UNDERSTANDING CARE USE OF CHILDREN WITH COMPLEX PROBLEMS

A family and care perspective

Noortje M. Pannebakker

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Colophon
The research presented in this thesis was performed at TNO, Child Health Department, Leiden, and Leiden University Medical Center, Department of Public Health and Primary Care, in collaboration with partners of the youth Academic Collaborative Centre SAMEN. The research was funded by the Dutch organization for Health Research and Development (ZonMw, the Netherlands).

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CHAPTER 1

INTRODUCTION AND AIMS OF THIS THESIS

Introduction and aim of the thesis

The general aim of this PhD thesis is to enhance understanding of care use by children with complex problems, and of the challenges to organizing care for these children. In this introduction we first discuss the characteristics of children with complex problems, their care use, and the intensity with which they use care. We subsequently discuss possible barriers expected by parents when accessing treatment for their child. We then focus on the organization of care services for these children and discuss the care coordination method Wraparound care. We conclude with the study context, research questions, and outline of the dissertation.

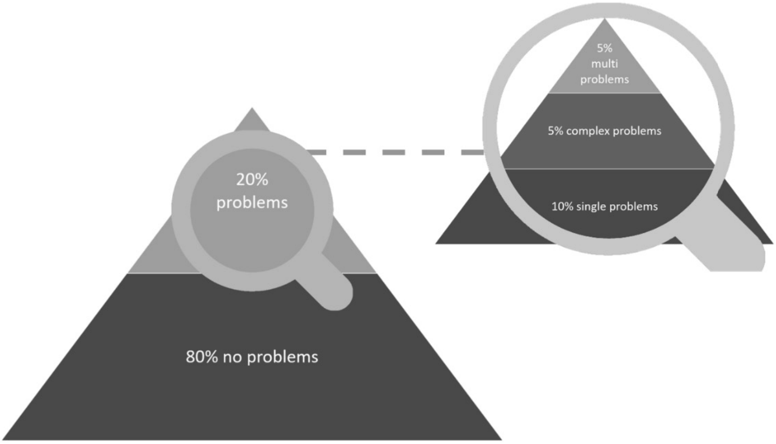
Children with complex problems

Children known to have or be at risk of complex problems (CP) have a greater need for health services than children in general because of their chronic physical, developmental, behavioral or emotional condition(s); this is because their problems interact and enhance vulnerabilities [1-4]. To meet demands in various areas of their lives, children with CP need the support of different professionals. Parents or other siblings may also have health or psychosocial problems, and socio-economic problems can add an additional burden. This leads to a busy treatment schedule for families of children with CP; Dutch studies have shown that it is not uncommon for 16 social workers to be active in a family [5]. This also raises the question about efficient care: different treatments must enhance each other, and family goals should be adapted to all family members and professionals involved [6]. In the Netherlands, a specialized social worker offers care coordination to ensure integration of treatment by professionals active in the family.

Children with CP run a high risk of poor mother-child attachment and of developing behavioural and emotional problems [1-3]. As these families have a high level of care consumption, especially psychosocial care services, such care utilizes a major part of the budgets of these services [7-8].

The subgroup with the highest levels of CP, the so-called multiproblem families, are of particular interest to researchers and policymakers. Their complex problems often develop into chronic conditions, leaving them dependent on care services for almost their whole lives [9]. These families are an example of hotspotters, a group of frequent care users whose needs lay a heavy burden on Western health care personnel attempting to offer adequate help [10]. Some Western countries have developed policies and programmes targeting multiproblem families, e.g. the ‘Troubled families’ programme in the United Kingdom [11-12] and the ‘One family, one plan, one care coordinator’ programme in the Netherlands [13].

Figure 1 Study group and prevalence in the general population



In Western countries the group at risk for CP is estimated to involve approximately 10% of the families in the general population; 5% of the families have a child with CP, and roughly 1-5% are multiproblem families (see Figure 1) [14]. Based on Dutch data, 30 patients (1.5%) in the practice of an average general practitioner are part of a multiproblem family [15-16]. The same prevalence is found in other groups of frequent care users, or hotspotters [17].

Care use by children with CP

Care use by children with CP is a typical subject of research in the field of psychosocial care, including child mental healthcare, and child and family services. It is, however, likely that these children also use health services, i.e. the general practitioner and medical specialists, for their chronic conditions. Little research has yet been done on the general care use of children with CP. More insight into the determinants impacting general care use will help to clarify these high levels of care consumption.

In this dissertation we focus on three aspects of care use: 1. care use itself, 2. intensity of care use, and 3. barriers to accessing care services. Research into determinants of care use is often based on Andersen and Newman's behavioral-health model of access to care [18]. This comprehensive framework seems to fit well with the wide range of problems experienced by children with CP. The model describes care use on the basis of three factors: 1. predisposing factors, i.e., a child's characteristics or abilities to use a specific service; 2. enabling factors, i.e., means whereby a family accesses care; and 3. health care needs. Studies show that use of psychosocial care by children with CP and their parents is impacted by various predisposing factors (such as gender and cultural identity); enabling factors (such as social support or barriers to care) and need factors (such as a child's emotional or behavioral problems or parenting concerns) [19-23]. However, studies on care use specifically targeting multiproblem families is scarce.

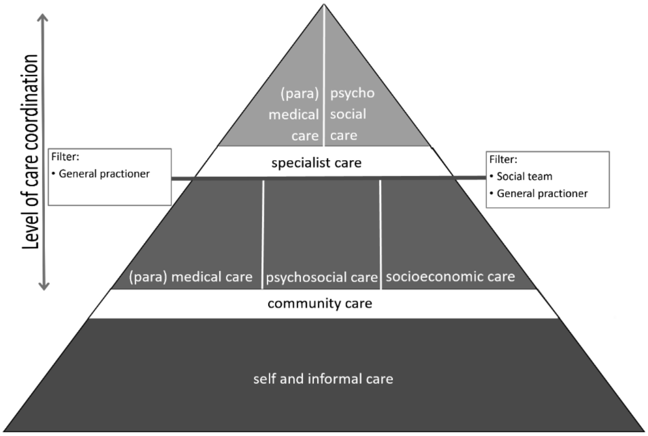
Little is known about the intensity with which children with CP use psychosocial and health care, i.e. the number of contacts with care providers. The few studies on this topic show that factors predicting the intensity of use differ from those predicting whether care is used at all, indicating a need to further explore intensity of use [24-27]. The scarce literature shows that intensity of care use is impacted by predisposing factors: child's age, parental educational level and psychosocial problems; enabling factors: social support and parental health care use; and need factors: psychosocial problems [24-27]. To understand the high care consumption of children with CP, we need a better understanding of these factors.

Although children with CP are typically frequent users of psychosocial care services, only around one third of children with CP successfully enroll in psychosocial care [28-29]. One explanation for this low rate is found in barriers to care, like logistical barriers or barriers related to perceptions about psychosocial care in general or about the effect of treatment. The scarce research on barriers to psychosocial care of children with CP focuses on barriers actually experienced, but overlooks families not accessing care because they envisage unsurmountable barriers [30]. Research on anticipated barriers will help to improve accessibility to psychosocial care by children with CP[31].

The Dutch care system and its fit with children with CP

In the Netherlands, children and their families have three gatekeepers to care, together equipped to provide a broad triage covering medical and psychosocial problems: 1. preventive child health care or well child clinics, 2. local social teams, and 3. family practitioners. These gatekeepers also provide community care to children with mild problems. In case of more severe problems, they refer children to specialist care. Children with health problems are referred to a medical specialist; children with psychosocial problems are referred to a psychologist, psychiatrist or specialist social worker. Socio-economic problems like poverty or housing problems are dealt with by municipality services like depth counselling at the level of community care. The general practitioner and medical specialist are financed by health care insurance companies, and the other services by the local government. A care coordination method like Wraparound Care is typically part of the treatment of children with CP (see Figure 2). Based on the input of the other professionals, the family, and their social network, the care coordinator develops a chronic-condition management plan to prevent these children and their parents from becoming multiproblem families.

Figure 2 Pathway to care for children with CP (adapted from Goldberg and Huxley [32])



Care coordination to integrate care for children with CP

To deal with children with CP, several Western countries have developed programmes which often require care coordination as a method to integrate care. Integrated care focuses on seamless organization of care to fit the needs of the child whose demands require the help of more than one care professional [33]. This client-centred ideology also promises financial benefits because care is efficiently organized rather than supply-driven [34].

An internationally well-used care coordination method is Wraparound Care [35]. Wraparound Care (WAC) was the base for the ‘One family, one plan, one care coordinator’ programme in the Netherlands (NJI, 2011), and forms the backbone of the pathway to care for children with WP. WAC is based on three core components: 1. activating family members and the social network; 2. integrating the care provider network, and 3. assessing, planning and evaluating the care process. The first studies into the effectiveness of WAC are promising [36].

The impact of this client-centred care coordination method depends greatly on the extent to which it is used as intended by all care providers. This is a comprehensive implementation challenge. Unfortunately, in the field of psychosocial care, systematic implementation of innovations like WAC is scarce [37-38].

Study context

This study took place within the Academic collaborative centre-youth SAMEN. Such centres are ideally suited to unravel troublesome problems like the high care-consumption of children with CP. Academic collaborative centres-youth are long-term partnerships between one or more (local) youth psychosocial services, the education sector, universities, (local) governments, and clients. The centres aim to bridge the worlds of academia and psychosocial care practice by improving generation and transfer of both knowledge and skills between participants, thereby improving youth services.

The Netherlands Organization for Health Research and Development (ZonMw) granted funding for the cohort and implementation study conducted for this dissertation. The study was carried out by the Netherlands Organisation for Applied Scientific Research (TNO), Department of Child Health. The studies were done in cooperation with three specialist psychosocial care services (BKK, MEE and Bureau Jeugdzorg Haaglanden) and the preventive Child Health Care services in urban areas of The Hague and Leiden. For the cohort study we also collaborated with Leiden University Medical Center (LUMC), Department of Public Health and Primary Care. This department also facilitated the PhD trajectory. The Medical Ethics Committee of LUMC reviewed the study protocol and declared approval for this study unnecessary under Dutch Law (reference number C12.041).

Outline of the dissertation

The aim of this thesis is to better understand care use, its intensity, and its barriers among children with CP, and the challenges faced by professionals using the care coordination method Wraparound Care to integrate the professional network supporting these children. The findings will result in recommendations for practice, policy makers, and future research. We have formulated the following research questions:

1. Which predisposing, enabling, and need factors impact the use and intensity (number of contacts with care providers) of overall and psychosocial care use by children with CP?
2. A. What do parents expect concerning practical barriers to psychosocial care use by their children with CP?
   B. Which predisposing, enabling, and need factors are associated with expected practical barriers for children with CP using psychosocial care or no care at all?
3. Which predisposing, enabling, and need factors are associated with overall and psychosocial care use by both children of multiproblem families and their parents?
4. Which background characteristics and determinants of implementation hinder or facilitate adherence to the care coordination method Wraparound Care by professionals working in child and family services?

Chapter outline

In the first three chapters we focus on the experiences of parents of children with CP. In *chapter 2* we present the longitudinal results of our study of care use by children with CP. We study which child's needs and family characteristics impact the use of care services and its intensity. *Chapter 3* describes the practical barriers to care expected by parents of children with CP when enrolling for psychosocial care. In *chapter 4* we explore the factors associated with care use by multiproblem families, using cross-sectional data. In *chapter 5* we turn to the professional. We describe the use and determinants that hinder or facilitate the use of Wraparound Care by professionals in psychosocial care. Finally, *chapter 6* presents the main findings emerging from this research, discusses our findings in comparison to other studies, presents the implications for professionals and policy makers concerning children with CP, and gives recommendations for further research.

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2

CHAPTER 2

CARE USE AND ITS INTENSITY IN CHILDREN WITH COMPLEX PROBLEMS ARE RELATED TO VARYING CHILD AND FAMILY FACTORS: A FOLLOW-UP STUDY

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Abstract

Background: There is little evidence on the child and family factors that affect the intensity of care use by children with complex problems. We therefore wished to identify changes in these factors associated with changes in care service use and its intensity, for care use in general and psychosocial care in particular.

Methods: Parents of 272 children with problems in several life domains completed questionnaires at baseline (response 69.1%) and after 12 months. Negative binominal Hurdle analyses enabled us to distinguish between using care services (yes/ no) and its intensity, i.e. number of contacts when using care.

Results: Change in care use was more likely if the burden of adverse life events (ALE) decreased (odds ratio, OR=0.94, 95% confidence interval, CI=0.90-0.99) and if parenting concerns increased (OR=1.29, CI=1.11-1.51). Psychosocial care use became more likely for school-age children (vs. pre-school) (OR=1.99, CI=1.09-3.63) if ALE decreased (OR=0.93, CI=0.89-0.97) and if parenting concerns increased (OR=1.26, CI=1.10-1.45). Intensity of use (>0 contacts) of any care decreased when ALE decreased (relative risk, RR=0.95, CI=0.92-0.98) and when psychosocial problems became less severe (RR=0.38, CI=0.20-0.73). Intensity of psychosocial care also decreased when severe psychosocial problems became less severe (RR=0.39, CI=0.18-0.84).

Conclusions: Changes in care-service use (vs. no use) and its intensity (>0 contacts) are explained by background characteristics and changes in a child’s problems. Care use is related to factors other than changes in its intensity, indicating that care use and its intensity have different drivers. ALE in particular contribute to intensity of any care use.

Introduction

Little research has been conducted on factors affecting the intensity of care use by children with complex problems (CP). The need of these children for health and social services, especially psychosocial care, is typically greater than would be expected based on their chronic physical, developmental, behavioral or emotional conditions; this is the case because their problems interact and enhance vulnerabilities [1-4]. These children are also referred to as members of troubled families or hotspotters [5-7]. Children with complex problems form the top 5% of children with the most challenging problems, amounting in the Netherlands to 170,000 children. Western countries struggle to organize effective and efficient care pathways for these children [8]. As a result, a major part of the budgets of psychosocial services is spent on children with CP [9,10].

The determinants of care use as such have been studied in depth, revealing several factors that impact access [11-16]. Less attention was paid to understanding the intensity of care use, i.e. the number of contacts with care providers. The scarce literature shows that higher intensity of care-service use by children with CP is related to two main groups of factors: child factors (age and impact of psychosocial problems); and parental factors (educational level, healthcare use, social support, and parental psychosocial problems) [17-20]. Research shows that the determinants affecting care use (yes/no) and the intensity with which it is used differ when studied simultaneously [17-19]. This suggests that intensity of care use may be a unique component of the help-seeking behavior of families with a child with complex problems. A better understanding of the intensity of care use will help us to organize more efficient care paths for these children.

Research on determinants of care use is often guided by Andersen and Newman's behavioral-health model [21]. This model was developed to explain the use of care by an individual or population and has shown its value as comprehensive model for this purpose in health care research during the past decades [22,23]. The model describes care use on the basis of three factors: 1. predisposing factors, i.e., a child's characteristics or abilities to use a specific service (such as age); 2. enabling factors, i.e., means whereby a family accesses care (such as social support); and 3. healthcare needs (such as a child's psychosocial problems). This broad framework is a good fit with the wide-ranging problems experienced by children with CP. Our study is the first to apply this framework to the intensity of care use by these children.

We previously reported that overall care use was associated with social support and psychosocial problems and that the use of psychosocial care was associated with a child's age and parenting concerns, based on a cross-sectional study in families with severe complex problems [16]. In the current study with a follow-up design, we additionally examined changes in intensity of care use in children with and at risk on developing CP, ensuring a wide range of intensity of care use. Accordingly, the aim of this study is to identify the changes in the predisposing, enabling and need factors that are associated 1. with a higher likelihood of changes in use of care services and 2. with changes in the intensity of use. The care services use studied comprised a broad spectrum of general care services including health and psychosocial care, and also the subset psychosocial care, including child mental healthcare and child and family services. We selected several predisposing characteristics of the child (such as age and gender, and also including predetermined factors such as parental education level and adverse life events), as well as enabling (social support and parental care use) and need factors (chronical condition, psychosocial problems, satisfaction with the parent-child relationship, and parenting concerns). This selection was based on the literature regarding determinants impacting the intensity of use of psychosocial care by children, as well as on our former study [4-6; 11-16].

Method

Sample and procedure

For this longitudinal study, we followed a cohort of children with CP and their parents, living in an urban setting in the Netherlands. The study was conducted according to the Helsinki regulation. The Medical Ethics Committee at Leiden University decided that approval was not required under Dutch Law (C12.041).

We aimed to include parents of children with CP or at risk of developing them with a wide range in intensity of care use living in the community. We recruited these parents in the general population, using inclusion criteria that concurred with the framework for identifying families with CP [24,25]. We included parents when they met the following inclusion criteria: 1. they had a child between 18 months and 12 years and 2. they experienced at least one of the following conditions: A. the child's elevated total score on the parent-reported Strengths and Difficulties Questionnaire (SDQ) [26] or Brief Infant Toddler Social Emotional Assessment (BITSEA) [27]; B. persistent parenting concerns as judged by the preventive health care worker and/or parents; C. one or more major life event(s) during the past year as assessed using the standard screening questionnaire of the well child clinic [28] and D. care utilization of the child or parent in the past six months. Almost all respondents had three or more of these conditions (97%).

We identified the respondents during well-child visits, which are provided in the Netherlands by the preventive youth healthcare services. Attendance rates at these visits are high: 95% of all children [29]. To ensure the inclusion of children who used care with a high intensity, we additionally included children enrolled in specialist child and family services i.e. services that are only accessible after referral from primary care. Together this study group is expected to represent the whole group of children with CP or at risk of developing them.

We used the following inclusion procedure. First, a nurse, doctor or social worker identified parents based on our inclusion criteria, which were embedded in their routine intake questionnaire. Professional care givers then provided oral and written information about the study to the identified families and asked permission from parents to be called by a research assistant. Thereafter, the research assistant asked for informed consent regarding participation in this study.

Data were collected by trained research assistants at two time points, the first in 2013 (T1) and the second 12 months later (T2). Data were collected in a digital questionnaire, although parents could also opt to be interviewed by telephone in the language of their preference. Parents were reminded three times to fill in this questionnaire and received a gift certificate of 20 euros after doing so. Parents were informed that they could withdraw at any moment.

A total of 512 parents were approached, 354 of whom participated at T1 (response=69.1%). Of these, 272 participated in the follow-up at 1 year (T1-T2 response =76.8%), 239 from the well-child clinic group (T1=309), and 33 from the group of children using care in a high intensity (T1=45). Parents who dropped out at T2 had significantly more sons; more of them were of non-western origin and, on the basis of their home neighborhoods, and more of them had a lower socio-economic position [30].

Measures

We used validated questionnaires if available and assessed their reliability in the sample under study. The children’s service use and intensity of this use in the past six months were measured with the Questionnaire Intensive Care for Youth, a questionnaire measuring use of a pre-set list of types of Dutch services [31, 32]. This list has been adapted to the setting of care for youth from the valid and reliable Questionnaire for Costs Associated with Psychiatric Illnesses and Care Use (TiC-P) [33,34]. As allowed for by this standard questionnaire, we have added and omitted specific items of care services depending on their relevance for our target population. Moreover, respondents had the opportunity to add services we had not listed. Services are defined as any care provider or group of care providers. Dichotomized use at baseline and at follow-up led to four categories expressing change in use, i.e. “never used care”, “stopped using care”, “started using care” and “continued using care”. Intensity of care service use was measured as the number of contacts, defined as planned or unplanned contacts with a professional caregiver by telephone, email, or appointment or home visit; this did not include contacts to make an appointment. We made a distinction between 1. use of any services, which included the use of care delivered in the psychosocial or medical domain; and 2. use of psychosocial services, which included a subset of any care delivered by mental healthcare services, social care services, school care services or family services.

On the basis of Andersen and Newman's behavioral-health model of access to care, we measured potential determinants of care use, i.e. predisposing, enabling and need factors [21]. We used six predisposing factors: child's age; parents' educational level; household composition; child's ethnicity; parental mental health, and impact of any adverse life events the family had experienced (ALE). Parental mental health status was measured using the validated 12-item version of the General Health Questionnaire (Cronbach's α= .86) [35]. To measure the burden of adverse life events in the previous 12 months, we used the life-events scale of the Brief Instrument Psychological and Pedagogical Problem Inventory (Cronbach's α= .72) [36].

We measured three enabling factors: partner's provision of social support, family provision of social support, and care use by a parent. To measure social support, we used two subscales of the validated Dutch Family Functioning Questionnaire [37]: "relationship with partner"(Cronbach's α= .88), and "social functioning of the family" (Cronbach's α= .91). Parental care use was measured using the TiC-P, similar to the way the child's care use was measured (see above) [33].

We included four need factors in this study, i.e. a child's chronic condition; a child's emotional and behavioral problems; parenting concerns and a parent's assessment of the quality of their relationship with their child. Questions measuring a child's chronic health were the following. "Does your child have one or more chronic health condition—such as asthma, diabetes, ADHD or autism—for which treatment is or was needed? What is the impact of this condition on your child's daily life?" [38]. We measured child behavioral and emotional problems using the BITSEA (for children aged between 18 months and 3 years) and the SDQ (for children aged between 3 and 12 years). We constructed the variable as a dichotomy, to be able combine the scores on the different instruments for the whole group. The Dutch versions of both were found to be reliable [26, 39-42]. Cronbach's α's as measured in this study of the SDQ subscales range from .39 to .74 and Cronbach's α's of the two BITSAE subscales on our data were .67 and .80. To measure parenting concerns we used the following question: "In the last 12 months, have you had concerns about your parenting?"[43] Finally, parents' assessment of their relationship with their child was measured using the subscale of the validated Dutch Parenting Load Questionnaire (Cronbach's α= .83) [44]. Answers were given in a five point Likert-scale. We dichotomized scale sum scores using their medians as cut off.

Analyses

First, we described the background characteristics; the scores of the predisposing, enabling and need factors; the use and intensity of any care; and the use and intensity of psychosocial care, all at baseline (T1). Next, on the basis of patterns of use and intensity, we described the changes between baseline and follow-up of predisposing, enabling and need factors for use of any care and use of psychosocial care. Next, we used negative binomial Hurdle modeling to assess the associations between the changes in factors and the changes in care use and its intensity. The score of the dependent variable at T1 was entered as covariate in the Hurdle analyses to be able to address ‘change’ in the outcomes.

Our use of Hurdle modeling was intended to overcome the statistical challenges inherent to data on care use, which typically follow a distribution with many zeroes (no use of care) [45, 46]. Hurdle models have the advantage of estimating two separate parameters in one model to accommodate many zero counts: one dichotomous outcome regarding using care services or not (>0 contacts versus no contacts), and one continuous outcome regarding the number of contacts within the group using care services (>0 contacts). First we assessed the univariate associations of the changes in the independent variables with any care and psychosocial care. On the basis of backward elimination in Hurdle models of all independent variables that were univariately significantly related at the $p \leq 0.1$ level, we then assessed which predisposing, enabling and need factors, and changes in these, were associated with changes in use and its intensity. The criterion for removing a factor out from the final models was set at $p \leq 0.05$. Analyses were performed using SPSS 22.0 [47], and the Hurdle analyses were performed in R, version 3.3.2 [48].

Results

Response and respondents’ background characteristics

The sample included more boys than girls, more school-aged children than pre-schoolers, more children of two-parent families than one-parent families, and more children of Dutch ethnicity than of non-Dutch ethnicity (see Table 1). About half of the parents with a high educational level experienced mental health problems and/or experienced burden of adverse life events in the previous year.

Table 1 Respondents' baseline characteristics, and care use and intensity of use of any care and of psychosocial care

	Total	**Any care services**		**Psychosocial care services**	
		any use	**intensity when using**	**any use**	**intensity when using**
	N##	**n (%)a**	**mean (SD)b**	**n (%)a**	**mean (SD)b**
Total	272	203 (75)	21 (35)	121 (45)	25 (39)
Predisposing factors					
Child's gender					
Boy	152	117 (77)	24 (41)	67 (55)	29 (46)
Girl	120	86 (72)	17 (25)	54 (45)	20 (29)
Child's age					
Pre-school	107	67 (63)	25 (41)	38 (36)	28 (44)
School-aged	165	111 (67)	15 (23)	87 (53)	15 (19)
Parental educational level					
High	132	93 (71)	24 (39)	53 (40)	18 (26)
Low/ medium	138	109 (79)	16 (26)	67(49)	28 (43)
Household composition					
2-parent family	133	109 (82)	19 (34)	55 (41)	27 (39)
1-parent family	112	73 (65)	22 (37)	49 (44)	24 (45)
Other	23	19 (83)	26 (30)	15 (65)	20 (18)
Ethnicity					
Dutch	155	122 (79)	22 (38)	78 (50)	25 (48)
Western	24	16 (67)	17 (24)	11 (46)	17 (25)
Non-Western	91	64 (70)	20 (33)	31 (34)	28 (38)
Parent had mental health problems					
Yes	150	91 (75)	23 (42)	67 (45)	30 (47)
No	122	112 (75)	18 (25)	54 (44)	19 (26)
Burden of adverse life events					
High	133	100 (76)	26 (40)	64 (48)	30 (44)
Low	124	94 (75)	16 (31)	51 (41)	19 (35)
Enabling factors					
Partner's provision of social support					
High	140	105 (75)	25 (40)	53 (38)	22 (36)
Low	130	97 (75)	17 (31)	67 (52)	28 (42)
Family provision of social support					
High	139	110 (79)	19 (31)	70 (50)	18 (31)
Low	130	90 (69)	24 (40)	51 (39)	35 (47)
Care use by parent					
Yes	110	88 (80)	26 (38)	54 (49)	30 (40)
No	162	115 (71)	17 (38)	67 (41)	21 (39)
Need factors					
Burden due to chronic condition					
Yes	53	44 (83)	41 (53)	32 (60)	44 (55)
No condition/ no burden	217	159 (73)	25 (26)	89 (41)	18 (29)
Psychosocial problems					
Yes	124	100 (81)	26 (42)	64 (52)	32 (46)
No	138	95 (69)	14 (21)	53 (38)	13 (16)
Parenting concerns					
High	120	90 (75)	30 (44)	60 (50)	35 (47)
Low	152	113 (74)	14 (24)	61 (40)	15 (28)
Parental satisfaction with parent-child relationship					
High	144	115 (80)	33 (19)	61 (42)	22 (36)
Low	127	88 (69)	23 (39)	60 (47)	28 (43)

N is taken at T1 and n varies due to missing data. [a] Respondents using care and the within group percentage. [b] Mean and standard deviation of care contacts when a respondent was using care.

Care service use and its intensity, and scores on predisposing, enabling and need factors

At baseline, three-quarters of the children in our sample were using some sort of care, and 45% were using psychosocial care (Table 1). For any child using care services, the average intensity of care use was 21 contacts. The intensity of service use was higher if a child was using psychosocial care, with an average of 25 contacts in the previous six months. Predisposing and enabling factors followed a different pattern for 'any' and 'psychosocial care' use (yes/no) and their intensity (>0 contacts). However, need factors showed the same pattern both for any care use and for psychosocial care use: children whose parents reported a higher score on a need factor used care more often and with a higher intensity than those who reported a lower score.

Change in a child's predisposing, enabling and need factors for care service use and its intensity

Table 2 shows changes in predisposing, enabling and need factors and in care use (yes/no) and its intensity (>0 contacts) over time during the use of care services. Regardless of their difference score on the independent variable, most children were in the "continued care use" category for any care services, and in the "never used care" category for psychosocial care services. More children with an increase in the level of need factors tended to be in the "started care" category than those whose needs were decreased or remained unchanged.

Regarding change in the intensity of care service use (>0 contacts), we found in the "continuing care" category that children whose need factors had decreased also showed a decrease in the intensity of care use. In line with this finding, children with an increase in need factors also showed an increase in the intensity of care in the "continuing care" category. However, we did not find the same relationship for parenting concerns.

Table 2 Descriptives for the change in predisposing, enabling and need factors and any and psychosocial care use and its intensity by children with or at risk of developing CP

		Care service use (yes/no)				**Intensity/number of contacts when using care**			
		never used care	**stopped using care**	**started using care**	**continued using care**	**stopped using care**	**started using care**	**continued using care**	**T1**
								T2	
	N[#]	**n (%)[a]**	**n (%)[a]**	**n (%)[a]**	**n (%)[a]**	**mean (sd)[b]**	**mean (sd)[b]**	**mean (sd)[b]**	**mean (sd) [b]**
Results for any care									
Predisposing factors									
Δ Burden of adverse life events									
No change	181	21 (12)	38 (21)	16 (9)	106 (59)	7 (8)	19 (32)	25 (44)	19 (35)
Decrease	57	10 (18)	7 (12)	10 (18)	30 (53)	38 (15)	9 (9)	26 (30)	27 (35)
Increase	9	2 (22)	2 (22)	0	5 (56)	8 (10)	-	8 (11)	16 (13)
Need factors									
Δ Child's psychosocial problems									
No change	198	29 (15)	39 (20)	22 (11)	108 (55)	9 (12)	15 (28)	22 (34)	21 (30)
Decrease	39	9 (23)	7 (18)	3 (8)	20 (51)	48 (59)	4 (5)	29 (34)	10 (10)
Increase	21	1 (5)	2 (10)	3 (15)	15 (70)	10 (9)	15 (6)	21 (15)	35 (64)
ΔParenting concerns									
No change	197	26 (13)	37 (18)	17(9)	117 (59)	10 (13)	17 (32)	26 (41)	19 (24)
Decrease	17	3 (18)	3 (18)	2 (12)	9 (53)	5(3)	10 (11)	20 (22)	58 (92)
Increase	57	11 (19)	13 (23)	10 (18)	23 (40)	14 (24)	8 (8)	20 (36)	16 (30)
Results for psychosocial care									
Child's age[d]									
Pre-school	107	54 (50)	15 (14)	21 (20)	17 (16)	14 (22)	8 (13)	17 (16)	19 (18)
School-aged	165	51 (31)	27 (16)	25 (15)	62 (38)	12 (11)	10 (12)	36 (51)	22 (30)
Δ Burden of adverse life events									
No change	181	70 (39)	31 (17)	31 (17)	49 (27)	8 (8)	10 (14)	38 (54)	23 (32)
Decrease	57	19 (33)	4 (7)	12 (21)	22 (39)	36 (10)	7 (8)	25 (30)	19 (22)
Increase	9	4 (44)	2 (22)	0	3 (27)	7 (9)	-	14 (12)	13 (14)
Need factors									
Δ Child's psychosocial problems[c]									
No change	198	78 (39)	30 (15)	33 (17)	57 (29)	11 (12)	12 (14)	26 (36)	22 (30)
Decrease	39	16 (41)	6 (15)	7 (18)	10 (26)	8 (8)	3 (3)	44 (56)	13 (11)
Increase	21	7 (33)	3 (15)	4 (19)	7 (33)	30 (41)	8 (4)	15 (18)	28 (24)
Δ Parenting concerns[c]									
No change	197	75 (38)	28 (14)	28 (14)	66 (34)	13(13)	12 (15)	31 (48)	20 (22)
Decrease	17	6 (35)	3(18)	4 (23)	4 (23)	3 (2)	6 (3)	27 (29)	57 (82)
Increase	57	24 (42)	10 (18)	14 (24)	9 (16)	15 (12)	6 (8)	37(46)	13 (19)

[##] n varies due to missing data. [a] Respondents using care and the within group-percentage. [b] Mean and standard deviation of care contacts when a respondent who used care.

Table 3 shows the final Hurdle models regarding the multivariate associations of change in independent variables with change in use of any and psychosocial care, and their intensity (see Appendix for the results of the univariate regression models for all factors). First we discuss the zero part of the Hurdle models regarding care use (yes/no). The final model regarding use of any care consisted of burden of adverse life events (ALE) (a predisposing factor), and parenting concerns (a need factor). Whereas a decrease in ALE was associated with lower odds of change of care use, an increase in parenting concerns was associated with higher odds. Regarding psychosocial care use, the final model consisted of the same factors as use of any care, but with the addition of child's age. School-aged children had higher odds on change of psychosocial care use than did pre-school children.

Next, we discuss the count part of the Hurdle analyses (>0 contacts). Regarding the intensity of any care use, the final model consisted of burden of adverse life events (a predisposing factor), and psychosocial problems (a need factor). A child's decrease in ALE was associated with decreased intensity of use, and a child's decrease in psychosocial problems was associated with decreased intensity of psychosocial care, in comparison with children with no changes in their level of problems. The final model for psychosocial care services consisted only of psychosocial problems (a need factor), with associations similar to those for any care.

Table 3A. Final Hurdle models for change in factors associated with change in care use and its intensity by children with CP using care: multivariate odds ratios for changes in care use and rate ratios for changes in intensity of care use for any care and for psychosocial care services

	Δ Care service use (yes/no) adj. OR (95% CI)[ab]	**Δ Intensity/number of-contacts when using care** adj. RR (95% CI)[ac]
Final model for any care>>		
Predisposing factors		
Δ Burden of adverse life events[d]	0.94 (0.90;0.99)*	0.95 (0.92;0.98)**
Need factors		
Δ Child's psychosocial problems[d]		
No change	Ref (1)	Ref (1)
Decrease	0.73 (0.32;1.68)	0.38 (0.20;0.73)**
Increase	3.27 (0.69;15.48)	1.17 (0.54;2.56)
Δ Parenting concerns[c]	1.29 (1.11;1.51) ***	1.13 (0.99;1.29)
Final model for psychosocial care>>		
Predisposing factors		
Child's age[d]		
Pre-school	Ref (1)	Ref (1)
School-aged	1.99 (1.09;3.63)*	1.32 (0.72;2.43)
Δ Burden of adverse life events[d]	0.93 (0.89;0.97)***	0.98 (0.95;1.01)
Need factors		
Δ Child's psychosocial problems[e]		
No change	Ref (1)	Ref (1)
Decrease	0.84 (0.36;1.97)	0.39 (0.18;0.84)*
Increase	1.02 (0.36;2.92)	1.16 (0.46;2.90)
Δ Parenting concerns[c]	1.26 (1.10;1.45)**	1.08 (0.95;1.24)

[a] Backward stepwise regression analyses were conducted with the difference score of the factor, if available, and care use at T1 as covariate. The factors entered were parental educational level, child's age, burden of adverse life events, partner's provision of social support, child's chronic condition, child's psychosocial problems, and parenting concerns. The criterion for removing a factor from the model was set at P-value>0.05 [b] Predictors were removed in the following order: chronic condition, parental educational level, and partner's provision of social support [c] Only one factor, chronic condition, was removed from the model. [d] These factors are constructed as difference-of-scale scores between T2-T1. [e] This factor is constructed as difference of dichotomized scores between T2-T1. *p<0.05 **p<0.01 ***p<0.001.

Discussion

This study shows that changes in the predisposing and need factors of Andersen and Newman's behavioral-health model of access to care were relevant to explaining changes in care use and its intensity by children with CP or at risk of developing it. However, enabling factors were not. We also found that care use was related to factors other than changes in its intensity. Relative to the situation at baseline, when children experienced a diminished burden of life events (ALE) or when more parenting concerns were reported at follow-up, children were less likely to use any care or psychosocial care. School-aged children were also more likely than pre-schoolers to use psychosocial care. The intensity of any care use and of psychosocial care use decreased when the degree of psychosocial problems decreased. The intensity of any care use also decreased when ALE decreased. Moreover, where ALE was associated both with care use and with its intensity, parenting problems uniquely impacted care use and psychosocial problems uniquely impacted its intensity.

We found that several changes in predisposing (i.e. burden of ALE and a child's age) and need factors (i.e. parenting concerns and psychosocial problems) were associated with changes in care use and its intensity, both for overall care use and for the use of psychosocial services, but that changes in enabling factors were not. The determinants we found are in line with previous findings [49-55]. An explanation may be that enabling factors are harder to change than predisposing and need factors in the relative short time span of our study (one year). For example, it is more difficult for a child social worker to convince parents to make use of mental health care for their own mental problems than to address parenting concerns. This study shows the value of the Andersen and Newman model for studying the intensity of care use, especially in distinguishing enabling factors from other factors affecting families with a child at risk of CP or of developing them.

The results of this study added burden of ALE as a factor impacting change in intensity of care use. Research showed that ALE is an important determinant of care use in general [56, 57]. ALE will especially affect children with CP, interacting strongly with the other problems of these children, thereby leading to more intense problems. Unexpectedly, we found a slight negative relative risk between ALE and the intensity of any care use. We noted that the burden of ALE decreased in a relatively large group of children while they were using care. Children with CP may have been motivated to continue-treatment even when the burden of ALE decreased, because trauma-based therapies are known to have a positive effect on other emotional conditions [58,59]. Furthermore, when the safety of a child is at risk, as in cases of domestic violence, care professionals will ideally continue treatment to monitor the situation. Our results indicate that change in ALE is relevant to the whole care process, i.e. not only care use itself, but also to its intensity.

Although improving social support is at the core of treatment of families with complex problems, in the final models of our study this factor was absent [60]. It can be hypothesized that social support works differently for families with complex problems than for the general population [16, 61-63]. The families' social networks in case of CP are usually large and suitable for dealing with daily challenges of living with a child with complex problem[61-63]. However, regardless of their perceived social support, families will turn to professionals to bring about long-term improvements, surmising that they may not be able to achieve these improvements with their own network. Also, professionals may not yet have managed to bring about changes in the quality of support by the social environment because of the relatively short period of our study (one year). Although social support is a known determinant impacting a child's care use, more research is needed to understand how to optimize its impact for families of a child with CP.

Finally, we found that changes that changes in intensity with which care is used (>0 contacts) were affected by factors other than changes in care use in itself (yes/no). This supports earlier findings in the scarce research available on intensity of care use [8-10]. For both any care and psychosocial care, our study shows that parents with parenting concerns were more likely to use care, and the intensity of care use increased when there were psychosocial problems. Both need factors are known drivers of help-seeking behavior [64]. Our study showed that parenting concerns impacted care use but not intensity, while a child's psychosocial problems were relevant to intensity rather than to care use.

Strengths and limitations

A major strength of this study is its comprehensive use of the data, obtained by using the Hurdle model. This model overcomes the difficulties inherent to using a single model to assess factors that impact care use and its intensity, which cannot be assessed by mainstream generalized linear models. We therefore believe that the use of Hurdle models provides added value for researchers interested in care utilization. Another strength of the study is that the study group of children with or at risk of developing CP were living in the community, including children in treatment with different intensities of care use or not using care at all. In most other research the study groups are limited to children with CP who are using a specific treatment [8,25].

A limitation of this study concerned some small selective loss to follow-up. A relatively high number of children who were lost to follow-up were boys and had parents of non-western origin. Another limitation is that we used a self-report questionnaire to establish care use in the previous six months. This may have caused some recall bias, especially for intensity of care use and the determinants burden of ALE and impact of chronical conditions of the child. This may have added measurement error and thus a weakening of reported associations, probably without clear under- or overestimation.

Implications for practice

A new finding in this study is the effect that the burden of ALE has on the intensity of care use, a factor that is relevant to the whole care-seeking process, i.e. not only entering care, but also the intensity of its use. This shows the importance of providing interventions that focus on the effects of ALE, on the impact of these effects on intensity, and thus on the costs of care [67,68]. For this reason, those who assess and treat children with CP should pay close attention to adverse life events and the way children and their families deal with them.

We also found that, while a decline in psychosocial problems was associated with a decrease in intensity of care use, care use in itself was not affected by changes in psychosocial problems. Conceivably, various barriers hinder the process of starting care. In their recent systematic review, in which they provide an overview of the barriers facing children with or at risk of developing CP, Reardon and colleagues show how insufficient knowledge and understanding of psychosocial problems and the help-seeking process on the part of parents is a core component that hinders care use [65]. Policymakers and professional care providers should make efforts to educate parents on recognizing their child’s psychosocial problems, and also on the local pathways to help.

Implications for further research

With regard to care use and its intensity in this group of children, our study shows the enabling factors defined by Andersen and Newman to be less relevant than the predisposing and need factors [8]. To understand the contribution and any possible indirect impact of enabling factors, further research is required. We therefore have two recommendations: 1. a larger respondent group (to accommodate mediation analysis); and 2. extension of the time-lapse in the longitudinal design.

Regarding the enabling factor social support, more research is needed on how to improve the quality of support provided by the network of families with a child with complex problems. We advise the development and evaluation of a treatment module for parents and key persons in their social network to improve support skills. These new skills can be thought by volunteers who are able to model healthy support.

In this group of children we also found that the intensity of use of care services is affected by factors different from those influencing the use of care in itself. Understanding the mechanism underlying the intensity of care use can help the development of more effective and efficient pathways to care for children with or at risk of developing CP. This will require further research into this mechanism behind care use and its intensity by children with CP.

Conclusion

With regard to the use of any care, or psychosocial care, and the intensity of this care by children who with or at risk of developing CP, our study shows that changes in predisposing factors (i.e., a child's age and burden of life events) and need factors (i.e., a child's psychosocial problems and parenting concerns) are associated with change in use or intensity of use, and enabling factors are not. The importance of effective treatment of ALE is emphasized by the fact that ALE are a factor that contributes to the intensity of care use. The level of a child's psychosocial problems is also relevant to the intensity of care use (>0 contacts), but not to the use of care in itself (yes/no). To improve care use by children with these needs, policymakers should address parents' knowledge with regard to identifying psychosocial problems and the help-seeking process. Finally, our findings demonstrate the added value of studying the intensity of care use, especially on the basis of Andersen and Newman's model of care-seeking. Such study will improve our insight into the drivers of the intensity of care use by children with CP.

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4

CHAPTER 4

SERVICES USE BY CHILDREN AND PARENTS IN MULTIPROBLEM FAMILIES

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Abstract

Background: Multiproblem families are multi-users of psychosocial and health care services, but little is known about factors associated with their care utilization in the general population. The aim of this study was to assess which factors were associated with the overall and psychosocial care use of two members—i.e., child and parent—of each multiproblem family.

Methods: During well-child visits or psychosocial care, we identified 354 children and their parents who had problems in several life domains (response 69.1%). We used multivariate stepwise backward logistic regression analyses to identify the factors related to their use of overall and psychosocial care.

Results: A child's overall care use was associated with greater social support from family and friends (odds ratio, OR, 95% confidence interval, CI; OR =1.05, CI =1.01–1.08) compared to less perceived social support; and with more psychosocial problems in the child (OR= 1.84, CI =1.04–3.24). Child's psychosocial care use was more likely among older children (OR =1.94, CI =1.20–3.15); greater social support by family and friend (OR =1.03, CI =1.00–1.06); more psychosocial problems (OR =1.75, CI =1.04–2.97); and when there were more parenting concerns (OR =1.19, CI =1.06–1.33). Parental overall and psychosocial care use was more likely when the family experienced a higher number of life events (OR =1.27, CI =1.17–1.38, and OR =1.39, CI =1.25–1.55).

Conclusions: Care use in multiproblem families is related to family factors as well as psychosocial problems. It may be possible to use these family risk factors to identify such families early, whose intensive care use is possibly explained by the relationship with inadequate use of social support.

Introduction

Multiproblem families have problems in several areas of life, including poverty and psychosocial problems [1]. Children raised in such families run a high risk of poor mother-child attachment and of developing behavior and emotional problems [2-4]. Typically, these children and parents are multi-users of psychosocial care, such as social and mental healthcare. Research shows that these services spend up to 86% of their budgets on multiproblem families [5-6].

Several western countries have developed policies and programmes dealing with families with multiple problems, e.g. the ‘Troubled families’ programme in the United Kingdom the ‘One family, one plan, one care coordinator’ programme in the Netherlands and ‘Wrap around care’ in the Unites States of America [7-9]. These initiatives aim at more efficient pathways to care for multiproblem families. Less focus lies on understanding the mechanism behind the help seeking behavior of families [10]. Insight into the reasons behind care use of multiproblem families will improve our understanding of their care seeking behavior which may help to break the intergenerational cycle of intensive care use.

A-framework for understanding the factors associated with care use of multiproblem families is provided by Andersen and Newman’s behavioral-health model of access to care [11]. The Andersen framework determines access to care on the basis of 1. predisposing factors or an individual’s characteristics or abilities to use a specific service (such as gender, age and cultural identity); 2. enabling factors or means whereby a family accesses care (for example social support or practical barriers to care); and 3. healthcare needs (for example a child’s emotional or behavioral problems). We chose for this framework because it addresses multiple domains from a services user point of view. Furthermore, the dual emphasis on individual and family factors is a good starting point for understanding the complex and often intergenerational problems of multiproblem families. Goldberg and Huxley’s framework pathways to care is another well used framework for understanding care use [12]. The pathways to care of multiproblem families from a provision of services point of view has already been mapped according to this framework [7,13]. We feel that Andersen and Newman’s dual emphasis on individual and family factors is a better starting point for understanding the complex and often intergenerational problems of multiproblem families.

This study aims to understand the mechanism underlying care use by multiproblem families, which may lead to better support for children raised in these families. This requires research into a broad range of parents’ and children’s use of services such as mental health and social care services, debt counseling, general practitioners, and medical specialists [14]. The research question was: which factors of the Andersen and Newman’s model are associated with overall and psychosocial care use of two members – i.e. child and parent- of each multiproblem family? For this explorative study, we selected factors based on literature on care use by children with psychosocial problems and multiproblem families [5, 15,16]. We expected that the factors associated with care use reflected the multiple domains of problems of these families and included in this study not only need but also predisposing and enabling factors

Methods

This study is part of a cohort study on service use and its determinants among multi-problem families in an urban setting in the Netherlands. We used a cross-sectional design to study correlates of children and parents' care use. The study was conducted according to the Helsinki regulation. The Medical Ethics Committee of Leiden University assessed our study proposal and concluded that approval was not required under Dutch Law (C12.041).

Sample and procedure

The aim of our study was to better understand the mechanism underlying care use by multiproblem families. To reach this aim, we wanted to include multiproblem families among which the use of services varied. Therefore we took two samples:1. A community sample of multiproblem families who did and did not use care and 2. An added sample of high care use multiproblem families to ensure that care users were sufficiently represented. For the sample of the general population children aged between 18 months and 12 years had been identified during well-child visits. In the Netherlands these well-child visits are provided by preventive youth health care services and have a high attendance rate of 95% for children in our age-sample [18]. The sample with a high risk of care use consisted of families enrolled in child and family focused specialist psychosocial care services.

Families were included if they met one of the following criteria: 1. the presence in children aged 3-12 years of psychosocial problems as indicated by elevated scores on the routinely collected parent-reported Strengths and Difficulties Questionnaire (SDQ) [19] or, in younger children, the psychosocial problems indicated by the professional who made the assessment; 2. the identification by the preventive child healthcare worker of persistent parenting concerns; 3. the occurrence of one or more major life event during the past year; and 4. the use of care due to any of the previous criteria.

A total of 512 parents received a digital questionnaire or were interviewed by telephone in the language of their preference, 354 of whom (69.1%) participated. Of these354 parents, 45 parents were part of the extra sample of users of psychosocial care services. Two or more of the inclusion criteria were met by 96% of the parents, these parents are part of the final sample from hereon called the multiproblem family. Four out of five respondents met three or more inclusion criteria. In only 7%) of the respondents care use was combined with one other inclusion criterion. In 93% combinations of the other criteria, in addition to care use, were decisive for inclusion.

We do not know the reasons of non-respondents for not answering the invitation to fill in the questionnaire, despite their initial consent to participate. In the non-response group, compared to the response group, children were slightly younger (4.8 vs. 5.9 years, p< 0.001) and more parents had a low socioeconomic position according to their neighborhood (73.4% vs. 37.9%, p<0.001) [20].

Measures

Service use was measured as overall and psychosocial care use by a child from a multiproblem family in the previous six months. We also measured the overall and psychosocial care use by the child's parent. Overall care use involved any use of care and service delivered in the psychosocial or medical domain in the previous six months, e.g. by the general practitioner, paramedical services (e.g., physiotherapist), medical specialist, mental healthcare services, social care services, school care services or family services. The latter four types of care were also the components of psychosocial care use, which was defined as care use due to psychosocial problems. Overall care use was dichotomized as care or no care use, and psychosocial care as using psychosocial care versus using no care or using other types of care. All four dependent variables were measured using a framework adapted from the Trimbos/Imta questionnaire for costs associated with psychiatric illnesses (also known as TIC-P) [21].

Predisposing factors involved a child's gender and age, parents' educational level, household composition, ethnic identity as perceived by the parent, and the adverse life events they had experienced. Life events such as unemployment or loss of a loved one in the past 12 months were measured on the life-events scale of the Brief Instrument Psychological and Pedagogical Problem Inventory or KIPPPI (Cronbach's α.79) [22].

Enabling factors involved social support and care use by another family member. To measure social support, we used two subscales of the Dutch Family questionnaire [23]: 1. "social functioning of the family" (Cronbach's α= .91) and 2. "relationship with partner" (Cronbach's α= .83). A child's care use was the enabling variable of the parent's dependent variables, and a parent's care use was the enabling variable of the child's dependent variables.

Need factors involved a child's health, emotional and behavioral problems, and the parent's mental health and parenting concerns. A child's chronic health conditions involved the parent's response to the following question "Does your child suffer from one or more chronic health conditions—such as asthma, diabetes, ADHD or autism—for which treatment is or was needed?". A child's behavioral and emotional problems were measured using the Brief Infant-Toddler Social and Emotional Assessment (BITSEA) for children aged between 18 months and 3 years [24] and the

Strengths and Difficulties Questionnaire (SDQ) for children aged between 3 and 12 years [19]; the validated Dutch versions of both were found to be reliable (Cronbach's α's of the subscales SDQ ranging from .57 to ,82 and Cronbach's α's of the subscales BITSAE are .79 and .62) [25,26]. Parental mental health status was measured using the 12-item version of the General Health Questionnaire **(**GHQ12) (Cronbach's α= .87) [27]. Finally, parenting concerns were assessed using the following question "Did you have concerns about your parenting in the past 12 months?" [28].

Analysis

To impute missing values, we used predictive mean matching. The proportion of missings on the independent variables ranged from zero to two percent. There were no missing values for the dependent variables. We used multivariate imputation by chained equations to create 10 imputed data sets based on the predisposing, enabling and need factors specified above [29]. Uncertainty about the model estimates was reflected in differences between imputations in the different completed data sets.

After describing the background characteristics of the parents and children in the sample of multiproblem families, we used logistic regression analysis to assess the univariate associations between predisposing, enabling or need factors with the child's and parent's overall and psychosocial care use. Finally, to enter the variables in multivariate models, we used stepwise backward logistic regression analyses, entering variables that were significantly related with overall and psychosocial care use at univariate level, or were hypothesized on theoretical grounds to be important to care use. The criterion for keeping a variable in the backward regression model was set at a p-value smaller than 0.05. Confidence intervals for the outcomes were estimated by pooling results from the imputed data sets [30]. All statistical analyses were performed in SPSS version 20.0 for Windows [31].

Results

Characteristics of the respondents

Table 1 shows the characteristics of the sample. In the previous six months, three-quarters of the children and under half the parents had reported overall care use, and half the children and one fifth of the parents had used psychosocial care.

Table 1 Respondents' background characteristics and care use

		Total n (%)[#]
Child's gender	Boy	196 (58.9)
	Girl	137 (41.1)
Child's age[a]	Pre-school	126 (37.8)
	School-aged	207 (62.2)
Parent's gender	Man	39 (12.7)
	Women	291 (87.3)
Parent's age	< 36	171 (51.4)
	=> 36	162 (49.6)
Parent's educational level[b]	Low	22 (6.7)
	Medium	156 (47.3)
	High	152 (46.1)
Parent's cultural identity	Dutch	242 (74.2)
	Western	46 (14.1)
	Non-western	38 (11.7)
Household composition	Intact families	292 (88.5)
	Divorced families	38 (11.5)
Child's care use	Use of care	260 (78.1)
	No use of care	73 (21.9)
Child's psychosocial care use	Use	189 (56.8)
	No use	144 (43.2)
Parent's care use	Use	145 (43.5)
	No use	188 (56.5)
Parent's psychosocial care use	Use	74 (22.2)
	No use	259 (77.8)

[a] Pre-school:15-47 months; School-aged: 4-12 years. [b] "Low level" entails no, primary or lower secondary education, "average level" entails upper secondary education or post-secondary non-tertiary education, and "high level" entails tertiary education. *# n varies due to missing data.*

Table 2 Univariate and multivariate associations of predisposing, enabling, and need factors with overall and psychosocial care use by children from multiproblem families

	Overall care use		**Psychosocial care use**	
	OR (95% CI)[b]	*Adj. OR* (95% CI)[cd]	OR (95% CI)[b]	*Adj. OR* (95% CI)[ce]
PREDISPOSING FACTORS				
Child's gender				
girl (vs. male)	1.19 (0.70-2.03)		1.04 (0.67-1.61)	
Child's age [a]				
school-age (vs. pre-school)	1.21 (0.71-2.06)		2.33 (1.96-3.70)	1.94 (1.20-3.15)
Parent's educational level				
average (vs. low)	0.51 (0.12-2.22)		0.80 (0.31-2.05)	
high (vs. low)	0.34 (0.08-1.48)		0.52 (0.20-1.32)	
Parent's cultural identity				
Western (vs. Dutch)	0.56 (0.27-1.20)		0.49 (0.25-.98)	
Non-western (vs. Dutch)	0.70 (.34-1.46)		0.81 (0.43-1.55)	
Household composition				
intact (vs. divorced)	1.01 (0.92-1.11)		2.03 (0.97-4.27)	
Number of life events	1.29 (1.19-1.40)		1.13 (1.04-1.22)	
ENABLING FACTORS				
Partner's social support	1.00 (0.97-1.05)		0.97 (0.93-1.00)	
Social support by family and friends	1.04 (1.01-1.07)	1.05 (1.01-1.08)	1.01 (0.98-1.03)	1.03 (1.00-1.06)
parent's care use				
use (vs. no use)	1.58 (0.92-2.71)		1.50 (0.96-2.33)	
NEED FACTORS				
Child's chronic health problems				
problems (vs. no problems)	1.60 (0.83-3.06)		1.42 (0.85-2.36)	
Child's psychosocial problems				
problems (vs. no problems)	1.50 (0.88-1.53)	1.84 (1.04-3.24)	2.52 (1.61-3.95)	1.75 (1.04-2.97)
Parent's mental health problems	0.94 (0.87-1.02)		1.01 (0.94-1.09)	
Parenting concerns	1.04 (0.94-1.16)		1.21 (1.10-1.33)	1.19 (1.06-1.33)

Nagelkerke R^2=4.0-5.7% for overall care use and Nagelkerke R^2=12.8-14.9% for psychosocial care use. R^2 has different values due to multiple models after imputation of the data. [a]Pre-school:15-47 months; School-aged: 4-12 years. [b]*Univariate regression entering one independent variable in the model* [c] Stepwise backward logistic regression analysis entering all univariate variables in the model. The criterion for taking a variable out of the model was set at p-value > 0.05. [d] The order in which a variable was removed from the adjusted model was life events, cultural identity, child's age, child's chronic health problem, child's gender, partner's social support, household composition, parenting concerns, parent's educational level, parent's mental health problems, parent's care use. [e]The order in which a variable was removed from the adjusted model was child's chronic health problems, partner's social support, child's gender, parent's cultural identity, parent's educational level, household composition, parent's care use, parent's mental health problems, life events.

Table 3 Univariate and multivariate associations of predisposing, enabling and need factors with overall and psychosocial care use by parents in multiproblem families

	Overall care use		**Psychosocial care use**	
	OR (95% CI)[*b*]	*Adj. OR* (95% CI)[cd]	OR (95% CI)[*b*]	*Adj. OR* (95% CI)[ce]
PREDISPOSING FACTORS				
Child's gender				
girl (vs. male)	1.35 (0.87-2.10)		1.57 (0.93-2.63)	
Child's age [a]				
school-age (vs. pre-school)	0.97 (0.62-1.53)		1.06 (.62-1.82)	
Parent's educational level				
average (vs. low)	0.74 (0.30-1.81)		.52 (0.21-1.32)	
high (vs. low)	0.62 (0.25-1.53)		0.31 (0.12-0.79)	
Parent's cultural identity				
Western (vs. Dutch)	1.03 (0.52-2.07)		1.62 (0.76-3.44)	
Non-western (vs. Dutch)	1.08 (0.58-2.03)		0.91 (0.42-1.98)	
Household composition				
intact (vs. divorced)	1.37 (0.70-2.68)		1.88 (0.91-3.89)	
Number of life events	1.27 (1.17-1.38)	1.27 (1.17-1.38)	1.39 (1.25-1.53)	1.39 (1.25-1.55)
ENABLING FACTORS				
Social support by partner	0.95 (0.91-0.98)		0.93 (0.89-0.97)	
Social support by family and friends	1.00 (0.97-1.02)		0.96 (0.93-0.94)	
Child's [b] care use				
use (vs. no use)	1.58 (0.92-2.71)		1.64 (0.83-3.23)	
NEED FACTORS				
Child's chronic health problems				
problems (vs. no problems)	0.95 (0.57-1.56)		0.88 (0.48-1.62)	
Child's psychosocial problems				
problems (vs. no problems)	1.00 (0.65-1.55)		1.42 (0.85-2.40)	
Parent's mental health problems	1.10 (1.02-1.18)		1.09 (1.01-1.18)	
Parenting concerns	1.13 (1.04-1.23)		1.17 (1.06-1.29)	

Nagelkerke R^2= 12.6-13.2% for parent's overall care use f and Nagelkerke R^2=20.0-20.4% for parent's psychosocial care use. R^2 has different values due to multiple models after imputation of the data. [a]Pre-school:15-47 months; School-aged: 4-12 years. [b]*Univariate regression entering one independent variable in the model* [c] Stepwise backward logistic regression analysis entering all univariate variables in the model. The criterion for taking a variable out of the model was set at p-value > 0.05. [d] The order in which a variable was removed from the adjusted model was parent's educational level, cultural identity, child's chronic health problems, child's age, child's gender, household composition, parent's mental health problems, social support by partner, parenting concerns, child's psychosocial problems, social support by family and friends, child's care use. [e] The order in which a variable was removed from the adjusted model was cultural identity, parent's educational level, child's chronic health problem, child's age, child's gender household composition, parent's mental health, partner's social support, parenting concerns, child's psychosocial problems, social support by family and friends, child's care use.

Factors associated with care use

Table 2 shows our findings regarding children in multiproblem families, i.e., the univariate and mutually adjusted associations between various determinants of care use and overall and psychosocial care use. The final model of overall care use showed that children used overall care significantly more when social support from family and friends was higher~~,~~ and when the child had an elevated score for psychosocial problems. With each unit increase in the score on the social support scale the odds of using overall care increased 5%. Children with psychosocial problems had 84% odds higher overall use of care than children without such problems.

The use of psychosocial care was higher in school-aged children-those whose parents had more social support from family and friends, those with an elevated score on psychosocial problems and when the parents reported more parenting concerns. With each additional life event and each additionally reported area of parenting concern the odds of using psychosocial care by the child increased by 94% and 19%, respectively. With each unit increase in the score on the scale of social support, the odds increased by 3%. The odds of using care were 94% higher when the child was of school-age compared to pre-school age and 75% when the child had psychosocial problems, compared to not having problems.

Table 3 shows our finding with regard to parents in a multiproblem family, i.e., the univariate and the mutually adjusted associations of various determinants of care use with overall and psychosocial care use. The final model of overall and psychosocial care use showed that parents reported more overall care use when they had experienced more life events. With each life event the odds of using overall or psychosocial care by the parent increased by 27% and 39% respectively.

Discussion

This study shows that use of care by multiproblem families was related to a series of factors from the Andersen and Newman model of care use. For children of these families, the use of care is associated with an enabling factor (social support provided by family and friends) and a need factor (psychosocial problems of the child). Psychosocial care use was associated with the same two factors, plus a predisposing factor (the child's age) and a second need factor (parenting concerns). Parents’ overall and psychosocial care use was related to the predisposing factor adverse life events.

We found life events, a predisposing factor, to be associated with child’s and parent’s care use in multiproblem families. Life events are a known trigger for care use by children and adults alike [32,33]. Members of a multiproblem family are more likely than people in the general population to experience traumatic and stressful life events such as domestic violence [34]. The combinations of multiple adverse life events increase the risk of developing problems and may explain the association between life events and these children’s and parents’ care use [35-37]. Adverse life events may thus be a core factor in multiproblem families’ use of care.

The positive relationship between the enabling factor social support by family and friends and a child’s overall and psychosocial care use aligns with other studies on multiproblem families

[38]. Sousa (2009) found that such families' social networks are usually wide, and that while this seems to help families overcome daily difficulties, it does not generate long-term improvements in their lives [39]. Despite their wide social network, these families also use formal care to compensate for the shortfalls in the social support provided by their family and friends. This may explain their high care use [40]. Support from the social network and from care utilization seem to be parallel processes in the problem solving behavior of multiproblem families.

Although need factors were associated with children's care use, they were absent from the final models for parents. In line with earlier research, parent's care use was significantly associated at univariate level with parental mental health problems and parenting concerns [41,42]. In our final models, these associations were confounded by life events. The lack of an association with a parent's care use may be explained by the fact that many parents in our study had mild to severe mental health problems.

The relationship with the variables degree of child psychosocial problems and parenting concerns was consistent with that found in other research on the care use of children with emotional, behavioral or mental health problems [43-45]. We found that need factors are not the sole determinants associated with care use for children of multiproblem families in which predisposing and enabling factors are also associated with care use.

Strengths and limitations

A strength of this study is that we used a broad sampling strategy to fully include the wide range of multiproblem families, and not just those that had reached care services aiming at high-risk groups. Another strength is that we included families not enrolled in care: earlier studies of care use by these families were limited to families that were already using social and mental healthcare services [46].

A limitation is the use of a self-report questionnaire for care use, which may have led us to underestimate overall and psychosocial care use; information on the use of psychosocial care services is not yet uniformly registered in the Netherlands. Moreover, we mostly obtained information from mothers (88%), which may imply that we missed some of the paternal perspective, even though mothers and fathers did not differ statistically on the dependent variables (care use). Another limitation is the cross-sectional design of this study, which limited our potential for making causal inferences.

Implications for practice

Professionals in psychosocial care find it challenging to identify multiproblem families in an early stage of the treatment [46]. The relevant factors for care use found in this study will help the professionals with this identification. We found that life events is at univariate level associated with the care use of both the child and the parent: it is already clear from earlier studies that it is not so much the severity of the stressors that makes families use care, but more the multitude and combination of adverse life events [47,48]. This indicates that when a child enrolls in care, an important part of the assessment should be a screening of the presence of various life events.

We also found that multiproblem families are likely to report both high social support and high care use. This contrasts with findings in the general population of an inverse relationship, in which less social support is associated with greater care use [15]. This contrast may prove to be a key factor for identifying multiproblem families in psychosocial care.

Implications for research

Our research shows that Andersen and Newman's framework provides a suitable framework for understanding care use by multiproblem families. Our findings show that not only need factors, but also predisposing and enabling factors are relevant for understanding use of care by multiproblem families. The consideration of these additional factors enhances the understanding of care use of these families. As spending on these families accounts for a large portion of services' budgets, special attention should be paid to factors associated with their use of several different care services. To gain greater insight into the factors underlying care use by multiproblem families, we recommend that a follow-up study is conducted. Future research should also make an effort to include fathers in the study to ensure their views on child and family functioning are also represented. This study gives insight into the mechanism of care seeking behavior for multiproblem families. Qualitative design could help to understand this mechanism, especially with regard to the intergenerational transmission and high level of care use of these families. This intergenerational aspect could also be further investigated with accommodation of the parent-child dyadic structure in the analyses.

"Multiproblem family" is an all-purpose term that has no clear definition or conceptualization. The formulation of a clear set of characteristics to identify these families for research will improve our overall understanding of multiproblem families [45].

Conclusion

This study shows that care use by children in multiproblem families is associated with need factors (parenting concerns and the child's psychosocial problems); a predisposing factor (the child's age); and an enabling factor (the provision of social support by family and friends). Care use of parents of multiproblem families is related to the predisposing factor adverse life events. With its predisposing, enabling and need factors, the Andersen and Newman model adds to our understanding of care use by these families, and may lead to further understanding of the pathways leading to these families' care use. Inadequate use of social support may add to high care use. Assessing the presence of predisposing and enabling factors will add to the early identification of multiproblem families.

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CHAPTER 5

DETERMINANTS OF ADHERENCE TO WRAP-AROUND CARE IN CHILD AND FAMILY SERVICES

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Abstract

Purpose

The aim of this study is to understand the determinants of adherence to wrap-around care (WAC) by professional care providers working in child and family services. WAC is a care coordination method targeting families with complex needs. The core components of WAC involve activating family members and the social network, integrating the care provider network, and assessing, planning and evaluating the care process. WAC was introduced in the Netherlands using two approaches: the network approach (NA) and the team approach (TA).

Methods: A cross-sectional study was conducted using a digital questionnaire targeted at care providers. After imputation of missing data, univariate and-multilevel regression analyses were conducted to study the associations between adherence to the core components of WAC, the determinants of adherence and background characteristics.

Results: In total 145 out of 275 care providers (52.7%) responded to the questionnaire. Multilevel regression analysis showed that self-efficacy of the care providers and the way WAC is organised (NA versus TA region) were significantly associated with adherence to core components of WAC. Self-efficacy was significantly associated with all WAC core components (activating family members and the social network: stand. β (95% confidence interval)= .27 (.04-.50), integrating the network of care providers: stand. β (95% CI)= .27 (.05-.50) and assessing, planning and evaluating the care process: stand. β (95% CI)= .30 (.08-.52)). The way WAC is organised was significantly associated to two core components (activating family members and the social network: stand. β (95% CI)= .18 (0.1-.37) and integrating the network of care providers: stand. β (95% CI)= .25 (.09-.42)).

Conclusion: The way WAC is organised and the self-efficacy of care providers who use WAC are factors that are relevant for the redesign of the strategy for introducing WAC. Longitudinal research into the predictive value of determinants of adherence to WAC is advised.

Introduction

Optimal care for families with complex needs represents a challenge for both professional care providers and families. When treating these families, care providers often find it hard to deliver well-planned and patient-centred care [1]. These challenges are linked to a mix of family problems and multi-morbidity that make it difficult to meet the specific needs and preferences of families. Wrap around care (WAC) is a method for care coordination that targets these families with complex needs who use child and family services [2,3]. The core components of WAC are 1. activating family members and the social network, 2. integrating the care provider network and 3. assessing, planning and evaluating the care process [4,5]. A meta-analysis of the effectiveness of WAC found that it had a positive impact on the living situation of young people, juvenile justice outcomes, mental health outcomes, school performance and the overall functioning of the child [6].

The actual impact of methods like WAC is the product of the efficacy of the method (the extent to which WAC can resolve the problems that families encounter) and the level of adherence (the extent to which WAC is implemented by all care providers and the families). Full adherence to WAC will be unlikely in daily practice and depends on the systematic introduction of the method. Several models describe planning sequences for promoting the systematic implementation of an innovation like WAC in general terms [7-15].The first step involves identifying and analysing the determinants that impede or enhance the use of an innovation. Secondly, strategies targeting the most important determinants need to be put in place to introduce the innovation in conjunction with standard activities such as the selection and training of care providers and the evaluation of the innovation [16,17]. Thirdly, both care providers and clients should be studied to establish the extent to which the innovation is actually used and to examine the determinants of use in relation to the innovation strategies to which the care providers are exposed. There have been only a few analyses of the use of innovations or their determinants with a view to underpinning the systematic introduction of the intervention or method [18,19]. The aim of this study is, therefore, to improve our understanding of the determinants of adherence to wrap-around care (WAC) by professional care providers working in child and family services. This aim corresponds to the last step of the planning sequence described here. We examine the association between the degree of adherence to WAC core principles, the relevant determinants and background characteristics.

Methods

In this observational study, we followed the process and implementation of the WAC method that was used in two Dutch regions to organize the care for multi-problem families. These regions used a network-based approach (NA) and a team-based approach (TA) for delivering WAC was used. A short description of the approaches is given in the textbox. We categorized the innovation strategies for the introduction of the WAC innovation in each region using Fixsen's implementation model [16,17] without assessing the quality of the delivered strategies. The NA region accentuated opportunities for consultation with colleagues and training for the professional care providers. The TA region emphasised selecting team members, pre-service training and administrative support in the teams.

The child and family services and local government of the two regions participated in a Collaborative Research Centre in which this study took place (www.samenvoordejeugd.nl). Both local government as the budget holder and the child and family service organizations decided to implement WAC several years prior to this study as a solution for poor service provision for multiproblem families. The local governments and services organisations in both regions were unfamiliar with how to implement innovations like WAC systematically and participated in this study with the aim to redesigning their innovation strategy and to improve service delivery.

The innovation strategies of the regions were developed and delivered by implementation agents from the local government and child and family services. Occasionally, external experts were put in action, for example for training professionals on WAC. These activities were mostly funded by the local government. WAC was the only comprehensive method implemented in child and family services. In practice both regions lacked a comprehensive and structural approach for the organisation of WAC, without grounding the implementation of WAC on innovation theory or well accepted strategies at the start of the project. Therefore, researchers assessed the innovation strategies to the implementation of WAC in the two regions, using policy papers, interviews with care providers and managers who were responsible for use of WAC in the daily practice of youth care and interviews with representatives of the regional steering committees of WAC.

Innovation strategies to implement WAC

In this research, two approaches of innovation strategies to implement WAC were studied in two urban regions in the Netherlands. These network-based and team-based approaches included the following components [16]:

The network-based approach (NA)

In the NA region, each professional could decide on when to provide WAC to which family. The sixteen child and family services in the region employing the professionals were responsible to implement WAC in their organisations. Most of the professionals had pre-service training and could use coaching on the job to improve their competencies. The NA-region also conducted a programme evaluation. The regional steering committee that implemented WAC introduced several system interventions to support the professionals in their work. The region did not invest in staff evaluation and administrative support or other facilities during the implementation process. This region had been working with WAC for five years prior to the present study.

The team-based approach (TA)

The TA region formed three fixed multidisciplinary teams to which families could be referred for WAC. Local government had the responsibility for the implementation and not the eight child and family services that had delegated professionals to these teams. The local authority and child and family services in the TA region selected professionals that were delegated to the teams, trained them and created a facilitating organization around the teams. There was no coaching on the job or staff evaluation. Like in the NA region, a programme evaluation was conducted and several system interventions were introduced. This region had been working with WAC for two years.

Participants and design

A cross-sectional design was used to collect opinions and perceptions of professionals on adherence to WAC principles and its determinants using a survey. A random sample of 221 (27%) of all eligible care providers (n=813) working in the child and family services in the NA region were asked to fill in a digital questionnaire. All 54 care providers of the local WAC teams in the TA region were invited to participate in the survey. Participation in the study was anonymous. The Medical Ethics Committee considered her approval for this study as not necessary under the Dutch Law (C12.041).

Measurements

The digital questionnaire was developed in close collaboration with an expert panel of people involved in implementation: two coordinators, two policy-officers and four care providers working with WAC. The questionnaire addressed the care provider's self-reported adherence to the core WAC components and the determinants of adherence (see table 2).

The three core WAC components are: 1. activating family members and the social network, 2. integrating the care provider network and 3. assessing, planning and evaluating the care process [2004,2005]. Adherence to these core components was measured by asking the respondents to indicate (on a five-point Likert scale ranging from 'none of the families' to 'all families') the number of eligible families with whom they used the WAC components or principles. Adherence was defined as the degree to which the care provider used the recommended procedures and avoided procedures not considered to be advisable or acceptable [20]. A high degree of adherence to all three core components is necessary for the maximal impact of WAC.

Several determinants of adherence to the three core elements derived from a shortlist of 50 determinants impacting implementation of innovations [9]. This shortlist was based on a literate review on the implementation of evidence-based innovations and health promotion programmes in preventive child health care and schools and a Delphi study among implementation experts.

First, the experts [i.e. two implementation coordinators, two policy-officers and four care providers working with WAC] of each region made a selection of the shortlist of the determinants known to impact implementation based on two criteria: 1. the anticipated impact of a determinant on adherence and 2. the determinant had to be suitable to measure via a self-report questionnaire. The experts were aware of the constraints on the length of the questionnaire given by the organizations participating in this study. The experts then chose the final determinants based on consensus. The questionnaire was pre-tested which led to minor adjustments.

The respondents were asked to use a five-point Likert scale to indicate the perceived effect of each determinant on adherence (see table 1). The reliability of theses scales range from satisfactory to good. In addition, background characteristics were assessed: how WAC was organised (NA or TA), the WAC caseload (number of families in last six months), number of years of working experience of the care provider, sector of expertise of child and family services in which the respondents worked, and the educational level of the respondents.

Table 1 Scales, number of items, reliability and examples of questions in the questionnaire

Scale	Number of items	Reliability(α) / correlation coefficient (r)	Example of questions, answer categories and score range
Adherence to the core WAC components			
Activating family members and the social network	3	α = .70	In how many of the eligible families did you state the goals which were to be pursued by the family themselves? never (1)- in all families (5)- does not apply here (6) (6 categories)
Integrating care provider network	5	α = . 79	In how many of the eligible families did you collaborate with the providers of care for the child? never (1)- in all families (5)- does not apply here (6) (6 categories)
Assessing, planning and evaluating the care process	5	α = .86	In how many of the eligible families did you state concrete goals? never (1)- in all families (5)- does not apply here (6) (6 categories)
Determinants concerning the innovation			
Relevance for the families	1	-	To what extent do you feel WAC has an added value for families? no added value (1)- considerable added value (5) (5 categories)
Procedural clarity	5	α = .74	Estimate how familiar or unfamiliar you are with the key elements of WAC very unfamiliar (1) -very familiar (5)- does not apply (6) (6 categories)
Determinants concerning the user of the innovation			
Self-efficacy	2	r = .82	To what extent are your skills adequate to work with the WAC method? completely inadequate (1)- completely adequate (5) (5 categories)
Social support	2	r = .68	To what extent do you feel supported by your colleagues? not supported at all (1) - very supported (5) (5 categories)
Attitude	7	α = .61	To what extent do you think the goals of the treatment should be worded so that they are understandable for the family? not important at all (1)- very important (5) (5 categories)
Determinants concerning the organisation			
Available time and practical support	3	α = .69	To what extent do you receive adequate administrative and other types of support for organising practical issues related to WAC? completely adequate (1)- completely inadequate (5) (5 categories)
Satisfaction with WAC	1	-	To what extent are you satisfied with collaboration within WAC? completely dissatisfied (1)- completely satisfied (5) (5 categories)
Determinants of the context			
Legislation	1	-	To what extent does the WAC approach fit in with current legislation and regulations? very poorly (1) - very well (5) (5 categories)

Statistical analyses

The first step in the analysis involved establishing the scales for the measurement of adherence to the core components of WAC and the determinants using reliability analyses, principal axis factoring for non-normal and principal factor analysis for normal distributed scales. Secondly, multiple imputation was applied to adjust for missing values. This simulation-based approach creates a number of imputed (completed) data sets by 'filling in' plausible values for the missing data. The imputations are based on a model that uses information from other variables to achieve optimal estimates. Only imputations for the missing values between the lowest and highest values of the measured outcome variable are valid. Uncertainty about the model estimates is reflected in differences between imputations in the different completed data sets. We used multivariate imputation by chained equations to create ten imputed data sets based on general characteristics, determinants, measurements of adherence, and the WAC components [21]. We applied predictive mean matching to create multiple imputations. Confidence intervals for the outcomes were estimated through pooling results from the completed data sets [22].

Descriptive statistics were then used on the imputed data to give an overview of the characteristics of the respondents per region using t-tests or ANOVA. Total scale scores were calculated for each core adherence component and each region, with higher scores representing higher adherence to WAC. The associations between the background determinants, the determinants and the adherence to the three core components of WAC were then tested at the univariate level using logistic regression for categorical and linear regression for continue variables. The background determinants with a significant bivariate association and all other determinants were entered in multilevel regression models with organization as level and the WAC core components as outcome variables. All statistical analyses were performed in SPSS version 20.0 for Windows [23]. A two-tailed significance level of .05 was used in all analyses.

Results

Respondents and their scores for each core component

A total of 145 of the 275 care providers completed the questionnaire (52.7%), with missings varying from none to 35.9%: 97 care providers from the NA region (43.9%) and 48 care providers (88.9%) from the TA region (see table 2). The majority of the respondents had received higher vocational education and they worked in primary care or youth care. Significantly more respondents in the NA region were employed in the mental health services than in the TA region.

The care providers working in the NA region reported significantly higher adherence to the core components planning, assessing and evaluating the care process and integrating the care provider network than their counterparts in the TA region (see table 2).

Table 2 Characteristics of the respondents and mean scores for adherence to core WAC components by strategy (network-based or team-based)

		Network-based (n = 97)	**Team-based (n = 48)**	**Total (n = 145)**
		n (%)	n (%)	n (%)
Educational level	vocational education and training	7.2 (7.2)	6 (12.5)	13.2 (9.0)
	applied scientific and university	89.8 (92.8)	42 (87.5)	131.8 (91.0)
Sector of child and youth services	preventive child health care	19 (19.6)	10 (20.8)	29 (20.0)
	primary care	23 (23.7)	24 (50.0)	47 (32.4)
	mental health care *	29 (29.9)	3 (6.3)	32 (22.1)
	youth care	26 (26.8)	11 (22.9)	37 (25.5)
		M (SD)	M (SD)	M (SD)
Experience as care provider in child and family services in number of years		11.5 (9.3)	11.3 (8.3)	11.4 (9.0)
Caseload as care coordinator in past six months		2.7 (4.6)	2.6 (3.9)	2.6 (4.4)
Activating family members and the social network		2.1 (1.19)	2.5 (1.3)	
Integrating care provider network **		2.8 (1.58)	3.3 (1.6)	
Assessing, planning, and evaluating the care process **		2.6 (1.56)	3.5 (1.7)	

Values are expressed as a mean (M) and standard deviation (SD) or n (%). *p<0.05 **p<0.01

Table 3 Multilevel regression analyses and degree of adherence to WAC core components

	Activating family members and social network[a]		**Integrating care provider network**[b]		**Assessing, planning and evaluating the care process**[c]	
	β (95% CI)[1]	β (95% CI)[2]	β (95% CI)[1]	β (95% CI)[2]	β (95% CI)[1]	β (95% CI)[2]
Organisation of WAC (team-based=reference)	.16 (-.00-.32)	.18 (0.1-.37)*	.16 (-.01-.33)	.17 (-.00-.34)	.25 (.09-.40)**	.25(.09-.42)**
Relevance for families	.15 (-.01-.31)	.03(-1.14-.20)	.23 (.07-.40)**	.13 (-.04-.29)	.21 (.05-.37)*	.10 (-.06-.26)
Procedural clarity	.27 (.10-.44)**	.12 (-.07-.32)	.31 (.17-.48)***	.18 (-.01-.37)	.08 (.03-.13)**	14 (-.05-.33)
Self-efficacy	.25 (.09-.89)**	.27 (.04-.50)*	.29 (.14-.45)***	.27 (.05-.50)*	.27 (.11-.43)***	.30 (.08-.52)**
Social support	.14 (-.02-.30)	-.10 (-.33-.12)	.22 (.06-.38)**	-.02 (-.24-.21)	.20 (.04-.35)**	-.02 (-.24-.20)
Attitude	.22 (.06-.38)**	.14 (-.02-.31)	.14 (-.02-.30)	.04 (-.11-.20)	.13 (-.03-.29)	.04 (-.12-20)
Available time and support	.18 (.01-.35)*	.05 (-.15-.25)	.14 (-.03-.30)	-.07 (-.27-.13)	.12 (-.05-.29)	-.06 (-.25-.13)
Satisfaction WAC	-.04 (-.21-.12)	-.00 (-.17-.17)	-.06 (-.23-.10)	-.04 (-.21-.12)	-.10 (-.28-.06)	-.06 (-.23-.09)
Legislation	.06 (-.10-.23)	.03 (-.14-.20)	.17 (-.24-2.38)	.12 (-.05-.28)	.15 (-.02-.30)	.12 (-.02-.31)

*p< 0.05** p<.01 ***P<.001 [a] intraclass correlation p=0,05 [b] intraclass correlation p= 0,05 [c] intraclass correlation p=0,02. [1] β represents the standardized β of the univariate multilevel regression analysis with organization as level, adherence to WAC as outcome, the determinant as independent variable. [2] β represents the standardized β of the multivariate multilevel regression analysis with organization as level and adherence to WAC as outcome, the determinant as independent variables and all other determinants in the model as co-variate

Determinants of adherence

As seen in table 3, the determinants the way WAC is organised (NA or TA), the relevance of using WAC for the families themselves, support from colleagues and management reported by the care provider using WAC (social support), the attitude of the care provider towards WAC and the time available and practical support for using WAC were significantly associated in the univariate analyses with adherence to one or more core components, taking in account the level of organization. The procedural clarity of the method and the self-efficacy of the care providers using WAC were significantly associated with adherence to all core components.

In the multivariate models, the way WAC was organised and the self-efficacy of the care provider for WAC remained significantly associated with adherence to respectively two and all of the core WAC components. The way WAC was organised was significantly associated with higher adherence scores for the WAC core components activating family members and the social network and assessing, planning and evaluating the care process (with NA scoring higher than TA). Higher perceived self-efficacy was associated with higher scores for activating family members and the social network, integrating the care provider network and assessing, planning and evaluating the care process. The intraclass correlations of all three dependent measures were statistically significant.

Discussion

This study shows that adherence to wrap-around care (WAC) among professional care providers working in child and family services is linked to the self-efficacy of the care providers and the way WAC is organised. The network-based approach (NA) to implementation led to more positive results than the team-based approach (TA).

Research into adherence to WAC principles showed that adherence to the core component activating family members and the social network was relatively weak by comparison with the other two core components [24]. Another study noted the absence of support systems for families with complex needs, making it difficult for WAC teams to attain the desired adherence to the core component activating family members and the social network [4]. In these circumstances, the self-efficacy of the professional toward WAC principles may be decisive in terms of achieving the desired involvement and the activation of the families and the social network, as we found in this study.

We found confounding effects of six of the eight determinants in relationship to adherence with self-efficacy. Research shows that the perceived self-efficacy of professionals is a known determinant of the implementation of innovations in health care [9]. Although implementation research looking at WAC focuses more on the organisation culture or climate, this study found that self-efficacy as perceived by the care providers and the way WAC is organised regionally, rather than in a single organisation, are also important determinants that should be targeted when introducing the value-driven WAC care-coordination method [2].

We also found that the way WAC was organized is relevant for adherence to two core components. The finding that NA leads to higher adherence than TA was not expected. A known risk of top-down and large-scale implementation processes such as those used in the NA region is that they fail to address local needs and concerns. These proven difficulties are circumvented when WAC is introduced using local teams. The two regions differed in their approaches, which possibly have suppressed the variables significantly at univariate level. The organization of WAC may encompass these separate variables who showed to be relevant at univariate level. For example, the determinant procedural clarity was associated with all WAC core components at univariate level. However, in the multivariate model the associations of clarity with the outcomes dropped and were no longer significant. This is explained by the confounding effect of the other determinants, including the way WAC was organized. The clarity of the WAC method could have been a more prominent feature in the NA region, where there was more experience with WAC procedures than in the TA region.

Strengths and limitations

Non-response was higher in the NA region than in the TA region. Although the characteristics of the non-responders were not systematically collected, this higher non-response could have led to an overestimation of adherence in the NA region. The significant higher amount of care providers in mental health services in the NA region is due to the limited amount of care providers in the TA region. All the care providers in mental health services of the TA region participated in this study. The respondents do have a wide range of experience with WAC varying from non-existent to substantial.

The length of the questionnaire was limited due to time constraints for the organizations participating in this study. More influential determinants may therefore have been missed [25]. Further development is advised to enhance the validity of the scales measuring adherence and its determinants. Nevertheless, allowing the professionals involved with the implementation of WAC to choose the determinants that they found most appropriate made it possible to adapt the questionnaire to the specific challenges faced by the regions. Another limitation was the use of self-reported adherence measures, which may result in the overestimation of actual adherence by comparison with other methods such as observations [26].

The results for the multilevel models on the non-imputed data were in line with the results for the imputed data: associations between self-efficacy of the care givers, the way WAC was organized and adherence to several core components of WAC were also found. On top of these determinants, attitude of the care provider towards WAC also showed a significant association to the adherence to WAC in the non-imputed data.

Implications for practice

Our findings imply that the self-efficacy of care providers should be at the heart of implementation strategies for WAC. Triangulation by means of several group meetings with care providers was used to establish an in-depth picture of how their self-efficacy relating to WAC can be improved. Care providers said that they did feel insecure with respect to mastering the value-based WAC method. They had no previous experience with value-driven methods, and had worked in the past only with clear guidelines of protocolled methods. The care providers preferred learning on the job as a way of mastering working practices based on values. Modelling, which is a feature of learning on the job, is a known way of increasing self-efficacy in line with Bandura’s social cognitive theory [2].

In addition, we advise focusing on the other determinants that are significantly associated with implementation when redesigning the innovation strategy, taking into account the differences between the approaches in the two regions where this study took place. Steps should be taken to ensure that professionals feel that they have the support of their colleagues and management, that they have enough time and the practical support they need to use WAC, that care providers have a positive attitude towards WAC, that they understand the relevance for the families and that the procedures for using WAC are clear. We recommend a bottom-up, team-based approach, since theory predicts that this approach is most likely to lead to support and motivation for the users of the WAC method.

Recommendations for further research

More research is needed to equip care providers with the methodological tools required to ensure that they have the feeling that they master WAC. Longitudinal research is recommended into the predictive value of the determinants of adherence to WAC and the effect of how WAC is organised. Testing should include not only self-reported adherence but also observations or case records of what WAC care providers actually do in practice. Recently the Team Observation Measure was developed for valid observations of use of WAC components in practice [28]. A qualitative design could give more insight in how the different ways WAC was organized affect the adherence to WAC. Finally, research is required into the effect of adherence to WAC by care providers in terms of improving family functioning.

List of abbreviations

Wrap-around care is abbreviated as WAC

Competing interests

The authors report no financial or non-financial competing interests

Authors' contributions

PK and NP were both actively involved throughout all the different stages of this research, from conception and design and interpreting of data and drafting the manuscript. MF made a substantial contribution in the conception of the theoretical framework of implementation of innovation in health care, the development of the questionnaire, interpreting the results and drafting of the manuscript. EV made a contribution analysis and interpreting the data. Finally, both MN and SR oversaw the interpreting of data and drafting of the manuscript. All authors approved the final version for publication and agree to be accountable for all aspects of the study they were involved in.

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6

CHAPTER 6

GENERAL DISCUSSION

The aim of this dissertation is to enhance the understanding of care use by children known to have or be at risk of complex problems (CP). We divided the subject into: care use, its intensity, and barriers to care. We also focused on multiproblem families, where we found the subgroup of children with the highest level of CP. Finally, we consulted professionals to understand the challenges of coordinating care for these children and their families. In this chapter we present and discuss the main results of our research for this PhD thesis. We also present implications for professionals and policymakers, as well as implications for future research.

Main findings

The main results of the four studies conducted are presented below, per research question:

Research question 1: Which predisposing, enabling, and need factors impact the use and intensity of overall and psychosocial care use by children with CP?

We used two waves of our cohort of children with CP. We found changes in use and intensity to be associated with changes in predisposing and need factors, but not with enabling factors. Change in overall care use was associated with a decrease in the burden of adverse life events (ALE) and with increasing parenting concerns. Change in psychosocial care use was associated with decrease in ALE, increase in parenting concerns, and older age of children (school-aged children vs. pre-school). Regarding intensity of use, we found that overall care use decreased when ALE decreased and when psychosocial problems became less severe. Intensity of psychosocial care also decreased when the severity of psychosocial problems declined.

Research question 2A: What do parents expect concerning practical barriers to psychosocial care use by their children with CP?

For this study, we used cross-sectional data of the cohort of children with CP. We found that a majority of parents expected practical barriers, i.e. logistic obstacles like transportation problems or inconvenient services (73%). Furthermore, parents of children using psychosocial care expected more barriers than those (at the time) using no care at all.

Research question 2B: Which predisposing, enabling, and need factors are associated with expected practical barriers for children with CP using psychosocial care or no care at all?

We found that expected practical barriers for children using psychosocial care were associated with predisposing and enabling factors, but not with need factors. More barriers were associated with children of school-age (vs. pre-school), of migrant background, having older parents, and having increased number of adverse life events and less social support from family and friends.

Research question 3: Which predisposing, enabling, and need factors are associated with overall and psychosocial care use by children of multiproblem families and their parents?
We included the baseline scores of multiproblem families of our cohort of children with CP. We found that care use was related to several predisposing, enabling, and need factors. A child's overall care use was associated with having greater social support from family and friends, and with having a greater number of psychosocial problems. Psychosocial care use was more likely among older children, and among those having greater social support by family and friends, more psychosocial problems, and more parenting concerns. Overall and psychosocial care use by parents was associated with experiencing a greater number of life events.

Research question 4: Which background characteristics and determinants of implementation hinder or facilitate adherence to the care coordination method Wraparound Care by professionals working in child and family services?
We conducted a cross-sectional survey in a sample of professionals working with Wraparound Care (WAC). First, we found adherence to the WAC core component *activating family members and the social network* to be relatively weak in comparison with the other two core components: *integrating the network of care providers* and *assessing, planning and evaluating the care process*. We also found self-efficacy of the care providers to be significantly associated with adherence to the three WAC core components. The way WAC was organized (as a broad network or in specially trained teams) was significantly associated with two core components: activating family members, and integrating the network of care providers.

Discussion of the main findings

We first discuss factors impacting psychosocial care use of children with CP and their parents' expectations regarding barriers to psychosocial care. Then we elaborate on factors influencing overall care use for children with CP in comparison to their psychosocial care use. We also expound on factors impacting care use by children and parents from multiproblem families to enhance understanding of care use by this subgroup with the highest level of CP. Finally, we discuss the factors impacting the degree to which professional youth care workers use the Wraparound Care method when helping children with CP.

Table 1 presents the main findings of our research on factors impacting care use by children with CP. We categorize these factors using Andersen and Newman's behavioral-health model of access to care [1]. Per category this includes the following variables: 1) predisposing factors: a child's age and adverse life events, 2) enabling factors: social support of family and friends, and 3) need factors: a child's psychosocial problems and parenting concerns.

Table 1 Overall results of cohort study on care use, its intensity and barriers to care, divided into severity of CP and type of care

	Known with or at risk of complex problems				**Multiproblem families**				
	Child				**Child**			**Parent**	
	Δ Care use		**Δ Intensity use**		**Barriers**	**Care use**		**Care use**	
	Psychosocial care	**Overall care**	**Psychosocial care**	**Overall care**	**Psychosocial care****	**Psychosocial care**	**Overall care**	**Psychosocial care***	**Overall care**
Predisposing factors									
Child age (pre- vs. school-age)	+	n.s.	n.s.	n.s.	+	+	n.s.	n.s.	n.s.
Adverse life events	-	-	n.s.	-	+	n.s.	n.s.	+	+
Enabling factors									
Social support by family and friends	n.s.	n.s.	n.s.	n.s.	-	+	+	n.s.	n.s.
Need factors									
Child's psychosocial problems (yes vs. no)	n.s.	n.s.	-	-	n.s.	+	+	n.s.	n.s.
Parenting concerns	+	-	n.s.	n.s.	n.s.	+	n.s.	n.s.	n.s.

*Parental psychosocial care use - significant positive association with parental mental health problems
**Barriers to care – significant positive association with ethnicity (non-western vs. western and native) and parental age (> 36 vs. younger)
+ significant positive association; – significant negative association; n.s. no statistically significant association

Psychosocial care use by children with complex problems

We first address the predisposing, enabling, and need factors influencing psychosocial care use by children known to have or be at risk of complex problems (CP). Psychosocial care is a subset of overall care, entailing care services delivered by mental healthcare, social care, school care or family services in the past six months.

Predisposing factors

We found that predisposing factors: child's age, and experience of adverse life events (ALE) impact care use, its intensity, and barriers to psychosocial care.

Child's age

Of children with CP, those of school age used psychosocial care more often than pre-school children, and their parents expected more practical barriers to access care. These findings are in line with previous studies [2-5]. Detecting CP and its risk factors in young children is difficult, because CP involves an interaction of needs, lack of skills, and unfavorable economic circumstances rather than reflecting one specific problem [6]. The younger the child, the harder it is to establish how or when these interwoven vulnerabilities will develop into complex problems. These uncertainties in the development of CP make it difficult for a professional to detect early warning signs, and then discuss them on time with parents to motivate them for treatment beyond the singular, often health-related, problem.

Adverse life events

We found a decrease in burden of adverse life events (ALE) to be associated with more care use, lower intensity of use and decrease in expectations of practical barriers. First, the negative association of ALE with care use and its intensity was not expected [7,8]. Children with CP are more likely to use care than people in the general population because they typically experience more traumatic and stressful life events [9]. It may be that the positive effect of trauma therapy on other emotional conditions motivates children with CP to continue treatment even when the burden of ALE decreases [10,11]. Second, the positive association between expected practical barriers and ALE is in line with earlier research [2]. It is possible that ALE upsets the fragile balance which the family needs to overcome practical barriers to care and eventual use of care when needed. Our results place ALE at the core of the whole care process of children with CP, i.e. not only care use itself, but also its intensity and the barriers to its use

Social support by family and friends as enabling factor

We found that social support by family and friends impacted expectations of barriers to care for children known to have or be at risk of CP, but did not impact psychosocial care use and its intensity.

Social support

Although we found a high level of social support to be associated with fewer expected practical barriers to psychosocial care, we were surprised to find that it had no relationship with changes in care use and its intensity [12]. There are two possible explanations for this. First, research, including our implementation study on WAC, showed that professionals struggle to make sustainable changes in the quality of social support of vulnerable families [13]. Secondly, the single year of follow-up in our study was possibly too limited to detect meaningful changes, especially for the families not receiving treatment. The negative association between social support and barriers was as expected, indicating that families with children with CP have adequate social networks to overcome daily difficulties, like finding someone to babysit when taking a child to treatment. Although social support is a known determinant impacting a child's care use in general, more research is needed regarding the use of social support to improve treatment for children with CP.

Psychosocial problems and parenting concerns as need factors

We found that the need factors: child's psychosocial problems and parenting concerns, were associated with psychosocial care use and its intensity, and not with barriers to care.

Psychosocial problems

Our results show an association between a decrease in a child's psychosocial problems and lower intensity of care use by children with CP. These findings are in line with earlier research [14,15]. However, assessing psychosocial problems for children with CP is a major challenge. Research indicates that children with CP are not automatically labelled as such when using standard screening surveys, probably because screening surveys do not have cut off scores for this target group, or are not applicable for detecting such problems[16]. Assessment of psychosocial problems alone is not enough to distinguish children with CP from children with a singular psychosocial problem. Children with CP will also have other need factors in at least two of the following domains: 1. parental factors, 2. parenting concerns, 3. family functioning, 4. contextual factors, 5. social network, and 6. issues with psychosocial care services [16]. Risk factors for these domains have not yet been identified. This study shows that psychosocial problems are an important factor related to care use by children with CP, but more research is needed into the risk factors in other life domains of these children.

Parenting concerns

An increase in parenting concerns was associated with changes in psychosocial care for children with CP. This confirms findings in earlier studies [17,18]. As parents with severe parenting concerns are more likely to seek help for their child, parenting concerns are an important indicator for referral to care [19]. Unfortunately, agreement between parents and professionals about severe parenting concerns is lower for parents with children with CP, possibly because these parents are less likely to express their concerns [20]. Better recognition of parenting concerns by professionals may thus enhance early detection and timely help for these children.

Barriers to care

In line with other studies, we found that most parents expect practical barriers to care, and continue to do so even when already in treatment, and especially when receiving psychosocial care [21,22]. In the paragraphs above we have already discussed the impact of a child's age, ALE, and social support on barriers, and add here that parents of non-western migrant background and of older age expected more practical barriers. Our findings indicate that parents of a child with CP find it challenging to navigate the system of psychosocial care services. To improve access to these services, anticipated practical barriers need to be addressed even when a child is already using care. This is especially important when children are of school-age and the family has experienced ALE, has a limited network, or belongs to an ethnic minority.

Overall care use of children with CP

One of the aims of this dissertation was to examine the differences between the predisposing, enabling, and need factors influencing overall and psychosocial care use of children with CP. Overall care use referred to any use of care and service delivered in the psychosocial or medical domain in the previous six months by the general practitioner, paramedical services (e.g., physiotherapist), medical specialist, mental healthcare services, social care services, school care services or family services. A child's age, ALE, and parenting concerns differently impacted overall care use compared to psychosocial care.

A child's age did not impact overall care use but did impact psychosocial care (see above). This is a favorable result for the accessibility of overall care. We also found that ALE impacted intensity of overall care but not psychosocial care. Other studies showed that ALE impacts intensity of care use over time [23]. Probably the positive effect of trauma based treatments in psychosocial care use, discussed above, may not be found nor expected for use of (para)medical care. This study shows that a child's age and ALE differently impact overall and psychosocial care use by children with CP.

Finally, we found that with an increase of parenting concerns, psychosocial care use became more and overall care use less likely. This finding was in line with our expectations. Professionals in psychosocial care services should be aware that they can miss underlying general health problems because they are trained to focus primarily on psychosocial factors. A child with CP typically has a wide variety of problems, often related to both psychosocial and general health conditions. This study also shows that parents expressing their parenting concerns use more psychosocial care than overall care possible leading to missing underlying health problems.

Care use by multiproblem families

Another aim of this dissertation was to examine whether use of care by multiproblem families is influenced by different factors than use of care by the total group of children with CP, and to examine which factors impact parental care use. We found that factors impacting care use by a child of a multiproblem family generally resemble those of the total group of children with CP, but differ with regard to social support by family and friends, the child's psychosocial problems, and parenting concerns.

Unexpectedly, more social support was associated with a high level of care use by multiproblem families, but social support did not impact care use by children with CP. Earlier studies found a reverse relationship in the general population, i.e. more social support associated with less care use [24,25]. Researchers have already argued that although the network of multiproblem families is wide and suitable for overcoming practical day-to-day challenges, the quality of support offered is typically low, which prevents these families from making long-lasting improvements in their lives [26]. Often the network of multiproblem families is centred around family members [24]. Loved ones often face the same vulnerabilities as the problem family, making it difficult *to provide adequate support; often their parents live in the same bad neighborhood, or siblings* bear the same vulnerabilities of a deprived childhood. As for the professionals, research shows that they are reluctant to involve the social network of multiproblem families, for reasons still unknown [25]. Our studies show that although social support is a key factor distinguishing multiproblem families from other families with a child with CP, the network is unequipped to make long-lasting changes to improve the quality of life.

We unexpectedly found that although a child's psychosocial problems impact use of care by multiproblem families, they did not impact changes in care use for the broader category of children with CP. In spite of overwhelming evidence that psychosocial problems are drivers of psychosocial care use [3-5], we consider our findings explainable in that the time span of our study was only a year. Our community based sample of children with CP, whether with or without treatment, showed only limited changes in their level of psychosocial problems. Research over a longer time span is needed to assess the impact of psychosocial problems on changes in care use by children with CP and of multiproblem families.

We found that parenting concerns did not impact overall care use by multiproblem families, but were relevant for care use by children with CP. Multiproblem families are typically easy for professionals to recognize [27], possibly minimizing the added value of parenting concerns for seeking treatment. Our study shows that parenting concerns play no role in factors related to care use by multiproblem families.

Regarding care use by parents in a multiproblem family, we found it to be associated with ALE as well as their own mental health problems. These findings correspond with earlier studies [28, 29]. Our study showed that both parental mental health problems and childrens' psychosocial problems are at the core of the help-seeking behaviour, thus underlining the importance of screening for these problems in both parents and children of a potential multiproblem family. The finding that ALE impacted parental care use suggests that a parent's lack of ability to cope with the struggles of the family is one of the factors to look for in a parent when screening for multiproblem family. These results emphasize the need for screening for mental health problems and ALE of the parent of a multiproblem family.

Adherence to Wraparound Care (WAC)

We also studied challenges faced by professionals when using the care coordination method Wraparound Care (WAC), designed to help children with CP. WAC is based on three core components: 1. activating family members and the social network, 2. integrating the care provider network, and 3. assessing, planning, and evaluating the care process [30, 31]. We found the professional's self-efficacy and the way WAC is organized to be associated with the level of adherence to WAC.

Self-efficacy

In line with earlier research, we found greater self-efficacy of the professional to be associated with higher adherence to all three core components of WAC [32]. An explanation may be the elaborate set of capabilities incorporated in WAC, such as the ability to activate the family and their social network. WAC is not a typical treatment with prescribed protocols like those which most professionals learned at school and are accustomed to work with; it is a value driven process for care planning and service delivery. Moreover*,* although the manual of WAC prescribes the timing for application of core components during treatment, the specific actions or treatment methods to address these components are left to the professional's judgment. This lack of guidance can lessen a professional's sense of self-efficacy. Furthermore, WAC is still a one-size-fits-all method for children with CP although this group is known for its wide variety of problems. Little research has been done into effective treatment options for subgroups. Our studies into care use by children with CP, for example, show that with regard to the activating of social support, treatment options should be tailored to the capabilities and environment of the multiproblem families themselves. Our study thus suggests that a professional's self-efficacy is a key factor for adherence to WAC, possibly because of a lack of guidance on treatment options for different subgroups of children with CP.

Organization of WAC

We found the way WAC was organized to be related to the level of adherence to the core components activating the family and their social support and integrating the professional network. However, we found that a top-down network based approach led to greater adherence than a team based bottom-up approach. This was unexpected because top-down network based approaches typically fail to address local needs and concerns which are especially important when integrating the professional network, and thereby hinder the implementation of the innovation [33, 34]. This raises the question: what are the best ways to organize implementation of WAC? Unfortunately, in the field of psychosocial care, systematic implementation of innovations like WAC is scarce, and studies on the subject are lacking [35]. In their comprehensive review, Colldrin and colleagues (2017) advise addressing three levels of needs and concerns to facilitate implementation of WAC: 1. a system level, to address needs concerning interagency collaboration, accountability structures, and flexible funding; 2. the team level[36, 37], to address concerns such as including the attendance of the family of the child at team meetings [38, 39]; and 3. the level of the care coordinator, to address the training and skills of the coordinator [40]. Our study indicates a need for more research on how to address local needs and concerns, to provide insight into more effective ways to organize implementation of WAC.

Methodological considerations

In this section we describe the main strengths and limitations of our study regarding the quality of the sample, the quality of the information obtained, and causality.

Quality of the sample

A major strength of our cohort was that it was a community-based sample of children known with or at risk of developing CP; this included children using different intensities of care, or no care at all. In most other research, samples have been limited to children with CP who are using a specific treatment [41, 42]. As our studies cover a broader range of children, both with and without care, we can generalize conclusions to the general population in an urban setting. To our knowledge, studies using similar community-based samples are rare, and fully lacking in the Dutch context. In our implementation study we also addressed a broad range of professionals whose, experience with WAC varied from non-existent to substantial, and who were involved with youth organizations varying from well-child clinics to mental health services. This facilitated inferences about determinants of successful implementation of WAC among a full range of youth care professionals.

A potential limitation of our cohort study is our use of care use as an inclusion criterion. We chose to oversample care use by our community sample to gain more insight into the development of CP short time span. Having a history of care use is part of what defines children with CP, and is thus one of our inclusion criteria; this may increase the risk of selection bias. However, in our study population, 97% of respondents met other inclusion criteria in addition to care use. Furthermore, our sample suits the aim of our study: to examine associations rather than prevalence.

Another limitation of our study is that families in a lower socio-economic position seemed somewhat underrepresented at T1, and were more likely to drop out at T2. Having a disadvantageous economic position is one of the main problems enhancing vulnerabilities of children with CP. We allowed for diversity by recruiting respondents from an urban area with severely deprived neighborhoods, and offering participants a telephone interview instead of an online enquiry. Nevertheless, despite our efforts to enhance response, underrepresentation of families from a lower socio-economic position may have had led to some underestimation of the strength of associations.

Quality of the data

Strong points in the quality of our cohort data include the extensive set of risk factors, the broad scope of both health- and psychosocial care use, and the use of two informants from each family, i.e. parents and child. This broad data set fits the wide variety of problems encountered by children with CP, and their parents.

A limitation was our use of self-reports to measure outcomes and intensity of care use in the past six months. Although we used the valid and reliable questionnaire Tic-P adapted to the setting of youth care, self-report [43, 44] may have been subject to recall bias. Recall bias may also have affected the measuring of risk factors such as the burden of ALE and the impact of the child's chronic conditions. This may have added measurement error and thus the impacts on reported associations, probably without clear under- or overestimation.

To enhance the validity of the questionnaire used in the implementation study, we followed a thorough process of questionnaire development, starting from a theory, and ensuring the face validity of questions used by conducting interviews with implementation agents as informants [33]. A limitation of the self-report adherence measures is that they may have led to an overestimation of adherence . The Wraparound team observation measure, proven to be a good alternative, was not yet available when we started our study [45].

Causality

Most studies included in this thesis had a cross-sectional design, limiting the potential to deduct causal inferences. However, the study on the intensity of care used the two waves of the cohort study, making it possible to correct the difference scores of outcome measures for difference scores of determinants, which in essence is a cross-sectional approach to analysis of longitudinal data. This analysis procedure gives insight into the impact of changes in factors and care use over time. Furthermore, with our extended set of predisposing and enabling factors we included several confounding factors proven relevant for care use, based on earlier studies [23, 46-48]. Nevertheless, the explained variances of our models were moderate, suggesting that we may have overlooked other factors impacting care use.

Implications

Our findings have several implications for care professionals and policy makers. These implications involve the identification and treatment of children with CP, and multiproblem families, as well as the implementation of WAC. Finally, we present our recommendations for further research to better understand care use of children with CP and expedite the implementation of WAC.

Implications for practice and policy

Implications for the identification of children with complex problems, and multiproblem families

Our findings have several implications for the identification of children with CP. First, we found that early detection of these children is difficult because of uncertainties regarding how CP develop; we therefore advise establishing a broad risk profile to identify them. Our studies indicate several risk factors: child's age, adverse life events (ALE), child's psychosocial problems, and parenting concerns. This risk profile should also include risk factors from other life domains [49]. When a child is identified as being at risk, follow-up assessment is needed to determine whether he or she indeed has CP. In the Netherlands such assessments could be performed by one of the three gatekeepers to psychosocial and health care: the general practitioner, local social teams, or preventive child healthcare. The latter in particular provides an excellent opportunity to detect CP at an early stage. Preventive child healthcare already has a high attendance rate in the general population, and conducts standard screening of both medical and psychosocial problems at several moments in a child's early life [50]. The development and implementation of a risk profile for children with CP could further augment timely identification.

We found that better recognition of parenting concerns may also improve identification of children with CP. We advise using tools for and training in shared decision-making to improve recognition of these parenting concerns. These tools and training can be included when training professionals in the use of WAC [51, 52]. Furthermore, we found that parents who express their parenting concerns use more psychosocial care than overall care, suggesting that they may miss their children's underlying health problems. We therefore advise psychosocial care professionals to look out for possible health problems when a child is diagnosed with CP. Both the general practitioner (the doctor who best knows the family), and the doctor or nurse in preventive health care (easily accessible because they are typically members of the local social team), can be consulted on this topic. This additional information on possible health issues and how they interact with psychosocial problems will ensure that the treatment plan covers all the needs of the child.

Our findings further point to two specific implications for identification of the subgroup multiproblem families. First, we found that children from these families have several risk factors that distinguish them from the group of children with CP as a whole; these risk factors, social support and parenting concerns, should be incorporated in the proposed follow-up assessment of children with CP. Second, our results show that early identification of parents' mental health problems and ALE helps with detecting multiproblem families. In-depth assessment of ALE is important, not only of recent but also past ALE during the childhood of the parent, because this can continue to affect his parenting [53-55]. We also advise incorporating these parental factors in the follow-up assessment. Our results call for extra attention to social support, parenting concerns, and parental risk factors in the follow-up assessment of children with CP, to identify multiproblem families.

Treatment of children with complex problems and multiproblem families

Our findings also have implications for the treatment of these children. First, we found that ALE play a significant role in the entire care process: not only care itself, but also its intensity and the barriers to its use. We advise structural assessment of ALE, and the use of evidence-based treatments where needed. Assessment should also entail an in-depth interview, going back to the younger years of the child. This could help to limit the risk of new ALE, thus breaking the intergenerational cycle of family events like violence, mental illness, and substance use [56]. During the termination phase of treatment, professionals should also offer tailored psycho-education regarding the re-occurrence and impact of ALE on the family, as these children typically face a greater risk of ALE [57]. Instruction to simplify reconnection with the care coordinator in case of an ALE should be included in this psycho-education. Furthermore, to lower barriers to reconnection, the care coordinator should maintain contact with the family, possibly at known milestones in the life of the child, like starting elementary or secondary school. Easy reconnection with the care coordinator can prevent children from relapsing after an ALE, and thus keep their problems from developing into multiple ones.

Second, we found that to improve access to psychosocial care, expected practical barriers need to be addressed, even when families are already using care. This applies especially when children are of school age, and/or when the family is experiencing ALE, has a limited network, and belongs to an ethnic minority. These findings are of interest to the three gatekeepers of the Dutch psychosocial care system: preventive child healthcare, local social teams, and the general practitioner, as well as to the central care coordinator of methods like WAC. Gatekeepers should especially address practical barriers to care of parents who have one of these risk factors. Moreover, the care coordinator should realize that even if families have once found their way to psychosocial care services, this does not mean they will find it again. We advise that care coordinators continuously address practical barriers and how to overcome them, for example by using the help of the social network or volunteers. Addressing these practical challenges is important not only to facilitate access to care, but also to ensure continued treatment.

We have one final recommendation regarding the treatment of multiproblem families. We unexpectedly found that support by a family's network of family and friends does not impact the high levels of care consumption. This calls for more research on the best way to activate such support [58]. Earlier studies have already indicated that the best intervention to activate social support requires a long-term approach, supervised by a care coordinator and involving a friend, family member, or volunteer who is able to model healthy support without expecting reciprocity at the beginning of the process[59]. Furthermore, the care coordinator should actively link formal and informal care and focus on the potential capabilities of families themselves [58-60].

Implications for the implementation of Wraparound Care

The findings in this dissertation also have implications for improving implementation of the care coordination method WAC. We found that a professional's perceived low self-efficacy is a key factor in non-adherence to WAC, possibly because of absent or inadequate training in care planning techniques, and insufficient guidance on treatment options for different subgroups of children with CP. In line with other studies of WAC, we advise developing a short list of effective interventions for different subgroups [61-63]. A Dutch inventory of effective interventions tailored for the subgroup multiproblem families has recently been made available [64]. When effective treatment options are not available, the use of a recently developed taxonomy can help professionals to reflect on their actions to improve the quality of care, for example by arranging supervision [58]. Finally, the development of a training module on care planning, based on several modelling techniques, can help to improve the level of self-efficacy of the professional [65]. Examples of modelling techniques include learning on the job, or a vlog series where the professional discusses and overcomes his/her challenges when using WAC. Providing training modules based on modelling techniques, and adding concrete treatment options to WAC will improve the self-efficacy of professionals.

Implications for research

Children with complex problems and multiproblem families

Our results indicate a need for more research into the risk factors for CP. We believe that Andersen and Newman's behavioral-health model of access to care provides an excellent conceptual framework to study these factors [66]. In children with CP we found changes in predisposing, enabling, and need factors -- for example in social support and psychosocial problems – to be infrequent and difficult to achieve, regardless of whether or not a child is undergoing treatment. We therefore advise using an extended time span to study these children to better understand how CP develop.

Based on the findings in this dissertation, children from multiproblem families are a subgroup of children with CP which should be identified and treated differently than the total group of children with CP. Our findings also suggest looking closer at possible other subgroups of children with CP, for example by using a prediction tree analysis, and developing tailored pathways to care for these groups.

We have found that factors impacting care use and factors impacting its intensity are not the same. This implies a need to study both aspects to understand the care seeking process of children with CP. As these children typically have higher care consumption than one would expect, based on their chronic condition alone, the need for more research the intensity of care use is clear.

We have also found that families expected many practical barriers, even when already in treatment. Children with CP need the support of different professionals to meet their needs in various areas of life. It would be interesting to learn how parents and children themselves feel they might overcome this challenge, and how the care coordinator of WAC could be of help.

Finally, in our studies we focused on a quantitative approach to give insight in care use of a community based sample of children with CP. This approach yielded interesting questions for further investigation of the mechanisms behind our findings, for example the intergenerational aspect of care use of multiproblem families, minority parents' expectations about barriers to care, and the interaction between factors of Andersen and Newman's framework of behavioral-health model of access to care. We advise a more in depth qualitative approach to address these additional questions.

Implementation of Wraparound Care

As WAC is the designated coordination method of care for children with CP in the Netherlands, we advise continued attention to its implementation, evaluation, and further development. This calls for an elaborate research agenda, probably best coordinated by a national agency aimed at expediting use of and adherence to WAC in the Netherlands.

Conclusion

The results of our studies augment the understanding of care use by children with CP, including the factors associated with their care use, the intensity of care use, and barriers to its use. These factors: child's age, ALE, child's psychosocial problems, and parenting concerns, provide a good starting point to develop a risk profile to detect children with CP. We argue that all gatekeepers to care for children: the local social team, the general practitioner, and preventive health services should be aware of these factors when identifying and helping children with CP. We also found that use of psychosocial care and overall care is affected differently by the factors child's age, ALE, and parenting concerns. These findings imply that gatekeepers to care should be aware that children with CP often have both psychosocial and health issues, and should assess how these interact. Our findings also show that multiproblem families are a specific subgroup that should be detected and treated somewhat differently from the total group of children with CP, and social support is one of the main factors that requires such a tailored approach. Finally, our findings indicate that a professional's self-efficacy and the way WAC is organized impact adherence to WAC. These findings call for further development of WAC and research into effective implementation strategies, probably requiring a structured community-oriented approach, organized in regional healthcare centers.

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APPENDICES

SUMMARY
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SUMMARY

Summary

The aim of this dissertation is to enhance understanding of care use by children known to have or be at risk of complex problems (CP). The thesis addresses their care use, its intensity, and barriers to care. We also address multiproblem families, involving a subgroup of these children with the highest level of CP. Finally, we studied professionals to understand the challenges they meet in organizing care for these children and their families when using Wraparound Care (WAC). This care-coordination method is used in the Netherlands as the backbone of treatment for children with CP.

Children with CP have a greater need for health services than the average child because their chronic physical, developmental, behavioral or emotional conditions interact and enhance their vulnerability. Children with CP require support from various professionals to meet their needs in various areas of life. Worldwide, around 5% of children suffer from CP, amounting in the Netherlands to 170,000 children. Children with CP run a high risk of poor mother-child attachment and of developing behavioural and emotional problems. They typically have high levels of overall care consumption, but especially of psychosocial care. As a consequence, up to 86% of the budgets for these services are spent on children with CP and their families.

Chapter 1, the introduction to this thesis, provides background information on children with CP and the subgroup with the most complex problems, called multiproblem families. We discuss Andersen and Newman's behavioral-health model of access to care which we used to structure our studies on care use. The model describes care use on the basis of three factors: 1. predisposing factors, i.e., a child's characteristics or abilities to use a specific service; 2. enabling factors, i.e., means whereby a family accesses care; and 3. health care needs. Furthermore, we elaborate on the Dutch care system and its fit with children with CP. We also discuss the care-coordinating method WAC. Finally, we explain the context of the Academic collaborative centre SAMEN, in which the research took place. At the end of Chapter 1 we present the research questions. These are:

1. Which predisposing, enabling, and need factors impact the use and intensity (number of contacts with care providers) of overall and psychosocial care use by children with CP?

2A. What do parents expect concerning practical barriers to psychosocial care use by their children with CP?

2B. Which predisposing, enabling, and need factors are associated with expected barriers to children with CP who use psychosocial care or no care at all?

3. Which predisposing, enabling, and need factors are associated with overall and psychosocial care use by both children of multiproblem families and their parents?

4. Which background characteristics and determinants of implementation hinder or facilitate adherence to the care coordination method Wraparound Care by professionals working in child and family services?

Care use by children with complex problems

Research on care use by children with CP is scarce, as is the understanding of the high level of care consumption by these children and their families. **Chapter 2** describes our study of factors that affect two key components of care use: care use itself and the intensity of its use (i.e., if >0 contacts). We studied overall care use and psychosocial care use as part of that. Psychosocial care included services offered by mental healthcare, social care, school care and family services. We assessed associations of changes in the determining factors, and in care use and its intensity, between the two waves in a cohort of children with CP. We found several risk factors to be associated with care use and its intensity: child's age, burden of adverse life events (ALE), child's psychosocial problems, and parenting concerns. Most findings were in line with available evidence, but a new finding was that ALE contributes to intensity of use. We unexpectedly found a child's psychosocial problems not to be associated with use of care in itself, but only with the intensity of care use.

Expected barriers to care by children with complex problems

Although only about one third of children with CP successfully enroll in psychosocial care, little is known about their reasons not to access care. In **Chapter 3** we explore the expectations of parents of these children regarding barriers to psychosocial care, and the factors that influence these expectations. We asked the parents of our cohort questions about their expectations regarding practical barriers, such as transportation problems or inconvenient services. We found that the majority of parents expected practical barriers, even when already using psychosocial care. Parents of children not using care during the past six months expected more barriers when their child was a daughter, and reported less social support from family and friends. Of children already using psychosocial care, parents expected more barriers if their child was of school age, of non-western origin (vs. native), parents were older, and the child experienced more adverse life events or less social support.

Care use by multiproblem families

Chapter 4 assesses factors impacting overall and psychosocial care use by members of multiproblem families, who make up the subgroup of children with the highest levels of CP. Policymakers and practitioners have special interest in this subgroup because they want to understand the dependency on long-term care of these families. We used baseline data from both parents and children in the multiproblem families selected out of our broader cohort of children with CP. Regarding the child’s care use, we found that the overall care use risk factors were the social support of their family and friends, and their psychosocial problems. A child's psychosocial care use was associated with age, social support by family and friends, psychosocial problems, and parenting concerns. We unexpectedly found higher levels of social support to be associated with higher care use. Parental overall and psychosocial care use were impacted by only one factor, i.e. the number of adverse life events.

Implementation of the care coordination method Wrap around care

Chapter 5 addresses the role of professionals in coordination of care for children with CP. We aimed to assess which determinants impede or expedite the implementation of Wraparound Care (WAC). In the Netherlands WAC is embraced as the most promising method to coordinate care for children with CP. Its impact depends greatly on the extent to which it is used as intended by all care providers. Unfortunately, in the field of psychosocial care, systematic implementation of innovations like WAC is scarce. We developed a survey to measure adherence to the core components of WAC and the determinants affecting this adherence. The survey was filled in by professionals from a broad field of youth psychosocial care services, varying in experience with WAC. First, we found adherence to the WAC core component *activating family members and the social network* to be relatively weak in comparison with adherence to the other two core components: *integrating the network of care providers* and *assessing, planning and evaluating the care process.* We also found a higher level of self-efficacy to be associated with higher adherence to WAC. Finally, the way WAC was organised affected adherence, with a broad network approach having more positive results that via a specialized team.

Discussion

Finally, **Chapter 6** presents the main results of this thesis, and its implications for early detection and treatment of children with CP and future research. First, we found several risk factors for the identification of children with CP: child’s age, adverse life events (ALE), child’s psychosocial problems, and parenting concerns. These factors provide a good starting point to develop a risk profile to identify potential children with CP. This profile could be implemented in the triage of all gatekeepers to care for children: 1. the local social team, 2. the general practitioner, and 3. preventive health services. More research is needed to understand risk factors in other life domains, such as the socio-economic domain. We also found that better recognition of parenting concerns may improve access to psychosocial care. Tools for shared decision-making could help, and should be implemented in Wraparound Care.

Regarding the treatment of children with CP, we found that experiencing ALE plays a significant role in the entire care process, not only the care itself but also its intensity and the barriers to its use. Structural assessment and easy approachability to the care coordinator in case of a new ALE could prevent children with CP from developing multiple problems.

We also found that parents continue to experience practical barriers, even when their child is already using psychosocial care. This applies especially when children are of school age, and/or when the family is experiencing ALE, has a limited network, and belongs to an ethnic minority. We advise gatekeepers and care coordinator of WAC always to address potential barriers. It would be interesting to learn how parents and children themselves feel they might overcome barriers, and how the care coordinator could be of help.

Our studies further showed that psychosocial care use and overall care use can be affected differently depending on a number of factors; this underlined the importance for gatekeepers to be aware that children with CP often have both psychosocial and health issues. We also advise gatekeepers to assess the interaction of these psychosocial and health issues, possibly by consulting health workers.

The results of our studies indicate that children from multiproblem families are a specific subgroup that should be identified and treated somewhat differently than the total group of children with CP. Extra attention to social support, parenting concerns, and parental risk factors in the follow-up assessment of children with CP can help to identify multiproblem families. To limit their high levels of care consumption, more research is needed to understand how social support can be provided by volunteers and the care coordinator.

Finally, our study on adherence to the care coordination method WAC indicates that it is impacted both by the professional's self-efficacy and the way WAC is organized. Providing training modules based on modelling techniques, and adding concrete treatment options to WAC will improve the self-efficacy of professionals. Finally, the impact of the local organization on adherence to WAC calls for research into effective implementation strategies, which in turn requires national collaboration. Further development of WAC and greater understanding of the factors impacting care use by children with CP will help to make their pathway to care more efficient and effective.

SAMENVATTING

Het doel van dit onderzoek is om de kennis over de zorg van kinderen met (een risico op) complexe problemen (CP) te vergroten en op basis daarvan aanbevelingen te doen voor het verbeteren van deze zorg. De focus van ons onderzoek ligt op het gebruik van zorg, de intensiteit van dit gebruik en barrières als een kind met CP zorg gaat gebruiken. Ook kijken we naar het zorggebruik van multiprobleem gezinnen, de subgroep gezinnen met de meeste complexe problemen. Tenslotte onderzoeken we wat zorgprofessionals nodig hebben om de zorg van kinderen met CP te coördineren met de methodiek Wrap around care.

Kinderen met CP hebben een grotere behoefte voor ondersteuning dan je zou verwachten op basis van hun chronische, fysieke, ontwikkelings-, gedragsmatige of emotionele problemen. Deze behoefte is groter omdat hun problemen elkaar versterken en hun al bestaande kwetsbaarheden vergroten. Kinderen met CP hebben in de regel veel zorg nodig, van verschillende hulpverleners uit verschillende domeinen. Rond de vijf procent van de kinderen heeft CP; dit zijn 170,000 kinderen in Nederland. Ze hebben een verhoogde kans op slechte hechting en het ontwikkelen van ontwikkelings-, gedragsmatige- of emotionele problemen. De zorgconsumptie van kinderen met CP is vaak hoog, dat geldt vooral voor zorg in het psychsociale domein. Meer dan 80% van de budgetten voor psychosociale zorg voor jeugd gaat naar deze kinderen en hun gezinnen.

Hoofdstuk 1 is de inleiding van het proefschrift. We geven achtergrondinformatie over kinderen met CP en beschrijven het zorgaanbod voor deze kinderen. We introduceren het framework voor zorggebruik zoals ontwikkeld door Andersen en Newman dat we gebruiken als basis voor de verschillende onderzoeken. Dit framework bestaat uit drie clusters: 1. “predisposing” factoren, oftewel de achtergrondkenmerken van een kind; 2. “enabling” factoren: de(on)mogelijkheden van het kind om in zorg te komen; en 3. “need” factoren, oftewel de zorgbehoeften van het kind met CP. We gebruiken in onze onderzoeken deze drie-indeling, maar spreken voor de leesbaarheid enkel van factoren. Ook bespreken we Wrap around care (WAC), de methodiek voor zorgcoördinatie die in Nederland standaard wordt gebruikt in de behandeling van kinderen met CP. WAC bestaat uit drie kernelementen: 1. versterken van de eigen kracht van het gezin; 2. samenwerking tussen professionals betrokken bij het gezin; en 3. doelgericht werken door de zorgcoördinator. We introduceren het samenwerkingsverband waarbinnen het onderzoek plaatsvond, de Academische Werkplaats-jeugd SAMEN (www.werkplaatssamen.nl). We eindigen het hoofdstuk met een beschrijving van de onderzoeksaanpak en de onderzoeksvragen. Deze zijn:

1. Welke factoren hebben impact op het gebruik van zorg en de intensiteit van dit gebruik door kinderen met CP, voor zorg in het algemeen en psychosociale zorg in het bijzonder?
2. A. Welke praktische barrières verwachten ouders indien zij zorg voor hun kind met CP zouden gaan gebruiken?

B. Welke factoren hangen samen met de verwachte praktische barrières, terwijl ze op dit moment psychosociale zorg of helemaal geen zorg gebruiken?

3. Welke factoren hangen samen met zorggebruik in het algemeen en psychosociale zorg in het bijzonder, door ouders en kinderen van multiprobleem gezinnen?
4. Welke achtergrondkenmerken en belemmerende factoren voor implementatie hangen samen met het bedoeld gebruik van Wrap around care van zorgprofessionals uit het psychosociale domein?

Zorggebruik door kinderen met complexe problemen

Er is maar weinig bekend over het zorggebruik van kinderen met CP. In **hoofdstuk 2** presenteren we de resultaten van de studie naar verandering in factoren die samenhangen met veranderingen van hun zorggebruik (wel/ niet) en de intensiteit van dit zorggebruik (het aantal contacten). We bekeken het zorggebruik in het algemeen, waaronder (para)medische en psychosociale zorg, en specifiek de psychosociale zorg die daar onderdeel van uitmaakt, gedefinieerd als zorg geboden door de GGZ, maatschappelijk werk, jeugdbescherming, geïndiceerde jeugdgezondheidszorg, zorg vanuit school en opvoedondersteuning. We gebruikten de gegevens van ons prospectieve cohort bestaande uit 356 gezinnen met een kind met CP, in ernst variërend van een risico op CP tot multiproblemen. De gegevensverzameling betrof een online zelfrapportage gevragenlijst voor ouders met vragen over hun kind in de leeftijd van achttien maanden tot twaalf jaar. We maakten gebruik van de voormeting en de nameting na twaalf maanden. Verschillende factoren hingen longitudinaal samen met gebruik van zorg en een hogere intensiteit van dit gebruik: leeftijd van het kind, ervaren last vanwege ingrijpende levensgebeurtenissen, psychosociale problemen van het kind en opvoedzorgen van de ouders. De meeste bevindingen zijn in lijn met eerder onderzoek, maar er zijn twee opvallende bevindingen. Ten eerste hangen ingrijpende levensgebeurtenissen niet alleen samen met het gebruik van zorg, maar ook de intensiteit van dit gebruik. Ten tweede hangen psychosociale problemen niet samen met zorggebruik, maar wel met de intensiteit van dit gebruik als er gebruik is.

Verwachtingen van ouders over barrières in de zorg voor kinderen met complexe problemen

Slechts een derde van de kinderen met CP gebruikt psychosociale zorg. In **hoofdstuk 3** beschrijven we welke verwachtingen ouders hebben over barrières als zij gebruik zouden gaan maken van zorg voor hun kind met CP en welke factoren samenhangen met deze verwachtingen. We vroegen de ouders van ons cohort in de beginmeting welke praktische barrières zij verwachtten, bijvoorbeeld rond vervoer naar de behandellocatie of het vinden van een oppas. De meerderheid van de ouders verwachtte een of meer praktische barrières, zelfs als hun kind al psychosociale zorg gebruikt. Als een kind al psychosociale zorg gebruikte, verwachtten ouders meer barrières als zij zelf een hogere leeftijd hebben, minder sociale steun van vrienden en familie ervaren, het kind ouder is, van niet westerse origine is, of minder ingrijpende levensgebeurtenissen heeft meegemaakt. Als een kind in de afgelopen zes maanden geen behandeling heeft gehad, verwachten ouders meer praktische barrières als ze een dochter hebben en als ze minder sociale steun ervaren.

Zorggebruik van multiprobleem gezinnen

Het doel van **hoofdstuk 4** is om inzicht te krijgen in factoren die samenhangen met zorggebruik door ouders en kinderen van multiprobleem gezinnen. De complexe problemen zijn bij deze kinderen ontwikkeld tot een chronische aandoening, waardoor het waarschijnlijk is dat zij hun leven lang afhankelijk zijn van zorg. Beleidsmakers en zorgprofessionals hebben bijzondere aandacht voor deze subgroep omdat zij deze levenslange afhankelijkheid van zorg willen voorkomen. We onderzochten cross-sectioneel welke factoren samenhangen met zorggebruik in het algemeen en psychosociale zorg in het bijzonder.

We selecteerden de multiprobleem gezinnen uit ons cohort van kinderen met CP. Het algemene zorggebruik van een kind van een multiprobleem gezin hing samen met hun psychosociale problemen en met de sociale steun van familie en vrienden. Het gebruik van psychosociale zorg door het kind hing samen met de leeftijd van het kind (oudere kinderen meer dan jongere kinderen), psychosociale problemen (met problemen meer dan zonder), sociale steun van familie en vrienden (negatieve associatie) en opvoedzorgen van ouders (positieve associatie). Hierbij is vooral opvallend dat meer ervaren sociale steun samenhing met hoger zorggebruik. Zorggebruik van de ouder van een multiprobleemgezin, zowel algemene als psychosociale zorg, hing positief samen met een enkele factor, namelijk het aantal ingrijpende levensgebeurtenissen.

Invoering van Wrap around care, de methodiek voor zorgcoördinatie

In **hoofdstuk 5** richten we ons op de zorgprofessional die met Wrap around care (WAC) werkt. Doel was inzicht krijgen in het gebruik van WAC en determinanten die dit gebruik beïnvloeden. Ondanks het feit dat het effect van een methodiek sterk afhangt van de mate van gebruik zoals bedoeld (adherentie), is onderzoek naar systematische implementatie van vernieuwingen zoals WAC schaars. We ontwikkelden een vragenlijst waarmee we het bedoeld gebruik van kerncomponenten van WAC en de determinanten die dit gebruik beïnvloeden kunnen meten. Deze online vragenlijst werd ingevuld door 275 zorgprofessionals uit het psychosociale domein. Deze zorgprofessionals verschilden in opleiding, ervaring in het werken met WAC en werkten in verschillende organisaties. Zorgprofessionals scoorden relatief laag op gebruik van de kerncomponent versterken van de eigen kracht van het gezin ten opzichte van de twee andere kerncomponenten samenwerken tussen professionals en doelgericht werken door de zorgcoördinator. Verder hingen de determinanten eigen-effectiviteit van de professional en de wijze waarop WAC is georganiseerd (via gespecialiseerde teams of in een breed netwerk van samenwerkende organisaties) samen met de mate van gebruik van WAC zoals bedoeld.

Aanbevelingen en conclusie

In het **laatste hoofdstuk** bespreken we de betekenis van de bevindingen uit dit proefschrift voor toekomstig onderzoek en het (vroeg)signaleren en behandelen van kinderen met CP. Allereerst benoemen we de in onze onderzoeken gevonden risicofactoren voor het identificeren van kinderen met CP: de leeftijd van het kind, ingrijpende levensgebeurtenissen, psychosociale problemen van het kind en opvoedzorgen van de ouders. Deze risicofactoren vormen de basis voor een te ontwikkelen risicoprofiel voor deze kinderen. Dit profiel kan gehanteerd worden bij de triage door de drie poortwachters in de zorg voor jeugd 1. de lokale sociale/ wijkteams; 2. de huisarts en 3. de jeugdgezondheidszorg. Verder onderzoek is nodig om dit risicoprofiel uit te breiden naar andere levensdomeinen, zoals de socio-economische situatie van het gezin.

Een van de gevonden risicofactoren voor CP is de opvoedzorgen van ouders. De toegang tot zorg kan verbeterd worden door hulpverleners te trainen om deze zorgen beter te herkennen. We adviseren dat in het zorgaanbod voor kinderen met CP, zoals WAC, bestaande methoden of tools gericht op gezamenlijke besluitvorming tussen hulpverlener en gezin worden opgenomen.

Dit proefschrift geeft ook handvatten voor het verbeteren van de behandeling van kinderen met CP. Het belangrijkste handvat is gebaseerd op onze bevinding dat ingrijpende levensgebeurtenissen niet allen impact hebben op zorggebruik zelf, maar ook op de intensiteit waarmee zorg wordt gebruikt en op de verwachte barrières in de toegang tot zorg. We adviseren dan ook dat zorgprofessionals doorlopend aandacht hebben voor ingrijpende levensgebeurtenissen, zowel al meegemaakte levensgebeurtenissen als gebeurtenissen die tijdens de behandeling optreden. Verder zouden er na afsluiting van de zorg afspraken gemaakt moeten worden om bij het optreden van levensgebeurtenissen laagdrempelig in contact te kunnen komen met de zorgcoördinator. We verwachten dat uitvoering van deze aanbevelingen leidt tot preventie, waarmee (gedeeltelijk) voorkomen kan worden dat complexe problemen ontwikkelen tot multiproblemen.

Ouders verwachten praktische barrières indien zij zorg zouden gaan gebruiken voor hun kind met CP, ook als hun kind al gebruikt maakt van psychosociale zorg. We adviseren dat zorgcoördinatoren en de poortwachters van de zorg voor jeugd in hun consulten altijd potentiële barrières adresseren. Dit kan het gebruik van zorg door kinderen met CP ten goede komen.

De factoren die samenhangen met zorggebruik in het algemeen zijn andere dan de factoren die samenhangen met het psychosociale zorggebruik dat daar deel van uit maakt. Kinderen met CP hebben vaak zowel psychosociale als fysieke problemen, die vaak interacteren met elkaar. We adviseren de poortwachters en zorgcoördinator hier oog voor te houden en aanvullend expertise in te winnen wanneer nodig.

We zien aanwijzingen dat multiprobleem gezinnen een aparte doelgroep zijn die kan worden onderscheiden van de brede groep kinderen met CP. Daarom moeten ze op een andere wijze gesignaleerd en behandeld worden. We stellen voor om een follow up-assessment te ontwikkelen voor multiprobleem gezinnen, in aanvulling op de signalering van CP met behulp van het eerder genoemd risicoprofiel. Risicofactoren voor multiproblematiek zijn sociale steun door familie en vrienden, opvoedzorgen en risicofactoren van ouders. Verder adviseren we ontwikkelonderzoek naar manieren hoe sociale steun geactiveerd kan worden, bijvoorbeeld door inzet van vrijwilligers of een zorgcoördinator. We verwachten dat dit bijdraagt aan het verminderen van het hoge zorggebruik van multiprobleem gezinnen.

Tenslotte bespreken we de betekenis van de resultaten van ons onderzoek naar de invoering van de zorgcoördinatiemethodiek WAC. Het gebruik van WAC zoals bedoeld hangt samen met de eigen-effectiviteit van de zorgprofessional en de wijze waarop WAC is georganiseerd. We hebben twee adviezen om de eigen-effectiviteit te vergroten: 1. gebruik modelling technieken bij het trainen van WAC, zoals learning on the job en 2. maak een overzicht van effectieve behandelopties in elke fase van de zorgcoördinatie beschikbaar om handelingsverlegenheid te ondervangen. Rondom het determinant de wijze waarop WAC is georganiseerd, adviseren we onderzoek naar effectieve implementatiestrategieën, en dan met name preferente wijzen om de WAC regionaal te organiseren. Dit vraagt om landelijke samenwerking.

Afsluitend concluderen we dat dit proefschrift toepasbare kennis heeft opgeleverd over de implementatie van WAC en factoren die het zorggebruik van kinderen met CP bepalen. Hiermee kunnen de zorgpaden voor deze kinderen effectiever en efficiënter ingericht worden. Meer onderzoek blijft echter nodig om de complexe problemen en het hoge zorggebruik van deze kinderen beter te begrijpen.

DANKWOORD

Dankwoord

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CURRICULUM VITAE

Curriculum vitae

Noortje Martine Pannebakker was born in Schiedam in 1980. In 1999, she started her undergraduate education in Psychology at the University of Leiden. She obtained her masters in both child developmental psychology and health psychology in 2004. Her master thesis focused on families with complex and multiproblems. After her graduation she started working as a family counsellor and cognitive behavioural therapist at the mental health clinic Parnassia- Bavo Europoort. Between 2007 and 2010 Noortje worked as a policy maker and public affair officer at the youth social work organization Jeugdformaat. From 2011 onwards, Noortje worked on her PhD project Care use of children with complex problems at LUMC, department of Public Health and Primary Care. During this period she was employed by TNO Child Health. Her PhD project was conducted within SAMEN, the Collaborative Centre youth in the Dutch urban area of The Hague (werkplaatssamen.nl/english). This centre aims to improve the transfer and generation of knowledge and innovations between practitioners, policymakers, researchers, the education sector and clients. Noortje is the coordinator of this collaborative centre. She continued working at TNO, currently as a consultant. She participates in projects aiming to improve services in the social domain, combining her expertise on implementation, learning communities, health services research and coordinating coalitions and partnerships.

LIST OF PUBLICATIONS

Pannebakker NM, Chung M, Broerse A. Kocken PL. Een Haagse best practice voor het coördineren van zorg vanuit het Centrum voor Jeugd en Gezin. Tijds gezondheidswet 2012; 90: 394–397.

Pannebakker NM, Kocken PL, Theunissen MHC, van Mourik K, Crone MR, Numans ME, et al. Services use by children and parents in multiproblem families. Child Youth Serv Rev 2018;84:222-228.

Moor I., Pannebakker, NM, Wins S, Kocken PL. De ervaringen van multiprobleem gezinnen met communicatie in de zorg. Tijds gezondheidswet 2018; 96: 329–331.

Pannebakker NM, Fleuren MAH, Vlasblom E, Numans ME, Reijneveld SA, Kocken PL. Determinants of adherence to wrap-around care in child and family services. BMC Health Serv Res 2019;19(1).

Pannebakker NM, Kocken PL, van Dommelen P, van Mourik K, Reis R, Reijneveld SA, et al. Care use and its intensity in children with complex problems are related to varying child and family factors: A follow-up study. PLoS ONE 2020;15(5).

PORTFOLIO

PORTFOLIO

PhD student: NM van Bolhuis-Pannebakker F
Primary thesis advisor: prof.dr. ME Numans
Other thesis advisor(s): Prof. dr. S.A. Reijneveld

Research programme: 31202 Prevention, Population and Disease management (PrePoD)

Title of Thesis: Understanding care use by children with complex problems

PhD training

	Year	Hours
Mandatory courses		
- PhD Introductory Meeting (done)	2020	
- BROK Course (done)	2018	
Generic/disciplinary courses		
- several courses in statistics		100
- project management (incompany TNO)		150
- course research communication		110

Attended lectures, LUMC presentations, participation in meetings

- presentation at LUMC-colleagues PHEG
- chairman expertmeeting

Congress attendance and poster or oral presentations

- oral presentation
- workshop
- oral presentation

Other activities (such as journal club)

- dissemination: interview
- dissemination: Dutch peer reviewed article
- dissemination: Dutch peer reviewed article
- dissemination: interview

- dissemination: interview
- guidance of a masterstudent
- guidance of a masterstudent

TOTAL number of hours **360**

Publications

	Year
Publications in peer reviewed journals (article, review, editorial, letter to editor)	
- Services use by children and parents in multiproblem families; Pannebakker Noortje M., Kocken Paul L., Theunissen Meinou H. C., et al.; 2018; Journal article	2018
- Determinants of adherence to wrap-around care in child and family services; Noortje M. Pannebakker, Margot A. H. Fleuren, Eline Vlasblom, et al.; 2019; Journal article	2019
- Care use and its intensity in children with complex problems are related to varying child and family factors: A follow-up study; Pannebakker, N.M.; Kocken, P.L.; Dommelen, et al.; 2020; Journal article	2020