The impact of parental cancer on children
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Psychosocial consequences for children of a parent with cancer: a pilot study
Abstract

When cancer is diagnosed in a parent, this may also have consequences for the children. The purpose of this pilot study was to gain more insight into the psychosocial consequences for children of a parent with cancer, from the perspective of both the children and their parents. For this study, 14 families participated in semistructured interviews and completed standardized questionnaires. Interviews were tape-recorded, transcribed and analyzed using content analysis techniques. No significant difference was found in behavioral and emotional problems between the children of these families and the normative sample. However, parents reported problems on a borderline and clinically elevated level in one-third of the children, and three of seven children self-reported problems on these levels. The interview results showed that parents reported (temporary) behavioral problems in most children during the acute stage of their parents’ illness. Other problems, such as anxiety, sleeping disorders and compulsive behavior, persisted for longer. Parents reported that their children had more problems than the children themselves reported. This finding was not supported by the quantitative analysis. The results form the Child Behavior Checklist and the Dutch version of the Family Adaptability and Cohesion Evaluation Scales showed that children of families with poor family functioning were more vulnerable. In particular, extremely high adaptation (chaotic) and extremely low family cohesion (disengaged) seemed related to the prevalence of emotional and behavioral problems in these children. Absence of home health care was an additional burden for adolescent children.
Introduction

Cancer is a life-threatening illness that has an impact not only on the patient, but also on the other family members (1,2). Cancer causes fear of death and uncertainty about outcome. For families with young children or adolescents, there are additional burdens in adjusting to this threatening situation (3). Children’s sense of security will be affected because the parent might die of cancer (4,5). Their needs will be unfulfilled because the routine of everyday life is disturbed by treatment schedules and repeated hospital admissions and visits. As a consequence, parents will not be able to give as much time and attention as usual to their children. Frequently, children and adolescents take over the parental tasks during the illness. These new responsibilities can reduce their time for normal daily activities such as playing, other leisure activities or doing homework (6). Therefore, children of cancer patients also must adapt to the new family situation.

Parents must face the burden of their own emotions and needs concerning diagnosis and treatment. In addition, they must support their children emotionally. A further difficulty for parents seems to be the assessment of what children understand about illness and what and how they can explain cancer and treatment to them (5,7). Parents do not want to give the child false hope, but they find it also difficult to be honest about the threat and uncertainty of cancer (8).

Parents do not always recognize their children’s distress (9). Their reports of the emotional and behavioral adjustment of their children in the months after diagnosis seem to differ from those of the children (10-12). Whereas the children report a negative impact on their self-esteem and adaptation, their parents report that the children experience minimal behavioral or emotional problems (10,12,13). Heiney et al. proposed that children may hide their true emotions to protect their parents. They stated also that parents have more difficulty assessing their children’s emotional state accurately when they have higher levels of anxiety themselves.

Some researchers have suggested that children of patients with cancer adjust well to their parent’s disease and treatment (14). However, other researchers have found that these children and adolescents are at risk for internalizing behavior and somatic problems, anxiety, poor self-esteem, depression, or problems at school (4).

Parents with cancer often ask oncology nurses and doctors about the possible psychosocial consequences of their illness and treatment for their children (8). Because cancer care professionals are focused primarily on the treatment and wellbeing of the patient, they profess to have little knowledge of how children cope with their parent’s illness. Therefore, it is important to increase their understanding of the reactions of children when their parent has cancer. With this knowledge, they will be better able to advise and support parents who want to know more about how they can take good care of their children and adolescents in this situation.
The current knowledge on this topic, based mainly on American and British research, offers surprisingly limited practical information. Children of different cultural backgrounds may react differently. Earlier studies found that children in an American norm group had significantly more emotional and behavioral problems than children of a Dutch norm group(15-18). In addition, the health care system for patients with (and their families) in the Netherlands is different from that of other countries. For instance, everybody has healthcare insurance in the Netherlands, so worries about medical expenses are not an issue. Such variations in health care systems may lead to differences in the way children cope with their parent’s disease. This pilot study was designed to explore the psychosocial functioning of Dutch children who have a parent treated for cancer and the variables that may positively or negatively relate to the development of emotional and behavioral problems. This study had a retrospective cross-sectional and descriptive design. Qualitative and quantitative methods were triangulated.

Methods

Procedure
The medical oncologist or oncology nurse introduced the study to patients with children living at home at the time of their regular check up in the outpatient clinic of the Department of Medical Oncology, University Medical Center Groningen, The Netherlands. Parents were given written information about the study and an adapted version for their children. The parents informed and discussed study participation with their children. When written informed consent was obtained, questionnaires were mailed to the parent with cancer and children older than 10 years. An appointment for the interviews was made by telephone. Parents and children were asked to complete the questionnaires independent of each other before the interviews took place. Written permission was obtained from the participants for the interviews to be tape-recorded.

Instruments
The Child Behavior Checklist (CBCL/4-18) and the Youth Self-Report (YSR) were used to obtain the reports of parents and children on the emotional and behavioral functioning of the child. These standardized instruments are widely used in many countries including the Netherlands. Norm values for 4- to 18-year-old Dutch children are available. The reliability and validity of the CBCL and YSR are well established(15-18).

The CBCL is the parent form. It has two parts: one part consisting of 118 items describing a broad range of internalizing and externalizing problems and a second part measuring the competencies of children. The instrument yields an overall
measure of emotional and behavioral problems, the Total Problems Score (TPS), and an overall measure of competence in school, sports, social relationships, and other activities, the Total Competence Score (TCS). The TPS is a composite of externalizing (TES) and internalizing (TIS) behavioral problems together with additional items. This study used the t scores provided by the CBCL (Mean, 50 ± 10). These normalized standard scores, based on separate norms for boys and girls, have the advantage that all scales of the CBCL are mutually comparable and also comparable with the YSR, which is standardized in the same way. Higher scores on total problems and lower scores on total competence reflect poorer functioning. In the current study, the parents with cancer completed the CBCL.

The YSR is the self-report youth version of the CBCL for children 11 to 18 years of age. The YSR consists of 119 items. In the current study, children 11 years of age and older completed the YSR. Items on both versions of the CBCL problem scales are rated on a 3-point scale of “not true”, “somewhat or sometimes true”, and “very true or often true”. Item responses on the subscales of the TCS are recorded on 3- to 4-point scales. The CBCL and YSR have been shown to discriminate between children referred for mental health services and a similar group of nonreferred children. The clinical cutoff scores discriminate between children with normal, borderline clinical and clinical scores(17,18) (Table 1).

Family functioning was measured with the Family Dimension Scales (the Gezins Dimensie Schalen [GDS] in Dutch). The GDS is based on the Family Adaptability and Cohesion Evaluation Scales (FACES) by Olson et al.(19). The GDS has 44 items and measures family functioning as perceived by each family member on a 4-point scale. Two scales of this questionnaire were used: cohesion and adaptability. Each scale represents a continuum of family functioning. Family cohesion is the level of emotional connection or separation that family members have with one another(19). The cohesion scale ranges from extremely low (disengaged) through moderate levels (separated, connected) to extremely high cohesion (enmeshed). High scores on the Family Cohesion Scale reflect connected families characterized by emotional closeness.

Family adaptability is the capability of a family to change as appropriate its power structure, role relationships, and relationship rules in response to circumstantial (eg, a parent’s cancer) and developmental (eg, puberty) stress(20,21). The scale ranges from extremely low (rigid) through moderate levels (structured, flexible) to extremely high adaptability (chaotic). Moderate to high scores on the Family Adaptability Scale reflect an ability to adapt to change. The GDS can be used to discriminate between functional and dysfunctional families. Families with an extreme score on either adaptability or cohesion show unstable functioning. Families are dysfunctional if the family scores are extreme on both adaptability and cohesion.
Table 1

Parents’ and children’s T-scores on the total problems (TPS), internalizing problems (TIS), externalizing problems (TES) and total competence (TCS)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parents T-scores (n=12)</th>
<th>Children T-scores (n=7)</th>
<th>Cut-off scores</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TPS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>53.17</td>
<td>55.57</td>
<td>Clinical range: T score &gt;63</td>
</tr>
<tr>
<td>SD</td>
<td>13.18</td>
<td>9.93</td>
<td>Borderline clinical range: T score 60-63</td>
</tr>
<tr>
<td>Range</td>
<td>33-78</td>
<td>40-71</td>
<td></td>
</tr>
<tr>
<td><strong>TIS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>55.58</td>
<td>57.71</td>
<td>Clinical range: T score &gt;63</td>
</tr>
<tr>
<td>SD</td>
<td>14.24</td>
<td>9.86</td>
<td>Borderline clinical range: T score 60-63</td>
</tr>
<tr>
<td>Range</td>
<td>32-82</td>
<td>46-77</td>
<td></td>
</tr>
<tr>
<td><strong>TES</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>53.76</td>
<td>52.57</td>
<td>Clinical range: T score &gt;63</td>
</tr>
<tr>
<td>SD</td>
<td>11.96</td>
<td>9.13</td>
<td>Borderline clinical range: T score 60-63</td>
</tr>
<tr>
<td>Range</td>
<td>35-77</td>
<td>37-64</td>
<td></td>
</tr>
<tr>
<td><strong>TCS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>52.75</td>
<td>52.14</td>
<td>Clinical range: T score&lt; 30</td>
</tr>
<tr>
<td>SD</td>
<td>8.98</td>
<td>11.45</td>
<td>Borderline clinical range: T score 30-33</td>
</tr>
<tr>
<td>Range</td>
<td>38-65</td>
<td>33-66</td>
<td></td>
</tr>
</tbody>
</table>

The standardization is based on a control group of 669 family members out of 178 Dutch families. Norm data are available for mothers, fathers and children. The reliability of the GDS is high (Cronbach’s alpha is .87 for cohesion and .81 for adaptability)(22,23). In the current study, the parents with cancer and their children 11 years or older completed the GDS.

To assess in-depth information on topics most relevant to the children and their parents, semistructured nonrecurrent interviews were conducted by two interviewers. While the first interviewed the parent with cancer and the partner (if present),
the second interviewed the children. If a family had two participating children, they were interviewed separately. In one family, the parent with cancer and the child were interviewed together because the mother did not allow the interviewer to speak with her child separately. The interviews took place in the family’s home and required 60 to 90 minutes. All interviews were tape-recorded and fully transcribed.

**Data-analysis**

**Questionnaires**
The CBCL/4-18 and the YSR were scored using the supplied computer program. This program transformed raw scores into Dutch population $t$ scores. The scores of parents and children were compared with the scores of Dutch norm children to test for possible differences. The data obtained from the GDS were analyzed in relation to the Dutch norm population data to determine whether family functioning was perceived similarly or dissimilarly between the parents and children and the norm group. The relationship of family cohesion and adaptability reported by the parents and children to the prevalence of emotional and behavioral problems in children was investigated using correlational analyses (Pearson’s rho). The relationship between the reports of parents and the reports of the children on children’s emotional and behavioral problems, family adaptability, and family cohesion also were investigated.

**Interviews**
The transcribed interview data were analyzed according to multiphase content analysis. The researchers read the unabridged interview transcripts several times. The researchers read the unabridged interview transcripts several times. On the basis of the verbatim transcripts, the text was divided into coded fragments. During the second round, all fragments with the same codes were categorized, and the categories were labeled. In the next step, the most common labels were linked to central labels of a higher abstraction level. This provided a description and specification of central themes. Comparative analysis took place continuously during the study.

**Results**

**Respondents**
For this pilot study, 14 patients with cancer, 12 partners and 15 children (ages, 7-18 years) consented to participate. In 13 families, one child participated, and in 1 fami-
ily, two children took part in the study. Among the participants, 12 patients were married, and 2 mothers were widowed. The father had testicular cancer. Most of the mothers had experienced breast cancer (Table 2). The patients had completed their chemotherapy 2 to 52 months before the study assessment. Ten patients had received a multimodal treatment with surgery, chemotherapy and radiotherapy. Three patients had recurrent disease, but none was terminally ill. The analyses of the interviews provided four central themes: child’s functioning; family functioning; information and communication; and continuation of everyday life. The first two themes were assessed also with standardized questionnaires. The results of the first two themes are presented first, followed by the results of the remaining two themes.

**Child’s functioning**

**Children**
The seven children (1 boy and 6 girls) who completed the YSR did not differ from the normative Dutch sample (t̄ score mean, 55.57 ± 9.93), TIS (t̄ score mean, 57.71 ± 9.86), the TES (t̄ score mean, 52.57 ± 9.13) and the TCS (t̄ score mean, 52.14 ± 11.45).

In accordance with Achenbach’s criterion for borderline clinical and clinical cutoff scores (15,17), one girl (age, 17 years) scored in the clinical range on the TES. Another girl (age, 17 years) scored in the clinical range on the TPS and TIS; and one girl (age, 16 years) scored in the borderline clinical range of the TPS, TIS and TES and in the clinical range on the TCS (Table 1).

**Parents**
The CBCL was completed by 13 parents with cancer. One of the 14 parents preferred to be interviewed only. The partners also were interviewed only. Parents’ reports of their children’s functioning were not different from those of the normal population on the TPS (t̄ score mean, 53.17 ± 13.18), TIS (t̄ score mean, 55.58 ± 14.24), TES (t̄ score mean, 53.76 ± 11.96) and the TCS (t̄ score mean, 47.52 ± 8.98).

Using Achenbach’s criterion of symptomatology (16,17), one boy (age, 10 years) was scored by his parent within the borderline range of the TIS; one boy (age, 10 years) was scored within the borderline range on the TPS and within the clinical range of the TIS. One girl (age, 17 years) was scored within the clinical range of the TES and within the borderline clinical range on the TPS and TIS, and two girls (ages, 9 and 16 years) were scored within the clinical range on the TPS, TIS and TES (Table 1).
Table 2
Summary respondents

<table>
<thead>
<tr>
<th>Family</th>
<th>Diagnosis</th>
<th>Sex sick parent</th>
<th>Age sick parent</th>
<th>Partner</th>
<th>Sex child(ren)</th>
<th>Age child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Germ cell tumor</td>
<td>female</td>
<td>37</td>
<td>yes</td>
<td>girls</td>
<td>8 and 11</td>
</tr>
<tr>
<td>2</td>
<td>Soft tissue sarcoma</td>
<td>female</td>
<td>48</td>
<td>widow</td>
<td>girl</td>
<td>18</td>
</tr>
<tr>
<td>3</td>
<td>Breast cancer</td>
<td>female</td>
<td>53</td>
<td>yes</td>
<td>girl</td>
<td>17</td>
</tr>
<tr>
<td>4</td>
<td>Ovarian cancer</td>
<td>female</td>
<td>46</td>
<td>yes</td>
<td>girl</td>
<td>17</td>
</tr>
<tr>
<td>5</td>
<td>Testicular cancer</td>
<td>male</td>
<td>42</td>
<td>yes</td>
<td>boy</td>
<td>10</td>
</tr>
<tr>
<td>6</td>
<td>Breast cancer</td>
<td>female</td>
<td>49</td>
<td>widow</td>
<td>boy</td>
<td>12</td>
</tr>
<tr>
<td>7</td>
<td>Breast cancer</td>
<td>female</td>
<td>44</td>
<td>yes</td>
<td>girl</td>
<td>14</td>
</tr>
<tr>
<td>8</td>
<td>Breast cancer</td>
<td>female</td>
<td>38</td>
<td>yes</td>
<td>boy</td>
<td>10</td>
</tr>
<tr>
<td>9</td>
<td>Breast cancer</td>
<td>female</td>
<td>32</td>
<td>yes</td>
<td>girl</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td>Breast cancer</td>
<td>female</td>
<td>32</td>
<td>yes</td>
<td>boy</td>
<td>10</td>
</tr>
<tr>
<td>11</td>
<td>Breast cancer</td>
<td>female</td>
<td>51</td>
<td>yes</td>
<td>girl</td>
<td>16</td>
</tr>
<tr>
<td>12</td>
<td>Breast cancer</td>
<td>female</td>
<td>51</td>
<td>yes</td>
<td>girl</td>
<td>15</td>
</tr>
<tr>
<td>13</td>
<td>Breast cancer</td>
<td>female</td>
<td>48</td>
<td>yes</td>
<td>boy</td>
<td>18</td>
</tr>
<tr>
<td>14</td>
<td>Breast cancer</td>
<td>female</td>
<td>41</td>
<td>yes</td>
<td>girl</td>
<td>7</td>
</tr>
</tbody>
</table>

Child and parent agreement on child’s functioning
Correlational analyses showed that when children indicated higher scores on the TES, parents reported higher levels on the TPS ($r = .83$, $p = .021$) and the TIS ($r = .84$, $p = .014$). No other significant relationships were found. In four families, both the parent with cancer and the child scored within the normal range on the CBCL and YSR. In one family, a daughter (age, 17 years) reported clinical scores on the TIS, whereas her mother scored in the normal range. In another family, both the mother and the daughter (age, 17 years) indicated that the daughter had internalizing and externalizing problems. However, the mother reported clinical scores, whereas her daughter reported borderline scores on the TIS and the TES. In still another family, both the mother and the daughter (age, 17 years) indi-
icated the daughter’s clinical scores on the TES, but the mother reported borderline on the TIS, whereas the daughter scored within the normal range.

**Interviews**

Parents of 11 in 15 children observed changes in their children’s emotional and behavioral functioning shortly after diagnosis. They mentioned withdrawal (n=1), boisterous behavior (n=2), general anxiety (n=7) and hyperventilation (n=1). The functioning of the children normalized in a few months to a half-year. Other problems such as sleeping disorders (n=4), regressive development (n=1), and compulsive behavior (n=1) persisted longer than 6 months, sometimes years after the diagnosis. Also, six of the seven children who reportedly suffered from anxiety shortly after diagnosis were found continuously afraid that their parents were going to die. The seventh child’s fear of her own dying required psychotherapy.

Two children changed education level to an easier program, and two children repeated a year in school. These children did not perform badly at school before their parent’s illness.

Twelve parents reported their children as having more problems than the children reported. Two children, one younger child and one adolescent, tried to protect their parents, and therefore did not tell them about their nightmares. Four adolescent children judged that their behavioral changes were age related and therefore not so much caused by their parent’s disease.

According to 12 parents, disease and treatment were a continuous process. The stress fluctuated constantly during the various phases of the disease: diagnosis, treatment, and recurrence.

**Family functioning**

**Children**

Of the seven children who completed the GDS, three perceived their family as unstable with regard to adaptability and cohesion. According to them, their family functioned rigidly separated (n=1), rigidly connected (n=1), and structurally enmeshed (n=1). Four children perceived their family as functional. They experienced their family functioning as structurally connected (n=2) and flexibly connected (n=2). Fewer children rated their family as dysfunctional (study sample: 0.0%; control group: 10.8%). Somewhat more children perceived their family functioning as unstable (study sample: 42.8%; control group: 36%), and an equal percentage of children indicated that their family was functional (study sample 57.1%; control group 52.6%), as compared to the children in the norm population (Figure 1).
**Child reported family functioning and emotional-behavioral problems**

There was only one significant relationship between the family functioning variables and emotional-behavioral problems in children: the children who scored higher on the internalizing problems perceived their family as adapting chaotically ($r = .86; p = .013$).

**Parents**

Of the 12 parents with cancer who completed the GDS, 2 parents perceived their family as dysfunctional with regard to adaptability and cohesion: rigidly disengaged (n=1) and chaotically disengaged (n=1). Eight parents with cancer indicated that their family was unstable: structurally enmeshed (n=4), flexibly enmeshed (n=2), chaotically separated (n=1), and rigidly connected (n=1). Two parents with cancer described their family as functional (structurally connected).

The preceding results mean that more parents perceived their family as functioning less positively than the mothers in the norm group. In other words, fewer parents rated their family as functional (study sample: 16.7 %; control group: 52.5 %). More parents indicated that their family was unstable (study sample: 66.7 %; control group: 36.1 %), and somewhat more parents perceived their family as dysfunctional (study sample: 16.7 %; control group: 11.4 %) (Figure 1).

**Parent-reported family functioning and emotional/behavioral problems**

Family adaptability as perceived by the parents was significantly related to the emotional and behavioral problems they reported for the children. The more family adaptation was perceived as chaotic, the higher scores parents reported on the
TPS (r= .74; p=.009); the TIS (r= .73; p = .011) and the TES (r= .80; p= .003). When parents perceived less structured family adaptation, they reported higher scores on the TPS (r=-.68; p=.022), the TIS (r=-.60; p = .049) and the TES (r=-.70; p= .017). The lower the family cohesion (disengaged), the more internalizing problems parents reported (r= .65; p= .031). Separated, connected, or enmeshed cohesion and rigid or flexible adaptation were not significantly related to children’s emotional and behavioral problems as reported by their parents.

**Child and parent agreement on family functioning**

Descriptive statistics showed that none of the children perceived their family functioning as dysfunctional, whereas 16.7% of their parents did. Children indicated their family functioning more often as functional (57.1%) in contrast to the parents (16.7%). In addition, parents more frequently perceived their families to function in an unstable way (66.7%), as compared with their children (42.8%) (Table 3).

**Interviews**

In 10 of 14 families, the family members were more concerned about each other and became closer than before the illness. In 6 of 14 families, communication became more open after the diagnosis. Parents with cancer and partners perceived this more strongly than their children. This is a surprise because the results of the GDS (completed only by the parent with cancer) showed that two parents indicated their family as dysfunctional, eight parents as unstable, and only two as functional. Two parents with cancer mentioned that they were more worried about their children than before their illness. Both parents and children mentioned repeatedly that they were afraid to lose each other. Understandably, this fear was felt stronger in those families that had already lost a parent. For parents and older children in three families with a parent who had an incurable or recurrent cancer, the possibility of death posed a continuous threat.
The seven adolescent children, all with mothers who had cancer, were confronted with contradictory feelings. On the one hand, they wanted to break away from their parent, but on the other hand they realized they could lose their mother and wanted to spend more time with her.
The interviews showed two additional relevant factors related to emotional and behavioral problems in children. These factors are described in the following two sections.

**Information and communication**

Four married couples remarked that the way they informed their children and coped with the disease themselves influenced the children’s reactions. They mentioned that the more they were upset when talking to their children about cancer, the more the children were upset too.
All but one parent told the children about the diagnosis themselves. One widowed mother asked her babysitter, who had a good relationship with her children, to inform the children. According to 22 parents (12 of 14 parents with cancer and 10 of 12 partners), they had informed their children well and appropriately, taking their developmental age into consideration. When they told their children about cancer and its treatment, they used the information they had received themselves from the specialist or oncology nurse. Among 15 children, 13 found they were informed well enough and felt involved in everything their parent was going through. Because they knew what was the matter with their parent, they found it easier to talk about it with friends and family members.

The interviews revealed that children received sufficient support from peers, either enabling them to take mind off things or just allowing them to talk about their feelings concerning their parent’s cancer. However, adolescent children found that peers had difficulty putting themselves into their position. Six children of 11 years of age and older would have found solace in talking to peers experiencing the same adversity, especially during the first months after their parent’s diagnosis.

*Continuation of everyday life*

All parents reported that they put in great effort into continuing everyday life as normally as possible for their children’s sake. In doing so, they expected that their children would develop no or few problems. Practical support from the social network and professional help was mobilized to attain this goal.

Eleven families sought domestic help from home healthcare. The presence of a partner or children older than 12 years appeared to be an exclusion criterion for receiving professional help. These family members were considered able to take over the household tasks of the mother. Therefore, the request for domestic help from this professional organization was refused. For children of two of seven families with adolescents, the burden of housekeeping, in addition to their emotional distress caused by their parents’ illness, visits to their parent in the hospital, going to school and doing their homework, resulted in strain and consequently the development of emotional and behavioral problems.

*Discussion*

This pilot study examined the psychosocial consequences for children who have a parent with cancer, from the perspectives of both the children and parents. Obviously, any conclusions drawn from this study will be limited because of the small sample size. The power of statistical analysis is therefore also limited, but nevertheless showed some significant results.
The results from the questionnaires showed that the children did not differ significantly from the normative sample in prevalence of behavioral or emotional problems. However, parents reported emotional or behavioral problems in one third of the children and three of seven children self-reported problems on these levels. The interview results showed that 11 of 15 children had parent-reported temporary behavioral changes, and that 7 of the 15 children had prolonged problems. Additionally, anxiety reportedly prevalent among seven children during the first months after diagnosis continued to be present, but more as a specific fear for death and dying. The dissimilarity in the number of reported problems between the interviews and the questionnaires may have been caused by differences in the type of data being gathered. The results of the quantitative analyses describe significant emotional and behavioral problems only, whereas a broader range of problems in children was reported during the interviews. In addition, whereas the CBCL and YSR described problems over the preceding 6 months, the interviews focused on a longer period.

The results of the quantitative analyses showed no correspondence between the scores of the children and the parents on total problems or externalizing and internalizing problems. When children reported externalizing problems, their parents reported more problems in general and internalizing problems only. This is a surprise. Greater agreement on externalizing problems would be expected because externalizing behavior is more visible behavior. It may be that children expressed this kind of behavior more often among peers at school and not in the presence of their parents. Qualitative data showed that children had more behavioral or emotional changes and problems according to the parents than the children indicated themselves.

This outcome is in contrast to that of other studies(12,24,25). One reason for this finding could be a cultural one. Available studies so far have been based mainly on American and British research, and there is no empirical knowledge about the functioning of Dutch children of a parent with cancer. Another reason may be that children are afraid to overburden their parents, and therefore hide their feelings(10). Children of families with poor family functioning seemed to be more vulnerable because family functioning was significantly related to emotional and behavioral problems. In particular, extremely high adaptation and extremely low family cohesion were related to the prevalence of emotional and behavioral problems in children. Children less frequently described their family as dysfunctional and perceived their family as unstable less often than their parents.

It may be argued that the children were more optimistic concerning their family functioning than their parents. It may be that the children tried to present their families in a socially desirable manner(12), or that they were less inclined to judge their family as malfunctioning. Another reason may be that parents judged their family functioning more negatively because they expected that the illness would
have a negative impact on their family. This also may explain the finding that the parents and children in this study perceived their family adaptation and cohesion differently, whereas the parents and children in the control group were more similar in their perception of family functioning.

The qualitative analysis showed that a number of other factors were perceived as having an impact on the children’s coping with their parent’s cancer. Whether the child was well informed and whether the child could talk with others about the disease appeared to be relevant. Another important issue was whether parents were able to offer children a continuation of everyday life as normal as they were used to experiencing. Maintaining normalcy supposedly helped children and parents to deal with the illness and treatment. Parents and children of families unable to continue normal life because domestic help was lacking reported the family situation as more aggravating than the other families did. Thus, support from home healthcare could have a positive effect on the child’s functioning.

The parents in this study were not in a terminal phase of their disease. The results would probably have been different if the children had needed to face the near loss of their parent. It has been demonstrated that young children experience more stress when the parent’s death is imminent because of observed parental deterioration (26), anticipated mourning, and a profound sense of loss (27). Adolescents also struggle more during this phase of their parent’s illness because their expanded cognitive and empathic capacities make them more aware of their parent’s suffering and of the coming loss (28).

A study limitation was that no structural attention was paid to the occurrence of life events other than the parent’s cancer. However, other concurrent or prior life events may also be major stressors for children influencing their well-being. For instance, an adolescent girl in this study who reported problems within the clinical range had not only a mother with a recurrent cancer, but also a sister with a serious disease. Both events caused a lot of family distress. Therefore, attention to other life events should be recommended for future studies.

**Recommendations for cancer care**

A number of children seemed to be coping well, whereas others reported short- or longer-term problems. Better understanding of the factors contributing to the psychological stress of these children is necessary for the development of targeted interventions.

Family structure seems to be one of these factors. Assessment of how the family of a patient with cancer copes with stressors may help.

Parents indicated that when they were given comprehensible information about the disease and treatment, it was easier for them to tell their children about it. Therefore, the way that the oncology nurse and medical specialist inform the parents seems to have an impact on the information provided to the children, and
consequently on the children’s coping with the illness of their parent. This means that attention should be given to the provision of information to parents. Clinicians caring for childrearing patients with cancer need to understand what ways are best for supplying information about the illness to children of different ages. Consequently, they will be better able to advise parents how they can explain to their children what cancer and its treatment involve.

This study confirms once more that parental cancer has an impact on all family members, including the patient’s children. They deserve special attention and tailored care. Support from home healthcare is essential for enabling them to continue everyday life as normally as possible. Home healthcare organizations should consider not only the fact that the parent has cancer, but also the consequences the illness and treatment have for the socioemotional functioning of each family member.

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