The Impact of parents' chronic medical condition on children

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Chapter 11

General conclusions and discussion
11.1 General conclusions

The aim of this dissertation is threefold: (1) to give an indication of the impact of parental chronic medical condition (CMC) on children by way of differences in child functioning between families affected by parental CMC, families with healthy single parents, and families with two healthy parents, (2) to increase insight into risk and protective factors for developmental problems in children with chronically ill parents, and (3) to develop the Screening Instrument for Adolescents of Parents with Chronic Medical Condition (SIAPCMC), a short list of questions that can identify adolescents with developmental problems.

The findings suggest that in general, children can cope well with the parent’s chronic illness. In terms of parent-child attachment, coping skills, and diurnal salivary cortisol, adolescents with parental CMC did not seem to differ from adolescents without a chronically ill parent (Sieh, Visser-Meily, & Meijer, 2012d; Sieh, Visser-Meily, Oort, & Meijer, 2012g). Compared to adolescents of single parents, they indicated less stress, fewer school problems, and higher self-esteem. However, they reported significantly more internalizing problems than children from intact families with healthy parents, displaying unfavorable scores on many outcome variables, such as caregiving impact, self-report of daily hassles and stress, and grade point average (Sieh, Visser-Meily, & Meijer, 2012e). The percentage of (sub)clinically elevated scores in the internalizing spectrum was up to twice as high as in the normative sample of Dutch adolescents (Sieh, Oort, Visser-Meily, & Meijer, 2012b). In consequence, especially those children with elevated internalizing problems should receive support from their environment. Throughout this work, the family cluster effect, meaning that siblings and parents of families display statistically dependent outcomes, significantly contributed to the variance of many adolescent outcome variables, for example, internalizing problem behavior, caregiving variables, and quality of parent attachment. On that account, family research should routinely consider the between- and within-family effects.

A review of more than a decade of international research revealed that according to self-report and parent report, latency-aged and adolescent children with parental CMC displayed significantly more internalizing problem behavior than children with healthy parents (Sieh, Meijer, Oort, Visser-Meily, & Van der Leij, 2010a). To a small extent, having a parent with CMC had an effect on externalizing problem behavior. In terms of parent-reported total problem behavior in children, there was no difference between children of the target group and other children. The empirical studies presented here largely confirm the results from the review, though, externalizing problems were rare or even less prevalent than in other children. The absence of certain issues and positive aspects associated with parental CMC should not be ignored, but they should receive a central focus. Children who have a parent
suffering from a CMC do not form a risk group per definition. Hence, oversimplified generalizations and problematizations concerning these children should be avoided.

As theoretical background, this thesis used the family systems-illness (FSI) model and the transactional stress and coping (TSC) model. Inspired by the FSI model, the hypothesis was that adolescent stress would depend on specific illness-related factors, resulting in a differentiation into illness type in line with the diagnosis. The results suggested that illness type was of minor importance in the chronic stage of parental medical condition as it proved to be unrelated to child report of stress. Instead, family functioning played a major role in determining adolescent stress scores. Child report of stress was associated with the child’s perception of quality of parent attachment and the parent’s perception of quality of parent-child interaction (Sieh, Dikkers, Visser-Meily, & Meijer, 2012a). From a longitudinal study on children with a parent who suffered a stroke (Sieh, Meijer, & Visser-Meily, 2010b), it can be deducted that early prediction of long-term stress in children after parental stroke may be most accurate on the basis of children’s gender (female) and depressive symptoms in the chronically ill parent. Subsequently, it was confirmed that the ill parent’s depression and child report of stress were interrelated. Following the TSC model of Hocking and Lochman (2005), it was examined whether the effect of illness and demographic parameters on the child’s internalizing problems was mediated by the ill parent’s quality of life, family functioning, and child adaptational processes. In support of the TSC model, the findings provided evidence for these mediating processes. The child’s coping skills did not have a significant effect on internalizing problems, but active problem solving was significantly related to self-report of stress in children. The child’s perception of stress, daily hassles, and quality of parent attachment are important mediating variables between illness and demographic parameters, and adolescent internalizing problems (Sieh, Oort, Visser-Meily, & Meijer, 2012c).

An important objective of this thesis was to develop a screening instrument for adolescents affected by parental CMC. In our samples, externalizing problems were rare and internalizing problems were more common than in the general population of adolescents. The design of the screening instrument was therefore focused on internalizing problems. Four risk factors proved to predict approximately 60% of the variance in internalizing problems, that is, illness duration, feeling of isolation, alienation from the mother, and daily hassles affecting personal life (Sieh, Visser-Meily, Oort, & Meijer, 2012f). In addition, the unpredictability of parental illness, children’s caregiving responsibilities and activity restrictions, child report of stress, and active problem solving were significantly related to internalizing problems in adolescents. Eight questions that covered these underlying risk and protective factors were formulated and compose the Screening Instrument for Adolescents of Parents with CMC (SIAPCMC). A longitudinal study including 149 children showed that the SIAPCMC is a sensitive instrument to identify adolescents at risk for future
internalizing problems, indicating that clinical implementation of the SIAPCMC can be started (Sieh, Oort, Visser-Meily, & Meijer, 2012b).

### 11.2 Clinical implications

The fact that children affected by parental CMC display more adverse outcomes than other children suggests that they need assistance concerning their adjustment to chronic illness. Generally speaking, these children are characterized by greater internalization of problems like feelings of fear, sadness, and guilt. Such emotions are often illness-related; for example, children may feel guilty thinking to spend too much time with friends instead of caring for their parent (Armistead, Klein, & Forehand, 1995; Lackey & Gates, 2001; Pakenham, Bursnall, Chiu, & Cannon, 2007).

Children are often afraid of becoming ill themselves. Idiosyncratic fears involve those of worsening health, increasing impairment, and loss or death of the parent (Dearden & Becker, 2000; Sieh, Visser-Meily, & Meijer, 2011). In addition, children with parental CMC may not have sufficient time for school and social activities. As a consequence, they may earn lower school grades and feel lonely. Teachers, school psychologists, health practitioners, and other professionals who are in contact with these children should be alert for signs of developmental problems, mainly in the internalizing spectrum (i.e., anxious, depressed, and withdrawn behavior, and somatic symptoms), but also worsening school performance and social isolation should be of particular concern.

We advocate a family-centered approach that has consideration for the impact of parental CMC on the whole family (Visser-Meily et al., 2006). It is essential to consider the entire family and the environment of the family: chronically ill parents, spouses, children, the wider family, and financial, materialistic, and social resources. Possible targets for family-based interventions ideally focus on the quality of life, interpersonal relationships, and adaptational processes of family members. Parents may benefit from education about the role of parenthood or from parenting support in order to feel more secure about how to deal with parental CMC in the family. Approximately a third of the children in our sample had the desire to talk to a professional counselor (Sieh, 2009; Sieh et al., 2011). Interventions for children should incorporate the child’s coping skills, cognitive processes, and perception of stress. Interventions boosting protective factors such as active problem solving skills, social support, and high self-esteem appear to be suitable. Family psychoeducation combined with stress management may help through the process of adapting to parental CMC. Conversely, health practitioners should avoid blunt generalizations and unsubtle confrontational techniques.

An improvement of the current approach in rehabilitation medicine, which is still rather patient-centered, would be to amplify the consideration for the children...
and spouses of chronically ill parents. Health practitioners are recommended to pay attention to support needs of the family, while being alert that children do no estrange from their parents. They may simply invite children and spouses to a session with the parent who is ill. Children should not be excluded from the rehabilitation or treatment of the parent with CMC. They require information about CMC and have a desire for attention from health practitioners. Children can be invited to talk about how parental CMC has affected their life. They may be openly asked whether they need information about the diagnosis. Health care staff should create an opportunity for children to ask sensitive questions, for instance, whether parental CMC may be hereditary, severely impairing, progressive, or lethal. Oftentimes, the actual chance of becoming ill is much lower than what children believe and in many cases, CMC’s are not inherited at all. According to Romer et al. (2002), children may suffer from diffuse fantasies of worst-case scenarios. In our sample, children indicated that they would benefit from information on how to deal with their parent with CMC and what to do in challenging situations, for example, when their parent has a seizure. Every illness and every illness stage has its own characteristics to which children at different ages react in their own way. The family research project Children of Somatically Ill Parents (COSIP) from Romer et al. (2002) revealed that parents find it difficult to provide age-appropriate information. They often try to avoid burdening the child and fear a psychological break-down. Children frequently are ambivalent: they wish to have more information but are afraid to provoke preoccupations in the parent. Consequently, professional help may be needed to initiate a dialogue about hidden thoughts and feelings, breaking with the “conspiracy of silence”. Parents often doubt about how to recognize when children need help. A good indicator for children’s support need might be that peer friends visit the child at home less often, that the child does not talk about personal problems anymore (Romer et al., 2002), or that the academic performance worsens (Sieh, Visser-Meily, & Meijer, 2012d).

Children should be supported depending on their specific needs. Consequently, professionals should not rely on standard interventions. About a third of the adolescent sample in our study indicated that they would benefit from chatting sessions with other children in their situation (Sieh, 2009). More than a third of the children wished additional information about parental CMC, indicating that they would benefit from a website dedicated to children with parental CMC (Sieh et al., 2011). Considering that feelings of isolation are quite common among children with parental CMC, it is essential to check whether sufficient contact with peers is present, whether these children are restricted from engaging in social, leisure, and school activities, and whether they are overly involved in caregiving tasks. Approximately a third of the children in our sample reported a wish for support in the household (Sieh, 2009; Sieh et al., 2011). Where possible and affordable, health care staff may arrange professional care in the household for those children who indicate a high frequency of caregiving duties. Romer et al. (2002) suggest that it may be advanta-
geous to discuss precisely defined responsibilities that children are expected to fulfill. Also, help from non-professional caregivers such as family members, volunteers, or neighbors may be warranted and could be initiated by, for example, patient organizations or social workers.

Considering that parent attachment and stress appraisal proved to play a significant role in child adjustment to parental CMC, these factors should be targeted and combined in interventions. Our studies deliver evidence that harmonious family relationships can buffer stress in children. Family relationships should therefore be boosted. Similarly, attending physicians should be aware that there is a chance that children feel alienated from their parents. Family counseling or family workshops aiming to increase cohesion and resilience in families may be useful.

11.3 Limitations

This dissertation is not without limitations. First, the current empirical studies were conducted under a recruitment method that possibly induced sample selectivity. Only severe medical conditions were considered, so the presented results do most probably not apply to all adolescents with parental CMC. Also, most participants were recruited through care institutions that provide access to health care. Despite financial losses following the diagnosis of parental CMC, the majority of families had an adequate income. Besides, the samples mainly consisted of Caucasian families with a Western cultural influence. In fact, chronic illness has a different meaning depending on how the culture identifies symptoms and decides what is to be considered problematic behavior. Culture dictates both illness manifestation and resources allocated to the definition of illness (Helman, 2007). Further, the whole family was asked to participate. It may be assumed that participating families were more cohesive because they were willing to discuss illness-related matters that potentially uncover sensitive issues. In the studies described in chapters 3 to 9, children who participated may have benefited from the supposed openness of parents. Presumably, this openness can be associated with family cohesion or another underlying protective factor (Carr & Springer, 2002; Sieh et al., 2012c). We therefore believe that the results of this thesis may suggest lower problem scores than what an average child with parental CMC would display. In support of this notion, the study described in chapter 10 included adolescents who completed a test battery on the internet, and these adolescents seemed to exhibit worse outcomes than children described in the other chapters. We believe that children completing questionnaires on the internet initiated participation by themselves and were more independent of their parents with respect to their participation. They might therefore have reported less desirable behaviors, which fits into the idea of low social desirability.
Second, in all studies presented in this thesis, the samples of adolescents had a wide age range. Although the reliabilities for the scales of the Youth Self-Report (YSR) among children aged 10, 19, and 20 years were good (Sieh et al., 2012f), it is controversial to administer the YSR to children outside of the normative ages because the validity is not confirmed (Achenbach, 1991). As our samples were small and pubertal stages were not determined, conclusions with respect to pubertal stages or narrow age groups cannot be drawn. Also, no conclusions concerning differences between latency-aged and adolescent children can be deducted from our empirical studies. In our defense, a wide age range is preferable to reach a larger number of children who seem to form an especially vulnerable group during adolescence (Kraaij et al., 2003). Compared to latency-aged children, adolescents are more likely to have a parent at an older age, at which chronic diseases tend to become more common (World Health Organization, 2011).

Third, this dissertation sporadically suffers from low sample sizes. Especially chapter 3 about stress in children after parental stroke and chapter 6 about diurnal salivary cortisol concern studies with small samples that limit the generalizability of the results. In a few studies, overfitting may have been an issue despite evidence that this was not likely. Further, this dissertation could not simultaneously examine physiological and psychological outcome measures in children as the sample size for cortisol measures was too small for the number of parameters estimated. It would be groundbreaking to test a biosocial model that integrates physiological measures of stress as part of the sympathetic and parasympathetic nervous system, adverse psychosocial variables, family functioning variables, and prosocial behaviors and skills into one study. In support of the quality, this thesis consistently states hypotheses and the results are generally consistent within itself and with the larger body of literature (Sieh et al., 2010a).

Last but not least, this thesis unavoidably omits measures that may have contributed to new insight. For instance, the relationship between both parents and between parents and children was examined, though, we did not use questionnaires assessing the relationship between siblings or specific instruments for family functioning like the Family Assessment Device (Epstein, Ryan, Bishop, Miller, & Keitner, 2003). Besides, in spite of evidence for positive outcomes in children with parental CMC (e.g., Newman, 2002), this dissertation is focused on adverse child outcomes. Specifically, problem behavior is chosen as the main outcome variable in order to develop a screening instrument that can identify adolescents who display clinical levels of internalizing problems. Also, protective factors for adverse outcomes at the individual and family level are prominent in the thesis.
11.4 Future research

Considering the rising prevalence of children growing up with a chronically ill parent (Bach, 2008; Lubken & Larsen, 2006), research on the impact of parental CMC remains important. There are several recommendations for future studies. First, researchers should consider the complex family dynamics instead of focusing on family members alone. Effectively, this thesis shows that the family cluster effect explains a high percentage of the variance in the outcomes of family members. Not only is it important to account for the statistical dependence between the scores of siblings and between the scores of parents and children from the same family, it is also crucial to examine mutual family relationships in more detail. Future research could examine interpersonal relationships in more depth and zoom in on how parental CMC affects family interactions over time. Process variables concerning the impact of parental CMC may be difficult to measure with the instruments that are currently available, so future research should also develop and validate new instruments measuring processes like specific adaptations to illness-related disability. In connection with the first point, secondly, a longitudinal study would be suited to examine families on the long term. Investigating family dynamics before and after the diagnosis would be interesting, but this is difficult to achieve because CMC’s can hardly be predicted, and retrospective measures of pre-diagnostic family functioning may be less reliable. It would be intriguing to examine how mutual relationships change over time depending on whether the illness course is acute, progressive, or episodic. In specific cases (e.g., parental stroke), this has been done, however, more longitudinal research with larger samples is needed for firm conclusions (Sieh, Meijer, & Visser-Meily, 2010b). Third, future research should take a wider range of protective factors into account. This thesis mainly looked at social support and active problem solving as coping skills, which are just a fraction of what the coping system involves. For example, positive interactions with peers and fellow sufferers may play a buffering role (Pakenham & Bursnall, 2006) and those interactions may interfere with the social isolation that children with parental CMC frequently experience. Apart from coping skills and competences associated with developmental problems (Blackford, 1999; Newman, 2002), future research should pay more attention to specific positive outcomes that are not easily detected with instruments available for the general population. For example, future studies could incorporate children’s sense of contributing to society or sense of purpose, which may result from caregiving. Based on qualitative research (e.g., Lackey & Gates, 2001; Visser et al., 2004), a sense of purpose may be more common among children caring for a parent with CMC than among other children. Fourth, the SIAPCMC should be further validated. This may be achieved by administering the SIAPCMC to a larger sample, starting clinical implementation. Following children with parental CMC in late adolescence during an extended period may also increase our knowledge of their transition into
adulthood. Finally, a randomized controlled trial may be useful to design, offer, and test an online treatment versus face-to-face treatment based on cognitive behavioral therapy or family counseling to youth scoring above the cut-off score of the SIAPCMC. Accordingly, adolescents may be randomly assigned to several conditions. In addition, the cost-effectiveness of these treatments can be examined. Continuously, such a follow-up study would have the potential to foster the implementation of the SIAPCMC in the Dutch health care system. Last but not least, the SIAPCMC should be tested in latency-aged children. If the SIAPCMC does not prove suitable for this age group, an alternative screening instrument should be designed for these children.

11.5 Implementation of the SIAPCMC

The thesis itself will not include a user manual and a guide for social and public services and health care. However, the body of work shall be followed-up by an intensive period of implementing the SIAPCMC nationwide. We have been collaborating with other disciplines in accordance with the policy of the Dutch Ministry of Housing, Spatial Planning and the Environment and its sub-organizations, resulting in connections with professionals from psychiatric and care institutions, rehabilitation centers, the doctor’s practice, community centers, and youth welfare institutions. Besides, it is important to stay in touch with schools, volunteers, and youth organizations. Our connections with informal services such as those from patient organizations can also contribute to the widespread use of the SIAPCMC. After screening above the cut-off score, the referring physician and the affected adolescents need to know where and how to seek support, being able to choose from diverse forms of help. Most importantly, professional help must be present and available for youth in all Dutch provinces. We advocate close collaboration between agents who administer the SIAPCMC and those who offer interventions for adolescents and families, such as youth counseling services, youth care institutions, and family therapists, and other staff in social and psychiatric institutions. Implementing the SIAPCMC depends on the collaboration of services surrounding adolescents, chronically ill parents, and the wider family.

Social media (Twitter, Facebook, and Hyves) and other media (newspapers, newsletters, professional and academic publications, and interviews) can be practical to increase the familiarity with the impact of parental CMC on children and to foster the widespread use of the SIAPCMC. Social agents of adolescents with parental CMC can be informed through e-mails, information brochures, and postings on internet forums. Additionally, it may be useful to organize speeches and presentations at public events. Schooling and training programs in social services and sciences ideally include a section about parental CMC. It is recommendable to elabo-
rate on parental CMC in readers and textbooks, conveying an encouraging message to children with a neutral reference to the SIAPCMC. We offer a platform through a dedicated website (www.ziekeouder.com) on which the SIAPCMC, user manual, scoring system and relevant literature will be available for free. At last, it is valuable to spread our knowledge and to engage policy makers for further implementation.

11.6 Implications and impact statement

This thesis gives insight into risk and protective factors for adolescent problem behavior in families with a parent who suffers from a chronic medical condition. Children with a chronically ill parent display greater internalization of problems than other children, while externalizing problems are rare. Parents’ chronic disease has impact on the whole family. Children may experience both positive consequences, such as empathy and the absence of aggressive behavior, and negative outcomes like excessive caregiving responsibilities and elevated stress. We developed the SIAPCMC, which is a sensitive instrument to identify adolescents at risk for internalizing problems such as anxiety and somatic complaints. Future research needs to explore positive outcomes in children with a chronically parent. In addition, specific interventions for family members in need should be developed and tested for efficacy. A family-centered approach is to be advocated, bearing in mind strengths, vulnerabilities, and support needs of individual family members and the wider system.