

VU Research Portal

Coping with Pediatric Chronic Illness

Scholten, L.

2013

document version

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Scholten, L. (2013). *Coping with Pediatric Chronic Illness: Efficacy, Moderators and Mediators of a Psychosocial Group Intervention for Children and Parents*. [PhD-Thesis – Research external, graduation internal, Vrije Universiteit Amsterdam].

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl



Chapter 7

**Feasibility of a Psychosocial Group
Intervention for Children with Chronic
Illness and their Parents and Directions for
Future Implementation**

INTRODUCTION

Growing up with a chronic illness poses potential risk to the psychosocial functioning of children (LeBlanc et al., 2003; Pinquart & Shen, 2011). There is evidence that adjustment to pediatric chronic illness may be promoted by learning active coping skills using cognitive behavioral techniques (Barlow & Ellard, 2004; Beale, 2006; Thompson et al., 2011). In Chapter 4, results were reported of a randomized controlled trial (RCT) investigating the efficacy of a cognitive behavioral based group intervention (called ‘Op Koers’), which was designed to teach children with various chronic illnesses active coping skills in order to reduce behavior problems. Baseline data of this RCT revealed that almost half of the children that applied for the intervention had serious internalizing behavior problems, mainly of the anxious/withdrawn subtype (Chapter 2). Findings on efficacy demonstrated that the intervention had positive effects on internalizing and externalizing behavior problems, and that long term effects were mainly attributable to the involvement of parents in the intervention.

While evaluation with standardized questionnaires is vital to establish empirical evidence on efficacy, it does not provide practical information that is useful for implementation of interventions in clinical practice. It has been shown that even when interventions are proven to be effective, the translation of these interventions into clinical practice remains a complex and haphazard process (Spirito & Kazak, 2006; Stark, 2010). This is problematic, because it is recognized that poorly implemented and executed interventions are significantly less effective (Berwick, 2003). Therefore, for successful implementation it appears to be important to evaluate practical issues and subjective experiences of participants.

The current study aimed to investigate feasibility of the ‘Op Koers’ intervention by evaluating several outcomes related to implementation during the RCT, in order to be better able to optimize future implementation in clinical pediatric practice. First, we discuss recruitment and logistical issues of conducting ‘Op Koers’ in three academic hospitals, four non-academic hospitals, and two primary schools for chronically ill children, during the RCT. Second, we assessed if the intervention goals matched the support needs of the families. And finally, we evaluated satisfaction with the intervention reported by children, parents and psychologists.

METHODS

Participants and Procedures

Participants came from a multicenter RCT that was designed according to the Consolidated Standards of Reporting Trials statement (Schulz et al., 2010). Full details of the content of the intervention, study procedures and efficacy were previously described



in Chapters 3 and 4. In this chapter, we particularly report on procedures that could be relevant for implementation in clinical practice.

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. Pediatricians were approached from different departments. After willingness to contribute to the study they made up a list of potential patients who were eligible in collaboration with their administration. Eligibility criteria included: (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. Informed consent forms with detailed information about the interventions and randomization were sent to the eligible families. Participants were randomized into a child-only intervention, a parent-child intervention, and a waitlist control group. To spread recruitment, Interventions were carried out over three time periods.

‘Op Koers’ intervention

Children in both intervention groups (child-only and parent-child) received the same group course consisting of six weekly 90-minute sessions, and a booster session after 6 months, with four to eight participants per group. Five coping strategies were taught: (1) information seeking and information giving about the disease (‘good to know better’ principle), (2) use of relaxation during stressful situations and medical procedures (using exercises), (3) increase knowledge of self-management and compliance, (4) enhancement of social competence (group discussions, role playing), and (5) positive thinking (effective use of the Thinking-Feeling-Doing model; replacement of inaccurate thoughts) (Kendall & PanichelliMindel, 1995). Two slightly different versions of the protocol were developed, one for children at primary school age (8–12 years old) and another for adolescents (12–18 years old).

The parent component consisted of six 90-minute sessions parallel to the child sessions. Parents were reinforced in sensitively attending to their child’s needs, and in encouraging their child to use the five aforementioned coping strategies. The parent intervention fitted into the learning goals of the child intervention. Three learning goals were central to the parent component: (1) Learning: to understand what the children learn (psycho education, group discussions), (2) Observing: to be sensitive to children’s cognitions and feelings (by assignments to talk about feelings with their child), and (3) Motivating: to stimulate their children to apply the learned skills in daily life (by assignments to support their child to ask questions to the doctor). All sessions took place in the hospital/school where the child was recruited. Two qualified psychologists or one psychologist and one other mental health care professional (later referred to as

psychologists), carried out the child group, and the parent group, based on a detailed manual. All psychologists ($n = 39$) were extensively trained in the protocol. A detailed content of the interventions is described in our previous chapters (3 and 4).

Measures

Information on *recruitment* was obtained by evaluating response and attrition rates. *Logistical issues* were reported in an evaluation questionnaire directly after the three interventions periods, by psychologists who carried out the intervention in each of the nine centers (open question: "What logistical issues rose from conducting the interventions?").

Information on the *support needs* was reported in a baseline demographic questionnaire by parents prior to the intervention and information on the extent to which these support needs matched the intervention was reported by psychologists directly after the interventions (in the evaluation questionnaire). Parents were asked to report the problems their children experienced with handling the consequences of their illness (open question). Psychologists reported two items on the way the child intervention and the parent component in general matched the support needs of children and parents ('I found that the content of the child/parent course matched the support needs of the children/parents'), and two items on the way intervention goals were met ('I think that the child/parent course achieved that children cope better with their illness'), on a 5-point scale (ranging from: 'not at all' to 'very much'). For these questions, a cut-off was indicated at 3 for each item.

To assess *satisfaction* with the intervention, evaluation forms were collected from children, parents and psychologists directly after the intervention. Children who participated in the child-only or the parent-child intervention completed a 9-item questionnaire; parents who participated in the parent-child intervention completed a 12-item questionnaire. First, participants were asked about their satisfaction with the content regarding each individual learning goal on a 4-point scale (example for children: "How did you like the relaxation exercises?", 0 = did not like it, 1 = somewhat liked it, 2 = liked it 3 = don't know; example for parents: "How useful did you find the relaxation exercises?", 0 = not useful, 1 = somewhat useful, 2 = useful, 3 = very useful). In addition, children and parents were asked to report on a 3-point scale if they: 1) believed that what they learned in the intervention was useful (0 =not useful, 1= somewhat useful, 2 = very useful), 2) used the learned skills in everyday life (0 = no, 1 = sometimes, 2 = yes), and if yes, what kind of skills they used the most (open question); 3) found that the home-work assignments were useful (0 =not useful, 1= somewhat useful, 2 = very useful), and 4) would recommend the intervention to others (0 = no, 1 = maybe, 2 = yes).

Psychologists completed 2 items on overall satisfaction with the program , on a 4-point scale (ranging from: 'not at all' to 'very much'). In addition, they were asked if they enjoyed to carry out the intervention on a 5-point scale (ranging from: 'I did not like



it' to 'I liked it very much'), and on how they thought of the intervention as an addition to the psychosocial care in their hospital (ranging from: 'not valuable addition' to 'very valuable addition). For these questions, a cut-off was indicated at 3 for each item.

Data analyses

To indicate satisfaction of children, parents, and psychologists, descriptives and percentages were computed. Chi square tests were used to compare the percentages of satisfaction in the child-only versus the parent-child intervention, and the child versus the adolescent protocol.

RESULTS

Recruitment

Of those given the opportunity to participate, positive response was received from 19% ($N = 218$) of the families. Ten children were excluded because they did not meet inclusion criteria, five families failed to provide written informed consent, and nine dropped out because of travel distance and scheduling problems. As a result, a total of 194 families participated in the RCT. There was 7.0% attrition in the child-intervention, and 4.1% in the parent-child intervention. For this study we only used data from children and parents who participated in the intervention groups, and filled in the evaluation questionnaire directly after the intervention ($N = 95$, 80%). Children's ages ranged from 8.01 to 18.07 years (mean age = 12.11 years, $SD = 2.73$); 63% of the participants were between 8-12 years old, 37% was between 12-18 years old. 53% were boys.

Logistical issues

Psychologist ($n = 35$, 90%) reported the following issues that concern logistical issues:

- For the hospital administration it was difficult to track down the addresses of children with rare chronic illnesses who had no frequent checkups in the hospital.
- Pediatricians and nurses often forgot to distribute pamphlets and inform families about the intervention.
- Travel distance was reported as burdensome by some families.
- In some cases parents wanted to participate, but children (often adolescents) did not.
- It was difficult to find a time point on which the group could be scheduled.
- Several parents (mostly fathers) wanted to participate; however, groups were during their work time.
- Conducting the parent-child intervention required four psychologists at the same time, which was not possible in three out of the nine settings, because of limited numbers of psychologists working in those centers.

Support needs

Parents reported several different child adjustment problems, for which they asked support in the intervention. Open answers could be differentiated into seven different categories,: physical problems (e.g. pain, fatigue), acceptance problems (e.g. does not want to be sick, does not want to talk about his/her illness or treatment), social problems (e.g. finds it difficult to talk to others, is being bullied), emotional/ behavioral problems (e.g. feels sad, worries a lot, is often scared or angry), participation problems (e.g. cannot compete in activities/sports, misses school a lot), compliance problems (e.g. does not take his/her medication, fails to comply with regulations from the doctor), or no problems. As shown in Table 7.1, problems were distributed quite evenly, with compliance problems as most reported, and participation problems as least reported. 13% of the parents reported that their child had no adjustment problems. Parent-reported child adjustment problems match the focus and intervention goals of ‘Op Koers’.

Of the psychologists, 96% reported that the child intervention matched the support needs of the children, and 77% reported that the parent component matched the support needs of the parents. The most frequently noted ($n = 4$) comments on the content of the parent component was that parents desired more opportunity to exchange personal experiences with the other parents than the protocol allowed for.

TABLE 7.1 Parent-reported Child Adjustment Problems (N = 161)

	<i>n</i>	%
Adjustment problems		
Physical problems	24	15
Acceptation problems	30	19
Social problems	21	13
Emotional problems	22	14
Participation problems	10	6
Compliance problems	33	21
No problems	21	13

Satisfaction with the program

Satisfaction with the intervention reported by children, parents and psychologists is reported in Table 7.2. Overall, children were highly satisfied with the content of the intervention. They most often liked the information and exercises related to the intervention goal ‘treatment and compliance’, and they less liked the ‘relaxation exercises’. Parents were also satisfied with the parent component of the program. They thought the content on ‘social competence’ and ‘positive thinking’ was the most useful, but also ‘learning’ (to understand what the children learned), and ‘observing (to be sensitive to children’s cognitions and feelings) were viewed as helpful. Satisfaction reported by the children on



all the five learning goals did not differ between the child-only and the parent-child, and also not between the child and adolescent version of the protocol ($p > .05$).

Furthermore, 91% of the children, and 83% of the parents believed that what they learned in the intervention was useful, and 76% reported that they used the learned skills in everyday life. Out of this 76%, 14% reported that they used the skills related to information seeking/ giving the most (e.g. 'how to tell others about your illness?', and 'how to ask questions to your pediatrician?'), 53% reported that they used the relaxation exercises the most (e.g. 'relaxation when you are scared or when you worry', and 'relaxation tricks for medical procedures', 30% reported to use the skills related to positive thinking and worrying the most (e.g. 'when you think positive, you feel better, and 'what to do when you worry?'), and 3% reported to use all learned skills equally often. 98% Of the children and parents thought that the home-work assignments were very useful. 92% of the children and 86% of the parents would recommend the program to others.

Psychologists who carried out the intervention were overall highly satisfied with the content of the intervention (Table 7.2). In addition, 92% enjoyed giving the intervention, and 93% labeled the intervention as a valuable addition to the psychosocial care in their hospital.

TABLE 7.2 Satisfaction of Children ($N = 95$) and Parents ($N = 42$) with the Content of the Intervention Separate for each Intervention Goal, and Overall Satisfaction Reported by Psychologists ($N = 35$)

Children¹	-	+/-	+	?
Information seeking	3%	44%	45%	7%
Relaxation exercises	40%	24%	32%	4%
Social competence	2%	39%	54%	5%
Positive thinking	6%	37%	52%	5%
Treatment and compliance	4%	34%	56%	6%
Parents²	-	+/-	+	++
Learning	2%	14%	69%	14%
Observing	0%	17%	62%	21%
Motivating	0%	14%	67%	19%
Information seeking	14%	33%	43%	10%
Relaxation exercise	21%	33%	33%	12%
Social competence	0%	12%	64%	24%
Positive thinking	0%	12%	48%	41%
Treatment and compliance	2%	33%	41%	24%
Psychologists³	-	+/-	+	++
Content child-only intervention	0%	0%	6%	94%
Content parent-child intervention	0%	0%	3%	97%

¹ - = did not like it, +/- = somewhat liked it, + = liked it, ? = don't know.

² - = not useful, +/- = somewhat useful, + = useful, ++ = very useful.

³ - = not at all satisfied, +/- = somewhat satisfied, + = satisfied, ++ = very satisfied

DISCUSSION

Findings of this evaluation study indicated that the ‘Op Koers’ intervention is feasible for implementation in clinical practice of pediatric settings given its (1) low intervention attrition rates, (2) appropriate content as illustrated by the overlap of reported support needs and intervention goals, and (3) overall satisfaction with the program reported by participants and professionals.

The results indicated several avenues for improvement of the ‘Op Koers’ intervention, such as revision of the relaxation exercise, and more time for exchange of personal experiences in the parent protocol. Furthermore, findings of this study evoked several issues noteworthy to address with regard to future implementation.

First, the response rate of families who applied to the intervention was relatively low (19%). On the one hand, because we actively recruited children and parents by a letter from their own pediatrician, a higher percentage could be expected. On the other hand, the response might not be representative for implementation in clinical practice, because families were not only invited to participate in an intervention, but also for participation in an RCT (with randomization, and four assessments). Therefore, for implementation in clinical practice we expect a slightly higher response percentage, also considering reported mental health care use of 25% of children with chronic illness (LeBlanc et al., 2003). Nevertheless, there are several efforts that could improve participant recruitment. Increasing awareness among health professionals related to the targeted population is often the first step (Cuijpers, van Straten, Warmerdam, & van Rooy, 2010). Multi-disciplinary teams treating these children might consider recruiting participants actively in the out-patient clinics, by recommending the intervention to their patients during regular checkups, or by sending out annual recruitment mailings. In addition, organizing interventions at regular time points might help to systematize recruitment, and keep stakeholders alerted. It is important to inform health care providers that the intervention is preventative and that no particular level of adjustment problems is necessary. Furthermore, systematic screening of adjustment problems in clinical practice may increase identification of potential participants (Haverman et al., 2012).

Second, conducting a group intervention, especially an intervention that includes a separate parent component, requires extensive logistical efforts for both participants and professionals. Several families in our sample gave logistical problems as a reason not to participate. Research on various types of programs serving different populations consistently showed that time demands and scheduling issues were the main barriers to parent participation (Ingoldsby, 2010; Taliaterro, DeCuir-Gunby, & Allen-Eckard, 2009). Also, parents from large families (three or more children) and dual earner families have been found to be significantly less likely to enroll on and attend parenting programs (Eisner & Meidert, 2011). Offering the intervention in the special schools for chronically ill children might overcome logistical issues for participation of children attending these schools, because groups are conducted during school time. However,



this is no solution for parent participation. In addition, conducting the parent-child intervention required four psychologists at the same time, which was not possible in three out of the nine settings in our sample. Therefore, although this might be difficult, it should be encouraged that professionals should find innovative ways to schedule interventions at times and places that are most suited for the families, and interventions might be carried out by other health care professionals than clinical psychologists (e.g. social workers, nurses, psychology interns, child health therapists). Finally, because we found that adolescents were less likely to apply than younger children, offering the intervention online may optimize the reach of adolescents because it eliminates barriers such as travelling time and distance, and it fits the digital environment that adolescents live in nowadays. A promising first effort of an online chat intervention for children who are treated for cancer is currently being evaluated in our hospital, and future efforts will be made to translate this program into an intervention for children with various chronic illnesses and their parents.

Third, in order to ensure engagement of participants to an intervention it is important that the support needs of the participants matches the intervention goals. In the current sample, the intervention goals seemed to match reported support needs to a high extend. All reported adjustment problems were addressed in one or more of the intervention goals, except for the physical problems. However, 13% of the parents reported that their child had no problems, but applied for the intervention anyway, indicating that a small percentage of families viewed the intervention as preventative, or participated simply because they were invited. When support needs of families that apply to the intervention do not match the content of the intervention in future clinical practice (e.g. when risk factors that are not targeted in the intervention are present), different interventions might be necessary to promote adjustment. A possible next step might be to tailor interventions for children with chronic illness more to individual needs, or to offer stepped care (Kazak, 2006). In the end, this might increase effectiveness and lowers costs overall (Bower & Gilbody, 2005).

Fourth, although good implementation has been linked to positive and intended outcomes, strict treatment integrity to the intervention protocol is often difficult to achieve in the complex and multifaceted contexts of pediatric settings (Flaspohler, Meehan, Maras, & Keller, 2012). Unfortunately, evidence on how to ensure that the intervention is executed the way it was intended, or even better, that the working mechanisms remain intact after implementation, is scarce. One way to ensure treatment integrity is adequate training of professionals providing the intervention (Nation et al., 2003). For 'Op Koers' an extensive train-the-trainer workshop will be developed in order to improve proper adoption of the protocol. In addition, implementation research is necessary to investigate effectiveness in clinical practice.

Fifth, an implementation process is only successful if it is sustainable, and the intervention gets a structural place in the setting it is implemented in (Hulscher, Wensing & Grol, 2000). Although 93% of the psychologists labeled the 'Op Koers' intervention

as a valuable addition to the psychosocial care in their center, this does not mean that implementation will be successful. The busy schedules and increasing cuts in funding for pediatric psychologists do not make implementation of a new intervention a priority. There is not much evidence about factors that ensure sustainability of implementation in clinical practice (Flay et al., 2005), but there are indications that monitoring results might improve sustainability (Moulding, Silagy & Weller, 1999; van Yperen & Veerman, 2008). Several government agencies in the Netherlands have implementation on their agenda (NJI, ZonMW). They recommend to approximate implementation as a planned process with different phases (dissemination, adoption, implementation and assurance), and to use strategies that consider the population and the context (Yperen & Veerman, 2008). In addition, implementation research is necessary to investigate which strategies are successful, and which are not.

Finally, because parents reported that they would like to share more time in expressing their emotions, and because research points in the direction of significant stress in parents of children with chronic illnesses (Hatzmann, Heymans, Carbonell, van Praag, & Grootenhuis, 2008; Murphy, Christian, Caplin, & Young, 2007; Wolfe-Christensen, Mullins, Stinnett, Carpentier, & Fedele, 2009), we would recommend the development of interventions that focus on distress of parents themselves.

CONCLUSION

This study provides evidence of feasibility of a parent-child cognitive behavioral group intervention that is aimed to promote adjustment in children with chronic illness. Possible directions for future implementation are; 1) improve recruitment methods (e.g., systematic screening), 2) be innovative to overcome logistical problems (e.g., offer interventions online), 3) beware of the match between support needs and intervention goals (e.g., tailor interventions to individual needs or offer stepped care), and 4) improve treatment integrity (e.g., extensive training). In sum, implementation is a complex process, in which different and innovative strategies must be used to gain success, and which should be monitored by research.

