The impact of parents' chronic medical condition on children
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Citation for published version (APA):
Sieh, D. S. (2012). The impact of parents' chronic medical condition on children

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Chapter 1

General introduction
1.1 General introduction

A growing number of parents with young children develop a chronic medical condition (CMC). Such medical conditions involve one or more organ systems impairing health and psychological functioning for at least 3 months (Brown, 2006; Lubkin & Larsen, 2006). CMC’s are characterized by long continuance of adverse physical symptoms, such as pain and fatigue, which may be intermittent or continual depending on the underlying condition. Generally speaking, neither vaccines nor medication can prevent or cure CMC’s, so most conditions last for a lifetime. Being chronically ill is accompanied by functional impairment including mobility limitations and dependence in activities of daily living. Caregiving needs and the dependence on health care can lead to a significant loss of autonomy (Plochg, Juttman, Klazinga, & Mackenbach, 2007).

Worldwide, the number of individuals with CMC is still on the rise. In developed countries, the most common forms of CMC include rheumatoid arthritis, cardiovascular diseases (e.g., stroke), cancer, chronic respiratory diseases, and diabetes mellitus. These conditions are the leading cause of mortality in the world, accounting for 63% of all deaths. A substantial proportion of chronic medical conditions are autoimmune diseases, such as multiple sclerosis and rheumatoid arthritis. Autoimmune diseases occur in 8% of the population, while 78% of those affected are women (Fairweather & Rose, 2004), and they are the leading cause of death among young and middle-aged women (Walsh & Rau, 2000). In 2008, an estimated 36 million deaths worldwide were due to non-communicable diseases up from 35 million deaths in 2004 (World Health Organization, 2011).

Internationally, approximately 10% of children grow up with a parent who is affected by CMC (Worsham, Compas, & Ey, 1997). In the Netherlands, a study revealed that 13.2% of children have a parent with CMC (Goldschmeding, Van de Looij-Jansen, & Butte, 2006). This prevalence is rising, not only because of the increasing occurrence of autoimmune diseases (Bach, 2008) and improved medical techniques that augment the life expectancy of parents with CMC, but also because parents are conceiving children at an older age. In turn, older age is associated with an increased vulnerability for CMC (Lubkin & Larsen, 2006; Shifren & Kachorek, 2003).

CMC affects the whole family (Visser-Meily & Meijer, 2006). About one in four individuals with CMC has one or more activity limitations (Anderson, 2004). These limitations, in turn, have an impact on family life and individual family members (Visser-Meily et al., 2005a; Visser-Meily et al., 2009). When a parent is chronically ill, the family situation changes permanently. Family functioning is likely to be impaired when the illness duration increases (Schrag, Morley, Quinn, & Jahanshahi, 2004). All family members have an elevated risk for depressive symptoms (Han & Haley, 1999; Visser-Meily & Meijer, 2006). Both spouses and children are required to take care of
the parent with CMC. Children frequently have to fulfill caregiving responsibilities that may be inadequate for their age (Korneluk & Lee, 1998; Meijer, Van Oostveen, & Stams, 2008). They may feel overwhelmed with the emerging caregiving tasks and may experience emotions of guilt when they spend time away from the parent with CMC. Worries about the health condition of the chronically ill parent and about becoming ill themselves are widespread among children with parental CMC (Armistead, Klein, & Forehand, 1995; Lackey & Gates, 2001). A Dutch study found that almost half of the children reported general fears about the future (Dufour, Meijer, Van de Port, & Visser-Meily, 2006). In comparison with their peers whose parents do not suffer from an illness, children with parental CMC have higher scores for somatization and life dissatisfaction (Pakenham, Burtnall, Chiu, Cannon, & Okochi, 2006). The risk for internalizing problems in these children may be considerable. Internalizing problems refer to problematic behaviors that are directed toward the self (i.e., anxious, depressed, and withdrawn behavior, and somatic complaints). The relevance of research on parental CMC becomes even more evident considering that developmental problems starting early in childhood may persist until adulthood (Lackey & Gates, 2001; Schrag et al., 2004).

There are two predominant theories with regard to the relationship between parental CMC and child adjustment. First, this thesis is inspired by the family systems-illness (FSI) model, which is described in Chapter 4. The FSI model suggests that in order to explain a child’s stress level, it is essential to consider parental illness type, and individual, family, and illness life cycles. Illness types can be categorized on the basis of the presence of disability (non-disabling versus disabling), its onset (gradual versus acute), its course (progressive, episodic, or constant), its outcome (fatal versus non-fatal), and the stage of the illness (crisis, chronic, or terminal). This dissertation focuses on the chronic stage of parental medical conditions. Prominent issues in the chronic stage are interpersonal conflicts in family relationships concerning topics such as averting exhaustion, maintaining autonomy, and preserving intimacy in the face of severe impairment or possible death. Family relationships may act as a buffer against adolescent stress, providing resources and possibilities for resilience and growth (Rolland, 1999). Second, the transactional stress and coping (TSC) model, which is documented in a detailed manner in Chapter 5, serves as theoretical framework. The TSC model proposes that the impact of CMC on internalizing problems in children is mediated by the ill parent’s quality of life, family functioning, and child adaptational processes (Lazarus & Folkman, 1984; Hocking & Lochman, 2005). On the one hand, high levels of stress may increase the chance of internalizing problems in adolescents. On the other hand, protective factors such as adequate family functioning and functional coping (e.g., social support seeking and active problem solving) can interfere with undesirable levels of stress, decreasing the risk for adolescent problem behavior. Most children seem to cope well with parental CMC (Annunziato, Rakotomihamina, & Rubacka, 2007; Romer et
al., 2002). Protective factors may account for the ways in which these children are resistant to developing problems. By identifying risk and protective pathways to internalizing problems, the main objective of this dissertation is to develop a screening instrument for children with parental CMC. This is part of secondary prevention which aims to identify children in need of early intervention before developmental problems persist. This dissertation examines those characteristics of children, parents, parental illness, and the family which play a significant role in the manifestation of children’s internalizing problems. The ultimate aim of this thesis is to design a screening instrument that can identify developmental problems in adolescents who have a parent suffering from a CMC. The study focuses on adolescents aged 10 to 20 years as they seem to form an especially vulnerable group (Kraaij et al., 2003). Compared to latency-aged children, adolescents are more likely to have a parent at an older age, which may bring along an increased chance of having a parent with a chronic illness. Also, especially adolescents might have experienced the impact of parental CMC for an extended period. Insight into the relationship between illness-related stressors and adolescent developmental problems is essential for designing interventions for those adolescents who need help. A screening instrument may contribute to the identification of adolescents who require interventions in order to prevent upcoming problems.

Numerous risk and protective factors for developmental problems and especially adverse outcome variables in adolescents with parental CMC have been examined. Researchers have investigated demographic characteristics of children and parents, illness characteristics, and the psychosocial variables of children, parents, and the family as a whole (Korneluk & Lee, 1998, Romer et al., 2002). Oftentimes, prior research in the field has some shortcomings, which this thesis will respond to. First, the majority of studies have not considered the family cluster effect which means that family members possess a very similar genetic makeup and share the same environment, resulting in characteristics that are statistically dependent on each other (Snijders & Bosker, 1999). Second, previous studies have seldom included comparison groups for children with parental CMC. Additionally, in those studies including a comparison group, many researchers have opted for children with mentally ill parents instead of a normative reference group. This may obstruct differences between children with parental CMC and children with healthy parents, hindering conclusions about the overall impact of parental CMC on the child. Third, prior research has not examined physiological variables as part of child adjustment to parental CMC. This thesis will address the limitations of prior research by using multilevel analyses which serve as a control for the family cluster effect and determine predictors at the individual and family level. In addition, this work will make a comparison between families with parental CMC and two reference groups: families with healthy single parents and intact families with healthy parents. Such an approach facilitates answering the question of whether lack or partial involvement of
a second parent contributes to between-family differences in child outcomes. Similar to children with parental CMC, children with single parents display worse outcomes than children with two healthy parents on a number of measures like problem behaviors and academic performance (Amato, 2000; Amato, 2001; Hoffmann, 2006; Romer et al., 2002). Apart from that, children with parental CMC will be compared to children with single parents and two healthy parents in terms of a physiological stress measure, namely salivary cortisol, which is a stress hormone.

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), intending to identify adolescents with developmental problems.

1.2 Thesis outline

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.

The first study (Chapter 2) is a meta-analysis of 19 international studies examining differences in problem behavior between children with parental CMC and children who do not have chronically ill parents or norm groups by way of overall effect sizes. The remaining dissertation research investigates children in the Netherlands.

The second study, Chapter 3, is based on longitudinal data for 44 children with a parent who has suffered a stroke. This study is part of the Functional Prognosis after Stroke (FuPro-Stroke) caregiver study, aiming to predict child report of stress three years after parental stroke.

The data used for Chapters 4 to 9 were collected from the family home between 2008 and 2011. Chapters 4 and 5 are theory-driven articles inspired by the family systems-illness (FSI) model and the transactional stress and coping (TSC) model, respectively, using the data for 160 adolescents with chronically ill parents from a new sample. Chapters 6 to 8 describe a comparison between adolescents with parental CMC, adolescents of healthy single parents, and adolescents of healthy married parents. Chapter 6 illustrates the diurnal salivary cortisol pattern in adolescents from the three family types. Chapter 7 compares depression in married parents affected by CMC, healthy single parents, and healthy married parents in relation to clinical and non-clinical adolescent functioning in these family types. Chapter 8 addresses the differential characteristics for adolescents with chronically
ill and healthy parents. Chapter 9 focuses on risk factors for problem behavior in adolescents with chronically ill parents.

Chapter 10 is based on data for a new sample of adolescents recruited between 2011 and 2012, and it describes the development of the SIAPCMC. For this purpose, 149 adolescents from 104 families were recruited. Adolescents completed a test battery including the Youth Self-Report and the Dutch Stress Questionnaire for Children in 2011 and 1 year later, resulting in a longitudinal data set.