A taxonomy of care for children and adolescents with behavioural and emotional problems
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The aim of this study is to partly open the black box of care and treatment that is provided to children and adolescents with behavioural and emotional problems by developing, testing and applying a taxonomy to classify the most salient aspects of the care and treatment provided. Finding a way to systematically assess information on the characteristics of care and treatment is of interest to practice, policy, research and education. This introduction will first examine the main types of psychosocial problems. Second, attention will be drawn to the different fields of care and the settings in which care and treatment are provided. In addition, we will discuss the interventions available for children with psychosocial problems and the diversity of the labels describing these interventions. Subsequently, we will explore the need to elaborate a care taxonomy and introduce the Collaborative Centre on Care for Children and Youth (C4Youth), which coordinated this study and is specifically concerned with the behavioural and emotional problems of children and adolescents. Finally, the research questions will be introduced and an outline of the remainder of the thesis will be presented.

Around 10-25% of children and adolescents suffer from behavioural and emotional problems to some degree (Maschi, Schwalbe, Morgen, Gibson, & Violette, 2009; Spijkers, Jansen, & Reijneveld, 2013). These problems can be roughly divided into two groups: internalizing and externalizing problem behaviour. While externalizing problem behaviour (e.g. aggressiveness, delinquent behaviour and hyperactivity) is visible from the outside in terms of the child's or adolescent's behaviour, internalizing problem behaviour (e.g. anxiety, depressive feelings, reservedness and psychosomatic complaints) is not always visible but affects the emotional state of a child or adolescent (Jansen et al., 2012).

The use of services by children and adolescents with these psychosocial problems depends, among other things, on individual, family and school factors (Cabiya et al., 2006; Maschi, Schwalbe, Morgen, Gibson, & Violette, 2009; Reijneveld et al., 2014). Girls are more often overly represented in the primary health care and mental health care sectors, while boys are more often referred to the special education, substance abuse and juvenile justice sectors (Maschi et al., 2009). A study by Reijneveld and colleagues (2014) showed that at the age of 10-11 the use of services was higher among boys, while at the age of 19 it was higher among girls. The use of specialized services increased among girls and decreased among boys during adolescence, while the use of general services increased for boys as well as girls. In addition, research has shown that parental psychopathology lowers the parents' thresholds for evaluating their child's behaviour as problematic, which in turn influences the use of service by these families (Cabiya et al., 2006; Maschi et al., 2009). Learning disabilities, special education and being expelled or suspended from school were also risk factors for higher use of services (Cabiya et al., 2006). Since psychosocial problems at a younger age are predictors of adolescent psychopathology, it is of major importance to provide adequate assistance that addresses a child's problems at an
Introduction

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BEHAVIOURAL AND EMOTIONAL PROBLEMS

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Since psychosocial problems at a younger age are predictors of adolescent psychopathology, it is of major importance to provide adequate assistance that addresses a child’s problems at an
early stage of development (McDougall, 2011). To date, overviews of the care and treatment offered to children and adolescents with behavioural and emotional problems have only been provided at a general macro level (Bot et al., 2012; Cabiya et al., 2006; Garland et al., 2010; Maschi et al., 2009; Van Eijk, Verhage, Noordik, Reijneveld, & Knorth, 2013). Therefore, there is still a large gap in empirical knowledge, and a more detailed level of description that takes into account the relevant child and care characteristics is required. Creating an overview of the most salient aspects of child and family services will be very valuable in practice, allowing us to gain greater insight into care and treatment processes and assisting to optimize the care trajectories of the children, adolescents and families concerned.

FIELDS OF CARE FOR BEHAVIOURAL AND EMOTIONAL PROBLEMS
The care and treatment of children with behavioural and emotional problems and their families is offered within different fields of care. The labels used to describe these fields vary between countries. Therefore, below we will explain the labels used in this study to describe these various fields of care in the Netherlands.

PRIMARY HEALTH CARE (PHC)
Primary health care (PHC) aims to promote, protect and secure child and adolescent well-being and focuses on short-term and fairly mild problems (Faber, Burgers, & Westert, 2012). In this study, PHC is equivalent to preventive health care for children, for which municipalities take responsibility. Although care offered by general practitioners (GPs) is formally part of PHC, this care was not taken into account in this study. The advantages of PHC in the Netherlands include the fact that access is independent of insurance status, highly educated practice nurses are involved, an electronic exchange of client information is available, the quality of the care offered is monitored, and professionals are well paid and motivated (Faber et al., 2012). In this study, ‘preventive health care offered to children, adolescents and their families’ and PHC are synonymous.

CHILD AND YOUTH CARE (CYC)
In addition to paying attention to the personal well-being of young clients, child and youth care (CYC) focuses mainly on the social and economic backgrounds of children and adolescents suffering from behavioural or emotional problems (Hill & Aldegate, 1996; Reijneveld et al., 2014). CYC offers outpatient and home-based care and treatment programmes, with out-of-home care trajectories for youngsters in family foster care and residential care if needed. Child and youth care is also referred to as ‘children's social care’, ‘social care’, ‘child welfare services’, ‘child and adolescent social care’, or ‘child, youth and family care’. In this study, care offered in this field will be referred to as ‘child and youth care’ (CYC).

MENTAL HEALTH CARE (MHC)
The care offered by mental health care organizations is mainly aimed at the behaviour and/or the
emotions of the child or adolescent and is less focused on environmental factors (Reijneveld et al., 2014). Mental health care includes outpatient care and inpatient care and treatment. It is also referred to as ‘child and adolescent mental health care’, ‘youth mental health care’ or ‘mental health care institutions’. In this study, ‘mental health care’ (MHC) will be used to indicate care offered to children and adolescents with mental disorders.

**SETTINGS FOR PROVISION OF CARE**

While the Ministry of Health, Welfare and Sport is responsible for overall youth policy and most specialized services, the Ministry of Security and Justice is responsible for juvenile justice policy and related institutions in the Netherlands (Bosscher, 2012). The provincial authorities and the local authorities also have responsibilities concerning youth policy and related health care services. The decentralization of the administrative and financial responsibilities concerning these health care services is planned for 2015, moving them from the national and provincial governments to local governments. Thus, local governments will soon be responsible for the universal (youth work, child care, regular schools), preventive (child health care, general social work, parenting support, youth and family centres) and specialized services (provincial youth care services, youth mental health care services, child protection services) offered within their specific region (Bosscher, 2012).

Within the fields of PHC, CYC and MHC, treatment can be offered as ambulatory/outpatient care, home-based care, day treatment, residential care or family foster care. Ambulatory/outpatient care is provided to the client at the location of the care provider. A part of this type of care may also be home-based, meaning that the professional offers care and treatment within the child’s home (Harder et al., 2013; Van Eijk et al., 2013).

Day care and treatment for children with behavioural and emotional problems consists of an intense form of support. The treatment is provided as an inpatient service during the day, without removing the child entirely from home, to which they return in the evening (Van der Ploeg, 2011).

Residential care is provided to children and youth when other types of care and treatment do not seem to be sufficient (Harder et al., 2013). Children and adolescents up to the age of 18 may, voluntarily or involuntarily, be removed from their own home environment for a certain period of time. In a small number of cases care and treatment is offered in the context of the juvenile justice system. In the Netherlands, there are four types of residential care: 1) residential child and youth care, 2) inpatient mental health care, 3) residential care for youth with mild mental disabilities, and 4) institution-based correctional services (Harder et al., 2013).

Family foster care is offered to children and adolescents up to the age of 18 who cannot live with their biological parents. The foster carers generally take care of the child until the biological parents are again able to look after their child. However, in a number of cases reunification is impossible (Strijker, 2010). There are two main types of family foster care: formal foster care and kinship care (Strijker & Knorth, 2007).
INTERVENTIONS FOR CHILDREN AND ADOLESCENTS WITH BEHAVIOURAL AND EMOTIONAL PROBLEMS

The number of interventions available for children and adolescents with psychosocial problems has increased tremendously during recent decades (Kazdin, 2000; Loeffen, Ooms, & Wijgergangs, 2004; Veerman, Janssens, & Delicat, 2005). Because care organizations use various names to label these interventions, the field of psychosocial care and treatment for children and youth is rather non-transparent. Differently labelled interventions can contain similar content and similarly labelled interventions can in fact contain different content (Lloyd-Evans et al., 2007). While evidence on the effectiveness of interventions has become increasingly important, statements concerning the effectiveness of the care and treatment offered are difficult to make due to a lack of detailed information on these interventions (DeJong, Horn, Gassaway, Slavin, & Dijkers, 2004; Fein, 2002; Maschi, Hatcher, Schwalbe, & Rosato, 2009; Messer & Wampold, 2002; Van Yperen, 2010). The fact that most of these interventions have not been ‘proven’ to be effective does not automatically mean that they do not work in daily practice. However, it does imply that more research on the characteristics of care and treatment is needed to establish the efficacy of each intervention.

Research on the characteristics of care and treatment starts with clearer descriptions and structuring of interventions (Hoffman et al., 2014). Assessing the manuals used in an intervention provides an opportunity to determine whether it is ‘well defined’ or not. An evaluation such as this can be done by applying four criteria: (1) whether a protocol description is available, (2) whether the intervention is theoretically well founded, (3) whether empirical research has been done on the intervention, and (4) whether scientific literature has been published on the intervention (cf. Veerman & Van Yperen, 2008). If all four criteria are met, an intervention can be regarded as ‘well defined’; if not, the intervention may be considered ‘poorly defined’.

In addition, a method is required that enables the characterization of the content of ‘well-defined’ and ‘poorly defined’ interventions at a more detailed level. This not only allows us to distinguish similarities and differences in the content of these interventions, but also to find ways to reduce the apparently large number of interventions to a smaller number of distinct interventions. Based on earlier studies, a decrease in the number of interventions is expected to be greater within the ‘poorly defined’ group (Loeffen et al., 2004; Veerman et al., 2005) than within the group of ‘well-defined’ interventions (Hibbs, 2001; Van der Linden & De Graaf, 2010).

Moreover, the degree to which well and poorly defined interventions are used in daily practice is expected to differ across various types of care organizations. MHCs have a relatively long tradition concerning the use of evidence-based care and treatment (Hibbs, 2001; Van der Linden & De Graaf, 2010). Therefore, the number of ‘well-defined’ interventions used within MHCs is expected to be relatively high in comparison to the use of ‘poorly defined’ interventions. This is also expected to be the case for the PHC field, but to a somewhat lesser extent than within MHCs. Furthermore, this ‘evidence-based practice revolution’ has only recently started within CYC (Corcoran, 2007), resulting in the expectation that the larger part of interventions offered will still be ‘poorly defined’.

Describing interventions more clearly is a first step in obtaining evidence on their potential
effectiveness. Information should be gathered in a valid and reliable way. To achieve this, a care taxonomy that enables the classification of care and treatment modalities in a structured and standardized way would be very helpful. Such a taxonomy could provide us with the opportunity to answer the key question in intervention evaluation research: whether there is an association between the problem behaviour presented, the care/treatment provided and the outcomes after completion of the intervention (Abraham & Michie, 2008; Michie, Hyder, Walia, & West, 2011; Miller & Row, 2009; Ten Brink, Veerman, De Kemp, & Berger, 2004).

TAXONOMIES

A care taxonomy is needed to structurally record information concerning the care and treatment provided to children and adolescents with behavioural and emotional problems. Such a taxonomy will offer a classification system which enables us to categorize the most salient aspects of the care offered in a valid and reliable way (De Jong, 1995). There are currently several taxonomic instruments available which enable the classification of the behavioural and emotional problems of children; for example, the Diagnostic and Statistical Manual of Mental Disorders (DSM, American Psychiatric Association, 1994), the International Classification of Diseases (ICD, World Health Organization, 1993) and the International Classification of Functioning (ICF, World Health Organization, 2002). While these taxonomies classify health problems and diseases to a great extent, they do not classify information on aspects of the care provided to children, adolescents and their families. In fact, to our knowledge, an overview of care taxonomies has not been done.

Such an overview of the taxonomic instruments available in the field of child, youth and family care to classify the most important aspects of the care and treatment process would thus be very much welcomed, providing us with information on potentially relevant domains, the various terminology used and the level of classification within these domains (De Jong, 1995). The level of classification within a care taxonomy may vary depending on the potential users of the instrument. Micro-level classifications refer to the techniques and activities that are used during the treatment, while meso-level classifications refer to treatment programmes on a more aggregated level. Also, depending on the potential ‘users’ of the taxonomy, the instrument might be further elaborated for conceptual or clinical use. Conceptual use would mean the application of a taxonomy to intervention manuals (Abraham & Michie, 2008; Michie et al., 2011), while clinical use would mean application in daily practice (Van Yperen, Konijn, & Ten Berge, 1999).

After a literature review revealed the small number of care taxonomies available and the paucity of relevant scientific research (see Chapter 2), we concluded that there was a strong need to develop a taxonomic instrument, and we decided to take up this challenge. In so doing, we also decided that well-documented information on the steps undertaken during the development of a taxonomy of care would be very useful. Indeed, describing these various steps would enhance reproducibility and be important for assessing the psychometric qualities of the instrument. These
psychometric qualities are important to guarantee the reliable and valid collection of knowledge on the most salient aspects of the care offered. However, as will be shown in Chapter 2, this type of information is nearly always lacking when it comes to care taxonomy instruments.

Furthermore, the taxonomic instrument should be manageable by and feasible for professionals to use. This means that developing a taxonomic tool demands intense cooperation between the realms of practice and research. For this and other reasons, a collaborative centre (C4Youth) was set up in the northern Netherlands in 2009. We will expand on this in the next section.

**ACADEMIC COLLABORATIVE CENTRES: COLLABORATIVE CENTRE ON CARE FOR CHILDREN AND YOUTH WITH BEHAVIOURAL AND EMOTIONAL PROBLEMS (C4YOUTH) AS AN EXAMPLE**

The intertwining of research, education and clinical care has become indispensable within the field of academic medicine (Health Council, 2000). In the Netherlands, this started with the financing of collaborations between university hospitals and general practitioners (Schadé, 1996). These university hospitals were considered academic knowledge centres, undertaking research and education, and introducing innovations in the care offered to patients (Reijneveld, Gunning-Schepers, & Schadé, 1997). The new role for academic knowledge centres is twofold. First, these academic collaboration centres should reduce the gap between research and practice. Second, professionals could improve their functioning in daily practice by using the outcomes of research to optimize diagnosis and treatment of medical and psychosocial problems (Health Council, 2000).

The creation of academic knowledge centres was also required within the field of care for youth. Given the relatively large number of children and adolescents suffering from behavioural and emotional problems, there was a need for greater knowledge about pivotal aspects of the chain of care, as well as the long-term outcomes concerning the care provided within primary health care, child and youth care, and mental health care (Courtney & Thoburn, 2009; Stein 2008). As indicated above, there is little evidence on the effectiveness of the care offered in both the short and longer terms (Libby, Saranga Coen, Price, Silverman, & Orton, 2005). More knowledge about outcomes could be gathered by combining knowledge from research and practice (including clinical practice, education and policy).

The Netherlands Organization for Health Research and Development (ZonMw) has been financing academic collaboration centres within the field of care for youth since 2009. The Collaborative Centre on Care for Children and Youth (C4Youth) is one of the academic collaboration centres established in the northern Netherlands. Its first goal is the exchange of knowledge between the realms of research, practice, education and policy (Knorth, Reijneveld, Van Eijk, Noordik, & Tuinstra, 2012). Its second goal is to gather evidence on both the functioning of the entire chain of care for children and adolescents and on long-term outcomes, which is the task of a longitudinal prospective cohort study called TAKECARE (Tracing Achievements, Key processes and Efforts in professional care for Children and Adolescents REsearch – see Verhage, Noordik, Knorth, & Reijneveld, 2014). The cohort study covers the field of primary health care (PHC), child and youth care (CYC) and mental health care (MHC). The aim of this major study is to gather knowledge about the care offered to children...
and adolescents within various fields of care.

The TAKECARE study covers three different research themes, each focusing on different aspects of the care process (Figure 1.1). Regarding the first theme, the aim is to increase our understanding of the process that leads children and adolescents with emotional and behavioural problems, and their families, to enter into care, and the association of this entry into care with subsequent care, including mid-term and long-term care outcomes. The second theme is the main subject of this study: it focuses on gathering information about the content of the care that is actually provided to children and adolescents with behavioural or emotional problems and their families. The third theme aims to unravel the role of client-professional communication by focusing on client’s priorities and experiences in relation to outcomes, such as participation, learning processes and improved psychosocial health.

![Figure 1.1: Research themes of TAKECARE](image)

**RESEARCH QUESTIONS**

The study that we report on in this thesis aims to unravel the issues discussed above. To do so, the following research questions will be addressed:

1. Are there taxonomic instruments in the field of child, youth and family care which are capable of classifying the most important aspects of the care process? What kinds of domains do these taxonomic instruments contain?

Considering the results obtained by addressing this first question, we decided to develop a new care taxonomy on the basis of the following four questions:

2. Which steps are required in the development of a taxonomy of care? What are the results concerning the conceptually relevant domains, the standardization of levels of classification and terminology used, and a final classification system at the meso-level?

3. What are the psychometric qualities of the taxonomy of care? Is the taxonomy a reliable and feasible instrument?

4. To what degree can similarities and differences in the content of ‘poorly defined’ interventions within and across care organizations in a catchment area be determined?
5. To what extent can the number of ‘well-defined’ interventions in a catchment area be reduced based on their content? Is there a difference between ‘well-defined’ and ‘poorly defined’ interventions in terms of the level of reduction?

Finally, the application of the taxonomic instrument in the northern Netherlands addressed the question:

6. Which types of care are provided to children and adolescents with behavioural and emotional problems within and across care organizations in the catchment area? Does this differ depending on the age and gender of the target group?

OUTLINE OF THE STUDY

Chapter 2 begins with a description of a literature review of the taxonomic instruments available in the field of child, youth and family care. The review focused on the field in which the taxonomy was developed, whether it was conceptually or clinically applied, the unit of analysis, the domains and sub-axes and the level of classification. The limitations of the few taxonomic instruments found and the domains which should be included in any care taxonomy will also be discussed. In Chapter 3, the stages of the empirical development of a taxonomy of care will be elucidated. Subsequently, the final version of our classification system, called TOCFY, will be presented, along with the relevant domains of the taxonomy of care, and the levels of classification and terminology used. In Chapter 4, we report on a study of the inter-rater reliability and feasibility of the care taxonomy. Percentages of agreement were used to analyse the extent of agreement between the two raters. Feasibility was measured by assessing the degree to which the professionals could apply the domains, categories and sub-categories of our care taxonomy. In Chapter 5, the aim was to classify the content of ‘poorly defined’ care provided to children with behavioural or emotional problems and their families within and across care organizations in our catchment area, the province of Groningen. Four criteria were used to differentiate between ‘poorly defined’ and ‘well-defined’ interventions. We used a topical expert’s assessment methodology to present an overview of distinct types of ‘poorly defined’ interventions. In Chapter 6, we report on the results of a study on ‘well-defined’ interventions in the northern region using the same methodology as that described in Chapter 5. An overview of distinct types of interventions will also be provided and the results regarding well-defined and poorly defined interventions compared. In Chapter 7, the focus is on the type of care provided to children and adolescents with behavioural and emotional problems in our catchment area. A comprehensive overview of the types of care offered will be presented, taking into account several child characteristics, care characteristics, the evidence base of the interventions, and the settings in which care and treatment are provided. Finally, in Chapter 8 we will draw some conclusions concerning the main findings and discuss these findings in a broader context. In addition, the strengths and limitations of the study will be addressed and, at last, the implications for research, practice, policy and education will be discussed.
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