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Chapter 2

Behavior Problems in Children with Chronic Illness Applying for Psychosocial Care: Risk and Protective Factors

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Submitted for publication

ABSTRACT

Objective: To describe behavior problems in children with various chronic illnesses (CI) who seek psychosocial support, and to examine associated risk factors and protective factors.

Methods: Parents and children who signed up for a cognitive behavioral based group intervention on coping with CI ($N = 194$) completed online questionnaires. Multiple linear regression analyses were conducted on internalizing and externalizing behavior problems with illness severity, coping strategies, self worth, parenting stress, and perceived parent-child relationship security.

Results: Parents and children reported elevated levels of internalizing problems. More use of child disengaged coping, lower self-worth, less security of the parent-child relationship and more parenting stress were uniquely associated with more behavior problems.

Conclusion: Behavior problems of children with CI should be considered as an outcome of a dynamic process in which interrelated risk and protective factors contribute. Implications for screening and intervention are outlined.

Key words: chronic illness, coping, self-worth, parent-child relationship, parenting stress, behavior problems.

INTRODUCTION

Children and adolescents growing up with chronic illnesses, such as diabetes, asthma, arthritis, and inflammatory bowel disease are confronted with stressors like hospitalizations, activity restrictions due to medical regimens, and uncertainty about the course of the illness. Chronic exposure to stress has adverse effects on psychosocial functioning (Barlow & Ellard, 2006; Lavigne & Faierroutman, 1993; LeBlanc, Goldsmith, & Patel, 2003). Internalizing problems, such as anxiety and depression, and externalizing problems, such as aggression and noncompliance, are potential concerns for children with chronic illness (Soliday, Kool, & Lande, 2000). A recent meta-analysis reported elevated levels of behavior problems, mainly of the internalizing type, in children with chronic illness compared with their healthy peers (Pinquart & Shen, 2011). To adequately prevent and treat these problems it is important to select and develop appropriate interventions that match the level of risk, and support-needs of families that cope with chronic illness. This study describes the level of behavior problems in children with various chronic medical conditions that seek psychosocial support, and examined associated risk and protective factors.

Transactional models of child adaptation to chronic illness recognize the importance of numerous psychosocial risk- and protective factors that could be targeted and modified in interventions (Thompson, 1996; Wallander & Varni, 1998; Brown, Doepke, & Kaslow, 1993; Kazak et al., 2007). Specifically, the disability-stress-coping model of Wallander & Varni (1998) identifies several illness (e.g. severity, duration), stress-processing (e.g., cognitive appraisal and coping strategies), intrapersonal (e.g., temperament, self esteem/competence, and motivation), and social ecological (e.g., family environment, hospital environment, social support, and parental functioning) factors (Wallander & Varni, 1998). The interplay among these factors is thought to account for a considerable amount of the variance in psychosocial functioning in children with a chronic illness.

Previous research has demonstrated that psychosocial functioning varies with respect to disease type (Pinquart & Shen, 2011). One explanation may be differences in illness severity among diseases (Lavigne & Faierroutman, 1993; McQuaid, Kopel, & Nassau, 2001) regarding, for example, the intensity of the treatment and hospitalization (Wamboldt, Fritz, Mansell, McQuaid, & Klein, 1998), visible symptoms of illness (Hysing, Elgen, Gillberg, & Lundervold, 2009; Haverman et al., 2012), limitations in school attendance (Haverman et al., 2012), and a poor or uncertain disease prognosis (Mishel et al., 1991). However, studies that include both illness- and psychosocial risk-factors in the same regression models provide compelling evidence that illness factors account for little of the variability in psychosocial problems compared to psychosocial factors (Lavigne & Faierroutman, 1993).

Studies on stress-processing factors show that use of maladaptive or adaptive coping strategies is associated with psychosocial functioning of children with CI and cancer (Patenaude & Kupst, 2005; Stam, Grootenhuis, & Last, 2001; Burlew, Telfair,



Colangelo, & Wright, 2000). For instance, self-criticism and social withdrawal, which are disengaged coping strategies, are strongly related to anxiety or sadness among children with CI (Compas et al., 2006; Spirito et al., 1994). In contrast, problem solving and cognitive restructuring, which are engaged coping strategies, have been associated with better psychological outcomes (Gil, Williams, Thompson, & Kinney, 1991; Meijer et al., 2002).

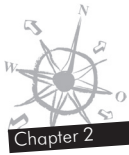
Empirical studies on intrapersonal factors often focus on global self-worth and self-concept (Appleton et al., 1994; Burlew et al., 2000; Simon, Barakat, Patterson, & Dampier, 2009). Growing up with chronic illness can limit children in achieving every day successes (e.g. social, athletics and academic), which are necessary to develop a positive view of the self (Harter, 1986). Although studies that compare children with chronic illness with healthy peers often reveal no significant differences in overall self-worth (Arnold & Chapman, 1992; Lemanek, Horwitz, & Ohenebrempong, 1994; Schuengel et al., 2006), there are also several studies that indicate that self-worth is negatively associated with internalizing behavior problems in children with chronic illness (Aasland & Diseth, 1999; Appleton et al., 1994; Burlew et al., 2000; Simon et al., 2009).

A growing body of evidence supports the association between social ecological factors (e.g., parental functioning, family environment) and child adjustment outcomes in childhood chronic illness (Thompson, Gil, Burbach, Keith, & Kinney, 1993). For instance, parenting stress was associated with higher levels of internalizing symptoms in children with chronic illness (Mullins et al., 2004). Furthermore, it is often assumed that parenting stress exerts effects through the parent-child relationship (Deater-Deckard, 1998); however, few studies with children with chronic illness have examined parent-child attachment security as a potential protective factor. Secure parent-child attachment, which involves a sensitive and responsive caregiver to the child's need for proximity, promoted optimal development (Wan & Green, 2009). In turn, insecure parent-child relationships, characterized by lower carer sensitivity, were associated with more depressive symptoms in children with asthma (Bleil et al., 2000).

Previous studies have predominantly been conducted in groups of children with specific diagnoses, and did not include children based on apparent need of support. Existing intervention programs are mostly developed for a single diagnosis (Beale, 2006; Plante et al., 2001), even though the psychosocial challenges associated with different chronic illnesses may show considerable overlap. In order to provide leads for interventions that are suitable for children with various chronic illnesses, the current study aimed to give insight in behavior problems, and associated risk- and protective factors in children affected by chronic illness applying for a psychosocial group intervention. Specific insight in this specific group is helpful in bringing forward a more focused and effective intervention program targeted to the needs of these children.

To adequately select appropriate interventions it is important to identify the level of risk and distress presented. To match risk levels to interventions, Kazak (2006)

developed the Pediatric Psychosocial Preventative Health Model (Kazak et al., 2011). This pyramid-shaped model defines three health care levels. When families have limited risk factors and are resilient (Universal level), it is suggested to provide general support (e.g. give information). When some risk factors are present, along with moderate levels of distress (Targeted level), it is recommended to monitor distress and provide preventive interventions. When more risk factors are present and distress becomes persistent, clinical treatment from a health specialist (e.g. pediatric psychologist) is necessary (Clinical level) (Kazak et al., 2011). Because families in our sample applied for a psychosocial intervention, they might represent the targeted or clinical level. Therefore, we expected slightly elevated levels of mainly internalizing behavior problems compared to the normative sample, and also compared to children with CI in general. Furthermore, we hypothesized that next to illness characteristics, stress-processing (engaged- and disengaged coping), intrapersonal (self-worth), and social-ecological (parenting stress and the security of the parent-child relationship) factors combined would explain a considerable amount of variance in internalizing and externalizing behavior problems, regardless of the influence of illness severity. Of specific interest were factors that would uniquely contribute to the prediction of problems, because those factors should particularly be targeted in interventions.



METHODS

Design

Participants came from a multicenter randomized controlled trial (RCT) designed to test the effectiveness of a psychosocial group intervention that aims to prevent and/or reduce behavior problems in children with chronic illness (Scholten et al., 2011). The current study presents cross-sectional results from the baseline data. The study protocol was reviewed and approved by the Medical Ethical Committee of the Academic Medical Center Amsterdam.

Participants and Procedures

Between May 2009 and August 2010, 1,134 children and adolescents from three academic hospitals, four non-academic hospitals, and two primary schools for chronically ill children were invited to participate in a psychosocial group intervention through a letter from their pediatrician and pamphlets available in the outpatient clinics. Positive response was received from 19% ($N = 218$) of the families. This percentage was expected, considering reported mental health care use of children with CI (LeBlanc et al., 2003), combined with the obligations of participating in a RCT. Eligibility criteria included the following: (a) diagnosed with a chronic illness (van der Lee et al., 2007); (b) 8-18 years of age, or enrolled in at least the fifth grade of Dutch primary school;

(c) absence of severe learning difficulties; (d) ability to complete Dutch questionnaires. Inclusion criteria were checked in a telephone screening, and 10 children were excluded. Informed consent forms with detailed information about the interventions and randomization were sent to the eligible families. Five families failed to provide written informed consent and nine dropped out because of travel distance and planning conflicts. As a result, 194 families participated in this study.

Of all 194 participating families, baseline questionnaires were available from parents ($n = 178$) and/or children ($n = 184$). Children's ages ranged from 7.52 to 18.07 years (mean age = 12.03 years, $SD = 2.68$); 50% were girls. Children were under medical care for 45 different diagnoses. The five most common diagnoses were: type 1 diabetes ($n = 57$, 29%), auto-immune diseases ($n = 24$, 12%), kidney disease ($n = 24$, 12%), inflammatory bowel disease ($n = 19$, 10%), and asthma ($n = 18$, 9%). Mean age at diagnosis was 5.97 years ($SD = 4.82$) and over one-third of the children were diagnosed at birth ($n = 65$, 35.7%). The majority of the children and their parents were born in the Netherlands ($n = 133$, 69%), had a medium to high income ($n = 137$, 70%), and lived in a two-parent household ($n = 155$, 80%). Approximately one-half of the parents had received higher education ($n = 90$, 46%).

Measures

Behavior problems were assessed with the Child Behavior Check List (Dutch version) [Parent Report Form (PRF) 4-18 years and Youth Self Report (YSR) 11-18 years] (Verhulst, 1996; Verhulst, 1997). Questionnaires consisted of 120 PRF and 119 YSR problem items and a 3-point Likert scale [from 'not true' (= 0) to 'very true or often true' (= 2), regarding behavior during the past six months]. Items from the narrowband subscale 'Somatic Complaints' (contributing to the broadband scale 'Internalizing Problems') were disregarded in further analysis given the nature of the sample (Perrin et al., 1991). Consequently, 'Internalizing Problems' included the subscales 'Anxious/depressed' and 'Withdrawn/depressed'. The Externalizing Problems scale included the subscales 'Rule-breaking behavior', and 'Aggressive behavior'. These raw scale scores were used in the analyses. Internal consistencies for the PRF and YSR internalizing and externalizing scales ranged from $\alpha = .84$ to $\alpha = .91$. Dutch norms are available (Verhulst, 1996; Verhulst, 1997). To indicate the percentages of children scoring within the subclinical or clinical range, T scores were computed from the raw scale score. A T score of 63 (90th percentile in the norm population) demarcates the clinical range, which is an indication that a child has clinically relevant symptoms and needs professional help.

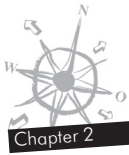
Coping strategies of the child were measured using an adapted version of the Coping Strategies Inventory (CSI). The CSI is a self-report questionnaire, and assesses coping thoughts and behaviors in response to a specific stressor (Tobin, 1991). A 32-item version is widely used (Madanswain et al., 1994), and validated in pediatric literature (Blount et al., 2008). For the current study, the 8 items with the highest factor loadings were used (Tobin, 1991). Children were asked to describe a specific stressful

event and to evaluate 8 different responses to this event on a 5-point scale ranging from “I never do this” to “I always do this”. These 8 responses represent two particular coping strategies: 1) problem engaged coping, which consists of two problem solving (e.g., “I worked on solving the problems in the situation”), and two cognitive restructuring responses (e.g. “I convinced myself that things aren’t quite as bad as they seem”), and 2) emotion disengaged coping, which consists of two responses that reflect self criticism (e.g., “I blamed myself.”), and two that indicate social withdrawal (“I avoided being with people”). Internal consistencies were acceptable ($\alpha = .66$, and $.60$, 4 responses) and comparable to other studies (Addison et al., 2009).

Self-worth was assessed with the global self-worth scale of the Perceived Competence Scale for Children (8-12 years) and the Perceived Competence Scale for Adolescents (12-18 years) (Treffers, 2002; Veerman, 1997). The global self-worth scale in the child-version (8-12 years) consists of 6 items, and in the adolescent version (12-18 years) consists of 5 items (e.g., ‘Some children are happy with themselves’ versus ‘Other children would like to be someone else’). Respondents first had to decide which of the items in the pair better described them, and then they had to choose between ‘sort of true’ or ‘really true’. In order to combine children and adolescent scores in the analyses, we used the raw scale scores divided by the number of items. Adequate reliability and content validity with samples of children with and without illnesses has been reported (Treffers, 2002; Veerman, 1997). Internal consistency in the current sample was satisfactory (child-version $\alpha = .78$, adolescent-version $\alpha = .89$).

The *emotional security of the parent-child relationship* was measured using the Child Security Scale (CSS) (Kerns, Aspelmeier, Gentzler, & Grabill, 2001). Children rated 15 statements (e.g., ‘I feel my mother really understands me’) on a 5-point scale ranging from “totally agree” to “totally disagree”. The CSS exhibited good convergent validity with measures of attachment in children aged 10-12 years old (Kerns, Tomich, Aspelmeier, & Contreras, 2000). Children completed the CSS about both parents. Internal consistency was $\alpha = .75$ and $\alpha = .81$ for the mother and father, respectively. We used the mean of the total scale scores from the mother and father ($r = .52$, $\alpha = .85$).

Parenting stress was assessed using the short version of the ‘Nijmeegse Ouderlijke Stress Index (NOSIK), which is a revised Dutch version of the Parenting Stress Index (De Brock, Vermulst, Gerris, & Abidin, 1992). It contains 25 items that could be rated on a 6-point scale ranging from 1 = disagree very much to 6 = agree very much. An example of a question is: ‘My child turns out to present more problems than expected’. The NOSIK consists of 2 subscales, with 11 items referring to child characteristics (e.g. adjustment, mood) and 14 items referring to parent characteristics (efficacy, depression) within the care giving context. For comparison to the norm we used the raw total score, however; to prevent overlap between the child characteristics and the outcome measure, only the parent scale was used in further analyses. The internal consistency of this scale was adequate in the current study ($\alpha = .86$).



Background and illness characteristics were obtained from parents. Family composition, socioeconomic status (income), ages, genders, and ethnicities were recorded. Illness characteristics (illness type, duration and severity) were also collected. To assess illness severity, a proxy measure for illness severity was constructed based on 13 possible consequences of chronic illness experienced in the past year, as rated by parents (0 = 'no', 1 = 'yes', scale 0-13): doctor visits, hospitalization, surgery, use of medication, dietary consequences, visible malformations, use of appliances, limitations

TABLE 2.1 Descriptives and Norm Comparison of Internalizing and Externalizing Problems and Risk- and Protective Factors

	Range	Current sample M (SD)	Norm M (SD)	T
Outcome variables, parental report		N = 178	N = 493	
PRF Internalizing problems	0-42	12.92 (8.13)	5.80 (5.20)	11.69**
PRF Internalizing problems (excl. SC) ¹	0-42	8.65 (5.95)	5.80 (5.20)	6.39**
Anxious/depressed	0-26	5.28 (4.08)	2.95 (2.78)	7.61**
Withdrawn/depressed	0-16	3.38 (2.58)	1.58 (1.90)	9.29**
Somatic complaints	0-20	4.27 (3.54)	1.23 (1.78)	11.47**
PRF Externalizing problems	0-64	8.42 (7.21)	6.70 (6.30)	3.18**
Rule-breaking behavior	0-30	1.89 (2.27)	2.13 (2.56)	-1.43
Aggressive behavior	0-34	6.53 (5.56)	4.58 (5.53)	4.67**
Outcome variables, child report		N = 110	N = 564	
YSR Internalizing problems	0-42	14.95 (8.89)	9.95 (7.15)	5.91**
YSR Internalizing problems (excl SC) ¹	0-42	9.91 (6.77)	9.95 (7.15)	-0.06
Anxious/depressed	0-26	5.90 (4.70)	4.25 (3.50)	3.68**
Withdrawn/depressed	0-16	4.01 (2.55)	2.90 (2.45)	4.56**
Somatic complaints	0-22	5.05 (3.32)	2.85 (2.60)	6.93**
YSR Externalizing problems	0-70	8.28 (5.88)	9.90 (7.05)	-2.88**
Rule-breaking behavior	0-34	3.02 (2.26)	3.65 (3.40)	-2.93**
Aggressive behavior	0-36	5.26 (4.19)	6.25 (4.45)	-2.47*
Risk- and protective variables				
Illness severity	0-13	4.34 (1.52)		
Emotion disengaged coping N = 184	4-20	7.74 (3.51)		
Problem engaged coping N = 184	4-20	9.92 (4.15)		
Self worth N = 186	0-4	3.13 (0.73)		
Parent-child relationship N = 186	15-75	60.74 (7.36)		
Parenting stress (total scale) N = 176	25-150	52.37 (21.90)		

PRF = Parent Report Form, YSR = Youth Self Report

¹Excluding the "somatic complaints" items.

²Effect sizes from the meta-analysis of Pinquart & Shen (2011). Hedge's d was converted in Cohen's d. Effect sizes ≤ 0.2 were considered small, effect sizes of approximately 0.5 were considered moderate, and effect sizes of approximately 0.8 were considered large (Cohen, 1988).

* $p < .05$; ** $p < .01$.

in diet, exercise, hearing, vision, and speech (Hatzmann, Maurice-Stam, Heymans, & Grootenhuis, 2009).

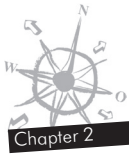
Data Analysis

Statistical Package for the Social Sciences (SPSS) version 19.0 was used for all analyses. Preliminary analyses of variance tested whether it would be necessary to control for age, gender, ethnicity, Socio-economic status (SES), illness type, illness duration, and illness severity. Control variables were only included in the analyses when significantly ($p < .05$) associated with both outcome and predictor variables. All outcome variables were coded so that higher scores reflect higher levels of the concept being measured.

Behavior problems were compared with norm data, using one-sample *t*-tests. Effect sizes (*d*) (Cohen, 1988) were calculated by dividing the difference in mean score between children with CI and the norm group by the standard deviation of the norm group's scores. Effect sizes were also compared to those from a meta-analysis on behavior problems in children with CI in general (Pinquart & Shen, 2011), using 95%-confidence intervals (95%-CI). Furthermore, the percentage of children who scored in the subclinical or clinical range of the externalizing and internalizing problem scales was described based on clinical cut-off scores in the general Dutch population (Verhulst, 1996; Verhulst, 1997).

To study risk- and resistant factors associated with behavior problems, first, Pearson correlations of coping, self-worth, parent-child relationship and parenting stress with externalizing and internalizing problems were calculated. Second, multiple linear regression analyses were performed to examine the unique contributions of coping, self-worth, parent-child relationship and parenting stress (predictors) to the regression models of internalizing and externalizing problems, while controlling for background and illness characteristics (control variables). A priori power analysis indicated that a sample size of $N = 172$ was required for the proposed regression analyses ($\alpha = .05$, power = .80, a maximum of 10 predictors in a model with

<i>d</i> (95%-CI)	Pinquart ² <i>d</i> (95%-CI)
	N = 51.422
1.04 (.87-1.21)	0.51 (.47-.54)
0.51 (.35-.67)	-
0.67 (.5-.83)	0.53 (.48-.57)
0.79 (.63-.96)	0.57 (.52-.62)
1.09 (.92-1.25)	0.72 (.66-.78)
0.25 (.09-.42)	0.24 (.21-.27)
-0.1 (-.26-.06)	0.33 (.28-.39)
0.35 (.19-.52)	0.40 (.35-.45)
	N = 51.422
0.62 (.42-.82)	0.27 (.18-.36)
-0.01 (-.21-.19)	-
0.40 (.2-.6)	0.25 (.14-.37)
0.44 (.24-.64)	0.34 (.22-.45)
0.74 (.54-.94)	0.53 (.38-.67)
-0.25 (-.45--.05)	-0.01 (-.10-.08)
-0.22 (-.42--.02)	0.10 (-.06-.26)
-0.23 (-.43--.03)	0.10 (-.02-.22)



a small to medium effect size of $f^2 = .10$). Post-hoc power analyses for the presented regression models indicated that the regression models had sufficient power (.99). Given the value of R^2 , Cohen's f^2 is calculated to indicate the effect size of the multiple regression model. Analyses of the self-reported outcomes (YSR) were limited to children aged 11 years and older ($n = 105$). Analyses of variance indicated that, in the present study, children older than 11 years of age who filled in the YSR did not differ from children who were too young to complete the YSR regarding gender, psychosocial functioning (PRF), and predictor variables ($p > .05$).

RESULTS

Behavior problems

Descriptive data on outcome- and risk- and protective factors are presented in Table 2.1. For internalizing problems, including the 'somatic complaints' items, both parents and children reported significantly higher levels of internalizing problems than the norm population (Table 2.1). Comparison of the confidence intervals revealed that effect sizes were significantly larger than the effect sizes found in the meta-analysis of behavior problems in children with CI in general (Pinquart & Shen, 2011). For internalizing problems excluding the 'somatic complaints' scale, parents reported more internalizing problems than the norm, while levels of self-reported internalizing problems were comparable to the norm. Parents reported more externalizing problems and children reported less externalizing problems than the norm population. Most effect sizes for externalizing problems were lower than the effect sizes reported in the meta-analysis of Pinquart and Shen (2011). Excluding somatic complaints from the internalizing scale, 48% of parents and 15% of children reported internalizing problems within the subclinical or clinical range. Percentages of externalizing problems within subclinical or clinical range were 19% based on parental report, and 4% based on self-report.

Risk Factors and Protective Factors

As demonstrated by the correlations in Table 2.2, most risk- and protective factors were significantly related to the internalizing and externalizing problems. Illness severity was merely associated with parent-reported internalizing problems. More use of disengaged coping strategies, lower self-worth, and a less secure relationship were associated with more behavior problems. Less use of engaged coping strategies was associated with more parent and self-reported internalizing problems, but was not associated with externalizing problems. Higher parenting stress scores were significantly related to higher problem scores, except for self-reported externalizing problems.

To identify the unique contribution of each predictor for each outcome, beta coefficients of the regression models are reported in Table 2.3. Illness severity was

TABLE 2.2 Correlation Matrices of Outcomes and Predictors (PRF, $n = 178$; YSR, $n = 110$)

	1	2	3	4	5	6	7	8	9	10
Outcomes										
1. PRF Internalizing problems	-	0.53**	0.34**	0.04	0.31**	0.19*	-0.15*	-0.33**	-0.17*	0.50**
2. YSR Internalizing problems		-	0.19*	0.43**	0.17	0.35**	-0.22*	-0.56**	-0.38**	0.28**
3. PRF Externalizing problems			-	0.56**	0.14	0.23**	-0.04	-0.30**	-0.25**	0.46**
4. YSR Externalizing problems				-	0.04	0.37**	-0.01	-0.28**	-0.46**	0.19
Predictors										
5. Illness severity					-	0.08	-0.16*	-0.12	-0.04	0.17*
6. Emotion disengaged coping						-	0.08	-0.40**	-0.33**	0.11
7. Problem engaged coping							-	0.18*	0.11	-0.19*
8. Self worth								-	0.48**	-0.25**
9. Parent-child relationship									-	-0.19*
10. Parenting stress										-

PRF = Parent Report Form, YSR = Youth Self Report

* $p < .05$; ** $p < .01$.

entered as a control variable in the model for parent-reported internalizing problems, and continued to explain unique variance. Age was entered as a control variable in the model for self-reported internalizing problems, but explained no unique variance. None of the other socio-demographic or illness related control variables were entered in the regression analyses because the Pearson correlations between these variables and the outcomes or predictors were not significant.

More use of emotion disengaged coping contributed uniquely to explaining higher levels of self-reported internalizing and externalizing problems. Problem engaged coping explained no unique variance in behavior problems. Lower self-worth was uniquely associated with higher levels of self- and parent-reported internalizing problems. Lower security of the parent-child relationship contributed uniquely to explaining higher levels of self-reported externalizing problems. Higher parenting stress was uniquely associated with higher levels of parent-reported behavior problems.



TABLE 2.3 Multivariate Effects of Risk-and Protective Factors on Internalizing and Externalizing Problems

	PRF			YSR			PRF			YSR		
	Internalizing problems ¹			Internalizing problems ¹			Externalizing problems			Externalizing problems		
	B	SE B	β	B	SE B	β	B	SE B	β	B	SE B	β
Age	-	-	-	-.34	0.29	-0.11	-	-	-	-	-	-
Illness severity	0.98	0.26	0.24**	-	-	-	-	-	-	-	-	-
Emotion disengaged coping	0.10	0.12	0.06	0.31	0.16	0.19*	0.19	0.15	0.09	-0.35	0.15	0.23*
Problem engaged coping	0.01	0.10	0.01	-0.18	0.14	-0.12	0.15	0.13	0.08	0.079	0.13	0.05
Self worth	-1.46	0.62	-0.18*	-3.76	0.86	-0.44**	-1.38	0.81	-0.14	-0.15	0.82	-0.02
Parent-child relationship	0.02	0.06	0.02	-0.09	0.08	-0.11	-0.08	0.08	-0.08	-0.26	0.08	-0.34**
Parenting stress	-.33	0.05	0.44**	0.10	0.07	0.13	0.38	0.06	0.42**	0.09	0.07	0.13
Model	$R^2 = .38$			$R^2 = .39$			$R^2 = .27$			$R^2 = .27$		
	$F(6,168) = 16.43^{**}$			$F(6,103) = 10.48^{**}$			$F(5,168) = 12.13^{**}$			$F(5,103) = 7.12^{**}$		
	$f^2 = .61$			$f^2 = .64$			$f^2 = .37$			$f^2 = .37$		

PRF = Parent Report Form, YSR = Youth Self Report

¹Excluding the "somatic complaints" items.

f^2 = Effect sizes of ≤ 0.02 were considered small, effect sizes of approximately 0.15 were considered moderate, and effect sizes of approximately 0.35 were considered large (Cohen, 1988).

* $p < .05$; ** $p < .01$

DISCUSSION

Findings revealed heightened internalizing behavior problems among children affected by chronic illness applying for a preventive group intervention. Externalizing problems were also elevated, but to a lesser degree. It should be noted that in the older subgroup of children providing self-report, behavior problems did not appear elevated, if somatic complaints were disregarded. Among families seeking help for psychosocial difficulties, parents and children may therefore not always share the same perception of the need for such support. Our findings are consistent with results from previous studies, and underline the value of multi-informant assessments, and caution in interpreting internalizing problems scales with somatic items (Perrin et al., 1991).

Findings on risk- and protective factors were partly consistent with our hypotheses and previous research. Results from the bivariate analysis confirmed the expected significant associations of stress-processing, intrapersonal, and parental factors with behavior problems, and the multivariate analysis showed that the risk-protective factors combined explained a considerable amount of variance in internalizing and externalizing behavior problems ($.35 \leq f^2 \leq .64$). However, unique predictive value of these risk-protective factors depended on outcome and informant. First, more use

of disengaged coping strategies was associated with more self-reported internalizing and externalizing problems. This bolsters the impression that avoidant thoughts and behaviors negatively affect the adaptability of children with CI, making them more vulnerable to the development of emotional and behavioral problems (Thompson et al., 1993). Child engaged coping was bivariately associated with internalizing problems, but the correlations were weak, and in the multivariate analysis, disengaged coping and self-worth had stronger links. This leads to the tentative assumption that the use of more disengaged coping strategies makes children more vulnerable for problems than the use of less engaged strategies. However; to form theory on this issue future research should investigate the differences between coping strategies more thoroughly. Second, in agreement with our hypothesis and other studies higher self-worth was associated with less internalizing problems, as reported by the child as well as the parent (Burlew et al., 2000; Simon et al., 2009). This indicates that negative thoughts and beliefs about the self increases risk, and that this should be targeted in interventions for children with CI. Third, also consistent with findings in other studies (Mullins et al., 2004) our results indicated that higher parenting stress predicted more parent-reported internalizing and externalizing problems in children. Because parenting stress only explained unique variance in parent reported outcomes, an alternative interpretation could be that the effect of parenting stress is exercised through parental perceptions of child functioning. Finally, a more secure parent-child relationship was related to fewer self-reported externalizing behavior problems. This finding demonstrates that children with CI might benefit from a secure parent-child relationship, and supports the notion that the effect of chronic illness, as well as the effect of other chronic stressors (Willemsen, Schuengel, & Koot, 2011), can be limited by a secure parent-child relationship. Interventions that involve parents may therefore be more effective than interventions that focus solely on children (Wysocki et al., 2000; Drotar, 2005).

The results of our study indicate that families that applied for a psychosocial intervention varied in their level of risk and distress. According to parents, almost half of the children in our sample had serious internalizing problems, mainly of the anxious/withdrawn subtype. Given the associations between internalizing problems and self-worth and parenting stress, this group is also exposed to serious risk factors at the child and parental level. These families appear to belong to the clinical (high risk) level of the Pediatric Psychosocial Preventative Health Model (Kazak et al., 2011) and need intensive types of care. However, on average self-reported behavior problems were comparable to the norm, and only 15% of the children scored themselves in the clinical range, indicating that large part of the sample belonged to the targeted or universal level. For families with low levels of risk, brief and non-intensive interventions (e.g. online psycho-educational programs), might be enough to prevent psychosocial problems. To provide the best suitable care, individual risk-screening might be necessary (Kazak et al., 2011), and should include multi-informant data on the level of behavior problems, and stress processing, intrapersonal, and parental risk factors.



Given the cross-sectional research design, caution is necessary when interpreting associations as causal. Longitudinal studies (and, ultimately, intervention trials) are necessary to test whether changes in risk factors over time lead to changes in behavior problems. Furthermore, although the findings of this study are based on multi-informant data, reporter bias is possible, and the use of observational data might enhance the internal validity of the results. Also, families applied for a randomized controlled study, possibly affecting the characteristics of the participants. Finally, our coping measure was self-translated and internal consistencies were merely acceptable. Specific coping strategy measures with good psychometric quality are scarce, especially in the Netherlands. Future research should explore the development and validation of specific coping measures for children with CI.

Notwithstanding these limitations, this study contributes to existing knowledge about the links of coping, self-worth, and parenting with behavior problems of children with CI by focusing on a population of children with various health conditions who applied for psychosocial care. Results emphasize the importance of screening for risk-factors in order to match families to appropriate interventions. Furthermore, findings highlight the need for targeted family-based interventions that focus on empowerment and resilience in children with CI.