The impact of parents' chronic medical condition on children
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Summary

The impact of parents’ chronic medical condition on children

Approximately 10–13% of adolescents grow up with a parent who has a chronic medical condition (CMC), and they prove to be at an increased risk for internalizing problems which may require professional help. Presumably, the daily confrontation with the emotional and practical consequences of parental illness (financial deterioration, caregiving, daily hassles, parental depression, etc.) leads to stress in adolescents. Subsequently, the child’s perception of stress may result in problem behavior, psychosocial problems, and low school functioning. Considering that early intervention can prevent persistent problems, it is important to identify at-risk youth. 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a short list of questions that can identify adolescents at risk for internalizing problems such as anxious and withdrawn behavior.

This thesis includes nine studies which are presented in separate chapters. The first two studies focus on latency-aged and adolescent children, while the remaining chapters only include adolescents aged 10 to 20 years. Chapter 2 is an international meta-analysis of 19 studies and Chapter 3 is a longitudinal Dutch study on stress in children after parental stroke. Chapters 4 to 9 are based on data collected from Dutch families between 2008 and 2011. Chapter 10 uses longitudinal data from a new sample of 149 adolescents who completed questionnaires on the internet be-
tween 2011 and 2012. All chapters except for Chapter 3 include mixed illness samples.

Chapter 2 presents a meta-analysis reporting the effect sizes for internalizing, externalizing, and total problem scores of 1,858 children aged between 3 and 25 years (mean age = 11.9 years). Children who have a parent with CMC displayed more internalizing problems and slightly more externalizing problems than children of parents without CMC or children from the normative sample of the Youth Self-Report (YSR). No effect was found for total problem scores as measured by the YSR. Effects for internalizing and externalizing problem behavior were larger in non-cancer studies, in samples including younger children and younger ill parents, in samples defined by low average socioeconomic status (SES), and in studies which include more parents with long illness duration.

In Chapter 3, a longitudinal study examines 44 children aged 7 to 18 years and their parents \((n = 29)\) in 9 participating rehabilitation centers across the Netherlands to assess risk factors for stress in children 3 years after parental stroke. The results revealed that girls experienced more stress than boys. Spouses' depressive symptoms during the first year after stroke were positively correlated with child report of stress. Patients' depressive symptoms 2 months after discharge from the rehabilitation center, 1 year, and 3 years post-stroke were also positively correlated with stress in children. At 2 months post-rehabilitation, the perceived quality of marital relationship was related to child report of stress. Stress was not associated with patient gender and physical functioning. The most accurate basis for the early prediction of long-term stress in children following a parental stroke may be the child’s gender (female) and depressive symptoms in the patient.

Chapter 4 is inspired by Rolland’s family systems-illness (FSI) model, examining predictors of stress in 158 adolescents aged 10 to 20 years (mean age = 15.1 years) who have a parent with CMC. The hypothesis was that child report of stress can be explained as a function of parental illness type (disability of the parent, and onset, course, outcome, and stage of illness), depressive symptoms in the ill parent, family functioning (quality of marital relationship, parent attachment, and parent-child interaction), and the adolescent’s gender and age. The results showed that low adolescent stress scores were related to the adolescent’s perception of high quality of parent attachment and the parent’s perception of high quality of parent-child interaction. Girls were more likely to display elevated stress levels. Adolescent stress was not linked to illness type. Our results partially supported the FSI model. In the chronic stage of parental illness, adolescent stress does not seem to vary in line with the illness type.

Chapter 5 follows the transactional stress and coping (TSC) model, assuming that family functioning and child adaptational processes (e.g., daily hassles, stress, and coping) mediate the relationship between illness and demographic parameters, and children’s internalizing problems. To test the tenability of the TSC model, data
from 160 adolescents between 10 and 20 years (mean age = 15.1 years) and their parents were analyzed, using multilevel structural equation modeling. The results indicated that after major adaptations, the TSC model was supported. There was strong evidence that apart from family functioning and children’s daily hassles and stress, also the ill parent’s quality of life mediated the effect of parental CMC on adolescent internalizing problems. A lengthy duration of illness was directly associated with higher internalizing problem scores. While active problem solving and social support seeking were not directly related to adolescent internalizing problems, they significantly interfered with children’s self-esteem and psychological stress levels.

Chapter 6 compares cortisol samples taken from 100 adolescents of three groups with either healthy single, chronically ill, or two healthy parents. Three salivary cortisol samples were taken after awakening, one sample at noon, and one sample at 20:00 p.m. during a non-school day. Cortisol is a stress hormone that may be considered an objective measure for physiological stress. Differences and interaction effects between measurements (five times a day), group membership, and covariates were tested by way of linear mixed modeling, repeated measures. Covariates were children’s sex and age, socioeconomic status (SES), and parental depression as measured by the Beck Depression Inventory. The three groups did not differ significantly in terms of the amount of salivary cortisol, even after controlling for the covariates. Cortisol was not significantly predicted by family type. The gender of the child (male) and the age of the child (older children), as well as lower parental depression were associated with increased cortisol values. The main conclusion is that all three groups appeared to display a healthy salivary cortisol pattern.

Chapter 7 investigates the data from 389 adolescents (mean age = 15.2 years) and their parents from intact families with parental CMC, single parent families, and intact families with healthy parents (comparison group). Relations between parental depression and adolescent functioning were examined from a family perspective. Multilevel analyses revealed that adolescents with chronically ill and single parents displayed more internalizing problems and lower school grades than adolescents in the comparison group. Adolescents of single parents reported more stress and school problems, as well as lower self-esteem related to school than adolescents in the other groups. Parental depression was related to child report of stress, regardless of family type. Being a girl and being older significantly contributed to the adolescent’s internalizing behavior and stress. In addition, older adolescents reported more externalizing problems and lower school grades. Adolescents with parental CMC seemed to function worse than adolescents with two healthy parents but better than adolescents from single parent families.

Chapter 8 addresses differential characteristics in behavioral, psychosocial, and academic domains among 161 adolescents from 101 families with a chronically ill
parent and among 112 adolescents from 68 families with healthy parents, accounting for statistical dependence within siblings. Multilevel analyses showed that 20% to 60% of the variance in most adolescent outcomes was due to the family cluster effect, especially in internalizing problem behavior, caregiving variables, and quality of parent attachment. Conversely, the variance in stress and coping scores, and school grades was mainly due to individual characteristics. Adolescents with parents affected by CMC displayed more internalizing problems than the comparison group and scored higher on the frequency of household chores, caregiving responsibilities, activity restrictions, isolation, daily hassles, and stress. Also, their grade point average was comparatively worse. The largest effect sizes of group differences were observed for grade point average and variables related to caregiving.

Chapter 9 deals with salient risk factors for problem behavior in adolescents affected by parental CMC. The YSR was completed by 160 adolescents (mean age = 15.1 years) from 100 families (102 chronically ill parents and 83 healthy spouses). Risk factors were measured at the child level (gender and age, frequency of household chores, caregiving variables, and daily hassles affecting personal life), at the level of parents (gender, age, depression, and caregiver strain of the spouse), at the level of parental illness (time since diagnosis, functional status, pain, general health perception, and unpredictability of the Illness), and at family level (SES, marital functioning, quality of parent attachment, and daily hassles concerning both parents). The results showed that 44% and 19% of the variability in internalizing and externalizing problems, respectively, was explained by the family cluster effect. Roughly 60% of the variance in internalizing problems was predicted by illness duration, adolescents' feeling of isolation, daily hassles affecting personal life, and alienation from the mother. Externalizing problems were predicted by the adolescent's gender (male), daily hassles concerning ill parents, and alienation from both parents. It can be concluded that the family cluster effect, psychosocial child variables, and parent attachment play a major role explaining problem behavior in adolescents with a chronically ill parent.

Chapter 10 describes the development of the Screening Instrument for Adolescents of Parents with Chronic Medical Condition (SIAPCMC), a short list of questions that aimed to identify adolescents at risk for internalizing problems. The chapter examines reliability, validity, sensitivity, and specificity of the instrument. To this end, a new sample of 149 adolescents (aged 10–20 years, mean age = 15.5 years) from 104 families was recruited. Adolescents filled in a test battery including the SIAPCMC and the Youth Self-Report both in 2011 and 1 year later, resulting in a longitudinal data set. The SIAPCMC showed excellent reliability (Cronbach’s alpha = .90) and good validity indices, and it appeared to be sensitive in identifying children with future internalizing problems. The results suggest that the SIAPCMC has sound psychometric properties and can be further tested in larger samples, starting clinical implementation.
Overall, the results suggest that latency-aged and adolescent children generally cope well with the parent’s chronic disease. In terms of parent attachment, coping skills, and salivary cortisol, adolescents with a chronically ill parent have similar scores as those who do not have a chronically ill parent. In fact, compared with adolescents of single parents, they report less stress, fewer school problems, and higher self-esteem. However, children with a chronically ill parent do report significantly more internalizing problems than children with healthy parents, and they score unfavorably on many outcome variables, such as caregiving impact, self-report of daily hassles and stress, and grade point average. Above all, child adaptational processes such as daily hassles and stress, and family functioning variables like parent attachment seem to predict developmental problems in children with a chronically ill parent. Hence, these children should receive support from their environment. Most importantly, coping skills, self-esteem, and healthy family relationships need to be fostered in order to reduce their stress levels. A family-centered approach is to be advocated.