Children's functioning following parental cancer
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General discussion
Positive and negative experiences during childhood may influence a child’s functioning. A parent with cancer is an event that causes a lot of stress and uncertainty and may change the life of children radically and for a long time. In the United States in particular a number of studies have been conducted lately paying attention to the impact of such an event on children. The results of these studies however are conflicting, for which several reasons can be argued. Often no distinction is made in gender and age of the children. Informants about the children’s functioning vary, sometimes the parents report and sometimes the children themselves. The quality of some studies is limited (e.g. study design, sample size), which may influence the validity and reliability of the results.

In the Netherlands so far no research has been performed into the consequences of the diagnosis cancer in a parent for children. Whether children have more problems than children who did not experience such a situation is unknown. This thesis focuses on the prevalence of problems in children under such circumstances and on factors that may interrelate with the degree in which these problems occur. The results are presented separately for boys and girls and for primary school children and adolescents. Children’s functioning is described from three perspectives, the parent’s with cancer, the spouse (if present) and the adolescent children. Further factors this study focused upon can be seen in Figure 1 (Introduction, page 24).

**Emotional and behavioural functioning**

Children’s functioning was studied in two ways: in a prospective, longitudinal study on the functioning of children at three measurement moments during the first year after diagnosis and in a cross-sectional study on the functioning of children 1 to 5 years after diagnosis. Children of parents with cancer who had their diagnosis four months prior to measurement appeared to experience a degree of emotional and behavioural problems comparable to children of parents with cancer diagnosed 1 to 5 years prior to measurement and to children of the norm group. Six and 12 months
later these children on average seemed to experience fewer problems than the two comparison groups. However, sons in the primary school age group and adolescent daughters appeared to experience more emotional problems 1 to 5 years after diagnosis than their peers, when looking at the mean scores of the total group. On individual level one of four or five children, depending on age and gender, both during the four-months period and 1 to 5 years after diagnosis, appeared to experience problems so serious that professional help was needed. A number of children with serious problems shortly after diagnosis recovered in the course of the year.

Cancer is a high impact and life threatening illness that in many cases disrupts a child’s life. The impact of the illness on the child could be expected to decrease with the lapse of time after diagnosis. Remarkably, children do not appear to experience more emotional and behavioural problems during the first year after diagnosis than children 1 to 5 years after diagnosis and some, depending on age, gender and measurement moment (6 or 12 months after diagnosis), experienced even fewer problems than children in the retrospective and the norm group. The first year after diagnosis may be very stressful for the parents due to the confrontation with the disease and the subsequent medical examinations and treatments. Particularly in this phase children may put aside their own needs and may not express their own problems when seeing their parent having a difficult time. There is also the possibility that the consequences of the parent’s illness do not become manifest until later. Previous studies show indications of a delayed effect which means that high impact events do not become noticeable at once but a number of years later. The explanation for a delayed effect is that children in the early phase of the parent’s illness have enough resources to be able to cope. These resources often disappear over time. Sample bias however might be another plausible explanation. The children reported about are the children who have participated in all three study measurements. Drop out children after first measurement seemed to have more problems than children who participated in all measurements.

Children of parents with cancer appeared to experience not so much behavioural problems such as aggressive or delinquent behaviour as primarily emotional prob-
lems such as fear and depression, withdrawal behaviour and physical complaints. This corresponds with previous quantitative research, but qualitatively oriented studies also report behavioural problems such as anger as a reaction of children of parents with cancer. Behavioural problems are also found in children of a terminally ill parent.

**Predictors of children’s functioning**

*Child characteristics*

Gender, age and temperament of children appeared to be related to the prevalence of emotional and behavioural problems. The results of our study show that adolescent daughters have more problems 1 to 5 years after diagnosis than adolescent girls in the norm group. Development theories suggest that adolescents tend to conform to traditional masculine and feminine role patterns. For adolescent boys this means that they focus more on matters concerning themselves, independence, self protection and autonomy. Girls are supposed to focus more on their social surroundings and they learn to care for the well-being of others. This difference in socialization and the subsequent feelings of responsibility of daughters for taking on care tasks may explain the vulnerability of adolescent daughters of parents with cancer. True enough, the increasing demands may also stimulate the daughter into acquiring new competences and so contribute to her feeling being able to do something for the parent. However, when the demands exceed her capacities and block her, development problems may follow.

The present study also shows that sons in the primary school-age have more problems. The less rapid development of boys in comparison with girls in language and the socio-emotional areas may be primarily an explanation. This ‘staying behind’ may interfere with the coping with a stressful event such as cancer. The literature about the consequences of a divorce for children shows that boys in this age are more vulnerable, but that varying mechanisms underlie boys’ and girls’ vulnerabil-
ity. \textsuperscript{10,11} Girls e.g. appear to experience problems primarily when feeling responsible for the conflict between the parents, whereas boys experience problems when not feeling able to cope with the situation. Similar processes may very well play a role in children with a parent with cancer. Further research is needed to be better able to explain the vulnerability of sons in the primary school age group.

Results suggest as well that the children’s temperament correlates significantly with the prevalence of problem. Shy and fearful children primarily show a high prevalence of emotional problems; children with a low frustration tolerance and children not so capable of ‘effortful control’ seem to have primarily behavioural problems. Although various studies show that these temperamental dimensions correlate as well with the functioning of children without an ill parent, it is suggested that this correlation is mainly found when children are confronted with a stressful event.\textsuperscript{12}

\textit{Parent’s characteristics}

Children appeared to experience more problems when the father had a cancer diagnosis than when the mother did. This result is at right angles to those of previous studies that showed that children of an ill mother almost always had more problems. The number of participating fathers in the present study is relatively low. Besides it is not clear to what extent the illness characteristics of the fathers were different from those of the mothers. Further studies with a larger number of participating fathers will make the effect of the gender of parents more researchable and interpretable.

Neither age nor educational level appeared to be related to the degree of problems in children. The general literature about this is rather consistent and describes that a higher educational level of parents correlates with a better functioning of children.\textsuperscript{13,14} These studies state that not the educational level in itself correlates with a higher problem risk in children but the often allied worse financial situation and worse working and living circumstances.\textsuperscript{13} It is not clear to what extent these factors have played a part in the present study.

Attention has been paid to the physical and mental functioning of the parent with
cancer and the spouse as well. As the parent and the spouse experience more limitations the problems in the children increase. The limitations that correlate with the problems in children depend on the age of the child. Primary school children primarily appeared to experience problems when both parents had physical limitations. Children in this age group depend on their day-to-day life on the care provided by their parents. More physical limitations in a parent will lead to a larger disruption of the life of these children. The prevalence of problems in adolescents seemed only to correlate with the physical limitations of the ill parent. A possible explanation for this may be that because of the physical limitations the realization dawns that the illness is serious indeed. Another explanation might be that the problems in adolescents might be a consequence of the increasing number of tasks that will have to be taken over from the parent who has physical limitations.

Another correlation was found between the mental functioning of both parent with cancer and spouse and the prevalence of problems in adolescents, whereas this was not found for primary school children. Adolescents are in a phase of dissociation of the parent and so dependent on the psychological stability and flexibility of parents. Apart from the decreased accessibility of a parent as a consequence of this, the parent may also in coping with the event be less capable of attending to and supporting adolescents.

*Family characteristics*

Primary school children of single-parent families and children with fewer siblings appeared to have more problems than children of two-parent families and with several siblings. Primary school children of single-parent families having more problems has been shown in previous studies among children of a parent with cancer and children in the general population. Children of single-parent families in this situation cannot of course be supported by a second, often healthy, parent. Besides, the threatening passing away of the parent in a single-parent family can bring with it more fear because the consequences for children have a higher impact than will be the case in two-parent families. This is notably found among primary school
children and not among adolescents. From developmental psychology however it is known that adolescents have more contacts outside the family. It may very well be that adolescents of small or single-parent families experiencing insufficient support, receive this support from peers or adults outside the family.

The more negative life events (such as illness in one of the other members of the family) a family had gone through the more problems a child of a parent with cancer experienced. This finding in accordance with other studies that report an increasing number of life events, despite the presence or absence of other risk factors, enlarges the risk of problems.²

Illness-related variables

Intensive treatment, post-treatment complications and recurrence are related to more problems in certain sub-groups of children, probably because the perception of the illness is more threatening in these situations. Time since diagnosis and length of treatment showed no correlation with problem prevalence in children. Although it seemed not surprising that the seriousness of the illness and the impact of treatment is associated with the functioning of children, previous studies lack proof of this correlation.¹⁷,¹⁸ Only recurrence showed an increased problem risk in family members (spouse, adult children).¹⁹

In the present study parents with divergent diagnoses were approached for participation. Thus a heterogeneous group of cancer patients participated with divergent types of cancer and treatment stages, with subsequent various physical and psychological limitations. The diversity in illness-related variables in this study makes the results difficult to interpret and further research necessary in order to obtain more insight into the impact of these variables. Possibly it is not as much the specific illness characteristics themselves that give indications for the problems children may experience, but the confrontation with cancer and the possible long-term consequences for the physical and/or mental functioning of the parents.
**Informant agreement**

The agreement between parents about the functioning of children appeared to be high, whereas between parents and children was low to moderate both during the first months and the years after diagnosis. The type of problem reported about (emotional or behavioural), age (primary school children or adolescents) and the gender of the child seemed not to have any effect on the degree of agreement. Mothers reported notably often a comparable level of problems to that of the adolescents themselves, whereas fathers often reported fewer problems. This suggests that mothers, despite the possible illness, are generally better able to assess the problems of their children than fathers. This may be due to the fact that children tend to discuss their problems sooner with the mother than with the father. Moreover, mothers might have more empathy for the impact such an event might have for their children.

**Methodological remarks**

The design of this study contains a number of strong characteristics. The results are first of all based on information obtained from a relatively large group of children and their ill and healthy parent. Family members provided at various moments in time information about the functioning of children. Contrary to earlier studies that mainly focused on children of just mothers with cancer, both mothers and fathers diagnosed with cancer participated in our study group. In addition the problems of children were inventoried by means of a questionnaire of which the validity and reliability have been shown nationally and internationally. Despite these positive study characteristics a number of remarks can be made. First, as a consequence of the relatively low response sample bias may have taken place. Although two third of the families that did not participate has reported the reason for non-participation in the study (from ‘participating is too large an emotional burden’ to ‘we have left the illness behind us’), it is difficult to conclude whether this
has led to an over- or an underreporting of problems. On the one side the problem-
experiencing families may have comprehended the necessity of the study and there-
fore participated, which may have led to over-reporting. On the other it may well
be that families experiencing problems or not informing their children and/or hav-
ing trouble communicating about the illness and its consequences refrained from
participating, which may have led to underreporting. This representativity more-
over is a matter of discussion in the longitudinal study because in addition a num-
ber of families dropped out before second and third measurement. Children having
dropped out after first measurement appeared to experience more problems than
children having participated in all measurement moments, which may have caused
underreporting of problems. Another marginal note about the representativity of the
results is the overrepresentation of the number of participating mothers diagnosed
with cancer in the cross-sectional study. The percentage of women in the age range
of 35-55 who have cancer is higher (±65%) than that of men.20 This percentage
agrees with the number of participating ill mothers in the prospective, longitudinal
study (67%), but is lower than the percentage in the cross-sectional study (81%).
Second, sometimes several children from the same family participated in the study,
for which no correction has taken place. Every child is unique and reacts in its own
way on the illness of the parent. There is no denying however that the functioning
of children in one family is interrelated, they are exposed to the same family and
surrounding characteristics such as parent’s functioning, manner of upbringing,
family functioning and life events. No multilevel analyses were performed in the
present study and so the interdependence of children from the same family has not
been taken into account which may have caused a distortion of the results.

**Future research**

Based on this study a number of recommendations can be made for further research.
Future studies should pay even more attention to the non-response. The risk of selec-
tivity generated by non-response could not be eliminated in this kind of research. Families who experienced study participation as too much of a burden can not be forced. In order to generate more clarity about non-response bias reasons for non-participating should be more accurate obtained. Furthermore, to get more clarity it is necessary to provide more insight into the characteristics (such as socio-demographic illness-related variables) of responders in comparison to the population.

A relatively large sample and quantitative research methods were used so consequently analyses are mostly executed on a group level. A limitation of this method is that no insight is obtained in the experiences and the degree of adaptation of children on individual level. As a supplement to the large-scale quantitative studies qualitative research methods can be used so as to provide better insight into the individual experiences of and consequences for children.\textsuperscript{21}

Internationally accepted, well-validated and age and gender standardized questionnaires were used to obtain information about the emotional and behavioural problems in children. These questionnaires however focused on general problems in children instead of on the specific consequences the illness of the parent may have for children. Earlier studies have shown that children may experience shame or feelings of guilt because they shy away from their parent, anger about the fact that the illness of the parent also brings restrictions for their own life or loneliness due to not wanting to ask for attention for their own problems.\textsuperscript{5} The use of questionnaires aimed at the specific consequences of this situation for the child may provide additional information.

Parent and adolescent reports were used to map out problems in children. Although the results indicate that the most reliable information comes from mothers and adolescents themselves, it is known that every informant’s report has its limitations. Parents do not always provide an accurate picture of the problems. First because it is difficult for an outsider to perceive emotional problems, more so because part of the child’s behaviour takes place outside the parent’s range of vision (at school for example). Adolescents in their turn will not very soon report socially unacceptable behaviour.\textsuperscript{22} For an overall view on the functioning of children it is advisable to
involve informants who have the opportunity to observe children in various circumstances. A teacher for instance or a child’s mentor, for a more complete picture. Longitudinal research in which children are followed for more than a year after diagnosis may provide more insight about the increase of problems in a child as a consequence of the diagnosis cancer in a parent and about the factors that may enlarge or diminish the risks of problems in the long term.

Next to the factors discussed in this thesis there are many other factors that may relate to the way a child copes with the event. Another publication of our research group found that the child-parent communication was related to the prevalence of stress response symptoms. Other factors needing attention in future research are mediating and moderating factors such as appraisal, coping and parenting, for children’s functioning when confronted with cancer in a parent, and family functioning and social contacts outside the family.

The present study focused on the negative consequences the diagnosis cancer in a parent may have for children. The confrontation with cancer may possibly also have positive consequences for a child, such as increased sensitivity, empathy, personal growth, increased feeling of competence and self-respect. Future research should therefore not only focus on the negative consequences but also pay attention to the positive consequences of the cancer experience for children.

**Practical implications**

Although the majority of the children appears to be resilient in coping with the illness of the parent the remaining minority experiences serious problems. There is no structural focus on the care for children of a parent with cancer in the Netherlands. This study may contribute to improving the skills level of caregivers who are confronted with patients with young children and so incite better care for these children. This can be done in several ways.

First it is important that parents, where needed, are supported in helping their chil-
dren to cope with this life event. Practice shows that parents often have questions about how best to do so. Parents should be better informed about the possible reactions of sons and daughters in various ages, and what is needed for children to cope. They can possibly observe problems sooner and seek adequate resources for solving them. In addition, parents should receive support in finding a balance between the demands of the illness and the treatment and the care and attention for the children. This support should especially focus on the consequences of ‘crucial moments’ in the illness process, as e.g. shortly after diagnosis, after recurrence, during heavy treatments or when experiencing complications, as well as on moments when the parent experienced serious physical or psychological complaints.

It is also important to pay attention to the spouse. As shown the consequences for children appeared to depend on the functioning of the spouse, who often has an important role in offering consistent and stable family life and in supporting the child.

Children under these circumstances are supposed to behave socially acceptable and might be restricted in expressing their feelings openly. By organising meetings children can be informed about the illness and its consequences for the family life in a way suitable for their age. Without the presence of their parents, children may feel more free to ask questions and express their fears and uncertainties. Moreover, they can exchange experiences with other children in a similar situation. They can learn that their own needs are important too and can be offered tools that satisfy their needs. Chances of a good coping process will be larger when children are offered a surrounding in which they are well informed and learn to not lose their own needs out of sight.

A protocol for the way in which children and families are best supported is not available. When offering support the uniqueness of a child and the family surroundings will have to be taken into account in all situations and a way will have to be found that suits the needs and customs of that child within the family.
References


