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REVIEW ARTICLE

## Coping with cancer: The perspective of patients' relatives

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### Abstract

Cancer affects not only patients but also their loved ones. *Material and methods.* This paper presents a selective, narrative review of psychosocial consequences of cancer and its treatment for relatives of patients, including parents and siblings of children with cancer, children of parents with cancer and partners of adults with cancer. *Results.* Remarkably, most relatives adapt well to the cancer of a loved one. That is only a minority appears to be at risk for psychological morbidity. Bereavement has been found to impact psychological well being in the short-term, but it does also not appear to be a major risk factor for severe psychopathology. The exception being the loss of a child; this often appears to have intense and long-lasting effects on the parents. Furthermore, especially women were found to be at risk for distress. *Conclusion.* Future studies that focus on the interactions between patients and family members – parents, children and partners – are of great importance to further the field by providing more insight into the family dynamics of dealing with cancer. Such insights will offer tools for (refining) interventions for families in need.

It is widely accepted that dealing with cancer is a family affair. Not only patients but also their loved ones have to deal with the consequences of the illness and its treatment, which may include disruptions of daily life, anxiety, depressive symptoms, worries about cancer recurrence, and the fear of loss and death. Furthermore, in dealing with the illness patients and relatives affect each other's adjustment, for example, through their coping behavior and the exchange of support. The aim of this paper is to identify and discuss psychosocial consequences of cancer for parents and siblings of children with cancer, children of parents with cancer and partners of adults with cancer.

### Material and methods

We selected (systematic) reviews and key papers focussing on psychosocial consequences of relatives of patients with cancer. It is important to note that our intention was not to provide a systematic and exhaustive review, but to bring the three areas of research on relatives of patients with cancer together

and to provide an overview of the main findings. The findings are presented in a narrative review format, first addressing consequences for parents and siblings of patients, next children of patients and finally partners of patients. Furthermore, we will present methodological limitations and issues in this field.

### Results

#### *Parents and siblings of children with cancer*

Consequences of pediatric cancer for the parents have been studied extensively. Not surprisingly, the parents are at increased risk of anxiety, depression and post traumatic stress at the time of the child's diagnosis and also several years ahead as compared with parents of healthy children. It seems that the distress decreases with time even though different stressors will linger such as worries about relapse, late effects and loss of the child [1,2]. The distress varies with different malignant diagnoses. Thus, it has been described that parents of children with acute myeloid leukemia, brain and bone tumors

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suffer more from psychological distress than parents of children with acute lymphatic leukemia. Support from relatives and friends is of utmost importance for the family to avoid long-term depression. Parents often feel they have no one to talk to and that they are avoided by others following their child's cancer diagnosis [3].

Grandparents often play an important role in supporting the family, but not much is known about their own experiences [4]. In a recent study eight grandparents were interviewed soon after the grandchild's diagnosis. Grandparents' found their role to be the one to support the family both emotionally and practically. Most of their knowledge about the child's disease was obtained from the internet [4]. Grandparents' experience a double trauma; they worry not only about the seriously ill grandchild, they suffer with their son or daughter as well. Often grandparents care for and support the siblings, as the parents for obvious reasons stay with the ill child.

To have a brother or sister diagnosed with cancer affects siblings, although the literature shows conflicting results [5]. These may be explained by several factors such as time of follow-up, age, sample size and mode of measurement. Some studies suggest that they suffer from psychological morbidity and psychosocial problems such as negative emotional reactions, sadness, helplessness and school difficulties while others describe no such risk. Female siblings have been found to suffer more than male siblings following their brother or sister's cancer diagnosis [6]. Yet, a few studies point to positive effects such as improved maturity and empathy [5]. Still, the siblings will notice a change in their daily life; nothing will be the same for a long period of time, if ever. Siblings have been referred to as the invisible children. Self-evidently the ill child will be at the focus of the parents' attention. It has been described that siblings of children with cancer often express strong negative feelings, such as anger, jealousy and anxiety. Siblings just as parents show intense adverse symptoms in connection with their brother or sister's diagnosis which will decrease over time [5,7]. Support from professionals has been shown to be of importance for the siblings well being. The life outside the family also changes for the siblings. To meet with others in a similar situation and to receive support and education have been found to benefit siblings [8].

*If the worst happens – bereavement.* The loss of a child is what parents fear the most. The grief following the loss of a child has been described as deeper and longer lasting than any other loss [9]. Bereaved parents are at increased risk of psychological morbidity and even mortality due to both natural and unnatural

causes for a long time following the loss [10,11]. Mothers are more likely to report long-term depression as compared to fathers, the same is true for low psychological well being [12]. Most often the seriously ill child suffers from more than one symptom prior to death [13]. This will affect the parents many years ahead. Unrelieved pain in the child has been found to affect the parents still four to nine years after the loss of their child [14]. It is of importance to identify modifiable or avoidable factors in the care of these children in order to improve the child's well being and to reduce psychological morbidity in family members. Several such health care related factors have been identified including symptom control, communication and psychosocial support [14–16]. The importance of information in health care is well known, yet there seems to be a barrier to communicate bad news. In particular, this applies to making parents aware of the transition from curative to palliative care. Parents who receive information about their child's poor prognosis and the decision to end curative treatment are more likely to care for their child at home until death [17,18]. In addition, parents who are aware of their child's imminent death suffer less psychologically in the long-term, especially fathers. Support from health care professionals during the child's illness and following the loss also facilitates parents' grief process. Not only does support from health care professionals mitigate grieving, even more so does social support from family, friends and others, even many years after the loss [16].

Siblings who lose a brother or sister to cancer often suffer additional loss as they for some time also lose their mother and father in to grieving. As mentioned earlier siblings of children with cancer have been referred to as the invisible children and this is probably even more true following bereavement. Bereaved siblings want open and honest communication within the family, adequate information from clinicians, involvement in the care of the sick child, and support to continue their own interests and life [19]. Health care staff may play an important role, due to their position and ability to communicate and involve the sibling in his or her brother or sister's illness and care. So far, there are no strategies known for optimal emotional and social support of siblings which emphasizes the need of research in this field.

*Conclusion.* Parents and siblings of children with cancer suffer from increased psychological morbidity in conjunction with the diagnosis, although it seems like their symptoms will decrease over time. Thus, it appears that time is a crucial factor for the presence and intensity of symptoms. In bereaved parents the problem of psychological morbidity entails similar symptoms although they are more intense and long

lasting. Health care professionals have an important role in supporting parents and siblings from the time of the child's diagnosis to cure or palliation to reduce their long-term suffering. Still, there is a need to identify families at risk and provide tailored support for them.

#### *Children of parents with cancer*

It has early on been suggested that serious illness in parents impacts the psychological well being in children [20]. During the development and treatment of cancer, children may experience that the disease transforms the parent both physically and psychologically, other family members worry, family routines and roles are disrupted, and the children may feel the underlying fear of death [21,22]. It is estimated that about one quarter of all cancer patients in treatment have dependent children, suggesting an extensive number of children potentially affected by parental cancer [23]. Even though cancer survival has improved [24], cancer is still one of the main reasons for children and adolescents to experience early parental death and the consequences that follow. We will below summarize the main findings on psychological well being in children and adolescents who experience parental cancer and all-cause parental bereavement, as studies examining consequences of parental death seldom focus on a specific cause of death.

*Parental cancer.* Most studies examining the effect of parental cancer on the child's psychological well being focused on general internalizing problems [24], which are a broad array of emotional problems directed inward affecting emotions and cognition [22], while fewer studies have assessed specific internalizing problems (e.g. anxiety and depression). Despite the broad approach the scientific evidence supporting an increased risk of poor psychological well being in children of parents with cancer is weak. A review by Visser et al. concluded that children's emotional problems lie within the normal range compared to norm and control groups [21]. Also, a review by Osborn examining three studies specifically on anxiety and depression conclude that there is currently insufficient evidence for the hypothesis that children of parents with cancer have an increased risk for anxiety and depression [24]. Still, some studies do suggest that self-reported psychological problems are slightly increased for adolescents of cancer patients compared to norms and parents' reports of the child's well being, particularly for adolescent daughters [21,24]. This could be due to adolescent's cognitive capabilities that make them, more than younger children, aware of the consequences of illness [21].

Studies have furthermore tried to disentangle factors that may increase the risk for psychological problems among cancer patient's children [21, 24–26]. Overall disease-related factors like time-since-diagnosis and physical impairment have not been found to be associated with psychological well being in the children [24,25], while depression in the parents and poor family functioning have been found to be associated with psychological well being in the children [25], particularly for girls [26].

*Parental bereavement in childhood and adolescence – consequences in childhood.* Parental bereavement in children has been suggested to be associated with psychopathology such as depression both immediately following parental death, but also later in life [27,28]. Still, only few small methodological flawed studies reported high rates of depression (26–31%) among children of deceased parents, for example [29]. Some studies have found that children are not at increased risk for severe depression, but that they are at significantly increased risk for mild depression compared to non-bereaved children [27,30,31] for up to at least a year after the death [27]. Van Eerdewegh et al. report on a community sample that 14% of bereaved children were classified as mildly depressed compared to 4% of controls [31].

Studies examining factors that may increase the risk of poor psychological well being in children following parental bereavement have focused on gender, family coping and functioning. Girls and boys may differ in the type of psychological disturbance being expressed. Where girls are more likely to show internalizing symptoms such as withdrawal and depression, boys show more externalizing difficulties like aggression or disruptive behavior [27]. One study showed that 2/3 of the children who were found to be severely depressed were girls [30]. A child's possibilities of dealing with parental bereavement has been suggested to be related to how the adults in the child's surroundings cope with the death and the changes that follow [32,33]. Depression in the surviving parent is a predictor of psychological problems and depression in the child [27,33]. The family's socio-economic status has also been shown to be important, with higher status being associated with better psychological well being in the child [33]. Studies on the effect of gender of the lost parent and whether the death is expected or not on the child's psychological well being have shown inconsistent results [27,33].

*Parental bereavement in childhood and adolescence – consequences in adulthood.* Although the literature for years has been inconsistent with regard to an association between childhood parental bereavement and

adult depression [28,34], recent studies including both cohort and controlled studies suggest that adults who have experienced early parental bereavement have an increased risk of depression including bipolar disorder and unipolar disorder [35–37]. Studies examining the role of the gender of the parent have indicated a greater effect of maternal death compared to paternal death on risk of depression, for example [35,36]; for an exception, see Jacobs et al. [37]. Also studies have examined whether women are more sensitive to the depressogenic effect of losing a parent than men, and the results are found to be inconsistent [36,38]. Suicide among parents in general, but not non-suicidal parental death in childhood has been suggested as associated with depression [35].

*Conclusion.* In summary, there is not convincing evidence supporting that parental cancer in childhood and adolescence may severely impact the psychological well being beyond the normal range. Existing data suggest that early parental bereavement does impact psychological well being beyond the normal range, but it is not yet clear if it is a major risk for severe psychopathology either in childhood or adult life.

#### *Partners of adults with cancer*

Early findings have indicated an array of potential issues partners have to cope with, including uncertainty about the course of the cancer, fear of the patient dying, concern over ways to comfort the patient, emotional strain in the patient and the family, problems concerning sexuality, and altered roles and lifestyles [39]. Although most partners appear to adapt well, a considerable minority reports high levels of distress or depressive symptoms. Studies using self-report measures of psychological morbidity have revealed prevalence rates between 20 to 30%, and studies using diagnostic interviews indicated rates of approximately 10% [40]. Furthermore, a large cohort study showed that partners of women diagnosed with breast cancer were found to be at a 1.39-fold increased risk of being hospitalized with an affective disorder compared to partners of women who were not diagnosed with cancer [41].

One question that has received ample attention is whether partners are as distressed as patients, or perhaps even more distressed since they are “helpless bystanders” who have to witness the suffering of the patient. The findings have been mixed. Some studies found partners to be more distressed, others found higher levels of distress in patients and again other studies did not find differences within couples [42]. One concern in this field of research is that patient-partner status and gender have often been

confounded; most studies have been conducted among couples dealing with breast and prostate cancer. When taking gender into account, a more consistent picture emerges. It appears that in most breast cancer studies, female patients reported more distress than male partners, while in most prostate cancer studies, female partners reported more distress than male patients. Indeed, a meta-analysis of distress in couples coping with cancer demonstrated that women consistently report more distress than men, regardless of whether they are the patient or the healthy partner in the couple [42]. Furthermore, the few studies that have included a comparison control group revealed that female partners showed increased levels of distress compared to their controls while male partners did not or only in the short-term [43,44]. It has to be noted though that most of the studies include partners of patients with a relatively good prognosis. In situations with a high caregiving demand, for example in the terminal phase of the cancer, or when the patient is relatively young, higher levels of distress may be found in both female and male partners. For an overview of correlates of partner distress, see Kim and Given [45] and Pitceathly and Maguire [40].

*Dyadic coping.* Patients and their partners not only have to cope with the consequences of the cancer and its treatment, but they also have to deal with each others emotions and coping responses. Traditionally, spouses have been considered sources of support for patients [46], but the dyadic perspective posits that partners may benefit equally from the support from patients. Furthermore, Manne and Badr [47] have described the marital relationship as a resource for both partners to draw from in dealing with the cancer and argued that relationship processes that bind patients and partners together are key in the adjustment to cancer. Relationship processes such as intimacy processes and emotional sharing may not be unique in couples dealing with cancer, but it has been proposed that partners may be aware of the important function of their relationship in dealing with the cancer and invest in it to maintain and improve it [47]. In line with this, it has been found that a considerable number of patients (42%) felt that the cancer had brought them closer to their partners [48]. Moreover, despite anecdotal information indicating that patients with cancer are often abandoned by their partners, divorce rates have *not* been found to be higher for individuals with cancer than individuals from the general population [49,50].

A literature is now developing that examines dealing with cancer (and other illnesses) from a dyadic perspective in which patient, partner and relationship characteristics are considered as determinants of distress and marital adjustment in patients as well



as partners. Advanced statistical techniques now make it possible to study the interaction between partners and analyze data on the couple level taking into account the interdependency of patient and partner data [51]. For example, Badr et al. [52] found that mutual avoidance and withdrawal was associated with cancer-related distress in both patients and spouses dealing with metastatic breast cancer, albeit more strongly in patients. In line with this, another study showed that collaborative coping was associated with less negative mood in both patients with prostate cancer and their partners [53]. Furthermore, support was found for the idea that past spousal support (i.e. before the diagnosis) influences the interpretation of current spousal behavior in that a lack of spousal active engagement was found to be associated with relatively low relationship satisfaction only if participants perceived the spouse to be little supportive in the past. This was found for both patients and partners [54].

*Psychological interventions for couples.* Research in the area of dyadic coping has resulted in the development and testing of psychological interventions for couples. A meta-analysis of Martire et al. [55] suggested that involving the spouse in interventions might have positive effects on depressive symptoms in both patients with a chronic illness and partners. The results of the interventions for couples dealing with cancer have shown promising results [56]. For example, interventions for couples dealing with cancer targeting the exchange of support within couples [57] and couples' communication and coping [58] revealed beneficial effects for both patients (e.g. less uncertainty, distress and relationships satisfaction) and spouses (e.g. improved quality of life and relationship satisfaction). However, the sparse literature and the methodological limitations such as the inclusion of non-distressed couples, small sample size, short follow-up time and measurement of outcomes in patients only underscore the need for more research. Since not all couples are in need for formal psychological support, future research should consider screening for psychological or marital distress in couples to allow a better evaluation of interventions [59].

*Conclusion.* In summary, the literature has shown increased levels of distress in a considerable minority of partners of patients with cancer, especially female partners. The dyadic approach has revealed that patients and partners indeed affect each other's adjustment. However, both theory-driven explanatory and intervention studies are needed to increase our knowledge of dyadic processes in cancer adaptation and to improve the care for those patients and their partners who are in distress.

### *Methodological issues*

Overall there are a number of methodological weaknesses associated with the studies described that have to be taken into account when interpreting the findings including small sample sizes unattainable for subgroup analysis, lack of proper control groups in comparative studies and cross-sectional designs [21,42]. Furthermore, studies examining relatives of adults with cancer have often focused on breast or prostate cancer, while the consequences of cancers with worse prognoses, the terminal illness phase and bereavement after cancer have been less frequently studied [21,42]. It has also been suggested that the broad assessment of psychological well being in many studies may not be sensitive to the types of concerns children experience [21]. Hence, future research might also consider other outcomes than general distress-related variables. For example, in studies of couples, relationship outcomes and caregiver burden have been studied. Related to the age of children, some studies have relied on the parents' reports of the children's well being. However, discrepancies have been reported between parents' experiences of the children's well being and the children's self-reported well being with children reporting a higher level of symptoms [24], suggesting the importance of using both parents and children as informants.

### **General conclusion**

This overview has shown that cancer has an effect on the whole family. Remarkably though most relatives adapt well to the cancer of a loved one. That is only a minority appears to be at risk for psychological morbidity. Bereavement has been found to impact psychological well being in the short-term, but it does also not appear to be a major risk factor for severe psychopathology. It has to be noted though that the loss of a child does appear to have intense and long-lasting effects on psychological well being. Furthermore, especially women (mothers, sisters, daughters and female partners) were found to be at risk for distress. Only more recently, studies from a dyadic or family perspective started appearing in the literature, mostly with respect to adult patients and their partners. Future studies that focus on the interactions between patients and family members – parents, children and partners – are of great importance to further the field by providing more insight into the family dynamics of dealing with cancer. Such insights will offer tools for (refining) interventions for families in need.

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