The impact of parental cancer on children
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Summary

Threatening events may cause symptoms of posttraumatic stress (PTSS) in children. PTSS consist of intrusion (intrusive and unpleasant memories relating to the event), avoidance (avoidance of stimuli associated with the event) and hyperarousal (such as sleeplessness, irritability and concentration problems). Children who have experienced a threatening event may also suffer from other emotional problems (withdrawal, anxiety, depression, and somatic complaints) and behavioral problems (aggressive and delinquent behavior). Cancer in a parent may be such a threatening event. Each year, 9000 young families are confronted with cancer in the Netherlands. Cancer is often associated with death, the treatment is frequently intensive and side-effects of treatment may be visible and frightening. Parents are often more frequently away from home because of clinical treatment and therapies at the outpatient clinic, possibly causing family life to be seriously disorganized. Therefore, parental cancer may have far-reaching consequences for the children. It requires all family members to adapt. The effects of the confrontation of cancer in a parent for child functioning have been under-explored, though attention for this topic has been increasing since the first publication in 1984. Most publications come from the United States and Great Britain. They mainly involve small studies, which are generally retrospective in nature. Moreover, they often report contradictory results. Until now, the psychosocial consequences for children who are confronted with parental cancer had not been studied in the Netherlands.

Chapter 1 presents the background of the thesis. In order to paint a picture of what families may go through when a parent has cancer, a brief survey of the main characteristics of cancer, the treatment, and the accompanying side-effects is provided. In addition, the theoretical background of the study is illuminated and the research model of the study is presented. In this study, we chose for a family system approach. The family systems theory assumes that a change in the condition of one family member, in this case parental cancer, affects the condition of other family members, such as the children’s functioning. For this reason, we believe this theory to be a suitable basis for the research model for the present thesis.

The first step in this project was to perform a literature review to gain insight into what was already known about the psychosocial consequences for children of a parent with cancer. This study is presented in Chapter 2. With the assistance of the electronic databases MEDLINE, CINAHL, Psychinfo, EMBASE and CancerLit, we searched for quantitative and qualitative studies, studies combining both research methods, and intervention studies published between January 1980 – March 2004. Fifty-two studies met the inclusion criteria which had been stipulated beforehand. Emotional problems in school-aged children (≤11 years) were reported in several
qualitative studies, but in only one quantitative study. In contrast, emotional problems in adolescents (≥12 years) were mentioned in both quantitative and qualitative studies, in particular in adolescent daughters of ill mothers. Behavioral and social problems in school-aged children and adolescents, in general, were not described by quantitative studies. Only one quantitative study reported physical complaints in school-aged children. In contrast, a number of qualitative studies reported physical and cognitive problems in children in both age groups and behavioral problems in school-aged children. The most consistent variables related to the well-being of children were parental functioning, marital satisfaction and family communication. Intervention studies directed at the needs of children and their families in this situation consistently described positive effects.

To get a first impression of what takes place in families when a parent is diagnosed with cancer, a pilot study was conducted. The results of this study are described in Chapter 3. Fourteen cancer patients (13 mothers, 1 father), 13 male spouses, and 15 children (10 daughters, 5 sons, ages 7-18) were interviewed. Ten of the ill mothers had breast cancer. Parents and children (from 12 years old) also completed validated questionnaires. On average, no significant differences were found with regard to emotional and behavioral problems in children of cancer patients in comparison with children of a normative sample. However, parents observed moderate to severe problems in one-third of the children of cancer patients, for which these children should receive professional support. Three of seven children reported moderate to severe problems themselves. Parents noticed (temporary) behavioral problems in most children at the beginning of the parents’ illness. Other problems—such as anxiety, sleeping disorders and compulsive behavior—persisted longer according to parents, sometimes for years after the parent’s diagnosis. Having adolescent children in the family proved to be a contra-indication for support from home health care aids, because the home health care organization assumed that adolescent children were able to take over the tasks of the ill parent. The lack of home health care, however, resulted in an additional burden on adolescent children. With regard to the effects of family environment, children from families that continuously adapted rules, roles and norms (chaotic families), and children from families with low family cohesion (disengaged) seemed to be most at risk for emotional and behavioral problems.

After the pilot study, a cross-sectional study was performed on the psychosocial functioning of children of parents diagnosed with cancer one to five years previously. Chapter 4 reports the prevalence of PTSS in 220 adolescent (11-18 years) and 64 young adult children (19-23 years). The study also examined factors possibly associated with PTSS. Eighty-two percent of the parents with cancer were women and breast cancer was the most common diagnosis. In 21% of the sons and 35% of
the daughters clinically elevated PTSS were found, a strong indication for severe adaptation problems. From these results, we can conclude that it would be advisable to refer those children to professionals specialized in psychosocial care.

How much time had elapsed since the parent’s diagnosis appeared not to be related to the extent to which children experienced PTSS. This means that children of parents who were diagnosed one year previously and children of parents who were diagnosed longer ago had similar levels of PTSS. Daughters reported more symptoms of intrusion and avoidance than sons, in particular daughters of ill mothers. Older daughters suffered more from intrusion than younger ones. Sons and daughters with higher levels of trait anxiety, those who were more inclined to react with anxiety in stressful situations, reported more PTSS. Intensity of the parent’s treatment seems not to have an effect on the severity of PTSS in sons and daughters. Daughters whose parents suffered from recurrent illness had more PTSS than daughters whose parents did not. Children (daughters in particular) with clinically elevated PTSS reported significantly more problems in internalizing and cognition than norm group peers from the Dutch population.

Little is known about the effect of the experience of such a stressful event as parental cancer on patterns of family communication. Open communication with children is often advocated when a parent has cancer, because this is believed to have a positive effect on child functioning. However, this assumption seems not to be evidence-based. Therefore, the communication patterns between parents and adolescents in families confronted with cancer were studied by comparing them with patterns of communication in families not confronted with cancer. In addition, the relationship between communication and child functioning was examined. This study is described in Chapter 5. With regard to open communication, we studied the quality of the exchange of information between adolescents and parents. For instance, we assessed the extent to which adolescents felt free to share their feelings and experiences with parents, the extent to which they felt that their parents took serious notice of what they told them, and whether adolescents were satisfied with the communication. Problem communication was also addressed by studying barriers in the communication with the parents, such as negative feelings about the communication with the parents (e.g., giving parents the silent treatment when they experience problems with parents, or saying things in emotional situations which they later on regret). Furthermore, adolescents were asked whether they thought they were selective in topics they discussed with their parents.

Adolescents (n=212) of parents who were diagnosed one to five years before assessment appeared to communicate less openly with mothers with cancer than adolescents of the reference group with their mothers. This was the only significant difference with the reference group. Thus, communication between adolescents and parents in families of cancer patients seems to differ little from that in families not
confronted with cancer. Daughters appear to communicate more openly with their ill parents than with the other parents. Recurrent disease and more intensive treatment were negatively related to communication. Sons reported more problems in the communication with ill parents in case of more intensive treatment or recurrent disease. Daughters experienced less open communication with both parents when ill parents underwent more intensive treatment.

When communication with the other parent was more open, daughters suffered fewer PTSS. When sons and daughters reported more problems in communication with the ill or the other parent, they experienced more PTSS. Problems in communication outweighed the lack of openness with regard to effects on PTSS. Problem communication with the other parent appeared to be the most important predictor of intrusion, while problem communication with the ill parent proved to be the most important predictor of avoidance.

It remains unclear why some children of cancer patients developed psychological problems, while others seemed to be doing well. Next to the characteristics of age and gender of the children, the illness and communication, parental characteristics might be of importance, but research addressing this subject is rare. Chapter 6 describes the results of a study on the effects of parental characteristics on the functioning of children. With regard to child functioning, we studied PTSS, internalizing problems (withdrawal, somatic complaints, anxiety and depression), and externalizing problems (aggressive or delinquent behavior). In this study, participating families were recruited from two sources. One group was approached in the hospital (hospital group) and the other group consisted of families that contacted the researchers themselves for study participation in response to media attention (external group). Children of the hospital group appeared to have more PTSS than children of the external group; parents with cancer of the external group were higher educated, older and more recently diagnosed. As these group differences could cause bias when groups were combined, the recruitment source was controlled for in the analyses. Data were analyzed from 293 adolescents (11-18 years), 146 parents diagnosed with cancer one to five years previously, and 129 spouses. In 27% of the families one child participated, in 55% two, in 14% three, in 3% four, and, in one family, five children participated. As findings could be biased when more children of a family are included, multilevel analyses were used in this study. This method of analysis gave us the opportunity to examine the extent to which variability in child functioning could be explained by individual child characteristics (characteristics that were different for each child, such as gender and age) and by characteristics that were similar for each child of a family (such as trait anxiety and PTSS in parents).

Of the total group of adolescents, 23% of the sons and 34% of the daughters reported clinically elevated PTSS. Additionally, daughters experienced more inter-
nalizing problems than norm group girls. We found lower educational level and higher trait anxiety of ill parents, recurrence, more PTSS in the other parents, and female gender of the adolescent all to be significant predictors of PTSS. With regard to internalizing problems, the following predictors were found: higher educational level and higher trait anxiety of ill parents, recurrence, and female gender of the adolescent. Higher trait anxiety of the other parents, marital satisfaction of both parents and older age of the adolescent were found to be predictors of externalizing problems. Adolescents within the same family appeared to score more similarly on PTSS, internalizing and externalizing problems than adolescents from different families.

Chapter 7. The preceding studies examined children of parents diagnosed with cancer between one and five years previously. The last study of this thesis focuses on the children’s functioning during the first year after the parent’s diagnosis. Chapter 7 describes a prospective study on the prevalence of PTSS in adolescent children at three assessments, namely, shortly after the parent’s diagnosis (T1), and six (T2) and twelve months (T3) later. Having three points of measurement made it possible to gain insight into changes in PTSS during the first year after the parent’s diagnosis. The adolescents’ PTSS at the three assessments were compared to PTSS of adolescents whose parents were diagnosed between one and five years previously. In addition, we examined which factors were related to the severity of PTSS and whether there was a relationship between PTSS and emotional, behavioral or cognitive problems. Lastly, predictive effects of initial PTSS on later PTSS and emotional or behavioral problems were studied. Forty-nine adolescents, 37 parents with cancer, and 37 spouses completed questionnaires at three assessments. Sixty-two percent of the parents with cancer were women, and breast cancer was the most common diagnosis. Clinically significant PTSS were found in 29% of adolescents at T1, in 16% at T2 and in 14% at T3. Ten percent reported clinically significant PTSS at all assessments. The symptoms declined during the first year after the parent’s diagnosis for both sons and daughters. Strikingly, children of recently diagnosed parents reported levels of PTSS similar to children of parents who were diagnosed one to five years previously. Six to twelve months after the parent’s diagnosis they reported even fewer PTSS than children of the reference group. This suggests that PTSS related to parental cancer fluctuate over time, with symptoms decreasing during the first year after the parent’s diagnosis and increasing during the subsequent years. It may well be that adolescent children of recently diagnosed parents were more focused on whether their parent would survive, and that PTSS declined when the parent seemed to respond well to treatment. An other explanation might be that children, after treatment is completed and life returns to normal, have more time to think about everything that happened. It is possible that they come more to terms with their experiences at that time.
Intensity and length of treatment appeared not to be related to PTSS. Adolescents who reported more PTSS also suffered more from other problems. Ill parents also observed more problems in adolescents with more PTSS, though to a lesser degree than the adolescents themselves. The parents without cancer did not report more problems in adolescents with more PTSS shortly after the parent’s diagnosis, but they did at six and twelve months later. They also observed fewer problems than adolescents with PTSS themselves. It seems that parents underestimated symptoms of adolescents with PTSS, because there appeared to be some underreportage of problems. The strength of the association between PTSS and somatic complaints seems to increase during the first year after the parent’s diagnosis, which suggests that adolescents with more PTSS express their symptoms increasingly somatically over time. Adolescents who suffered from more PTSS shortly after the parent’s diagnosis also had more PTSS and emotional problems later on in the year. This was not found for behavioral problems.

Finally, in Chapter 8 the main findings of this thesis were placed within a broader context. Methodological issues were discussed and, moreover, we examined how the results of the studies matched with the presented research model. The chapter concludes with implications for future research and clinical practice.