Family functioning and adolescents’ emotional and behavioral problems: when a parent has cancer

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Background: This article focuses on possible relationships between functioning of adolescents with a parent diagnosed with cancer 1–5 years earlier and family environment.

Patients and methods: In all, 138 patients, 114 spouses and 221 adolescents completed the Family Environment Scale. Additionally, adolescents filled in the Impact of Event Scale and Youth Self-report and parents reported on the adolescents’ functioning using the Child Behavior Checklist.

Results: Patients and spouses reported that their families differ from the norm; they are more expressive and social, better organized, less controlling and have less conflict. Adolescents reported the same and additionally find their family environment was weakly to moderately strongly negatively related to the adolescents’ functioning; family relationships related more strongly to the adolescents’ functioning than family structure did. No significant relationship was found between family environment and the adolescents’ cancer-related distress. Discrepancy in reports of family environment between parents and between parents and adolescents, in general, did not relate to the adolescents’ functioning or distress. Parent–adolescent discrepancy only correlated with adolescent self-reports of their functioning.

Conclusion: Families with parental cancer functioned positively. Despite this, family functioning seems to be a risk factor for behavioral and emotional problems in adolescents.

Key words: adolescents, distress, family environment, parental cancer

Introduction

A parent’s cancer diagnosis impacts the entire family. Literature has shown a number of psychological consequences for patients and spouses, including diminished quality of life, anxiety and depression [1, 2]. Also affected are the children. A review on children of cancer patients found problems being reported in various domains of child functioning, e.g. behavioral problems and disturbed physical and cognitive functioning [3]. Recent studies have found that adolescents reported impaired emotional and behavioral functioning [4] and that 35% of adolescent daughters and 21% of adolescent sons reported post-traumatic stress symptoms (PTSS) levels requiring professional care [5]. Adolescents are in a developmental phase in which they are aware of physical and emotional pain that a parent may be experiencing. They understand what death is and that their parent’s prognosis may be poor. This may place them at higher risk of developing psychological problems than their younger siblings [6, 7]. Furthermore, older children may take on responsibilities or partly assume parental roles, which may impair the normative development of establishing personal identity [7–9]. Thankfully, not all adolescent children of cancer patients develop psychological problems. Therefore, it is important to identify factors that may place certain adolescents at risk, thereby enabling mental health professionals to help children at an early stage.

Research has suggested that the quality of the family environment affects how family members make it through cancer [10–14]. In these reports, family cohesion, in particular, has been found to relate to how adults and children cope with stressful events. High emotional expressiveness and cohesion and low conflict in family relationships have been shown to predict better psychological adjustment to cancer [3, 10, 11, 15]. However, the number of oncology studies focusing on family functioning is limited and results sometimes conflict; for example, one study reported interestingly that a positive family environment

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correlated to higher anxiety and depression in adolescents [16]. Some studies focus on either only adults or on children with cancer. For these reasons and to bring more attention to this important subject, our team conducted the following study.

Our goal was to explore family functioning and possible relationships between family environment and adolescents’ functioning. We hypothesized that families confronted with parental cancer would report functioning more positively than a norm group [17]. Furthermore, we expected to find a significant relationship between family environment and the adolescents’ functioning and cancer-related distress.

Literature from studies examining families not confronted with cancer has shown relationships between discrepancy in how parents and adolescents viewed their family environment and lower self-competence [18], problem behavior [19], depression and anxiety [20] and poorer psychological well-being of adolescents [21], particularly for girls. We, therefore, expected that larger discrepancies would be related to more dysfunction and distress.

patients and methods

procedure

This study is part of a larger project examining how families function when a parent has cancer [4, 5, 22]. During a 2-year period, cancer patients at the University Medical Center Groningen undergoing treatment or seen for a follow-up visit were approached by oncology specialists and nurses. Patients were eligible if they had been diagnosed with cancer 1–5 years before study entry, had children 4–18 years at time of parent’s diagnosis and were fluent in Dutch. Written information was offered to all eligible patients and their partners. An adapted brochure was provided for the children. In accordance with Medical Ethical Committee policy, informed consent was given by each family member separately. After obtaining informed consent, researchers mailed packets to each family member containing questionnaires and prepaid return envelopes. Cancer patients, spouses, and children were instructed to fill in separate questionnaires independently of each other and not discuss their answers.

sample

A total of 476 families were approached for the study; 209 agreed to participate (44%). There were no significant differences between participating and nonparticipating parents regarding the ill parent’s gender, type of cancer or time since diagnosis. This study focused on families with adolescent children (11–18 years). Demographic information is summarized in Table 1. The vast majority of patients were married.

Patients were diagnosed with various types of cancer, including breast (54%), gynecological (11%), skin (9%), hematological (8%), urological (5%), soft tissue and bone tumors (5%), head/neck (3%), gastrointestinal (3%) and central nervous system (2%). Thirty-six patients indicated they had recurrent disease; remaining patients showed no evidence of disease.

Many families who declined to participate provided a reason why. Twenty-two percent gave an explanation directly related to the parents (e.g. having moved on with their lives or being too emotionally distressed). The children were named as the reason by 20% (e.g. lack of interest or another illness in the family or the busyness of parents or children. The remaining 33% did not explain their refusal to participate.

Table 1. Demographics

<table>
<thead>
<tr>
<th></th>
<th>Children</th>
<th>Patient</th>
<th>Spouse</th>
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<tbody>
<tr>
<td>Mean age in years</td>
<td>15.5 ± 2.0</td>
<td>45.4 ± 4.2</td>
<td>46.5 ± 5.5</td>
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<tr>
<td>Gender N (%)</td>
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<tr>
<td>Female</td>
<td>116 (52.5)</td>
<td>112 (81)</td>
<td>22 (19)</td>
</tr>
<tr>
<td>Male</td>
<td>105 (47.5)</td>
<td>26 (19)</td>
<td>92 (81)</td>
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<tr>
<td>Adolescents per family, N (%)</td>
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<tr>
<td>1</td>
<td>72 (52)</td>
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<tr>
<td>2</td>
<td>53 (38)</td>
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<tr>
<td>≥3</td>
<td>13 (9)</td>
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<tr>
<td>Marital status N (%)</td>
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<tr>
<td>Married/cohabiting</td>
<td>128 (93)</td>
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<tr>
<td>Divorced/widowed/single</td>
<td>10 (7)</td>
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<tr>
<td>Mean time since parent’s diagnosis in years</td>
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<tr>
<td>No evidence</td>
<td>102 (78)</td>
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<tr>
<td>Recurrence</td>
<td>36 (22)</td>
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</table>

instruments

Patients and spouses completed the Dutch version of the Child Behavior Checklist (CBCL) [23, 24]; adolescents completed the Dutch version of the Youth Self-Report (YSR), designed for children aged 11–18 [25, 26]. The CBCL and YSR consist, respectively, of 120 and 102 items and normative data for both tests exists. The internalizing, externalizing and total problem scales were used. The internalizing scale reflects the internal mental state, i.e. withdrawal, somatic complaints and anxiety/depression. The externalizing scales represent socially unacceptable behavior, e.g. delinquency and aggressiveness. The total problem scale is the sum of all scales: internalizing, externalizing, thought, social, attention and other problems. Higher scores indicate more problems. The reliability and validity of the CBCL/YSR has been supported in a great number of studies. In this study, Cronbach’s alphas on the three scales ranged from 0.84 to 0.94 for reports from the patients, spouses and adolescent children.

The Dutch translation of the Impact of Event Scale (IES) [27, 28] was used to measure adolescents’ cancer-related distress. The 15-item scale measures intrusive experiences (seven items) and avoidance of thoughts and images related to the event (eight items). The sum of the two subscales is the total score, which can range from 0 to 75; higher scores indicate more distress. The IES has been shown to be reliable [29] and Cronbach’s alpha in this study was high (a = 0.95).

Patients, spouses and adolescents filled in the Dutch version of the Family Environment Scale (FES) [30, 31], which consists of seven 11-item subscales: cohesion, expressiveness, conflict, organization, control, family values and social orientation. Respondents are asked whether statements about family environment apply to their family. Scores on each subscale range from 0 to 11; higher scores denote a more positive environment. Index scores can be calculated for Family Relationships Index (FRI), sum of cohesion, expressiveness and conflict; scores range from 0 to 33) and Family Structure Index (FSI, sum of organization and control; scores range from 0 to 22). Higher scores on the indices reflect more positive family relationships and more structure. The manual provides norm scores based on a sample of 1707 adults and 551 adolescents from The Netherlands. The FES has good test–retest reliability and an adequate internal consistency [30, 31]. Other (psycho-oncology) studies [11, 15, 32] have reported alpha coefficients.
similar to those in the present study, which ranged from 0.42 (cohesion) to 0.69 (conflict). However, these alpha coefficients are lower than those listed in the manual. We, therefore, followed the test creator’s recommendation not to over-rely on internal consistency values [33].

Lastly, demographic data were gathered from parents on date of diagnosis, type of cancer, treatment and disease status. Parents also reported children’s ages and gender.

analysis
The t-tests were carried out to compare all family members’ reports of family environment with the norm. Effect sizes were calculated to assess clinical significance [34]. Effect sizes ≥0.50 indicate a clinically significant difference; those <0.49 were considered small [35]. In addition, t-tests were carried out to compare patients’ reports of family functioning with spouses’, parents’ reports with adolescents’ and differences between boys’ and girls’ reports. A variable creating subgroups of adolescents was made to explore differences between those in early (11–13), middle (14–16) and late adolescence (17–18) in how children viewed family functioning. An analysis of variance tested differences between these subgroups. A variable was created to measure discrepancy between family members’ picture of the family environment [30] by subtracting the adolescent’s score from the parent’s (parent–adolescent discrepancy). This variable was used in correlational analyses. Pearson’s product-moment correlations were calculated to explore relationships between adolescent functioning and adolescent reports of cancer-related distress and each family member’s perception of the family environment and parent–adolescent discrepancy. Correlation coefficients <0.30 were considered weak, 0.30–0.50 moderately strong and ≥0.50 strong [34].

results
comparisons with norm and family members
In comparison with the norm group, parents found their family more expressive, less conflictual, better organized, less controlling and more social than the norm group (Table 2). The FRI was significantly higher than the norm. Cohesion and the FSI were similar to the norm. According to patients but not spouses, the family was less strict in their values. Effect sizes were small, with one medium effect size on spouses’ report of conflicts.

No significant differences were found between patients’ and spouses’ reports of family functioning. Inter-parent correlation coefficients ranged from moderately strong to strong: cohesion, $r = 0.43$; expressiveness, $r = 0.46$; conflict, $r = 0.50$; organization, $r = 0.56$; control, $r = 0.53$; family values, $r = 0.38$; social orientation, $r = 0.57$; FRI, $r = 0.54$; FSI, $r = 0.56$.

Adolescents’ reported that their family was more cohesive, expressive, organized and social and had fewer conflicts than the norm group (Table 2). The FRI and FSI were significantly higher. Adolescents reported no significant differences on control or family values. Medium effect sizes were found on conflict, social orientation and the FRI; small effect sizes were found on cohesion, expressiveness, organization and the FSI. No differences were found between boys and girls or between children in early, middle or late adolescence.

Since no significant differences were found between patient and spouses’ scores, a mean parent score was used in t-tests examining differences between parental and adolescents’ views of the family. Significant differences were found on all but one subscale, family values. Adolescents described their family as less cohesive, expressive, organized, controlling and socially oriented than their parents. The adolescents’ FRI and FSI scores were also significantly lower than the parents’ scores. Medium effect sizes were found for control, social orientation and the FSI and small effect sizes were found for cohesion, expressiveness, conflict, organization and the FRI.

adolescents’ functioning and family environment
To keep analyses manageable, the parents’ mean score on the FRI and FSI were used in correlational analyses (see Table 3). Time since diagnosis, treatment intensity and disease status were not significantly related to family environment or children’s functioning. Intra-family relationships according to parents correlated significantly to both patient and spouse

<table>
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<th>Table 2. FES descriptives and comparisons with norm group</th>
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<tr>
<td>Patients (SD)</td>
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<tr>
<td>Cohesion</td>
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<td>FRI</td>
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SD, standard deviation; FES, Family Environment Scale; FRI, Family Relationships Index; FSI, Family Structure Index.

* $p < 0.05$, ** $p < 0.01$. 

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reports of the adolescents’ problems and with the adolescent self-reports. Two correlations with patient reports were moderately strong; the others were weak. Family structure as viewed by the parents related significantly, though weakly, to all three scales of the patient reports of adolescents’ functioning, while only one weak correlation was found with spouse reports of the adolescents’ externalizing of problems. The adolescents’ cancer-related distress was not significantly correlated with the parents’ view of the family environment.

Intra-family relationships according to the adolescents related moderately strongly to weakly to patient reports of adolescents’ problems and spouse reports of externalizing and total problems and related moderately strongly to the adolescent self-reports on problems. Furthermore, the FRI weakly, negatively correlated with the adolescents’ cancer-related distress. Family structure according to the adolescents related only to their self-reports and not to either the patient or spouse reports.

adolescents’ functioning and parent–adolescent discrepancy

The amount of discrepancy between parents and adolescents did not vary depending on the adolescent’s gender or stage of adolescence. Parent–adolescent discrepancies on the FRI correlated significantly with spouse reports of externalizing and with all three scales of the adolescent self-reports (Table 3). Parent–adolescent discrepancies on the FSI related significantly to only the YSR total score. All correlations with parent–adolescent discrepancy were weak. No significant relationships were found between the adolescents’ cancer-related distress and parent–adolescent discrepancy.

discussion

Our findings support our first and second hypotheses. First, families with parental cancer function more positively according to parents and adolescents. All family members indicated that their family was more expressive, organized and social and had less conflict than the norm. Additionally, parents described their family as less controlling, while adolescents found their family more cohesive. Patients additionally reported stronger family values. Our results indicate that following cancer, family members perceive the family as functioning more positively in different domains. Secondly, family environment and adolescent functioning are related. Higher scores on family functioning are related to lower problem scores. It seems that intra-family relationships, how family member relate to each other, are strongly associated with adolescents’ functioning. Family structure seems to play a less important role; structure was weakly related to adolescents’ functioning.

In regard to the first hypothesis, higher levels of expressiveness and lower levels of conflict may imply that families with parental cancer communicate more openly and that exchange is constructive rather than negative. It would seem that family members are close. They talk frequently and harmoniously. Communication is considered important for
family functioning and is particularly important during adolescence [36, 37]. Families that express emotions openly have lower levels of distress [11]. A previous study conducted by our team found that open communication was related to fewer PTSS in adolescent daughters, while more problem communication was related to more PTSS [5].

Interestingly, adolescents reported their family to be more cohesive than the norm group, while their parents did not. A characteristic of adolescence is an increase in autonomy—the child breaks away from the family unit and forms his own identity. Families with younger children are naturally more cohesive because small children are less able to take care of themselves [9]. In families with a chronically ill parent, adolescents often assume additional tasks or more responsibilities. They give up some autonomy and spend more time with the family. Adolescents may interpret this as more cohesive, while parents may view their family’s cohesiveness as normal. However, considering that patients in our sample had been diagnosed an average of 2.8 years previously, it may be that adolescents confronted with parental cancer delay their disengagement from the family. Our findings seem to illustrate that adolescents display less emotional and behavioral problems when cohesiveness is higher. This would mean that while adolescents in our families may have less autonomy than their peers, it does not necessarily bother them. Interestingly, we did not find any differences between how boys or girls viewed the family’s functioning, in contrast to other studies [20, 38].

Family environment and children’s functioning were not significantly related to illness-related variables, in line with research reporting that cancer-related variables are unrelated to emotional functioning [39]. The amount of time since the patient’s diagnosis, disease status and treatment intensity all appeared unrelated to family functioning. It would seem that the positive affect on family environment after cancer is more permanent. Cancer’s effects are not all negative; positive effects have also been found [40]. Family environment may also be positively affected.

With regard to the findings for the second hypothesis, each parent was asked to report on the family’s and the adolescents’ functioning separately. Relationships with patient-perceived adolescent functioning were more often significant and stronger than relationships with spouse-perceived adolescent functioning. Being that the majority of our patients were women, our findings may imply that mothers and fathers view their relationship with their children differently or have different views on the relationship between family environment and how the children function. This is supported by two recent studies reporting that mothers’ reports of children’s functioning correlated more often significantly with the children’s functioning than the fathers’ [4, 41].

Intra-family relationships correlated weakly with adolescents’ cancer-related distress, but their view of family structure and the parents’ view of the family environment were not at all related to adolescents’ distress. It would seem that family environment does not offer much protection for, nor does it aggravate, cancer-related distress. Other factors, such as the adolescent’s personality traits, may be more strongly related to whether a child develops PTSS [5].

Adolescents viewed their family environment significantly differently than their parents, which is in line with research with the FES [30]. Our third hypothesis was that parent–adolescent discrepancies would relate to the adolescents’ functioning. This was unsupported. Incongruity in parents’ and adolescents’ views related only weakly to the adolescents’ self-reports and to spouses’ reports on externalizing of problems. More problems were reported when discrepancies were larger and externalization related more strongly to the size of the discrepancy than internalization did. This is consistent with a study reporting an association between parent–adolescent discrepancies and externalizing [18]. However, another study also reported a significant relationship between discrepancies and internalizing [20], something our study did not show. It is believed that discrepancies and disagreements between parents and adolescents serve to help the adolescent develop autonomy. However, in the short term this may be associated with higher stress in the family and maladaptive behavior.

One of our study’s limitations is the low response rate. While no differences were found between participants and nonparticipants regarding demographic and illness-related variables, 56% of those asked declined to participate. We cannot be sure whether the high nonresponse rate affected our findings or whether the prevalence of problems may have been underreported or overreported. Families gave reasons on both sides of the spectrum: some were too distressed and others reported having adjusted and moved on. Additionally, our population only included families with patients who survived. It is possible that these two factors may have led to a sample bias in our data. Our dataset included a number of families (48%) with more than one adolescent, which may mean that subjects are not independent of each other. However, all of our analyses were conducted at the child level and not the family level; we focused on individuals, not the family system. Furthermore, a multilevel study in this project reported that only a small percentage of the variation in children’s functioning could be explained on the family level [42]. A further limitation is the cross-sectional nature of our data which prevents us from drawing conclusions about causal relationships. Another point may be the low alpha coefficients for the FES. However, Moos [33] argued that one should not focus on the internal consistency statistic, which may be lower in homogenous groups. Nevertheless, this may be a source of unreliability in our study. Finally, the majority of our patients were female. This may seem skewed, but a majority of cancer patients in this age group are female [43].

In summary, we found that the family environment of families where a parent has cancer is different from the environment in families not confronted with cancer. Families seem to function more positively. This aside, a negative relationship was found between family environment and the children’s behavioral and emotional functioning. Our findings indicate that it may be helpful for health care professionals to pay attention to family
functioning in order to target adolescents at risk for developing problems.

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references