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*Published in:*  
European Journal of Cancer

**IMPORTANT NOTE:** You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2011

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Huizinga, G. A., Visser, A., Zelders-Steyn, Y. E., Teule, J. A., Reijneveld, S. A., & Roodbol, P. F. (2011). Psychological impact of having a parent with cancer. *European Journal of Cancer*, 47(Suppl 3), S239-S246.

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# Psychological impact of having a parent with cancer

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## Introduction

The diagnosis of cancer has a great impact on many aspects of the patient's and other family members' lives. It may cause substantial distress in the whole family system and especially in minor children as they are dependent on the care and custody of their parents. Children may experience a sequence of stress periods, beginning from the initial diagnosis of cancer and continuing throughout medical treatment to recovery. Many children face the continuous threat of the death of their parent. As cancer becomes more and more a chronic issue, parental cancer may have long-term negative consequences for children [1]. A confrontation with cancer in a parent may thus lead to temporary and long-lasting changes in their lives, and children have to adapt to these changes.

A recent population-based study in the USA estimated that 2.85 million children younger than 18 years live with a parent diagnosed with cancer. Furthermore, more than half a million children has a parent who is about to start cancer treatment or in recovery [2]. These high numbers of children confronted with parental cancer constitute a reason for gaining evidence on the psychosocial consequences of such a stressful event and to identify which children are more vulnerable. This evidence can be used to develop guidance for parents and/or healthcare providers in order to minimise the distress. Since 2000 the amount of studies published on the impact of parental cancer on children and their families has increased markedly. This paper will provide a narrative overview of the most important findings of systematic reviews and other key papers published during the last decade with regard to the psychosocial impact of parental cancer on school-aged children and adolescents, and the factors that mediate or moderate this impact. Intervention studies and studies focussing

on the bereavement of the children of cancer patients are outside the scope of this overview. The theoretical model of children's adjustment to parental cancer from Su and Ryan-Wenger [3] will serve as a basis for the presentation of the results. Their stress-coping model is based on a synthesis of the literature, and specifies the relationships between the stressor of having a parent with cancer, moderator and mediator variables, and child functioning. Outcomes may serve as a guideline for the support of families in this situation and future research. This paper will first address the psychosocial impact of parental cancer on school-aged children and adolescents. Second, significant moderating and mediating variables related to child functioning in this situation will be described. Third, overall conclusions and implications for healthcare providers will be discussed.

## *Search strategy for study identification*

The following electronic databases were searched for systematic reviews and key papers published in the period 2000–2010: PubMed, CINAHL and PsycINFO. The keywords used in this search were: 'parent', 'cancer', 'mothers and cancer', 'fathers and cancer', 'cancer and offspring', 'parent-child relationship', 'family communication', 'family functioning', 'parenting', 'child functioning', 'psychosocial functioning' and 'quality of life'. Additional studies published between 2000 and 2010 were obtained manually from the reference lists of the studies included.

## **Psychosocial functioning of children of cancer patients**

### *School-aged children (ages 4–11)*

Findings regarding emotional and behavioural problems in school-aged children of cancer patients

were inconsistent. Some studies found more emotional problems among children of cancer patients in this age group [4,5]; others found equal or better functioning compared with norm group peers [4–7]. Although there is some evidence that school-aged children who have a parent with cancer have more somatic complaints than peers from control or norm groups [4], there seems to be no evidence of lower social competence (skills in social contacts and leisure activities) [4,5]. One exception was a study in which school-aged sons of cancer patients were found to be more socially isolated than their peers [8].

#### *Adolescents (ages 12–18)*

Findings on the functioning of adolescent children of parents with cancer more consistently showed that these had more emotional problems and stress response symptoms (SRS) than norm group peers [4, 5,9–12]. Studies have found more somatic complaints in adolescents confronted with parental cancer and these problems varied from fatigue, abdominal pain, dizziness, sleeping problems to loss of appetite [4]. The social functioning of adolescents did not differ from that of controls or normal groups [4,5]. One study discovered similar psychological distress in adolescents who have a parent with cancer and controls [13], and some other studies reported better functioning [4]. During the last few years two studies focussed on positive changes in adolescent children following parental cancer [14,15]. These studies showed that almost half of adults whose parent had cancer during their childhood experienced post-traumatic growth issues [15]. The most significant area of post-traumatic growth concerned attaining a greater appreciation of life. Furthermore, more intimacy in relationships, an improved personal strength and positive changes in health-related behaviours were mentioned [14,15].

#### **Risk and resilience factors related to child functioning**

According to the stress-coping model of Su and Ryan-Wenger, risk and resilience factors related to responses of children who have a parent with cancer can be distinguished as moderators and mediators. Moderators are pre-existing variables that will influence the intensity of the stressor parental cancer. Mediators do not affect the intensity of the stressor, but influence the child's and family's responses to the situation that causes stress. Mediator variables are in particular suitable to be addressed in interventions [3].

#### *Moderating variables*

##### *Child characteristics*

**Children's age and gender:** In general, adolescents show higher levels of emotional problems than school-aged children [4]. Adolescents may be more vulnerable because they are at another developmental stage and have more cognitive abilities than school-aged children. Another explanation for this difference between age groups might be that adolescents are more at risk because of conflicting demands. They wish a greater independence from their parents and want to meet with friends. In the case of parental cancer, they might be instead confronted with more tasks at home [4] and might feel loaded down with additional roles and responsibilities [16]. The parental cancer experience adds to already challenging developmental issues for adolescents.

Furthermore, the gender of the child may be an important predictor of child functioning. Several studies reported more emotional problems in daughters than in sons [17,18]. Although some studies found more emotional problems in school-aged sons [19,20], adolescent daughters of cancer patients are commonly reported to be the most negatively affected group [4,5,17,19–21]. In contrast, one study found no significant differences in emotional and behavioural functioning between adolescent sons and daughters who have a mother with early breast cancer [10].

**Support network of children:** Children may obtain relief from their own support network when a parent has cancer. Children of cancer patients experienced fewer SRS when they received more satisfying social support during the first months post-diagnosis [22]. Valuable support shows consideration for the children's needs, time and individual space [23]. Several studies showed that keeping in touch with peers [9,16,24–27] and a “free zone” through normal activities with others [23,24,28] were helpful forms of support. However, adolescents seeking web-based support noticed that peers did not really understand what they were going through [29].

Next to peers and school, the parents and other family members were important sources of support [30,31]. Healthy parents can have a major protective function for children. Adolescents expressed, however, that some healthy parents were so overwhelmed by their spouse's cancer and the additional household tasks that they were not able to support their children emotionally [30]. Adolescents may also feel overlooked by their family members because those are dealing with cancer too, and by

the oncology staff because they are focussed on the parent's treatment [31]. Moreover, children may intentionally have little contact with the oncology staff, because they do not want to share their feelings with unfamiliar persons [32]. It may be hard for children of cancer patients to get access to the oncology staff for support [33].

School can also be an important source of support for children. Yet, adolescents reported that teachers were interested in how their parent was doing, but overlooked how they were feeling [32]. Another study reported that school personnel tried to be supportive for adolescents, such as providing them with general information about cancer, but their support did not seem to adequately address the adolescent's needs [34].

#### *Characteristics of parents and family*

**Gender of the ill parent:** The majority of studies examined the functioning of children whose mother had cancer. Until now, studies on the functioning of children who have a father with cancer are limited. This is not surprising, given the higher percentage of female cancer patients having minor children at home [2]. Just a few studies compared the functioning of children based on the gender of the ill parent. The results of these studies are not equivocal. One study reported that children had the most psychological problems when the mother had cancer [21]. Several studies demonstrated that adolescent daughters of mothers with cancer were the most vulnerable [4,11]. Other studies demonstrated, however, that school-aged and adolescent children of fathers with cancer had the most psychosocial problems [19,20]. Furthermore, several studies in adolescents did not detect an effect of the ill parent's gender on the adolescent's well-being [13,18,35].

**Nature of the parent's illness:** There is little evidence that the functioning of children and adolescents varies with stages of disease and treatment regimens [5,6,27,36]. This association may be related to the parent's physical functioning. The ill parent's physical condition was found to be related to the psychosocial functioning of school-aged children [36] and adolescents [36,37]. In cross-sectional studies, time since diagnosis was in general not related to child functioning [5]. Longitudinal studies, however, showed that the percentage of children who experienced emotional and behavioural problems or distress was highest within four months of the parent's diagnosis, but decreased over time [12,18]. Recurrent disease appeared to be an important predictor of SRS

and emotional problems, and extensive treatment of behavioural problems [17]. This may be associated with the finding that adolescents who perceived their parent's cancer as more serious reported more distress [11].

**Support from the network of the parents:** Children may benefit from their own network, but also from their parents' support network [3]. It was found that the most significant support networks for the ill parents were their spouses, family members, friends and parents of their children's friends [38,39]. The support from healthcare providers was also important [40]. Addressing the needs of children is, however, not a part of routine cancer care [41]. Parents expressed a lack of psycho-educational guidance and support from healthcare providers, in particular concerning their struggle in knowing how to talk to their children about cancer. They especially needed support with respect to the timing, wording and the amount of information. Furthermore, they required more information about how they could respond to their children's reactions [42–45]. Healthcare providers, such as oncology nurses, may, however, feel unable to react adequately to the needs of parents with cancer because they lack the knowledge and are afraid that talking about the children's worries will bring about more parental distress [46]. Other suggested barriers to healthcare providers addressing parenting issues were time pressure, having no recommendations for helping the children cope and finding it too emotional to talk with patients about their children [41]. Niemela and colleagues stated that the primary responsibility of healthcare providers involved in adult oncology care is the patient with cancer, and that these professionals cannot be expected to be experts in supporting the children of their patients as well [47].

**Family structure and socio-economic status:** The family setting (e.g. single parent, no or few siblings, oldest child) appeared to be an important predictor of psychosocial problems in school-aged children [36], and adolescent children of parents with cancer [4]. The effect of the family's socio-economic status on child functioning when a parent has cancer is still speculative [3].

#### *Mediating variables*

##### *Children's appraisal of the parent's cancer*

How children think about the parent's illness and the amount of information they need depends mainly on their age and cognitive maturity. In general, children

may feel that something is wrong before they are told that the parent has cancer. Even very young children have been reported to be aware that cancer is a life-threatening illness [48]. Children were more anxious when they were not informed about the parent's illness [3,24]. It appeared that children (>7 years) of parents with advanced cancer required truthful and age-appropriate information from different sources (parents, healthcare providers, books/leaflets and the internet) [33]. Another study showed that children (mean age 11 years) seemed to be well informed about factual issues regarding cancer, its implications and consequences [30]. Children's emotional functioning may be, however, affected by their perceptions of the seriousness and stressfulness of the parent's cancer rather than objective disease characteristics (such as type of cancer, stage of disease and time since diagnosis) [4,35]. Children of parents with recurrent disease appeared to experience more fear/worry than children from parents with primary disease [49]. It was found that it was in particular stressful for children to see their parent immediately after the operation, during chemotherapy and with hair loss [48].

#### *Children's coping strategies*

The way children cope with the parent's cancer may be related to their well-being. Coping can be distinguished as two types: '*problem-focused coping directed towards modifying the stressor, and emotion-focused coping directed towards modifying the emotional reactions to the stressor*' [3,30]. The emotion-focused coping strategies distraction and maintaining normality were found to be the most common strategies in children (>7 years) of parents with advanced cancer [27]. Another study in children (mean age 11 years) of cancer patients found that most of the children used both emotion-focused coping (distraction, keeping it in the head, and wishful thinking) and problem-focused (helping others, parentification) strategies. The parentification strategies children used were found to be both adaptive (deriving self-worth) and destructive (due to suppressing their own needs) [30].

#### *Parents' psychosocial functioning*

Just a few studies examined the well-being of cancer patients and spouses with minors at home. A substantial group of ill and healthy parents are reported to suffer from depression and cancer-related distress [50,51]. Furthermore, they may have more psychological distress than controls [7]. The psychosocial functioning of parents may be an important predictor of the emotional and behavioural functioning

of school-aged children and adolescents [4,36,37]. Parental depression was found to be a key factor for emotional problems in school-aged children [6,20] and adolescents [10,20,52]. Parental distress was found to be a risk factor for emotional problems in children of cancer patients, but this was also found in their classmates [7]. Moreover, it may be that parental depression affects the way child functioning is perceived. Although there is some evidence of a relationship between parental depression and child functioning, this association may be confounded by a tendency that depressed parents experience more problems in their children [5].

#### *Marital satisfaction*

Several studies reported that greater marital satisfaction had a positive effect on the functioning of children of cancer patients [4,17]. Other studies in families confronted with cancer, however, found no associations between marital satisfaction and child functioning [7,52].

#### *Parenting*

The quality of parenting can be affected when a parent has cancer [52]. There is preliminary evidence of an association between parenting quality and adolescent outcomes. Poorer parenting was found to be associated with poorer child outcomes [5,6,52]. Parental warmth and acceptance were significantly related to emotions and behaviours in school-aged and adolescent children of cancer patients, while this was not the case for their classmates [7]. It is absolutely clear that cancer patients with children at home put a lot of effort into trying to maintain normality [25,27,42,44,53,54]. Parents experienced informing the children about cancer as a major challenge [32,33,42], and needed more guidance about telling what and when [32]. They were concerned about the insecurity the diagnosis of cancer would bring to their children's lives and were alert to their children's well-being [44,45]. It seems, however, difficult for parents to recognise emotional and behavioural problems in their children. They may misunderstand their children's responses (such as outbursts of anger or withdrawal), because these reactions may belie the children's feelings [43,48].

#### *Family functioning*

The quality of the family environment when a parent is diagnosed with cancer may affect the well-being of children. Several studies have reported associations between family functioning and emotional and behavioural problems in children of cancer patients [6,10,13,20,25,50,55,56]. Daily family routines

often alter when a parent is diagnosed with cancer. For children such changes can be very hard and distressing. The role of the child within the family may also change [42]. Adolescent children have to take more responsibility for their siblings and are more involved in caring tasks at home [9,31,57,58]. Moreover, the parent's role may alter substantially. Some parents are more at home due to the illness, while others are separated from their children due to hospital admissions. Severe side effects of treatment may also affect the involvement of the parent in family activities [38]. Such changes may alter the parent-child relationship negatively [38,59,60]. Positive family experiences due to parental cancer were, however, also mentioned, such as the ability to spend more valuable time with the children than usual [54], and a deepening of relationships [27]. Furthermore, families with adolescents experienced their family as being relatively more expressive, cohesive, organised and sociable than the norm [56].

#### *Family communication*

Parents and children often perceive cancer as a threatening and uncertain illness. The way family members communicate is a key factor in children's and adolescents' adjustment to the illness [5,6,13,17,27,32,61]. However, sharing mutual emotions may be extremely difficult. Adolescents were concerned that their parent would die, but hesitated to share this thought with their parents [32]. Parents frequently avoided talking with their children, because they did not know how to react to questions about death [62]. Although parents would like their children to share their emotions openly with them, they seemed not to be good role models themselves. They provided their children mainly with factual information. It seemed that it was very hard for the healthy parents (mostly fathers) in particular to talk about their emotions [30]. In concordance, adolescent daughters were reported to communicate more openly with the ill parent than with the healthy parent. A good emotional contact with the healthy parent was, however, significant for child functioning. Adolescent daughters suffered from fewer SRS when the communication with the healthy parent was more open [63].

#### **Methodological issues**

Several methodological factors may account for the inconsistencies in the findings of the studies described. The studies are highly heterogeneous with regard to study design, methodology, cancer-related variables

and informants, which makes it difficult to integrate findings and draw conclusions. Moreover, the majority of the studies on child functioning are cross-sectional, which limits the potential for causal inferences. Until now, the number of longitudinal studies on the psychosocial impact of parental cancer on children is still limited. Sample sizes vary widely across studies, but are mostly small [4,9]. Quantitative studies compared the functioning of children of cancer patients primarily with that of instrument norms, while some studies used control groups as a comparison. Furthermore, quantitative studies seem to report fewer difficulties in children of cancer patients than qualitative studies. It may be the case that generic questionnaires used in quantitative studies are not sensitive enough to assess specific problems of children who have a parent with cancer [4]. Although the majority of studies addressed the well-being of children who have a mother with (breast) cancer, the stage of the parent's cancer differs widely across studies (e.g. early stage, advanced cancer or all stages of cancer).

#### **Conclusion and implications for healthcare providers**

This overview of studies published in the last decade has shown that cancer in a parent may be a significant stressor for school-aged children and adolescents. Studies revealed inconsistent results with regard to the impact of parental cancer on children. They were reported to function worse, equal to and better than norm or control groups. A minority of children, however, appear to be at risk of psychological morbidity. It seems that adolescents are the most vulnerable, in particular girls. Some studies reported both negative and positive consequences of parental cancer, and in the last few years some studies have focused in particular on post-traumatic growth in adolescents.

Our findings indicate that parental cancer is a family experience. The diagnosis and treatment of the parent appears to affect the whole family unit. Furthermore, the empirical evidence increases that children's adjustment following parental cancer is associated with factors concerning the child, parents and family. Guided by the stress-coping model of Su and Ryan-Wenger, we found that children's gender and age, and the quality of their support network were the most consistent child-level *moderators* of child functioning. The nature of the parent's cancer (including the ill parent's physical functioning), the quality of the support network of the parents and family structure were the most significant family-level moderators. Conclusions with regard to evidence

of effects of the parent's gender and family socioeconomic status could not be drawn. Children's appraisal of the parent's cancer, children's coping strategies, parents' psychosocial functioning, and the quality of parenting, family functioning and family communication were the most important *mediators* of child functioning. There was just a little evidence of an effect of marital satisfaction.

In order to provide tailored care for these children and their families, a family-orientated and child-centric approach in health care is recommended [10, 17,20,43,50]. Healthcare providers should be aware that parental cancer has an impact on all family members, including minors. Therefore, the first step is that they ask cancer patients whether they have children at home and how they experience the impact of the illness on their family. Subsequently, significant mediating variables of child functioning might be addressed in interventions to reduce the impact of the stressors [3]. It seems that the parents' psychosocial functioning (e.g. screening for symptoms of depression), parenting (e.g. how to maintain normality and how to cope with children's reactions), family functioning (e.g. how to cope with role changes) and family communication (e.g. how to talk to the children about cancer and emotions) are the first issues that should be addressed in adult oncology care. Given this broad range of mediating factors, parents may benefit from a multi-disciplinary support team. Next to social workers and psychologists, oncology nurses may play an important role in providing support and guidance to cancer patients who have children at home [38]. They may reduce the strain and burden of the illness and care-giving [64], and strengthen the coping resources of the cancer patient [65]. Some healthcare providers in adult oncology may, however, need additional training to be able to provide adequate support to these young families, because they are not educated in paediatric issues.

### Conflict of interest statement

All authors disclose that they have no financial or personal relationships with other people or organisations that could inappropriately influence (bias) their work.

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