and professional caregivers want to discuss which are not yet related to changes in the Strengths and Difficulties Questionnaire (SDQ), Parenting Stress Index Short Form (in Dutch abbreviated as NOSIK), Child Behaviour Checklist (CBCL) and Caregiver-Teacher's Report Form (C-TRF) total score.

Chapter 3, 'Preschool communication: early identification of concerns about preschool language development and social participation', deals with concurrent and predictive validity of the PEDS to assess parental and professional caregivers' language development concerns. A mediating effect of child social competence was found on the association between receptive and expressive language concerns and social participation at the age of 3 and 4 years. Particularly at the age of 4, the mediating effect of social competence was strong. These results are in line with earlier research showing an association between language difficulties, behavioural difficulties, and social participation (26, 27). For early identification of language needs, it is important to understand the pervasive nature of language development (8, 13, 19). The preschool period is a sensitive period, especially in overall communication development (7, 10). It is assumed that differences in young children's language development reflect differences in experience and in creating interactive routines, next to their biologically mediated genetic potential (24). Developmental growth in language skills is an important parameter of overall communication development (11). Language problems are often the first presenting symptoms of delay in the development of multiple basic functions including socialization and communication (3, 12). Early expressive and/or receptive language problems and behavioural problems may have long-term consequences (13). In particular, early receptive language problems are a significant risk factor for adult mental health (1). Early intervention is needed and has to be personalized; standard intervention programs have limited added value (25).

Chapter 4, 'Preschool social participation, the impact of early life stress and parental health', showed that children with early life stress (ELS) experienced more often distress, had more peer problems and received more often extra support at preschool. Their parents more often reported concerns, a higher number of concerns and perceived

more difficulties in parenting. Associations between parental and professional caregivers' perceptions of ELS and the level of preschool social participation were stronger for children of parents with 'poor health'. These MOM study results recognize that Early life stress (ELS) is a risk indicator influencing child health and wellbeing. (8). Whether someone experiences stress as negative, depends on the extent to which an individual has control over the given stressor and whether the person has coping resources (9-14). Thus, stress can be positive, tolerable or toxic, depending on the nature of the adversity, the individual's stress reactivity and the level of social emotional support (8).Toxic stress in childhood links adversity with poor health and health disparities (15, 16). Growing up safely requires prevention strategies to prevent toxic stress. More awareness is needed that children who do not meet criteria for a mental disorder but who have clinically significant impairment and distress represent an important group from a public health perspective (17-20). For early identification of children at risk for developmental delay, PCHC professionals should acknowledge current constraints of families and may examine the presence and impact of ELS in the lives of children and the health of their parents(21). Children's development and health are strongly influenced by how well their family functions. For children to be able to flourish and cope with stress, the quality of parental support and the educational context represent important resources for successful social participation across the life span(22-24). Therefore, health care professionals should be pay extra attention to parental health, and any imbalance between the parents' need for support and the support they actually receive (25).

In **Chapter 5**, **'Parental perceptions and Personalized Health Care to prevent child maltreatment'**, the MOM study results showed significant and strong associations between functioning of the child, quality of the environment, degree of care, and urgency of care and different variables: low parenting VAS, three or more PEDS concerns, seven or more risk factors, excessive amount of parental stress and an unstable parenting situation. These results confirm the importance of PCHC taking into account the quality of the educational context in order to effectively address the health and well-being of children (26). In the MOM study, the individual's social and educational environment including interpersonal relationships is hypothesized to be key to provide Personalized Health Care. Consequently, child maltreatment should not be seen as a diagnosis, but rather as a serious symptom of toxic stress in the child and the child's environment, including interpersonal relationships. The weighted information about health and development of each specific child can foster a dialogue between parents and professionals about senses of reassurance or alarm that there is something wrong and action and further monitoring is required, even though there is no certainty on the presence of child maltreatment (27). Then, personalized PCHC can be offered to support the capacity of parents and other caregivers and stimulate their health literacy in order to lower toxic stress and develop strong responsive early relationships with their children. Important are preventive

interventions aimed at easing the transition to parenthood, to support parenting self-efficacy and to control toxic stress. Being a parent is not just about parenting, it is a transition process that affects different aspects of a person's life such as relationships, work, finance, housing.

Chapter 6, 'The Developmental Score as a brief tool for Preventive Child Health Care to identify emerging preschool developmental problems impacting school readiness' showed usefulness of the D-score. In Dutch PCHC, for more then 50 years at each routine medical assessment between the ages of 1-month and 4 years, a trained PCHC professional (e.g. doctor, nurse) assesses whether a child fulfils a set of developmental behaviours and tasks, and assigns a pass/fail score to each child for each indicator. This set of 75 indicators is known as the Van Wiechen Developmental Scheme. Results of chapter 6 showed that controlled for gender, parental educational status and age mother at birth, there were relatively strong and significant associations between a Developmental score (D-score) at the age of 2-2.5 year and factors underlying social participation at the age of 4 years. A low D-score-for-age z-scores (DAZ) appeared to be a risk factor for e.g. professional caregiver perception of child's psychosocial wellbeing, presence of parental concerns, poor functioning of the child, and a high urgency of care. In addition, there was a strong association between the D-score and early life stress, and a cumulation of risk factors in the family. The results suggest that the D-score at the age of 2-2.5 years can provide additional input for early identification of developmental problems impacting preschool social participation and school readiness. Applying the D-score does not replace the appraisal of the PCHC professional. As all other information, the D-score of an individual child has to be seen in the context of all unique developmental process variables. In the overall assessment, the PCHC doctor will not only consider the information from the developmental examination, but also from the developmental context of the child to select children who require further support in the form of a 'watch and wait' strategy, assessment of other developmental domains, or referral to a specialist. In short, the D-score is considered to be a monitoring tool and not a screening instrument.

Because of the plateau effect, the apparent variability in D-scores beyond the age of 30 months is substantially lower than the true variability in development (28). It will, therefore, not be possible to use the MOM data to provide reasonable estimates of the distribution of the true (i.e., free of plateau effect) variability in development. Hence for now, it is not possible to calculate sensible reference values and standard deviation scores of development beyond the age of 30 months. Although the Van Wiechen developmental scheme was revised in recent decades, an update and more research with a bigger number of children is needed, to develop reference values and standard deviation scores of development beyond the age of 30 months. Finally, the D-score represents a sum score of several domains of motor, language, cognitive and personal development, a high score

on one developmental domain can equal out a low score on another domain. A possible next step in research is developing D-scores for each developmental domain.

Benefits for personalizing Dutch PCHC

Dutch PCHC has been in existence for more than a century and is nowadays governed by the Public Health Act 2008. The objectives of the PCHC program are to monitor growth and development, to detect health and social problems (or risk factors) early, to screen for metabolic conditions and hearing in the newborn, to deliver the national vaccination program, and to provide advice and information on health, growing up safely, and parental concerns of raising children. Over 90% of all children visit this free public service. For children older than 5 years of age, the preventive programs are performed in affiliation with schools and equally for children with learning problems attending special schools (29).

The MOM study aims to contribute to improving the current PCHC preschool monitoring and early identification of health problems by using multi- and cross-informant repeated measurements to enhance cross-domain collaboration from a life course perspective.

By mapping the protective and risk factors together with the family and other healthcare professionals, it can be determined which problems or risk factors should be addressed and which care partner should be involved.

From a public health perspective, children with symptoms of health problems below the threshold of a full-blown disorder represent an important group. These children may have significant clinical needs and are at risk of arrested development, not achieving their potential and capabilities (30). It has been suggested, however, that the sensitivity for detecting early mental health problems and symptoms is low (18, 31-33).

PCHC faces the challenge to identify emerging mental health and behavioural problems at a stage when symptoms do not yet map to specific diagnostic entities as described in mental health classification systems (4-6). As long as symptoms, complaints or problems do not cluster into a classifiable diagnosis, diagnostic criteria have limited value. PCHC has to deal with the level of suffering and signals of stagnating development of the child and family. In addition, next to comparison with the age group, it is also important to compare the child with itself as a control in the longitudinal follow-up by PCHC. The latter is an argument for personalized care and an argument against 'one-size-fits-all' thinking. Estimating the potential and capabilities of a child requires specialist knowledge and

experience, due to the fact that many tests and tools measure what a child has learned, but not what a child could learn. This requiers 'predict it and personalize it'.

Health and Social Participation, a dynamic developmental perspective

Understanding how determinants influence health is key to prevention strategies (34, 35). In the MOM study, a dynamic bio-psycho-social-ecological transactional developmental perspective was used as the basic theoretical framework to define health. Health is not the absence of disease, but can be formulated as the ability to adapt and self-manage in the light of physical, emotional and social challenges of life (36, 37). Successful social participation and development are a result of a complex interplay between factors impacting on health, and vice versa. Mental health can be equated with wellbeing, mediating the ability to realize one's abilities, cope with the normal stresses of life, work productively, and to contribute to society.

Thus, social participation is a broad concept including the objective state and the subjective experience of involvement in society. This concept has to be understood in the light of social roles and the ability to adapt and self-manage (6). Social participation can be viewed as meaningful engagement with others. Such engagement can work both positively and negatively in social contexts. Meaningful engagement as an outcome cannot be measured directly. Influence on (development of) meaningful engagement with others can be measured as a proxy outcome measurement of social participation. For example, for young children, play is an important social activity. The ability to interact with others and to establish relationships is of great influence on learning and development, and successful social adaptation and participation.

Prevention of 'growing into deficit'

To adapt to societal demands and to support health, PCHC has to be able to move from a conventional approach ('find it and fix it') towards the new paradigm 'predict it and personalize it'. From a unified theory of development, child development and health are determined by multidimensional dynamic processes in the longitudinal course of life resulting in an infinite variability of unique individuals (37, 38). In this respect, one size does *not* fit all.

In the MOM study, the concept 'growing into deficit' is used to comprehend these multidimensional dynamic processes, to understand health, development, disorders and disease, to assess risk and protective factors, and to connect with intervention models.

The aim of the MOM study is to improve early identification of health problems and personalized PCHC, thereby optimizing prevention of 'growing into deficit' (39).

Then, re-aligning the trajectory of health, development and successful social participation is optimal and treatment, if needed, is probably more cost-effective (6, 16, 37, 40-42).

To prevent 'growing into deficit', the focus in the MOM study is on variation in dimensional measures of behavioural and developmental phenotypes that underlie preschool development, health and school readiness, which in turn is strongly associated with future adult well-being (43, 44). School readiness is defined as an outcome of preschool social participation and is seen as a reliable predictor of social participation across the life span.

Context specific information for Personalized PCHC

Clinical reasoning and weighing all available information about children and their environment remains specialist work to provide personalized PCHC care. Dutch PCHC doctors are expected to be specialists in social medicine, the part of medicine that focuses on the interaction between health and the environment, both individually and at group/community level. Knowledge and skills are required to identify genetic baseline risks, initiating events and symptoms to prevent disease burden and enhance well-being (37, 45). These activities may be initiated by professionals but also involve a partnership with parents and professionals in non-health care settings who come in contact with children and their families (46).

According to a bio ecological model of development-in-context, it is important to obtain child context-specific information (20). In order to document children's development over time, monitoring development at multiple time points, across informants, instruments and contexts, is more valid and accurate than a single assessment (16, 38–41).

Parents, professional caregivers and PCHC professionals are all important perceivers with expert knowledge on child development from different perspectives. For early identification of developmental problems, special attention has been given to the validity of instruments about the perceived impact of concerns as concurrent and long-term predictors, and outcome domains such as health, well-being and social participation (42).

Combined with a PCHC physical developmental assessment of each child, the short and valid MOM study PCHC tools can improve early identification of health problems in daily Dutch PCHC practise. The MOM study PCHC 'toolkit' instruments showed to be useful to support preschool multi-axial and multi-informant screening and monitoring of general emerging problems and disabling symptoms in daily Dutch PCHC practice. The MOM PCHC monitoring instruments were found to meet the requirements to (1) easily obtain information in every day PCHC setting; (2) carry out dimensional assessment of symptoms and behaviour; (3) measure the progress of development of young children and their possible determinants of influence; (4) identify general signals and symptoms indicating a possible disruption or imbalance of the educational/parent–child system, not yet related to a specific diagnosis; (5) support communication between PCHC, parents and professional caregivers about their perceptions on health and development; (6) connect to needs and demands of the child and social system around the child and (7) promote shared decision making (19, 39).

Future Perspectives

A MOM toolkit with short instruments was developed for proactive and anticipatory preschool health monitoring. The purpose of the instruments is to support early identification of preschool health problems, balanced strategies and 'shared decision making' together with parents and other partners in the care sector. The instruments do not replace personal assessment by the PCHC professional. The use of instruments should make it easier to work together even more closely and more effectively. Using only tools for monitoring and triage may seem more efficient but are ultimately less effective to provide personalized PCHC, clinical reasoning and weighing all available information about children and their environment remains specialist work. In addition to physical consultation, tools can be helpful to effectively exclude or confirm certain determinants of health and development. Research on positive health tools shows the difficulties to blend two goals of both a dialogue tool and a measurement tool (47). Similar to the PCHC toolkit instruments, while the overall predictive accuracy of the 'child competence' VAS showed to be poor, the 'child competence' VAS can still be used as a conversation tool. For personalized PCHC, knowledge and skills are required to identify genetic baseline risks, initiating events and symptoms to prevent disease burden and enhance well-being (37, 45).

Next to the MOM study tools, there are other reliable and valid tools available to support continued communication between parents, professional caregivers and PCHC for monitoring development and early identification of health problems. Updated information from Family History can support early identification of children at risk for

complex disease. Parents suggest that the importance of Family History should be more emphasized (48). In the same study, parents emphasize the importance of a more trusting relationship with PCHC. As with live events, parental health, and other contextual topics like work and family matters, it's important to ask about Family History with any PCHC assessment. A relationship based on trust is needed to provide personalized care.

Personalized PCHC needs a holistic interpretation of risk factors in relation to other determinants of health and development. The process of development and social participation evolves as a 'dynamic cascade' of risk and protective factors which exists not in isolation. From a developmental transactional perspective, children and context are continuously shaping each other (37). At any moment in life, new information can provide a different perspective on symptoms. Outlining a perspective of the child's developmental trajectory with an image of depth and distance should be the result of all previously listed and weighed aspects of health. The developmental picture of each unique child is determined by how each person's information is labeled and what is recorded. For personalized PCHC, good registration of all determinants of influence on health and development is necessary.

Classification according to the domains of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) can help to see that overview in the correct perspective and to work towards a personalized interpretation of different determinants. It is a model to classify the different factors impacting social adaptation and social participation. The ICF-CY is based on the biopsychosocial model and offers the possibility to register more than just diagnoses. For personalized PCHC it is important to register variation in dimensional measures of behavioural and developmental phenotypes underlying development, health and social participation. Moreover, the ICF provides possibilities at a collective level: registering health and / or development determinants in an unambiguous and meaningful way, including the necessary unity of language within PCHC. This is not a matter of "counting" items from the PCHC files. In this way, the relationship between determinants that lead to mutual transactional influence can be established within an integrated biopsychosocial transactional theory of development combined with the growing into deficit concept. The MOM study adds information and tools for early identification of emerging symptoms and distress at a stage when symptoms do not yet map to specific diagnostic entities, from different perspectives.

Consequently, within the Public Health system, personalized health care requires continuing optimal collaboration between parents, practice, policy and research, for cross-domain knowledge transfer and exchange to assess the health of the child as well as the needs of the family from a life course perpective (26). The recurring crucial question should always be : *What collaborative efforts across all parts of society are needed at this*

moment for future health perspectives of this unique child? Public Health and Personalized PCHC can be seen as two sides of the same coin.

Early detection includes both early and timely identification of risks and problems. That is, early in the child's life, but especially timely in the developmental process of the problem itself. Not only the risk factors, but also the protective factors must be mapped out at every contact moment. It is important to record signals as factually as possible, whereby a clear distinction must be made between facts, circumstances, events, observations, perceptions, interpretations and sources. Toxic stress and violence in dependent relationships generally do not arise in an instant, but in a process in which risks arise, spread, persist and the stress in a family eventually rises to such an extent that the safe development of children is jeopardized . It should be emphasised that signs of a stagnating parenting situation must be recognized early.

The MOM study results suggest that parental issues can be predictive of early onset of a maladaptive system. This stresses the importance of monitoring all children, more targeted preventive approaches, and the delivery of more precise, personalized healthcare, to improve population health (49). Further research is needed to refine assessment procedures of early identification of maladaptive systems. The use of integrated population-based data can be part of a 'practical strategy' for better understanding dynamic risk and protective factors related to toxic stress and child maltreatment. Linked administrative data can provide, relatively low-cost, longitudinal and prospective information for tailored prevention strategies (50, 51).

Mapping mental representations for 'shared early identification'

The gateway for intervention is the interactive behaviour and subjective experience or mental representation. The mental representation is the own meaning/subjective experience of the child, mother, father, teacher, care provider. To help families develop and understand the perpetuating factors, mental representations need to be mapped. The MOM study shows that the different mental representations can be used efficiently for monitoring and early identification of health problems in all children. A personalized multimodal intervention should follow after triage by weighing risk and protective factors, including mental representations (37, 52). After mapping out, points for attention and problems are to be prioritized. The focus of the intervention and the ultimate result to be achieved should be determined in consultation with the family, 'shared decision making', with the first and most important question: *"What's in it for the child?".*

The next step

Partnership with policy, practice (parents, PCHC and education) and research, in particular support at management level, is necessary for the next step**:** an extended pilot to implement the MOM PCHC toolkit in daily practice for children aged 0-8 years. Structural participation of parents, professional caregivers and PCHC in both early and timely identification and prevention of risks and problems throughout the preschool period may support a smooth transition between home, preschool and primary school. The short and valid MOM study PCHC tools can improve a dialogue to: 1) Unburden and normalize by providing information, advice and support or by having a few conversations to support and reassure parents and young people, if necessary; 2) In collaboration with parents/carers assess whether extra support, help or care is needed and immediately get the right care or help; 3) Collaborate with professionals from education, pre-school facilities, youth care, general practitioners and other curative care providers, neighborhood teams and other relevant parties, to identify and offer good and rapid personalized care and support; 4) Advise municipalities and schools on collective measures/activities based on analysis of data obtained.

Personalized PCHC is aimed at promoting self-efficacy as early as possible, limiting expensive specialist care in the long term and reducing school dropout. Ultimately, the entire region will benefit from the MOM method to move towards a better educated and healthy population, a population which is more self-reliant, who makes less use of support and (collective) facilities and who contributes to a strong region in social and economic terms.

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SUMMARY

Personalizing Preschool Preventive Child Health Care
The MOM study

Summary

'No child left behind'

Preventive child health care (PCHC) can be summarized as the public health endeavour to address and influence the early conditions that place children at risk for less than optimal health, development and successful social participation. Early identification of children at risk for developmental delay or related problems is essential for optimal early intervention and support in the social/educational domain. To support child health and development and to make sure that 'no child is left behind', community must adapt to the needs of children's family and educational surrounding. Then, the probability of re-aligning the trajectory of development and successful social participation is best and treatment, thus, is more cost-effective. To adapt to an ever-changing society and social demand for help, PCHC will need to transform a conventional approach ('find it and fix it') into a dynamic strategic approach aimed towards the future: 'predict it and personalize it'.

Personalizing PCHC: the MOM study

Personalizing PCHC for early identification of preschool child health and developmental emerging problems is the rationale behind the Monitoring Outcome Measurements of child development (MOM) study. In the introduction of this thesis the rationale, paradigm and methodology for Personalizing PCHC is delineated. Then the general outline and aims of the MOM study and this thesis are described. Personalized PCHC is new, integrating predictive, preventive, participatory and personal components of medicine from a Public Health perspective for balanced health policy on community and individual level (instead of 'a one-size-fits-all' approach). An unified theory of development with an integrated bio-psycho-socio-ecological approach provides a conceptual framework that fosters an understanding of adaptation as a multi-dimensional developmental process. To prevent 'growing into deficit', the focus is on variation in dimensional measures of behavioural and developmental phenotypes that underlie preschool development, health and school readiness, which in turn is strongly associated with adult well-being.

The MOM study is a prospective observational study within PCHC practice. At two time points (ages 3 and 4 years), a community-based sample of 346 children was assessed using a multisource and cross-informant repeated measurement design to identify developmental pathways impacting school readiness as an outcome of social participation from a live course perspective. MOM obtained information on baseline risk and environmental factors to track predictive risk indicators for making multi-axial health profiles. Linked to the routine PCHC consultation, various instruments were completed by parents, teachers/employees from child care, kindergarten, preschool or primary school (hereafter: professional caregivers) and PCHC professionals, including

reference instruments to validate the MOM PCHC monitoring instruments. The MOM study PHCH 'toolkit' instruments were chosen to facilitate personalizing PCHC for all children. Among the available validated parent-completed monitoring tools, the Parents' Evaluation of Developmental Status (PEDS) was put in a key position in the MOM study. The PEDS is designed by Glascoe to elicit concerns and facilitate communication between professionals and parents in addressing developmental and behavioural problems in children. The MOM dataset also contains Developmental D-score data from 1602 children, measured on the Dutch Developmental Instrument (Van Wiechen) at consecutive visits at PCHC.

MOM research questions, results and reflections

General research questions were: (i) What is the predictive value of multi-informant perceived concerns in the preschool period at the age of 3 to 4 years in relation to preschool mental development and school readiness? (ii) What parental and environmental factors are most strongly associated with preschool mental development and school readiness at the age of 3 to 4 years? (iii) To what extent is the level of school readiness predicted by childhood developmental and environmental factors? (iv) Can the outcomes of the MOM study be translated to the practice of monitoring in PCHC?

In **Chapter 2, 'Validation of short instruments assessing parental and caregivers' perceptions on child health and development for personalized prevention',** the central issues are the psychometric properties of the Dutch Parent's Evaluation of Developmental Status (PEDS), a 'child behaviour' Visual Analogue Scale (VAS), a 'parenting' VAS and a 'child competence' VAS, at the age of 3 and 4 years. These instruments are a first step in validation of a potential future Dutch PCHC 'toolkit' with short instruments for multi axial and multi-informant screening and monitoring of general emerging problems and disabling symptoms. Results suggest that the PEDS, 'parenting' VAS and 'child competence' VAS are reliable, valid and useful as brief parent-reported monitoring tools in daily Dutch PCHC practice. The professional caregiver-reported 'child competence' VAS scored lower on only one aspect of validity. Overall predictive accuracy of the PCHC 'toolkit' instruments showed: good to excellent for 'parenting' VAS, fair to good for 'child behaviour' VAS and poor for 'child competence' VAS. The PEDS, 'parenting' VAS and 'child behaviour' VAS, demonstrated high sensitivity at various cut-off points of index test and reference standard. The high negative predictive values (NPV) are eligible as well, they ensure that most children who pass the 'screening' are truly healthy. Over-referrals within PCHC services in a first-stage PCHC screening are no problem, children benefit from additional preventive monitoring. The PEDS revealed questions, subjects and concerns about and across different child developmental domains that parents and professional

caregivers want to discuss which are not yet related to changes in the Strengths and Difficulties Questionnaire (SDQ), Parenting Stress Index Short Form (in Dutch abbreviated as NOSIK), Child Behaviour Checklist (CBCL) and Caregiver-Teacher's Report Form (C-TRF) total score.

Chapter 3, 'Preschool communication: early identification of concerns about preschool language development and social participation', deals with concurrent and predictive validity of the PEDS to assess parental and professional caregivers' language development concerns. This part of the MOM research investigates 1) the validity of the Parents' Evaluation of Developmental Status (PEDS) to assess language development concerns; 2) the cross-sectional association of language development concerns with social participation; 3) the longitudinal association of language development concerns with social participation, and 4) the possible mediating effect of social competence on the association between language development and social participation at the ages of 3 and 4 years.

A mediating effect of child social competence was found on the association between receptive and expressive language concerns and social participation at the age of 3 and 4 years. Particularly at the age of 4, the mediating effect of social competence was strong. These results are in line with earlier research showing an association between language difficulties, behavioural difficulties, and social participation. For early identification of language needs, it is important to understand the pervasive nature of language development. The preschool period is a sensitive period, especially in overall communication development. It is assumed that differences in young children's language development reflect differences in experience and in creating interactive routines, next to their biologically mediated genetic potential. Developmental growth in language skills is an important parameter of overall communication development. Language problems are often the first presenting symptoms of delay in the development of multiple basic functions including socialization and communication. Early expressive and/or receptive language problems and behavioural problems may have long-term consequences. In particular, early receptive language problems are a significant risk factor for adult mental health. Early intervention is needed and has to be personalized; standard intervention programs have limited added value.

Chapter 4, 'Preschool social participation, the impact of early life stress and parental health', examines the association between parental and professional caregivers' perception of early life stress (ELS) and social participation at preschool. In addition, the modifying effect of the risk factor 'parental health status' is assessed. In this study, social participation is operationalized using various instruments to assess factors underlying social participation: a child's general competence, attendance proportion and extra

support (at day care, kindergarten and preschool), the impact of distress, concerns about child development and behaviour, and difficulties in child upbringing and parenting.

Results showed that children with ELS experienced more often distress, had more peer problems and received more often extra support at preschool. Their parents more often reported concerns, a higher number of concerns and perceived more difficulties in parenting. Associations between parental and professional caregivers' perceptions of ELS and the level of preschool social participation were stronger for children of parents with 'poor health'. These MOM study results recognize that ELS is a risk indicator influencing child health and wellbeing. Whether someone experiences stress as negative, depends on the extent to which an individual has control over the given stressor and whether the person has coping resources. Thus, stress can be positive, tolerable or toxic, depending on the nature of the adversity, the individual's stress reactivity and the level of social emotional support. Toxic stress in childhood links adversity with poor health and health disparities. Growing up safely requires prevention strategies to prevent toxic stress. More awareness is needed that children who do not meet criteria for a mental disorder but who have clinically significant impairment and distress represent an important group from a public health perspective. For early identification of children at risk for developmental delay, PCHC professionals should acknowledge current constraints of families and may examine the presence and impact of ELS in the lives of children and the health of their parents. Children's development and health are strongly influenced by how well their family functions. For children to be able to flourish and cope with stress, the quality of parental support and the educational context represent important resources for successful social participation across the life span. Therefore, health care professionals should be pay extra attention to parental health, and any imbalance between the parents' need for support and the support they actually receive.

Chapter 5, **'Parental perceptions and Personalized Health Care to prevent child maltreatment'**, explores early identification of a maladaptive system as a risk factor for child maltreatment. The association between different hypothesized parental risk factors and social participation is assessed using 4 outcome measures: functioning of the child, quality of the environment, degree of care, and urgency of care. Two different risk factors are used: a cumulative risk factor and single risk factor. Various risk variables are included: parental concerns about parenting competency, child development and behaviour; parental health status; unstable parenting situation, and parental problems such as excessive amount of parental stress and parental traumatic experience. The cumulative risk factor is the total number of child and environmental risk factors present. Cross-sectional analyses are performed both with baseline data and with follow-up data. Similar findings at age 3 years and age 4 years could be interpreted both as a replication and as evidence that associations are similar at these ages.

The MOM study results showed significant and strong associations between functioning of the child, quality of the environment, degree of care, and urgency of care and different variables: low parenting VAS, three or more PEDS concerns, seven or more risk factors, excessive amount of parental stress and an unstable parenting situation. These results confirm the importance of PCHC taking into account the quality of the educational context in order to effectively address the health and well-being of children. In the MOM study, the individual's social and educational environment including interpersonal relationships is hypothesized to be key to provide Personalized Health Care. Consequently, child maltreatment should not be seen as a diagnosis, but rather as a serious symptom of toxic stress in the child and the child's environment, including interpersonal relationships. The weighted information about health and development of each specific child can foster a dialogue between parents and professionals about senses of reassurance or alarm that there is something wrong and action and further monitoring is required, even though there is no certainty on the presence of child maltreatment. Then, personalized PCHC can be offered to support the capacity of parents and other caregivers and stimulate their health literacy in order to lower toxic stress and develop strong responsive early relationships with their children. Important are preventive interventions aimed at easing the transition to parenthood, to support parenting self-efficacy and to control toxic stress. Being a parent is not just about parenting, it is a transition process that affects different aspects of a person's life such as relationships, work, finance, housing.

Chapter 6, 'The Developmental Score as a brief tool for Preventive Child Health Care to identify emerging preschool developmental problems impacting school readiness' examines to what extent the Developmental score (D-Score) at the age of 2-2.5 years has added value as a brief monitoring tool in a comprehensive PCHC 'toolkit' of instruments as a short first step to identify emerging developmental problems impacting preschool social participation at the age of 4 years. In addition, various background characteristics (gender, parental educational status, age of the mother at birth of the child, hereafter maternal age) and risk factors in the family (parental health, parenting, early life stress, number of risk factors) are measured to determine the association with the Van Wiechen D -score. In Dutch PCHC, for more than 50 years at each routine medical assessment between the ages of 1-month and 4 years, a trained PCHC professional (e.g. doctor, nurse) assesses whether a child fulfils a set of developmental behaviours and tasks, and assigns a pass/fail score to each child for each indicator. This set of 75 indicators is known as the Van Wiechen Developmental Scheme.

Results showed usefulness of the D-score. Controlled for gender, parental educational status and age mother at birth, there were relatively strong and significant associations between a D-score at the age of 2-2.5 year and factors underlying social participation at the age of 4 years.

A low D-score appeared to be a risk factor for e.g. professional caregiver perception of child's psychosocial wellbeing, presence of parental concerns, poor functioning of the child, and a high urgency of care. In addition, there was a strong association between the D-score and early life stress, and a cumulation of risk factors in the family. The results suggest that the D-score at the age of 2-2.5 years can provide additional input for early identification of developmental problems impacting preschool social participation and school readiness. Applying the D-score does not replace the appraisal of the PCHC professional. As all other information, the D-score of an individual child has to be seen in the context of all unique developmental process variables. In the overall assessment, the PCHC doctor will not only consider the information from the developmental examination, but also from the developmental context of the child to select children who require further support in the form of a 'watch and wait' strategy, assessment of other developmental domains, or referral to a specialist. In short, the D-score is considered to be a monitoring tool and not a screening instrument.

Because of the plateau effect, the apparent variability in D-scores beyond the age of 30 months is substantially lower than the true variability in development. It will, therefore, not be possible to use the MOM data to provide reasonable estimates of the distribution of the true (i.e., free of plateau effect) variability in development. Hence for now, it is not possible to calculate sensible reference values and standard deviation scores of development beyond the age of 30 months. Although the Van Wiechen developmental scheme was revised in recent decades, an update and more research with a bigger number of children is needed, to develop reference values and standard deviation scores of development beyond the age of 30 months. Finally, the D-score represents a sum score of several domains of motor, language, cognitive and personal development, a high score on one developmental domain can equal out a low score on another domain. A possible next step in research is developing D-scores for each developmental domain.

Chapter 7 summarizes and discuss the main MOM research findings of a PCHC 'toolkit' with short instruments, developed for proactive and anticipatory preschool health monitoring by using multi- and cross-informant repeated measurements to enhance cross-domain collaboration for personalized PCHC. Finally, benefits and future perspectives are discussed to support early identification of preschool health problems, balanced strategies and 'shared decision making' together with parents and other partners in the care sector. For personalized PCHC, good registration of all determinants of influence on health and development is necessary. For example, classification according to the domains of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) can help to see that overview in the correct perspective and to work towards a personalized interpretation of different determinants.

The instruments do not replace personal assessment by the PCHC professional, understanding how determinants influence health is key to personalized PCHC and prevention strategies. Consequently, within the Public Health system, personalized health care requires continuing optimal collaboration between parents, practice, policy and research, for cross-domain knowledge transfer and exchange to assess the health of the child as well as the needs of the family from a life course perspective. Finally, the next step is discussed: an extended pilot to implement the MOM PCHC monitoring 'toolkit' in daily practice for children aged 0-8 years for mapping mental representations for 'shared early identification' and personalized PCHC.

'MOM knows best'

MOM study results suggest that personalized PCHC is a useful and essential paradigm to improve early identification of emerging preschool problems and symptoms at a stage where signs and symptoms do not yet meet diagnostic criteria, but already give rise to early impairment and distress for both the children and their context, at home as well as in preschool. Personalized PCHC unifies predictive tools, physical examination and developmental assessment with the unique child and its engaged parents/caregivers. As such, personalized PCHC focusses on tailoring the management and delivery of preventive health care to the unique individual characteristics of each child. The MOM study PHCH monitoring 'toolkit' shows how to facilitate personalized PCHC for all children.

SAMENVATTING

Personalisering van de voorschoolse preventieve Jeugdgezondheidszorg De MOM-studie

Samenvatting

‘Geen kind buiten de boot’

Preventieve Jeugdgezondheidszorg (JGZ) kan worden samengevat als het onderdeel van de Publieke Gezondheidszorg met als taak het zo vroeg en zo tijdig mogelijk in kaart brengen en beïnvloeden van omstandigheden die van belang zijn voor een optimale gezondheid, ontwikkeling en sociale participatie van kinderen. Vroege identificatie van kinderen met een risico op ontwikkelingsachterstand of gerelateerde problemen is essentieel voor een optimale vroege interventie en ondersteuning van de brede opvoedingsomgeving. Om de gezondheid en ontwikkeling van kinderen te ondersteunen en ervoor te zorgen dat ‘geen kind buiten de boot valt’, moet de gemeenschap afstemmen op de behoeften van het gezin en de onderwijsomgeving van het kind. Dan is de kans op het optimaliseren van het ontwikkelingstraject en succesvolle sociale participatie het grootst en is de behandeling dus kosteneffectiever. Om af te stemmen op een steeds veranderende samenleving en maatschappelijke hulpvraag, zal JGZ een conventionele aanpak (‘find it and fix it’) moeten transformeren naar een dynamische strategische benadering gericht op de toekomst (‘predict it and personalize it’).

JGZ personaliseren: de MOM-studie

De rationale achter de MOM-studie (studie ‘Monitoring Outcome Measurements of Child Development’/‘Monitoring Ontwikkeling kinderen in Maastricht en omgeving’) is het personaliseren van JGZ voor vroege identificatie van opkomende gezondheids- en ontwikkelingsproblemen. In de inleiding van dit proefschrift worden redenen, het paradigma en de methodologie voor het personaliseren van JGZ uiteengezet. Vervolgens worden de algemene opzet en doelstellingen van het MOM-onderzoek en dit proefschrift beschreven. Gepersonaliseerde JGZ is nieuw en integreert predictieve, preventieve, participatieve en persoonlijke componenten van geneeskunde vanuit een volksgezondheidsperspectief voor een evenwichtig gezondheidsbeleid op gemeenschaps- en individueel niveau in plaats van een ‘one-size-fits-all’-benadering. Een uniforme ontwikkelingstheorie met een geïntegreerde bio-psycho-socio-ecologische benadering biedt een conceptueel kader dat het begrip van adaptatie als een multidimensionaal ontwikkelingsproces bevordert. Om ‘growing into deficit’ binnen het ontwikkelingscontinuüm te voorkomen, ligt de nadruk op variatie in dimensionale metingen van gedrags- en ontwikkelingsfenotypes die ten grondslag liggen aan de voorschoolse ontwikkeling, gezondheid en schoolrijpheid, aspecten die sterk geassocieerd zijn met het welzijn van volwassenen.

De MOM-studie is een prospectieve observationele studie binnen de JGZ-praktijk. Op twee tijdstippen (leeftijd 3 en 4 jaar) werd een steekproef van 346 kinderen uit de algemene bevolking gevraagd deel te nemen. Hierbij werd informatie uit meerdere bronnen en

van meerdere informanten verkregen om ontwikkelingstrajecten te identificeren die van invloed zijn op schoolrijpheid als een resultaat van sociale participatie vanuit het levensloop perspectief. Voor MOM zijn voorspellers van risico's geïdentificeerd zodat multi-axiale gezondheidsprofielen gemaakt konden worden. Gekoppeld aan het routinematige JGZ-consult zijn verschillende instrumenten ingevuld door ouders, leerkrachten/medewerkers uit de kinderopvang, peuteropvang en school (hierna: professionele zorgverleners) en JGZ-professionals, waaronder referentie-instrumenten om de JGZ-monitoringinstrumenten in de MOM-studie te valideren. De instrumenten in de JGZ-toolkit van de MOM-studie werden gekozen om het personaliseren van JGZ voor alle kinderen te faciliteren. Van de beschikbare reeds gevalideerde monitoring tools in te vullen door ouders, werd de PEDS ('Parents' Evaluation of Developmental Status'/'Evaluatie van de ontwikkelingsstatus door ouders') in een sleutelpositie geplaatst. De PEDS is ontworpen door Glascoe om zorgen van ouders aan het licht te brengen en de communicatie tussen professionals en ouders te vergemakkelijken bij het aanpakken van ontwikkelings- en gedragsproblemen bij kinderen. De MOM-dataset bevat bovendien D-score-gegevens over de ontwikkeling van 1602 kinderen, gemeten bij opeenvolgende bezoeken aan de JGZ met het Nederlandse Van Wiechen ontwikkelingsinstrument.

MOM onderzoeksvragen, resultaten en reflecties

Algemene onderzoeksvragen waren: (i) Wat is de voorspellende waarde van de ervaren zorgen van meerdere informanten in de voorschoolse periode op de leeftijd van 3 tot 4 jaar met betrekking tot de voorschoolse mentale gezondheid, ontwikkeling en schoolrijpheid? (ii) Welke ouder- en omgevingsfactoren zijn het sterkst geassocieerd met voorschoolse mentale gezondheid, ontwikkeling en schoolrijpheid op de leeftijd van 3 tot 4 jaar? (iii) In hoeverre wordt het niveau van schoolrijpheid voorspeld door ontwikkelings- en omgevingsfactoren in de kindertijd? (iv) Kunnen de uitkomsten van het MOM-onderzoek vertaald worden naar de praktijk van monitoring in de JGZ?

In **hoofdstuk 2, 'Validatie van korte instrumenten die de percepties van ouders en professionele zorgverleners op de gezondheid en ontwikkeling van kinderen beoordelen voor gepersonaliseerde preventie'**, staan de psychometrische eigenschappen van de Nederlandse PEDS, een 'kindgedrag'-Visueel Analoge Schaal (VAS), een 'ouderschap'-VAS en een 'kindcompetentie'-VAS, op de leeftijd van 3 en 4 jaar, centraal. Deze instrumenten zijn een eerste stap in de validatie van een mogelijke toekomstige Nederlandse JGZ 'toolkit' met korte instrumenten ingevuld door meerdere informanten voor multi-axiale screening en monitoring van algemeen opkomende problemen en invaliderende symptomen. De resultaten suggereren dat de PEDS, 'ouderschap'-VAS en 'kindcompetentie'-VAS betrouwbaar, valide en bruikbaar zijn als korte door ouders in

te vullen monitoringinstrumenten in de dagelijkse Nederlandse JGZ -praktijk. De door professionele zorgverleners gerapporteerde 'kindcompetentie'-VAS scoorde lager op slechts één aspect van validiteit. Algehele voorspellende nauwkeurigheid van de JGZ 'toolkit'-instrumenten toonde: goed tot uitstekend voor de 'ouderschap'-VAS, redelijk tot goed voor de 'kindgedrag'-VAS en slecht voor de 'kindcompetentie'-VAS. De PEDS, 'ouderschap'-VAS en 'kindgedrag'-VAS, vertoonden een hoge sensitiviteit op verschillende afkappunten van indextest en referentiestandaard. Ook de hoge negatief voorspellende waarden (NPV) worden geschikt geacht, ze zorgen ervoor dat de meeste kinderen die door de 'screening' komen echt gezond zijn. Te veel verwijzingen binnen de JGZ-setting in een eerste fase van JGZ 'screening' zijn geen probleem, de kinderen hebben baat bij aanvullende preventieve monitoring. De PEDS onthulde vragen, onderwerpen en zorgen over verschillende ontwikkelingsdomeinen van het kind die ouders en professionele zorgverleners willen bespreken en die nog niet gerelateerd zijn aan veranderingen in een vragenlijst voor het signaleren van psychosociale problemen bij kinderen (Strengths and Difficulties Questionnaire, SDQ), de verkorte vorm van de Nijmeegse Ouderlijke Stress Index (NOSIK), en een diagnostisch instrument om probleemgedrag en vaardigheden van kinderen en jongeren te kwantificeren (Child Behaviour Checklist (CBCL) en Caregiver-Teacher's Report Form (C-TRF) totaalscore).

Hoofdstuk 3, 'Voorschoolse communicatie: vroege identificatie van zorgen over taalontwikkeling en sociale participatie in de voorschoolse leeftijd', behandelt de concurrente en predictieve validiteit van de PEDS om de zorgen van ouders en professionele zorgverleners over taalontwikkelingsproblemen te beoordelen. Dit deel van de MOM-studie onderzoekt 1) de validiteit van de PEDS om problemen met taalontwikkeling te beoordelen; 2) de transversale associatie van taalontwikkelingsproblemen met sociale participatie; 3) de longitudinale associatie van taalontwikkelingsproblemen met sociale participatie, en 4) het mogelijke mediërende effect van sociale competentie op de associatie tussen taalontwikkeling en sociale participatie op de leeftijd van 3 en 4 jaar.

Sociale competentie van het kind bleek een mediator bij de associatie tussen receptieve en expressieve taalproblemen aan de ene kant en sociale participatie op de leeftijd van 3 en 4 jaar aan de andere. Vooral op 4-jarige leeftijd was het mediërende effect van sociale competentie sterk. Deze resultaten zijn in lijn met eerder onderzoek dat een verband aantoont tussen taalproblemen, gedragsproblemen en sociale participatie. Voor een vroege identificatie van taalbehoeften is het belangrijk om de pervasieve aard van taalontwikkeling te begrijpen. De voorschoolse periode is een gevoelige periode, vooral in de algemene ontwikkeling van de communicatie. Aangenomen wordt dat verschillen in de taalontwikkeling van jonge kinderen een weerspiegeling zijn van verschillen in ervaring en in het creëren van interactieve routines, naast hun biologisch gemedieerde genetische potentieel. Groei in spraak-taalontwikkeling is een belangrijke parameter van

de algehele communicatie-ontwikkeling. Taalproblemen zijn vaak de eerste symptomen van vertraging in de ontwikkeling van meerdere basisfuncties, waaronder socialisatie en communicatie. Vroege expressieve en/of receptieve taalproblemen en gedragsproblemen kunnen op lange termijn gevolgen hebben. Vooral vroege receptieve taalproblemen zijn een belangrijke risicofactor voor de geestelijke gezondheid van volwassenen. Vroegtijdige interventie is nodig en moet worden gepersonaliseerd; standaard interventieprogramma's hebben een beperkte toegevoegde waarde.

Hoofdstuk 4, 'Sociale participatie in de voorschoolse periode, de impact van stress op jonge leeftijd en de gezondheid van ouders', onderzoekt de associatie tussen de perceptie van ouders en professionele zorgverleners over stress van het kind op jonge leeftijd (early life stress; ELS) en sociale participatie op de peuteropvang. Daarnaast wordt het veranderende (modificerende) effect van de risicofactor 'gezondheidstoestand van de ouders' beoordeeld. In dit onderzoek wordt sociale participatie geoperationaliseerd met behulp van verschillende instrumenten om factoren die ten grondslag liggen aan sociale participatie te beoordelen: (a) de algemene competentie van een kind; (b) mate van aanwezigheid, en (c) extra ondersteuning, op kinderdagopvang, peuteropvang en school; (d) de impact van lijdensdruk; (e) zorgen over de ontwikkeling en het gedrag van het kind, en (f) ervaren moeilijkheden bij het ouderschap en opvoeden van kinderen.

De resultaten toonden aan dat kinderen met doorgemaakte stress op jonge leeftijd (ELS) vaker last hadden van stress, meer problemen met leeftijdsgenoten hadden, en vaker extra ondersteuning kregen op de peuteropvang. Hun ouders rapporteerden vaker zorgen over de ontwikkeling, een groter aantal zorgen en ervaarden meer problemen bij het opvoeden. De associaties tussen de percepties van ouders en professionele zorgverleners over ELS en het niveau van sociale participatie in de voorschoolse opvang waren sterker voor kinderen van ouders met een 'slechte gezondheid'. Deze MOM-onderzoeksresultaten onderschrijven dat ELS een risico-indicator is die van invloed kan zijn op de gezondheid en het welzijn van kinderen. Of iemand stress als negatief ervaart, hangt af van de mate waarin een individu controle heeft over de gegeven stressor en of de persoon over de juiste coping strategieën beschikt. Stress kan dus positief, draaglijk of toxisch zijn, afhankelijk van de aard van de tegenspoed, de stressreactiviteit van het individu en het niveau van sociaal-emotionele steun. Ingrijpende gebeurtenissen op jonge leeftijd die leiden tot toxische stress zijn geassocieerd met slechte gezondheid en, daardoor, met gezondheidsverschillen. Veilig opgroeien vereist preventiestrategieën om toxische stress te voorkomen. Er is meer besef nodig dat kinderen die niet voldoen aan de criteria voor een psychische stoornis, maar die klinisch relevante beperkingen hebben en lijdensdruk ervaren, een belangrijke groep vormen vanuit het oogpunt van de volksgezondheid. Voor vroege identificatie van kinderen met een risico op ontwikkelingsachterstand, moeten JGZ-professionals de huidige beperkingen van gezinnen erkennen en de aanwezigheid en

impact van ELS in het leven van kinderen en de gezondheid van hun ouders onderzoeken. De ontwikkeling en gezondheid van kinderen worden sterk beïnvloed door de kwaliteit van het gezinsfunctioneren. Om ervoor te zorgen dat kinderen kunnen floreren en omgaan met stress, vormen de kwaliteit van de ouderlijke ondersteuning en de educatieve context belangrijke bronnen voor succesvolle sociale participatie gedurende de hele levensloop. Zorgprofessionals dienen daarom extra aandacht te besteden aan de gezondheid van ouders en eventuele onbalans tussen de behoefte aan ondersteuning van de ouders en de ondersteuning die ze daadwerkelijk ontvangen.

Hoofdstuk 5, 'Percepties van ouders en gepersonaliseerde gezondheidszorg om kindermishandeling te voorkomen', onderzoekt de vroege identificatie van een onaangepast en onevenwichtig systeem als een risicofactor voor kindermishandeling. De associatie tussen verschillende veronderstelde ouderlijke risicofactoren en sociale participatie wordt beoordeeld aan de hand van 4 uitkomstmaten: functioneren van het kind, kwaliteit van de omgeving, mate van zorg en urgentie van zorg. Er worden twee verschillende risicofactoren gebruikt: een cumulatieve risicofactor en een enkele risicofactor. Er zijn verschillende risicovariabelen opgenomen: zorgen van ouders over opvoedingscompetentie, ontwikkeling en gedrag van het kind; gezondheidstoestand van de ouders; onstabiele opvoedingssituatie en ouderlijke problemen zoals overmatige hoeveelheid ouderlijke stress en ouderlijke traumatische ervaringen. De cumulatieve risicofactor is het totaal aantal aanwezige kinder- en omgevingsrisicofactoren. Cross-sectionele analyses worden zowel met baseline data als met follow-up data uitgevoerd. Vergelijkbare bevindingen op de leeftijd van 3 jaar en de leeftijd van 4 jaar kunnen zowel worden geïnterpreteerd als een replicatie en als bewijs dat associaties vergelijkbaar zijn op deze leeftijden.

De resultaten van de MOM-studie lieten significante en sterke associaties zien tussen het functioneren van het kind, de kwaliteit van de omgeving, de mate van zorg en de urgentie van de zorg en verschillende factoren: (a) problemen met de opvoeding; (b) drie of meer zorgen volgens de PEDS; (c) zeven of meer risicofactoren; (d) overmatige hoeveelheid van ouderlijke stress, en (e) een onstabiele opvoedingssituatie. Deze resultaten bevestigen het belang dat JGZ rekening dient te houden met de kwaliteit van de opvoedingscontext bij het effectief ondersteunen van de gezondheid en het welzijn van kinderen. In de MOM-studie wordt verondersteld dat de sociale en educatieve omgeving van het individu, inclusief interpersoonlijke relaties, de sleutel is om gepersonaliseerde gezondheidszorg te bieden. Daarom moet kindermishandeling niet worden gezien als een diagnose, maar eerder als een ernstig symptoom van toxische stress bij het kind en de omgeving van het kind, inclusief interpersoonlijke relaties. De gewogen informatie over gezondheid en ontwikkeling van elk specifiek kind kan een dialoog tussen ouders en professionals bevorderen. Samen wordt besloten welke actie en verdere monitoring nodig is, ook al

is er geen zekerheid over de aanwezigheid van kindermishandeling. Vervolgens kan gepersonaliseerde JGZ worden aangeboden om de capaciteit van ouders en andere zorgverleners te ondersteunen en hun gezondheidsvaardigheden te stimuleren om toxische stress te verminderen en sterke, responsieve vroege relaties met hun kinderen te ontwikkelen. Belangrijk zijn preventieve interventies gericht op het vergemakkelijken van de overgang naar het ouderschap, het ondersteunen van de zelfeffectiviteit van het ouderschap en het beheersen van toxische stress. Ouder zijn gaat niet alleen over ouderschap, het is een overgangsproces dat verschillende aspecten van iemands leven beïnvloedt, zoals relaties, werk, financiën, huisvesting.

Hoofdstuk 6, 'De ontwikkelingsscore als een kort hulpmiddel voor preventieve Jeugdgezondheidszorg om opkomende voorschoolse ontwikkelingsproblemen die van invloed zijn op schoolrijpheid te identificeren', onderzoekt in hoeverre de ontwikkelingsscore (D-score) op de leeftijd van 2-2,5 jaar toegevoegde waarde heeft als een kort monitoringsinstrument in een uitgebreide JGZ 'toolkit' van instrumenten. Er wordt gekeken naar de D-score als een korte eerste stap om opkomende ontwikkelingsproblemen te identificeren die van invloed zijn op de sociale participatie van de kleuterschool op de leeftijd van 4 jaar. Daarnaast worden verschillende achtergrondkenmerken (geslacht, opleiding van de ouders, leeftijd van de moeder bij de geboorte van het kind, hierna leeftijd van de moeder) en risicofactoren in het gezin (gezondheid van de ouders, opvoeding, stress op jonge leeftijd, aantal risicofactoren) gemeten om de associatie met de Van Wiechen D-score te bepalen. Gedurende al meer dan 50 jaar, bij elk routinematig Nederlands JGZ-consult in de leeftijd van 1 maand tot 4 jaar, beoordeelt een getrainde JGZ-professional (bijv. arts, verpleegkundige) of een kind een reeks ontwikkelingsgedragingen en -taken vervult. Voor elk kind en voor elke indicator wordt door de JGZ-professional een pass/fail-score ingevuld. Deze set van 75 indicatoren staat bekend als het Van Wiechen Ontwikkelingsonderzoek.

De resultaten toonden het nut van de D-score aan. Gecontroleerd voor geslacht, opleidingsstatus van de ouders en leeftijd moeder, waren er relatief sterke en significante associaties tussen een D-score op 2-2,5 jaar en factoren die ten grondslag liggen aan sociale participatie op 4-jarige leeftijd.

Een lage D-score bleek een risicofactor te zijn voor b.v. de perceptie van de professionele verzorger over het psychosociale welzijn van het kind, aanwezigheid van ouderlijke zorgen, slecht functioneren van het kind en een hoge urgentie van zorg. Bovendien was er een sterke associatie tussen de D-score en stress op jonge leeftijd, en een cumulatie van risicofactoren in het gezin. De resultaten suggereren dat de D-score op de leeftijd van 2-2,5 jaar extra input kan leveren voor vroege identificatie van ontwikkelingsproblemen die van invloed zijn op de sociale participatie van de voorschoolse opvang en

schoolrijpheid. Het gebruik van de D-score vervangt niet de beoordeling van de JGZ-professional, maar het helpt de JGZ-professional. Net als alle andere informatie moet de D-score van een individueel kind worden gezien in de context van alle unieke variabelen van het ontwikkelingsproces. Bij de algehele beoordeling zal de jeugdarts niet alleen de informatie uit het ontwikkelingsonderzoek, maar ook uit de ontwikkelingscontext van het kind betrekken om kinderen te selecteren die verdere ondersteuning nodig hebben in de vorm van een 'watch and wait'-strategie, beoordeling van andere ontwikkelingsdomeinen, of verwijzing naar een specialist. Kortom, de D-score wordt beschouwd als een monitoringinstrument en niet als een screeningsinstrument.

Vanwege een plateau-effect is de schijnbare variabiliteit in D-scores van het Van Wiechen ontwikkelingsonderzoek na de leeftijd van 30 maanden aanzienlijk lager dan de werkelijke variabiliteit in ontwikkeling. Dit betekent dat het verkrijgen van referentiewaardes voor de D-score voor leeftijden boven de 30 maanden niet zinvol is. Als het Van Wiechen instrument aangepast wordt zodat het beter geschikt is voor hogere leeftijden, kunnen in de toekomst wel referentiewaardes bepaald worden. Mogelijk heeft ook deze D-score een relatie met sociale participatie, maar dit zal in de toekomst onderzocht moeten worden. Ten slotte vertegenwoordigt de D-score een somscore van meerdere domeinen van motorische, taal-, cognitieve en persoonlijke ontwikkeling, een hoge score op het ene ontwikkelingsdomein kan een lage score op een ander domein maskeren. Een mogelijke volgende stap in het onderzoek is het ontwikkelen van D-scores per ontwikkelingsdomein.

Hoofdstuk 7 vat de belangrijkste MOM-onderzoeksresultaten samen; een JGZ 'toolkit' met korte instrumenten, ontwikkeld voor proactieve en anticiperende voorschoolse gezondheidsmonitoring. Daarbij wordt gebruik gemaakt van herhaalde metingen van informatie uit meerdere bronnen en van verschillende informanten om de domein overschrijdende samenwerking voor gepersonaliseerde JGZ te verbeteren. Tot slot worden voordelen en toekomstperspectieven besproken ter ondersteuning van vroegtijdige identificatie van voorschoolse gezondheidsproblemen, evenwichtige strategieën en 'gedeelde besluitvorming' samen met ouders en andere partners in de zorgsector. Voor gepersonaliseerde JGZ is een goede registratie van alle determinanten van invloed op gezondheid en ontwikkeling noodzakelijk. Zo kan classificatie met behulp van de domeinen van de International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) helpen om dat overzicht in het juiste perspectief te zien en toe te werken naar een gepersonaliseerde interpretatie van verschillende determinanten.

De instrumenten vervangen de persoonlijke beoordeling door de JGZ-professional niet; het begrijpen van de invloed van determinanten op de gezondheid is de sleutel tot gepersonaliseerde JGZ en preventiestrategieën. Bijgevolg vereist gepersonaliseerde gezondheidszorg binnen het volksgezondheidssysteem een voortdurende optimale

samenwerking tussen ouders, praktijk, beleid en onderzoek, voor interdisciplinaire kennisoverdracht en uitwisseling om de gezondheid van het kind en de behoeften van het gezin te beoordelen vanuit een levensloopperspectief.

Ten slotte wordt de volgende stap besproken: een uitgebreide pilot om de MOM JGZ-monitoring 'toolkit' in de dagelijkse praktijk te implementeren voor kinderen van 0-8 jaar voor het in kaart brengen van mentale representaties voor 'gedeelde vroege identificatie' en gepersonaliseerde JGZ.

'MOM kent het kind het beste'

MOM-onderzoeksresultaten suggereren dat gepersonaliseerde JGZ een nuttig en essentieel paradigma is om vroege identificatie van opkomende voorschoolse problemen en symptomen te verbeteren in een stadium waarin signalen en symptomen nog niet voldoen aan diagnostische criteria, maar al wel aanleiding geven tot vroege beperkingen en lijdensdruk voor zowel de kinderen en hun context, zowel thuis als op de peuteropvang. Gepersonaliseerde JGZ verenigt voorspellende hulpmiddelen, lichamelijk onderzoek en ontwikkelingsbeoordeling met het unieke kind en zijn betrokken ouders/zorgverleners. Als zodanig richt gepersonaliseerde JGZ zich op het afstemmen van het beheer en de levering van preventieve gezondheidszorg op de unieke individuele kenmerken van elk kind. De JGZ-monitoring 'toolkit' van de MOM-studie laat zien hoe gepersonaliseerde JGZ voor alle kinderen mogelijk kan worden gemaakt.

IMPACT

Personalizing Preschool Preventive Child Health Care
The MOM study

Impact

Gepersonaliseerde JGZ: impact

Waar 'impact,' in de oorspronkelijke betekenis van 'krachtige inwerking', vrij eenvoudig, voorspelbaar en meetbaar lijkt in termen van oorzaak-gevolg, wordt impact tegenwoordig vaak gebruikt om complexiteit, uitwisseling en interactie aan te duiden. Ook woorden als 'engagement,' de wereld verbeteren, 'agenderen' of 'een bijdrage leveren' passen bij impact, naast 'effect' of 'uitkomst' of 'consequenties'. De term impact kan verbindend werken als het woord een positief gevoel oproept in combinatie met de ruimte voor eigen interpretatie van de betekenis van het begrip impact. Samenwerken kan vlotter verlopen als er ruimte en aandacht is voor ieders persoonlijke doel en interpretatie. Bij samenwerking aan een gezamenlijk doel heeft iedereen andere belangen en spreekt ook een andere taal. Dat geldt ook voor samenwerken aan het vormgeven van optimale ontwikkelingskansen voor alle kinderen. In dat opzicht past de term impact al 'per definitie' bij de essentie van gepersonaliseerde jeugdgezondheidzorg als het gaat om 'krachtige inwerking door complexiteit, uitwisseling en interactie, met ruimte voor eigen interpretatie'.

Verbetering van de publieke gezondheid

MOM staat voor Monitor Ontwikkeling kinderen Maastricht en omgeving. De Monitor Ontwikkeling kinderen Maastricht en omgeving (MOM) studie is opgezet om vorm te geven aan gepersonaliseerde jeugdgezondheidszorg (JGZ) om in de voorschoolse periode risico's voor gezondheid, groei en ontwikkeling beter te voorspellen, vast te stellen en te kwantificeren. Goede monitoring van ontwikkelingsprofielen van alle kinderen verhoogt de kans om vroegtijdig te anticiperen op specifieke behoeften, zowel op individueel als op groepsniveau, met als uiteindelijk doel: optimale ontwikkelingskansen voor succesvolle sociale participatie.

De MOM-studie is oorspronkelijk gestart onder de vlag van de Academische Werkplaats Publieke Gezondheid Limburg onder het thema 'JGZ-professionals in dialoog met data' binnen het ZonMw project: 'Promoting physical and mental fitness. Evidence into practice and practice into evidence: closing the circle'. Optimalisering van de gegevensverzameling en databeheer stonden aan de basis van het onderzoek. Verbetering van de publieke gezondheid was destijds de reden voor de oprichting van een Academische Werkplaats Publieke Gezondheid Limburg. Door samenwerking van GGD Zuid-Limburg en het Maastricht Universitair Medisch Centrum kunnen praktijk-gebaseerde interventies worden onderzocht op hun effectiviteit. Vervolgens kunnen deze bewezen effectieve interventies ingebouwd worden in het gemeentelijke gezondheidsbeleid. Aanleiding was het feit dat Zuid-Limburg behoort tot de regio's met de laagste levensverwachting. De sterfte in Zuid-Limburg ligt hoger dan het landelijk gemiddelde. Zuid-Limburgers leven niet alleen korter

dan de gemiddelde Nederlander, ze leven ook minder lang in goed ervaren gezondheid. Er is meer aandacht nodig voor de preventie van gezondheidsproblemen, met extra aandacht voor de kwaliteit van de brede opvoedingscontext en het voorkomen van toxische stress en kansarmoede. Door het verbeteren van de gezondheid van jeugdigen kan indirect bijgedragen worden aan het voorkomen van complexe aandoeningen op latere leeftijd.

Onvoldoende zicht op ontwikkelingsprofielen in de voorschoolse periode

Voorkomen is beter dan genezen. JGZ heeft een belangrijke preventieve taak in het voorkomen van gezondheidsproblemen bij alle kinderen. Verbetering van de jeugdgezondheid komt ten goede aan de algemene publieke gezondheid daar kinderen de toekomstige volwassenen zijn. Het 'Verdrag inzake de rechten van het kind' is de internationaal wettelijke basis om voorwaarden te scheppen voor gezonde groei- en ontwikkelingskansen voor alle kinderen. In Nederland heeft de JGZ een wettelijke taak om de ontwikkeling van alle kinderen tot 18 jaar te monitoren voor vroegsignalering van problemen en vroegtijdige toeleiding naar passende ondersteuning (Wet Publieke Gezondheid 2008). De MOM-studie is gestart daar de JGZ in de (voor)schoolse periode onvoldoende zicht had op de ontwikkelingscurve en het risicoproces van het kind in interactie met de opvoedingscontext. De Inspectie voor de Gezondheidszorg gaf aan dat vroegsignalering van problemen bij de opvoeding en psychosociale problemen beter kon. De feitelijke prevalentie van psychosociale problemen bij 0-12 jarigen was onbekend. De cijfers liepen uiteen van ongeveer 5% tot ongeveer 30%.

Beter zicht krijgen op het ontwikkelingsprofiel en het risicoproces van een kind is van belang in het kader van passende steun voor kind en opvoedingscontext waaronder passend onderwijs. Als de opvoedingscontext c.q. (schoolse leer) omgeving niet afgestemd is op de competenties en het leerpotentieel van het kind zorgt dat voor een spanningsveld en mogelijke frustraties en lijdensdruk bij zowel kind als omgeving. Deze frustraties kunnen de ontwikkeling en succesvolle participatie belemmeren door gedragsproblemen, leerproblemen en schooluitval.

Het is dan ook de taak van de JGZ om beter te adapteren aan maatschappelijke vraagstukken zoals onder andere genoemd in het rapport 'Kwesties voor het kiezen' van het Sociaal en Cultureel Planbureau (SCP): kansengelijkheid in het onderwijs, armoede en onzeker werk. Met ongelijk verdeelde onderwijskansen worden ongelijke maatschappelijke posities van generatie op generatie doorgegeven. Dat geldt zeker voor kinderen met gedrag- en ontwikkelingsproblemen. Probleemgedrag bij jonge kinderen is geassocieerd met

latere problemen zoals criminaliteit. Het voorkomen van crimineel gedrag begint bij de opvoeding en bij goed onderwijs. Veel jeugdproblematiek gaat samen met gebrek aan sociale adaptatie, sociale redzaamheid en sociale weerbaarheid. Deze problemen kunnen weer leiden tot verminderde sociale participatie op volwassen leeftijd.

Vroegsignalering in samenwerking met ouders en ketenpartners wordt beperkt door het medisch model. Het medisch model sluit kinderen uit van zorg ingeval van problemen waarbij symptomen niet te clusteren zijn tot een diagnose, maar waarbij er wel sprake is van lijdensdruk en/of een stagnerende ontwikkeling. Het aantal kinderen waar het evident niet goed mee gaat, maar dat niet binnen de DSM-criteria valt, is naar schatting anderhalf tot tweemaal groter dan de prevalentie van kinderen mét een DSM-diagnose. Voor deze groep kinderen biedt een conventionele benadering maar beperkt hulp. Daarnaast is het van belang kind en opvoedingscontext te ondersteunen in een periode waar de kansen op verbetering het hoogst zijn en het meest (kosten)effectief. De ontwikkeling van een kind in de eerste vijf levensjaren is van grote invloed op de gezondheid en optimale leermogelijkheden op school. Deze leermogelijkheden zijn weer van invloed op succesvolle participatie in de maatschappij op volwassen leeftijd.

De JGZ maakt momenteel te weinig efficiënt en methodisch gebruik van informatie van de brede opvoedingscontext, onder andere de mening van de ouder over de ontwikkeling van hun kind en de mening van de leidster/pedagogisch medewerker van de peuteropvang en kinderdagverblijf in de voorschoolse periode. Signalering is een kerntaak van allen die als professionals met kinderen in aanraking komen. Uit onderzoek blijkt dat informatie van meerdere bronnen en een combinatie van methoden het succes op vroegsignalering verhoogt. Onderzoek heeft ook aangetoond dat het betrekken van ouders en leidsters/leerkracht in het proces de betrouwbaarheid van het ontwikkelingsonderzoek verhoogt.

De JGZ maakt ook onvoldoende efficiënt gebruik van een combinatie van persoonlijk contact en valide instrumenten voor triagemogelijkheden en dataverzameling. In een goed monitoring en triagesysteem horen instrumenten die snel en goedkoop ingezet kunnen worden als zeef voor vroegsignalering bij alle kinderen. Intensievere en duurdere instrumenten worden dan op indicatie gebruikt bij kinderen die geïdentificeerd zijn als potentieel "at risk". Daarnaast heeft een goede combinatie (multi-informant en multimethod) en herhaling van testen (repeated measures design) de voorkeur. In het bijzonder bij jonge kinderen fluctueert het gedrag afhankelijk van de stemming, de omgeving en hun snelle ontwikkeling. Ook dient men bij de keuze van instrumenten rekening te houden met de specifieke leeftijds- en ontwikkelingsfasen, beschikbare tijd en middelen in de JGZ en de mogelijkheden van de opvoedingscontext.

Verder zijn betere randvoorwaarden voor de praktijkprofessionals nodig om op een zorgvuldige manier data te kunnen verzamelen, te beheren en te communiceren. Een optimale dialoog geeft niet alleen informatie voor een persoonlijk ontwikkelplan van het kind en de opvoedingscontext, maar ook van de professionals, de organisaties en de beleidsmakers.

De werktitel gedurende de MOM-studie was dan ook: 'Preventive child health care in dialogue with data on developmental outcome. A study to assess the association between indicators of child development in the preschool period and successful adaptation to school'.

En wat heeft het kind nu aan MOM?

In het kader van de MOM-studie is een JGZ 'toolkit' met instrumenten ontwikkeld en op wetenschappelijke waarde getoetst resulterend in valide en betrouwbare instrumenten voor beter zicht op de relatie tussen vroege signalen van gedrag- en ontwikkelingsproblemen en succesvolle participatie op de (voor)school door JGZ-maatwerk in monitoring. De korte MOM JGZ instrumenten maken gebruik van het unieke kader van de JGZ om de ontwikkeling van alle kinderen te monitoren en de klinische gevolgen van beginnende problemen te signaleren en positief te beïnvloeden, met name de problematiek die (nog) niet binnen een diagnostische classificatie valt.

MOM heeft laten zien dat de JGZ door gebruik van de juiste instrumenten drie wenselijke manieren van informatieverzameling kan combineren: 1) door actieve informatieverwerving tijdens preventief gezondheidsonderzoek (PGO) in combinatie met informatie van opvoedingscontext; 2) als reactie op signalen van kind en/of opvoedingscontext; 3) door actieve continue monitoring in samenwerking met de opvoedingscontext.

De MOM-studie heeft ook laten zien dat de JGZ-ontwikkelingsprofielen kan maken door op een gepersonaliseerde manier zowel risico en beschermende factoren te verzamelen als ook te duiden en te wegen.

De MOM JGZ toolkit is gebaseerd op een internationaal geaccepteerd en wetenschappelijk onderbouwd theoretisch model als fundament voor discipline overstijgende integrale samenwerking in monitoring en vroegsignalering waarbij het belang van het kind bovenaan staat. De continue dynamische interactie tussen genen, gedrag en omgeving in het veroorzaken van problemen (en weerbaarheid) op latere leeftijd pleit voor het volgen van het ontwikkelingsproces vanuit een prospectieve benadering met een

gepersonaliseerde aanpak binnen het perspectief van het bio-psycho-ecologisch transactioneel model en het 'growing into deficit' concept.

Monitoring is geen momentopname maar een voortdurend proces van het verzamelen, combineren en interpreteren van informatie over het kind in de brede opvoedingscontext. De waarde van een monitorsysteem bij kinderen overstijgt het alleen meten van het ontwikkelingsproces bij kinderen. Data uit continue monitoring zijn ook van belang voor management en maatschappelijk beleid. Risico- en beschermende factoren bij kind en opvoedingscontext zijn van belang bij het maken van ontwikkelingsprofielen op zowel individueel als groepsniveau.

Het concept van 'growing into deficit' wordt gebruikt om de multidimensionale dynamische processen met betrekking tot gezondheid, ontwikkeling, aandoeningen en ziekte te begrijpen. Bij ieder mens is er sprake van een unieke combinatie van risico en beschermende factoren die de weerbaarheid, de ontwikkelingskansen en de mate van succesvolle participatie beïnvloeden.

Gepersonaliseerde JGZ richt zich bij alle kinderen op het zo tijdig mogelijk herkennen en erkennen van gedragssignalen en lijdensdruk die wijzen op risico's voor belemmering van een gezonde ontwikkeling. Hierbij wordt gebruik gemaakt van de participatie en perceptie van kind en omgeving in zowel continue monitoring, vroegsignalering als maatwerk in begeleiding. Door gepersonaliseerde zorg is het mogelijk de publieke gezondheid te verbeteren, door zo vroeg mogelijk in de ontwikkeling van het kind en zo tijdig mogelijk in de ontwikkeling van problemen maatwerk te leveren. 'Iemand zien staan', goed luisteren, kijken, en een respectvolle dialoog over de verschillende percepties, taken en verantwoordelijkheden zijn kernbegrippen voor gepersonaliseerde zorg en gedeelde besluitvorming.

De MOM toolkit bleek te bestaan uit betrouwbare en nuttige instrumenten ter ondersteuning van voorschoolse multi-axiale, multi-informant en multimethode monitoring en triage van algemeen opkomende problemen en invaliderende symptomen in de dagelijkse Nederlandse JGZ -praktijk.

De MOM JGZ -monitoringinstrumenten bleken te voldoen aan vereisten voor het snel en eenvoudig verkrijgen van informatie voor optimaal gepersonaliseerde JGZ-contactmomenten en monitoring van alle kinderen in de dagelijkse praktijk. De MOM-instrumenten zijn geïntegreerd in de infrastructuur voor de dagelijkse zorg voor alle kinderen met als uitgangspunt de wettelijke taakstelling en bijbehorende competenties van ouders/verzorgers en professionals die betrokken zijn bij de dagelijkse zorg voor ieder kind.

De instrumenten ondersteunen de communicatie tussen JGZ, ouders en professionele zorgverleners over hun perceptie van gezondheid en ontwikkeling. Er is meer ruimte voor de mening van de ouders/verzorgers over hun eigen welbevinden en gezondheid en de ontwikkeling van hun kind. Ouders/verzorgers zien hun kind iedere dag. Er wordt systematisch gebruik gemaakt van informatie van leidsters/leerkrachten. Zij weten veel over het gedrag van kinderen in hun speelzaal, kinderopvang of klas.

De instrumenten sluiten aan bij (inter)nationaal geaccepteerde en gevalideerde instrumenten. Ze ondersteunen het vroegtijdig identificeren en beoordelen van dimensies van symptomen, gedrag en lijdensdruk die wijzen op een mogelijke verstoring of onbalans van het kind-ouder/onderwijssysteem zonder dat ze gerelateerd zijn aan een specifieke diagnose. Ook meten ze de voortgang van de ontwikkeling van jonge kinderen en de mogelijke determinanten van invloed op de ontwikkeling. Ze hebben de mogelijkheid om zowel een momentopname te maken als het ontwikkelingsproces in tijd te evalueren.

Daarnaast zijn resultaten van het ontwikkelingsonderzoek met behulp van de instrumenten gedefinieerd, gecodeerd en in maat en getal uit te drukken. Gegevens uit de data –infrastructuur kunnen daardoor gekoppeld worden voor het maken, vergelijken en volgen van gezondheidsprofielen op individueel en op groepsniveau.

De meetinstrumenten in het MOM-monitorsysteem sluiten aan bij het streven naar afstemming en continuïteit van zorg met betrokken ketenpartners. In het continue ontwikkelingsproces zijn transitiemomenten kwetsbare momenten. Dit geldt niet alleen voor de transitie van in /uit de baarmoeder en van thuis naar peuteropvang en school, maar ook voor de (zorg)overdracht binnen en tussen de 0e naar 1e, 2e en 3e lijnszorg. Eenheid van taal bij het noteren van determinanten en het gebruik van uitkomstmaten ondersteunt de doelmatigheid van vroegsignalering, gedeelde besluitvorming en continuïteit van zorg.

MOM sluit inhoudelijk en procedureel aan bij eerder ingezette beleidsbeslissingen, ontwikkelingen en scholingen op het gebied van probleemoplossend buurt- en kindgericht samenwerken, vroegsignalering, hechting, versterking van de ketenzorg, samenwerking met ouders en het gebruikmaken van lokale mogelijkheden, zoals bijvoorbeeld: SamenStarten, Ketens voor de jeugd, Zorgstructuren, Matching Needs en Services, sociale buurt teams, Trendbreuk en de Educatieve agenda Limburg. Daarbij is het wenselijk dat er geen tweedeling bestaat tussen collectief gerichte preventieve zorg en zorg op maat. Voor goede preventie is het belangrijk dat collectieve preventie en zorg op maat complementair van elkaar gebruik maken: publieke gezondheid en gepersonaliseerde zorg zijn twee kanten van dezelfde medaille. Gepersonaliseerde JGZ heeft een potentiele impact op: 1) data infrastructuur voor onderbouwing van prioritering

van in te zetten zorg, efficiëntere inzet van zorg en financiële middelen zonder dat het ten koste gaat van de basiszorg voor alle kinderen; 2) duidelijke cijfers over prevalentie van zorgen, vragen, risicofactoren, beschermende factoren, gedragsproblemen, mate van competentie en participatie in de zorg voor jeugd; 3) data zijn digitaal in te voeren, waardoor ondersteuning van de vormgeving van een doelmatig digitaal kinddossier; het werken met algoritmes en een indeling in hoog/midden en laag risico kan helpen bij het prioriteren en operationaliseren van handelingsgerichte diagnostiek; 4) data zijn zowel te gebruiken voor aansturing van de inhoud van zorg als voor management en scholing. De data ondersteunen niet alleen het werken met persoonlijke ontwikkelplannen voor het kind maar ook die van de professional en de organisatie; 5) data ondersteunen het maken van ontwikkelingsprofielen van zowel kind en opvoedingscontext als van peuteropvang, kinderdagverblijf, buurt en gemeente als geheel; 6) negatieve etikettering wordt vermeden door expliciet te werken met veiligheid en ontwikkelingsmogelijkheden- en kansen ten opzichte van risicofactoren; 7) de MOM instrumenten verhogen de eenheid van taal en de efficiëntie door de structurele samenwerking en overdracht van gegevens tussen ouders en de verschillende disciplines werkzaam rondom het kind: JGZ, peuteropvang, kinderdagverblijf, onderwijs, jeugdzorg en geestelijke gezondheidszorg en gemeentelijke voorzieningen; 8) evidence based onderbouwing van vroegsignalering en interventies; 9) onderbouwing van een kosteneffectieve jeugdgezondheidszorg.

Gepersonaliseerde zorg, in het bijzonder voor kinderen en jeugdigen, kan de synergie tussen praktijk, beleid, onderzoek en onderwijs bevorderen. Door concrete integrale samenwerking en doelmatiger gebruik van beschikbare middelen kunnen meer kinderen en volwassenen succesvol (betekenisvol) participeren in de maatschappij.

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Curriculum Vitae

Bernice Doove is geboren op 7 februari 1962 in Den Haag als tweede van vier kinderen. Zij bracht haar jeugd door in Rijswijk, Leusden en Eersel, alwaar zij in 1980 haar Vwo-diploma behaalde. Datzelfde jaar startte zij met haar opleiding geneeskunde aan de Rijksuniversiteit Limburg, thans Maastricht University.

Tijdens haar werk als veldwerker bij het NIVEL te Utrecht, in de wachttijd voor de huisartsenopleiding, besloot Bernice te kiezen voor het prachtige vak van arts Jeugdgezondheidszorg (JGZ). In 1988 trad zij in vast dienstverband bij de JGZ van de Regionale Vereniging Het Groene Kruis Zuidelijk Zuid-Limburg, na diverse fusies inmiddels ondergebracht bij JGZ GGD Zuid-Limburg. Tussen 1999 en 2004 volgde zij de opleiding tot arts Maatschappij en Gezondheid-Jeugdarts bij TNO in Leiden. Sinds 2011 is zij ook opleider voor deze specialisatie binnen Sociale Geneeskunde. Behalve dit opleiderschap was Bernice de afgelopen jaren betrokken bij diverse projecten en activiteiten op het gebied van praktijk, beleid, onderwijs en onderzoek. Verder was zij gedurende haar opleiding geneeskunde en haar werk lid van verscheidene verenigingen, commissies en raden. Ook vervulde zij verschillende nevenfuncties.

Haar echte passie ligt echter nog steeds en vooral op de werkvloer van de dagelijkse JGZ-praktijk. In direct contact met kind, ouders en collega's, met een voorliefde voor de complexe gezinsproblematiek en systemische samenwerking.

Het is deze voorliefde die de drijfveer is geweest voor het vervullen van het PhD traject. Het onderwerp 'JGZ-professionals in dialoog met data' is gedurende dit traject doorontwikkeld naar een pleidooi voor gepersonaliseerde JGZ: 'Personalizing Preschool Preventive Child Health Care, the MOM study'.

Sport, in het bijzonder handbal, is altijd de belangrijkste hobby van Bernice geweest. Bernice heeft een relatie met Andy. Haar grootste rijkdom en trots zijn haar vier kinderen Rob, Hanneke, Koen en Bas, en haar kleinzoon Jack.

List of Publications

Present thesis

Chapter 2:

Doove, B., Feron, J., Feron, F., Van Os, J. & Drukker, M. Validation of short instruments assessing parental and caregivers' perceptions on child health and development for personalized prevention. *Clin Child Psychol Psychiatry, 2019: p. 1359104518822673*.

Chapter 3:

Doove BM, Feron FJM, van Os J and Drukker M (2021) Preschool Communication: Early Identification of Concerns About Preschool Language Development and Social Participation. *Front. Public Health 8:546536. doi: 10.3389/fpubh.2020.546536*

Chapter 4:

B. M. Doove, B. A. A. H. Schiffelers, C. Lukkien, J. van Os, F. J. M. Feron & M. Drukker (2021): Preschool Social Participation, the Impact of Early Life Stress and Parental Health*, Child Care in Practice, DOI: 10.1080/13575279.2021.1901655*

Chapter 5:

B. Doove, B. Cuppen, M. Drukker, J. van Os, F. Feron. Parental perceptions and Personalized Health Care to prevent child maltreatment. (*accepted by Journal of Maternal and Child Health, 24 June 2020)*.

Chapter 6:

Bernice M. Doove, Frans J.M. Feron, Jim van Os, Marjan Drukker. The Developmental Score as a brief tool for Preventive Child Health Care to identify emerging preschool developmental problems impacting school readiness. (*Under revision)*.

Publications outside this thesis

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GGM/PMH, Geestelijk Gezond Maastricht/Public Mental Health, 4e jaarconferentie 'Ruimte maken en kansen pakken', 25-11-2010. Werktafel: 'Aan de keukentafel: je hebt een hele wijk nodig om een kind op te voeden'

Symposium Landelijk AJN, Artsen Jeugdgezondheidszorg Nederland, 26-11-2010. Presentatie: 'Participation' 'Een JGZ 'toolkit' voor ontwikkelingsprofielen'.

Jaarcongres Jeugdgezondheidszorg: 'Een fundament voor vernieuwing', 16-12-2010. Workshop: 'MOM *knows best*. Anders kijken en meer zien in de JGZ'.

PAOG, Post Academisch Onderwijs Geneeskunde, JGZ: 'Waarden en normen in een Civil Society', 29-11-2011. Organisatie en inleiding.

NCVGZ, Nederlands Congres Volksgezondheid 2012, congres: 'Volksgezondheid 2.0', 11-04-2012. Poster presentatie 'The MOM study, Preventive Child Health Care and Developmental Surveillance'.

EPA-EU GEI, European Psychiatric Association (EPA) section Epidemiology together with the European Network of Schizophrenia Networks for the study of Gene-environment Interactions (EU-GEI), Conference 'Closing in on the Envirome in Mental Health', 14-06-2012. Poster presentation 'Early life stress in relation to preschool adaptation and social participation'.

Veiligheidshuis district Maastricht, conferentie: 'Vastpakken en niet meer loslaten', 27-09-2012. Presentatie 'Samenwerken in het Veiligheidshuis'.

Jeugdartsen Eindhoven, bijscholing: 'Verandering en beweging, van idee tot resultaat... en de (lange) weg daar tussenin', 19-04-2013. Presentatie: 'En het begint met een P… Participation'.

Multidisciplinair overleg JGZ Maastricht en Heuvelland, 2013. Presentatie door WESP student Barbara Schiffelers, 'Early life stress and social participation in the preschool period'.

MHeNS, School for Mental Health and Neuroscience, Research Day, 2013. Poster presentation 'Early life stress in relation to preschool adaptation and social participation'.

PAOG, Post Academisch Onderwijs Geneeskunde, JGZ: 'Academische Werkplaats Publieke Gezondheid Limburg', 22-10-2013. Presentatie 'The MOM study'.

Landelijk symposium: 'Signaleren van ontwikkelings- en opvoedproblemen in de wijkgerichte hulpverlening', 12-12-2013. Presentatie 'Komt een kind bij een dokter'.

Werkgroep Risicotaxatie JGZ 0-18, 5-2015. Document 'MOM balansmodel Risico en beschermende factoren Kind-Omgeving (incl. representaties/percepties) voor risicotaxatie en gepersonaliseerde JGZ'.

Academische Werkplaatsen Publieke Gezondheid Brabant &Limburg: 'Onderzoekers in de spotlight', 12-09-2016. Presentatie 'Komt een kind bij de dokter'.

Multidisciplinair overleg JGZ Maastricht en Heuvelland, 3-3-2017. Presentatie door WESP student Britt Cuppen, 'One size does not fit all. Using Personalized Health Care to prevent child maltreatment'.

PACT-project Samenwerken voor het jonge kind, 01-2018. Pitch 'Een pact tussen Ouders, Jeugdgezondheidszorg en Vroeg- en Voorschoolse Educatie 0-6 jaar'.

Multidisciplinair overleg JGZ Maastricht en Heuvelland, 9-11-2018. Presentatie 'Een sprong naar de maan', MOM study & D-score'.

CONTENT, Uit de praktijk, april 2019. Interview 'Kinderen eerst'.

PAOG, Post Academisch Onderwijs Geneeskunde, JGZ: 'Capita Selecta', 23-11-2021. Presentatie 'Parental perceptions and Personalized Health Care to prevent child maltreatment'.

MH&NS

2021

Linda Pagen | 17 December, 2021
Stress and Worry during cognitive aging: behavioral and neural correlates.
Supervisors: Dr. Heidi I.I. Jacobs, Prof. Dr. Benedikt A. Poser;
Co-supervisor: Prof. dr. Frans R.J. Verhey.

Christian Rauschenberg | 17 December, 2021
Transdiagnostic Approaches to Mental Health: Linking adversity, cognition, candidate mechanisms, and novel digital interventions.
Supervisor: Prof. Dr. J. van Os, UM, Utrecht University Medical Centre;
Co-supervisor: Prof. Dr. U. Reininghaus, Heidelberg University.

Christian Nogales Calvo | 16 December, 2021
Network Modules as Novel Molecular Disease Definitions for Precision Theranostics.
Supervisors: Prof. Dr. Harald H.H.W. Schmidt, Dr. Ana I. Casas Guijarro.

Margot Heijmans | 10 December, 2021
Track and treat Parkinson's disease using wearable sensors and MRI.
Supervisor: Prof. Dr. Yasmin Temel;
Co-supervisors: Dr. Pieter Kubben, Dr. Mark Kuijf.

Jessica Bruijel | 1 December, 2021
Tired of being tired: Fatigue and sleep following traumatic brain injury.
Supervisor: Prof. Dr. C.M. van Heugten;
Co-supervisors: Dr. A. Vermeeren, Dr. S.Z. Stapert.

Naomi Daniëls | 1 December, 2021
Bringing experience-sampling technology to family medicine: Feasibility, usability and lessons-learned.
Supervisors: Prof. dr. P.A.E.G. Delespaul, Prof. dr. A.J. Beurskens;
Co-supervisor: Dr. M.A. van Bokhoven.

Soraya Jonker| 19 November, 2021
Safety and Efficacy of Intraocular Lenses in Cataract - and Refractive Surgery.
Supervisor: Prof. Dr. R.M.M. A. Nuijts;
Co-supervisors: Dr. N.J.C. Bauer, Dr. T.T.J.M. Berendschot.

Ana Maria Alzate Sànchez| 9 November, 2021
Microelectrode recordings for deep brain stimulation: Patient specific variables yields fundamental and clinical insights into the human basal ganglia.
Supervisor: Prof. Dr. Y. Temel;
Co-supervisors: Dr. M.L.F. Janssen, Dr. M.J. Roberts.

Paula Bartholomeus| 9 November, 2021
ReAttach - A transdiagnostic intervention for adults and children with mental health problems.
Supervisor: Prof. Dr. T.A.M.J. van Amelsvoort;
Co-supervisors: Prof. Dr. M. Fitzgerald, Trinity College Dublin, Prof. Dr. D. Marazziti, University of Pisa.

Rik Schalbroeck| 5 November, 2021
Orderly chaos: social defeat as a risk factor for psychosis in autism.
Supervisors: Prof. Dr. J.P.Selten, Prof. Dr. L.F. de Geus-Oei, Leids Universitair Medisch Centrum, Prof. Dr. J. Booij, Amsterdam UMC.

Renzo Riemens| 5 November, 2021
Neuroepigenomics in Alzheimer's disease: The single cell Adds.
Neuroepigenomik bei der Alzheimer-Krankheit: Die Einzelzell ADds.
Supervisors: Prof. dr. D. van den Hove; Prof. dr. B. Rutten; Prof. dr. T. Haaf, Julius-Maximilans-Universität Würzburg
Co-Supervisor: Dr. G. Kenis; Prof. dr. C. Förster, Julius-Maximilans- Universität Würzburg; Prof. Dr. K.P. Lesch, Julius-Maximilans- Universität Würzburg

Vera Marsman-Bonekamp| 3 November, 2021
Beyond dis-ease and dis-order - Exploring the long-lasting impact of childhood adversity in relation to mental health.
Supervisor: Prof. Dr. J.J. van Os;
Co-supervisor: Dr. H.B. Lousberg.

Kim van der Linden| 11 October, 2021
Stress, anxiety and psychotic experiences in adults with autism spectrum disorder; and oberservational study in the context of daily life.
Supervisors: Prof. Dr. M.C. Marcelis, Prof. Dr. T.A.M.J. van Amelsvoort;
Co-supervisor: Dr. C.J.P. Simons.

Jeroen Habets| 1 October, 2021
Prediction and real-life monitoring of DBS motor response in Parkinson's disease.
Supervisor: Prof. dr. Y. Temel;
Co-supervisor: Dr. P. Kubben, Dr. M. Kuijf.

Mohammed Alahmari| 15 September, 2021
Radiological and radio-therapeutic nuances in skull base tumours.
Supervisors: Prof. Dr. Y. Temel; Prof. Dr. Ir. F.J.W. Verhaegen;
Co-supervisor: Dr. D. Eekers.

Michaël Veldeman| 15 September, 2021
Diagnosis and treatment of early and delayed cerebral injury after aneurysmal subarachnoid hemorrhage.
Supervisors: Prof. Dr. Y. Temel; Prof. Dr. H. Clusmann, RWTH Aachen;
Co-supervisor: Dr. R. Haeren.

Siyu Wu| 9 September, 2021
Modulation of myelin phagocytosis by means of anti-inflammatory treatment as a therapy of spinal injury.
Supervisors: Prof. Dr. B.W.W. Kramer; Dr. J. Mey, Toledo, Spain.

Wouter Hubens| 2 September, 2021
Glaucoma biomarkers in aqueous humor and blood.
Supervisor: Prof. Dr. C.A.B. Webers;
Co-supervisor: Dr. T.G.M.F. Gorgels.

Sjors van de Weijer| 1 September, 2021
Digital technology-enabled home health care - Gamification in online cognitive therapies for Parkinson's disease.
Supervisor: Prof. Dr. B.R. Bloem, RU Nijmegen;
Co-supervisors: Dr. A.A. Duits; Dr. M.L. Kuijf; Dr. N.M. de Vries, RU Nijmegen.

Lisanne Canjels| 31 August, 2021
Morphological and functional Magnetic Resonance Imaging at ultra-high field.
Supervisors: Dr. J.F.A. Jansen; Prof. Dr. Ir. W.H. Backes; Prof. Dr. A.P. Aldenkamp;
Co-supervisor: Dr. C. Ghossein-Doha.

Yentl van der Zee | 30 August, 2021
Novel Insights into the Neurophysiological and Epigenetic Changes in Major Depressive Disorder.
Supervisor: Prof. Dr. B.P.F. Rutten;
Co-supervisors: Dr. O. Issler; Dr. L. de Nijs; Dr. L.M.T. Eijssen, New York, USA.

Judith Lionarons| 9 July, 2021
Nonmotor comorbidities and somatic manifestations of Duchenne Muscular Dystrophy.
Supervisor: Prof. Dr. C.G. Faber;
Co-supervisors: Dr. G. Hoogland, Dr. J.G.M. Hendriksen, Kempenhaghe, Dr. S. Klinkenberg.

Gusta van Zwieten| 9 July, 2021
Silencing neural symphonies with deep brain stimulation.
Supervisors: Prof. Dr. Y. Temel, Prof. Dr. R.J. Stokroos;
Co-supervisor: Dr. M.L.F. Janssen.

Shuo Zhang| 7 July, 2021
A dark field illumination probe linked to Raman spectroscopy for non-invasivety etermination of ocular biomarkers.
Supervisors: Prof. Dr. C.A.B. Webers, Dr. T.T.J.M. Berendschot;
Co-supervisor: Dr. R.J. Erckens.

Ahmed Hassan| 7 July, 2021
FAIR and bias-free network modules for mechanism-based disease redefinitions.
Supervisors: Prof. Dr. H.H.H.W. Schmidt, Prof. Dr. M.J. Dumontier.

Anouk Geraets| 2 July, 2021
Biological determinants of depression, the role of cerebral damage, microvascular dysfunction, and hyperglycemia: a polulationbased approach.
Supervisors: Dr. M.T. Schram, Prof. Dr. F.R.J. Verhey;
Co-supervisor: Dr. S. Köhler.

Le Guo | 23 June, 2021
No, They Didn't? Oh, They Did!; Advancing Insights on Social Norm Interventions in Consumer Financial Decision-Making.
Supervisor: Prof. Dr. H.J.M. Smeets;
Co-supervisors: Dr. F.H.J. van Tienen; Dr. M. Gerards.

Yvonne van der Zalm | 18 June, 2021
An inquiry into various aspects of clozapine use: prescription, monitoring and mortality.
Supervisor: Prof. Dr. J.P. Selten, Prof. Dr. I.E. Sommer, UMC Groningen;
Co-supervisors: Dr. P.F.J. Schulte, GGZ N.H., Dr. F. Termorshuizen, GGZ Rivierduinen.

Onur Alptekin | 18 June, 2021
Methodological aspects of deep brain stimulation: the untold story behind DBS surgery.
Supervisor: Prof. Dr. Y. Temel;
Co-supervisors: Dr. E. Kocabicak, Samsun, Turkeydr., L. Ackermans.

Elaine Schepers | 17 June, 2021
The role of white noise speech illusions in indicating risk for psychotic disorders.
Supervisor: Prof. Dr. J.J. van Os;
Co-supervisor: Dr. R. Lousberg.

Christian Bertens | 7 June, 2021
Development of a non-invasive ocular drug delivery device.
Supervisor: Prof. Dr. R.M.M.A. Nuijts;
Co-supervisors: Dr. M. Gijs, Dr. F.J.H.M. van den Biggelaar.

Remco Santegoeds | 3 June, 2021
A journey of skull base chordoma: where imaging meets molecular biology.
Supervisor: Prof. Dr. Y. Temel;
Co-supervisors: Dr. L. Jacobi-Postma, Dr. D. Eekers.

Inge Verheggen | 1 June, 2021
Imaging blood-brain barrier function in aging.
Supervisors: Prof. Dr. W.H. Backes, Prof. Dr. F.R.J. Verhey;
Co-supervisor: Dr. A. Jahanshahianvar.

Douwe van der Heide | 27 May, 2021
On the assessment of symptom validity in refugee mental health.
Supervisors: Prof. Dr. H.L.G.J. Merckelbach, Prof. Dr. P.N. van Harten.

Gowoon Son | 26 May, 2021
Olfactory system pathology in Alzheimer's disease: evidences from rodent and human studies.
Supervisors: Prof. dr. H.W.M. Steinbusch, Prof. Dr. C. Moon, DGIST, South Korea;
Co-supervisor: Dr. A. Jahanshahianvar

Markos Xenakis | 26 May, 2021
Molecular complexity of voltage-gated sodium channels; theory and applications in mutation-response prediction.
Supervisor: Prof. Dr. H.J.M. Smeets;
Co-supervisors: Dr. P.J. Lindsey, Dr. R.L. Westra.

Alix Thomson | 21 May, 2021
From Micro to Macro: Unravelling the Underlying Mechanisms of Transcranial Magnetic Stimulation (TMS).
Supervisor: Prof. A.T. Sack;
Co-supervisors: Dr. T.A. de Graaf, Dr. T. Schuhmann, Dr. G.R.L. Kenis.

Ozan Cinar | 19 May, 2021
Combining In formation: Model Selection in Meta-Analysis and Methods for Combining Correlated p-Values.
Supervisor: Dr. W. Viechtbauer;
Co-supervisors: Dr. I.S. Gülöksüz.

Anne Koopmans | 12 May, 2021
CYP2D6 and CYP2C19 genotyping in psychiatry - Bridging the gap between practice and lab.
Supervisors: Prof. Dr. P.N. van Harten, Prof. Dr. H.W.Hoek, RUG;
Co-supervisor: Dr. D.J. Vinkers.

Ashwin Mohan | 29 April, 2021
Retinal oximetry in health and disease.
Supervisor: Prof. C.A.B. Webers;
Co-supervisors: Dr. T.T.J.M. Brendschot, Dr. R. Shetty, Bangalore, India.

Danique Hellebrekers | 23 April, 2021
Neurocognition and behaviour: diagnostic work-up and interventions in Duchenne and Becker muscular dystrophy.
Supervisors: Prof. J.S.H. Vles, Dr. J.G.M. Hendriksen;
Co-supervisor: Dr. S. Klinkenberg.

Milaine Roet | 16 April, 2021
Modulating microcircuits in depression.
Supervisor: Prof. Y. Temel;
Co-supervisor: Dr. A. Jahanshahianvar.

Julia van Tuijl | 16 April, 2021
Post-stroke epilepsy.
Supervisor: Prof. A.P. Aldenkamp;
Co-supervisors: Dr. R.P.W. Rouhl, Dr. E.P.M. van Raak.

Hans de Munter | 9 April, 2021
The patient's own bone marrow-derived stromal cells: disease modifiers in (neuro) degenerative disorders.
Supervisors: Prof. B.W.W. Kramer, Prof. E.CH. Wolters;
Co-supervisors: Dr. T. Strekalowa, Dr. J. Mey.

Sophie Leijdesdorff | 9 April, 2021
Ain't no mountain high enough - How to improve access to youth mental health care.
Supervisors: Prof. T.A.M.J. van Amelsvoort, Prof. A. Popma, AMC;
Co-supervisor: Dr. R.M.C. Klaassen, AMC.

Laura Vergoossen | 1 April, 2021
Brain Network Alterations due to Cardiometabolic Risk Factors; Insights from Population Magnetic Resonance Imaging.
Supervisor: Prof. W.H. Backes;
Co-supervisors: Dr. J.F.A. Jansen, Dr. M.T. Schram.

Ranjana J. Jairam | 24 March, 2021
Sacral nerve stimulation for lower urinary tract dysfunctions: towards better outcome.
Supervisors: Prof. Ph.E.V.A. Van Kerrebroeck, Prof. G.A. van Koeveringe;
Co-supervisor: Dr. D.M.J. Vrijens.

Luiz Kae Sales Kanazawa | 22 March, 2021
The antimanic-like effects of andrographolide and quercetin
Supervisors: Prof. J. Prickaerts;
Co-supervisor: Dr. Roberto AnDr.eatini, Paraná, Brasil.

Maria Ferrarac | 12 March, 2021
Early Intervention in Psychosis A data-driven population health approach to reduce the duration of untreated psychosis.
Supervisors: Dr. S. Gölöksüz, Prof. J.J. van Os;
Co-supervisor: Prof. V.H. Srihari (Yale University, USA).

Talakad Narasappa Sathyaprabha | 1 February, 2021
Cardiovascular autonomic regulation in health and neurological disorders.
Supervisors: Pof. B.W.W. Kramer, Prof. H.W.M. Steinbusch;
Co-supervisor: Dr. T.R. Raju, Bangalore.

Raoul Stevens | 15 January, 2021
Unboxing the Brain; Development of Technologies for Non-Invasive Assessment of Cerebral Pathologies.
Supervisor: Prof. T. Delhaas, Prof. W.H. Mess;
Co-supervisor: Dr. W. Huberts.

Clara Snijders | 8 January, 2021
Post-traumatic stress disorder epigenetic signatures of differential susceptibility to combat trauma.
Supervisor: Prof. B.P.F. Rutten;
Co-supervisors: Dr. L. de Nijs, Dr. G. Kenis.