
REVIEW ARTICLES

Children's and family needs of young women with advanced breast cancer: A review

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ABSTRACT

This article reviews literature about the impact of advanced breast cancer on children and families. It is clear that the adjustment of the family is influenced by disease stage and maternal adjustment, the needs of the particular child relating closely to their developmental stage. Interventions with children and families to promote adjustment when a parent has advanced cancer are also discussed, including implications for clinical practice.

KEYWORDS: Advanced breast cancer, Family, Children, Psychosocial

INTRODUCTION

Coping with breast cancer represents a major challenge for any woman, but the diagnosis of recurrent disease poses the further burden of adjusting to a shortened life expectancy in addition to coping with disease burden and treatments. Increasingly it is recognized that advanced breast cancer has a major impact not only on the woman, but also on her family, who must adjust to changes in roles and practical responsibilities, as well as the grief inherent in their situation. This systematic review of the literature gives an overview of the evidence about the psychosocial impact of advanced breast cancer on family members in general and children in particular, including interventions designed to promote adjustment.

METHOD

A computerized search of published literature was conducted to identify relevant articles examining the psychosocial impact of breast cancer on families

and children. Searches were conducted on databases pertinent to medicine, psychology, social work, nursing, humanities, and education, from 1980 to 2003. The key words used were: breast cancer-children, psychosocial, psychological and family, child and parent, mothers, family adjustment, terminal illness and child, terminal illness and adjustment. The reference lists of key articles were perused to identify additional relevant articles. Author searches were also conducted for further publications of leaders in the field.

Articles were included in the review if:

- The article was published in English in a refereed journal
- Psychological and emotional issues for the family and/or children aged under 21 years were key outcome measures
- The article reported original research or reviewed original research
- The study sample was comprised of cancer patients, at least some of whom had breast cancer.

Studies were excluded if the main outcome measure was adjustment of partners or carers only, without reference to the family as a whole, and if the out-

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come measure was bereavement, rather than issues pertinent to coping with advanced cancer prior to death.

Articles were appraised using standardised score sheets to extract relevant data. For clarity, results are presented under the following categories:

1. Literature reviews
2. Original research on the impact on the family
3. Original research on the impact on children and adolescents
4. Interventions.

RESULTS

Literature Reviews

A total of 16 reviews were identified: 9 pertained to the impact of mixed cancers on families, and 7 pertained exclusively to breast cancer.

Mixed Cancers

One of the earliest reviews identified the problems family members have with lifestyle changes, as well as living with uncertainty (Northouse, 1984). Another review examined ways of strengthening family supports, highlighting the exacerbation of pressures on the family during disease recurrence. Depression or marital tension experienced by the partner were also considered to affect the partner's relationship with the children, and in turn the child's psychosocial adjustment (Lewis, 1990). Sales (1991) gave an overview of family adjustment during phases from diagnosis to recurrence and the terminal stage, and found role overload and exhaustion to be more common during hospitalization. Similarly, coping with side effects of treatment posed a practical burden for families, with recurrence evoking a new sense of crisis. This theme is repeated in a subsequent review (Sales et al., 1992) in which the severity and suddenness of onset of illness and the patient's own level of distress are highlighted as affecting families, along with previous psychological problems and social supports of family members. Families with a member with cancer also identify the need for support from health professionals (Kristjanson & Aschcroft, 1994).

There is little literature exploring the precise meaning of cancer for children. One review (Hymovich, 1995) describes that it can variously mean changes in physical characteristics, self-concept, feeling, and life-style, as well as loss of support and a

need for information, all tempered by the emotional and cognitive development of the child. Overall, it is considered that the child's developmental needs will determine how best to intervene when a parent has cancer (Faulkner & Davey, 2002). Consistent with this approach, Johnson (1997) advocates that children should be provided with information appropriate to their developmental stage, and counselors and adults should not try to "protect" children by keeping things from them. The most recent review focused on specific strategies to assist adolescents facing the death of a parent, highlighting that the quality of relationship with the surviving parent and quality of care were central to promoting adjustment, along with open communication (Christ et al., 2002).

Breast Cancer

The earliest review specific to breast cancer noted that it is important to consider prior adjustment, as the normal pattern of family coping is considered to influence adjustment (Pederson & Valanis, 1988). Other reviews emphasize that the developmental stage of children dictates their needs when the mother has breast cancer, and open communication between parents and children is vital. In particular, young school-age children need reassurance that the family will hold together and they will be safe; older school-age children need concrete information; adolescents should be supported in their quest for independence, and children's efforts to engage in activities outside the home should be fostered (Northouse et al., 1991; Turner & McGrath, 1998). Northouse (1992), in a review of families adjusting to early breast cancer, contends that family members need to adjust to changes in roles and learn to balance the needs of all family members. This author adds in a later review that younger women experience more emotional distress than older women, and younger husbands report more problems carrying out domestic roles than older husbands (Northouse, 1994). The theme of developmental stage is later taken further by Northouse (1995), who reports increased psychological distress in adolescent daughters of cancer patients, compared with other children, a theme repeated by Quinn-Beers (2001). Northouse (1995) further notes that women with poorer prognoses and poorer adjustment report more adjustment problems in their children.

The Impact on the Family

Twenty-three studies were identified: 9 were studies of mixed cancer populations, 14 focused exclusively on breast cancer.

Mixed Cancers

The first four studies to be discussed did not include populations with advanced cancer or disease stage was not stated. Vess et al. (1985) studied 54 cancer patients and their partners and children, finding that spouses' communication patterns strongly influenced how well roles were enacted, along with the level of cohesion and conflict in the family. Difficulty with communication was also a theme cited in a qualitative study of 10 patients with children under 18 years of age (Hymovich, 1993). A study conducted with 143 patients and family members reported that poorer physical status of the patient and lack of personal and social resources was associated with poorer functioning in family members (Ell et al., 1988). The extent of the impact for family members was quantified in a more recent study. This examined the emotional adjustment of relatives of 108 patients newly diagnosed with cancer, finding that 48% scored above the usual cutoff for the General Health Questionnaire, suggesting significant psychological morbidity (Harrison et al., 1995).

The following five studies all included at least some patients with advanced disease. A study of 201 cancer patients and next of kin found mutuality of psychological response between patients and their families (Cassileth et al., 1985), a similar finding emerging from a study of 102 families with a member receiving palliative care for advanced cancer (Kissane et al., 1994). In the latter study, one-half of patients, one-third of spouses, and one-quarter of offspring fulfilled criteria for caseness using the Beck Depression Inventory. Similarly, assessment of the families of 757 patients referred to a palliative care service revealed that 32% of families had severe or overwhelming anxiety (Hodgson et al., 1997). Family anxiety also appears to be influenced by the age of the patient with cancer. Severe family anxiety was found to be twice as common if the patient was younger than 45 years old in a study of 302 families with a terminally ill member (Higginson & Priest, 1996). Families also reported concerns about communication and child care while the patient was undergoing treatment for advanced disease (Halliburton et al., 1992).

Breast Cancer

All of the following nine studies relate to families of women with early breast cancer. A study of 48 men whose wives had breast cancer, diabetes, or fibrocystic disease found that heightened illness demands placed on the father resulted in higher depression scores, this in turn affecting marital adjustment. More frequent interchange between fa-

ther and child also positively affected family functioning (Lewis et al., 1989). The relationship of the mother with her children, as well as her own level of well-being, have been reported to influence family adjustment, along with the quality of the marital relationship (Woods & Lewis, 1995). Imposition of illness and treatment demands were identified as key factors affecting the family in a study of 35 families (Hilton, 1993), but in a circular fashion the mother's perception of the burden posed by the illness for her family appears to be a significant source of her depressed mood (Lewis & Hammond, 1996). The sense of distress because the disease and treatment undermined the mother's usual role was explored in a qualitative study of 10 women with younger children or teenagers. Women in this study expressed concern that exhaustion from treatment reduced the emotional resources available for their family (Holmberg et al., 2001). Selective open disclosure was found to promote adjustment within families in a study of 41 couples (Hilton, 1994), although another study of 55 women found that many families talked little about the cancer in order to protect themselves (Hilton, 1996). A small qualitative study found that partners feel overwhelmed, and protection of family members was sometimes achieved through use of humor. Financial strain was reported to compound the difficulty coping (Hilton et al., 2000). Qualitative research suggests that lack of information for families about the reactions and specific needs of their children may make the family situation more difficult (Elmberger et al., 2000).

The following five studies all included at least some patients with advanced breast cancer, and similar themes emerged: the adjustment of the woman influenced family cohesion (Friedman et al., 1988), open family expressiveness favorably influenced the adjustment of the mother (Spiegel et al., 1983), and depressed mood in the mother affected the quality of the marriage, in turn leading to impaired family functioning (Lewis & Hammond, 1992). A study of 40 families found that increased illness demands and higher level of parental depression adversely affected family function (Lewis et al., 1993). Recently, assessment of 189 women with recurrent breast cancer confirmed the adverse impact of symptom distress on psychological adjustment of the patient, this in turn impacting on family adjustment (Northouse et al., 2002a).

The Impact on Children

Thirty-nine studies were identified: 18 were studies of mixed cancer populations, 21 were studies of breast cancer.

Mixed Cancers

Studies reporting impact on children. The first four studies to be discussed did not include populations with advanced cancer or disease stage was not stated. A study from 1982 found that children viewed cancer as more severe in its effects than other diseases such as diabetes or heart disease, and treatments were seen as being less efficacious (Michielutte & Diseker, 1982). Examination of the emotional adjustment of 80 children with a parent with cancer found 20% to have high self-reported anxiety, with child's low self-worth and poor adjustment of the ill parent the two main risk factors for children's adverse adjustment (Nelson & While, 2002). This is consistent with an earlier study of 33 parent/child dyads in which parental anxiety accounted for the greatest variance in child anxiety (Heiney et al., 1997). The source of parental anxiety may well relate to cancer treatments and the prognosis; however, in an iterative way, mothers appear to experience concern about whether they are giving enough emotionally to their children, and they describe a tension between wanting the child to feel included, balanced against fears about worrying or frightening the child (Fitch et al., 1999). Many mothers in this study chose not to talk about death or the prognosis.

The following seven studies all included at least some patients with advanced disease. A small early study found that children identified loneliness, apprehension, and helplessness as they contended with parental cancer (Rosenheim & Reicher, 1986). Birenbaum et al. (1999) also found significantly more behavioral problems than expected in a study of 31 children and 84 adolescents of a parent with cancer. The appraisal of the seriousness of the cancer, rather than the objective characteristics of the disease, was found to influence distress in a study of 110 children, with adolescent girls with a mother with cancer being most significantly distressed (Compas et al., 1994). A subsequent study of 134 children revealed increased avoidance in the case of worse stage and poorer prognosis, this in turn leading to increased distress (Compas et al., 1996). The concerns of 87 children aged 7 to 11 years, with a terminally ill parent, were explored by Christ et al. (1993). This study found that children commonly expressed guilt and responsibility for their parents' illness, great concern about the vulnerability of the well parent, and had difficulty understanding medical information about their parent. Increased distress was also reported by Siegel et al. (1996) in a study of 97 children aged 7 to 16 years with a parent with terminal cancer, compared with a large community sample of age-matched children. The

children whose parent had cancer had significantly higher scores on anxiety and depression, 27% of the study group having above average depression scores compared with 15% of the community sample. This is consistent with earlier research by the same authors, who also found lower self-esteem and deficits in social competence in children whose parent had terminal cancer (Siegel et al., 1992).

Studies reporting impact on adolescents. The following three studies all relate to adolescents whose parent had early cancer. Adolescents and young adults appear to struggle to adopt the changes in role and care-giving necessary when a parent has cancer (Germino & Funk, 1993), overall adolescents showing more anxiety and depression than young adults (Mireault & Compas, 1996). Nelson et al. (1994) explored the adjustment of 24 adolescents, identifying the following factors significantly associated with high anxiety scores: inability to discuss the parent's illness with the parent, having to spend less time with friends, having to spend less time on sport and leisure activities, deterioration in schoolwork, and continuing anxiety over the parent's illness.

The following four studies included populations with at least some parents with advanced cancer. Key themes identified by 120 adolescents with a parent with cancer included empathy for the ill parent, being helpless to relieve symptoms, increased involvement with parents, changes in household responsibilities, and guilt about critical feelings toward the ill parent (Christ et al., 1994). This study also reported that emotionally overwhelmed parents reacted angrily to adolescent aggression, creating a cycle of difficulties, and precancer relationship difficulties predicted increased difficulty following the diagnosis of cancer. Another study of 55 adolescents with a parent with cancer reported girls to experience more anxiety and depressive symptoms than boys, this relating at least in part to perceived higher family responsibility stress for girls than boys (Grant & Compas, 1995). Similarly, in a study of 76 adolescent and preadolescent boys and girls, the highest level of distress was reported by adolescent girls. Of particular concern was the finding that parents seemed unaware of distress in their children, rating them as asymptomatic even when the children reported elevated levels of psychological symptoms (Welch et al., 1996). Examination of the impact of parental cancer on 45 daughters found that 35.5% experienced problems with school, 37.8% difficulties with friends, and 39.9% with their own physical health, participants nominating open family communication as best facilitating adjustment (Leedham & Meyerowitz, 1999). A second com-

ponent of this study explored the way information was given about the parent's cancer. A total of 28.2% were extremely or fairly dissatisfied about the way this was done, common reasons for this being the way in which they were told, a delay in being told, or being given insufficient information.

Breast Cancer

Studies reporting impact on children. All of the following nine studies relate to children of women with early breast cancer.

The earliest of these, a qualitative study of 81 children aged from 6 to 20 years, highlighted the gap between what is provided and what is needed by children: More than a third of the children in this study felt that their family did nothing to help them cope (Issel et al., 1990). Single women in particular have been found to struggle with being less accessible to their children, with a higher proportion of their young children scoring in the abnormal range on global self-worth (Lewis et al., 1996). Hilton and Elfert (1996) found that school-age children tended not to express their concerns directly, rather revealing these by their behavior. In contrast, one study of 48 children found that the children of women with breast cancer scored better on measures of behavioral adjustment compared with children of mothers with diabetes or benign breast disease (Armsden & Lewis, 1994).

Even in early stage disease, children appear concerned that their mother could die (Zahlis & Lewis, 1998), and try to make sense of this by imagining life without her (Zahlis, 2001). However, appropriate emotional support cannot be provided in a context where the disease is not discussed nor children's concerns explored. Shands et al. (2000) found that mothers tended to offer information rather than check children's emotions or understanding. This study alluded to the theme of mothers avoiding discussion in order to protect their children, a finding replicated by Barnes et al. (2000) in a study of 32 women with a total of 56 school-age children. Hilton and Elfert (1996) also found that mothers feel that preschool children are too young to understand about the cancer, consistent with the findings of Barnes et al. (2002) that older children tend to be given information earlier than younger children. This latter study found that children of more highly educated mothers were given less information. Disconcertingly, a minority of children were told nothing until after their mother's surgery, and some nothing at all.

The following four studies included at least some women with advanced disease. An early study of 78 women found that over half reported changes in

their relationship with their children since the diagnosis of breast cancer, with the change being more marked in women with poorer prognosis (Lichtman et al., 1984). The link between maternal distress and child adjustment was explored in a study of 32 children that found that higher reported maternal distress was associated with more emotional and behavioral problems (Howes et al., 1994). More recently, Hilton and Gustavson (2002) explored children's perspectives of breast cancer treatment, finding that children's responses are influenced by what and how others told them about the parent's cancer, and they generally did not talk about their situation or concerns with siblings or friends. Most recently a study compared maternal preoccupation and parenting of 42 women with metastatic breast cancer compared with 45 women with early breast cancer (Sigel et al., 2003). Women with metastatic disease had lower self-reports of poor parenting of their children aged 8 to 16 years, and observed less externalizing behaviors of their children compared with those with early disease. It is unclear whether this actually represents "improved" adjustment as disease advances, or maternal minimization of unpleasant affects, coupled with children's efforts to exert some control over the difficult situation.

Studies reporting impact on adolescents. The following seven studies are all of adolescents of mothers with early breast cancer or disease stage was not stated. Interviews with 27 mothers and daughters identified five key issues about the impact of breast cancer: isolation and separateness, stigma, career choice, risk assessment and hypervigilance, and role reversal (Clarke, 1995). A small early study found that adolescent girls felt inadequately supported during periods of peak stress, although girls who voluntarily took over household tasks viewed this positively (Rosenfeld et al., 1983). However, reverting to precancer functioning after the increased independence necessitated during breast cancer treatment also appears difficult for adolescent daughters (Hilton & Elfert, 1996). This is consistent with a later report of treatment sessions with adolescents who described anxiety that changes in domestic responsibilities would alter their relationship with their mother (Spira & Kenemore, 2000). Some adolescents whose mother had breast cancer did better in social and academic activities when their mothers were more distressed (Hoke, 2001), raising the possibility that this enhanced performance was the result of active pursuit of activities as a way of coping with emotional turmoil at home. Furthermore, Chalmers et al. (2000) found that few students sought support from a school counselor regarding their mother's breast

cancer. Although sometimes recognition of their difficulties was needed, adolescents indicated it was important to not be treated very differently from their peers. Overall, the quality of the parent–adolescent relationship made a substantial difference to the degree to which the adolescent positively viewed themselves in a study of 70 adolescents with a mother with early breast cancer (Lewis & Hammond, 1996).

The following three studies explored the impact of maternal advanced breast cancer on adolescent daughters. The earliest study explored the adjustment of 60 women whose mother had breast cancer, compared with 60 controls (Wellisch et al., 1991). The mothers of 30 of the women in the study group had died. Overall, the daughters of breast cancer patients showed significantly less frequent sexual intercourse, lower sexual satisfaction, and greater feelings of vulnerability to breast cancer. Subsequent work with this population explored risk factors for adverse psychological outcome. Those who were adolescents at the time of their mother's diagnosis with breast cancer experienced the greatest adjustment problems, those who were children at the time had moderate adjustment problems, and those who were adults experienced the least problems (Wellisch et al., 1992). Finally, it appears that fathers are least likely to be remembered as presenters of prognostic information, and for the small subset of women aged between 1 and 10 years at the time of the mother's diagnosis, no information about the diagnosis was given for over a year (Wellisch et al., 1996). Overall these studies found that "daughters who have experienced the terminal illness and death of their mother experience more deprivation while she was ill and are at risk for less functional adjustment in later life" (Wellisch et al., 1996, p. 280).

Interventions

A total of 13 studies were identified: 10 described interventions to assist families or children of parents coping with cancer, 1 described training of teachers to assist children, and 2 gave overviews of key issues.

The earliest study described an intervention for the children of terminally ill parents, by means of collaboratively involving the parents to enhance childhood coping. Key themes were education of parents about children's needs, helping parents to tolerate their children's grief, and reassurance for the children about their fears of abandonment (Adams-Greenly & Moynihan, 1983). This theme of psychoeducation for parents facing terminal illness was also central to an intervention by Siegel et al.

(1990), in which open communication was also fostered, along with avoidance of unnecessary separations that increase anxiety in children. This approach is also consistent with the intervention devised by Christ et al. (1991) for children aged 7 to 16 years, with a terminally ill parent, in which emphasis was placed on enhancing the ability of parents to meet their child's heightened needs for emotional support. The authors noted, however, that parental denial of the severity of the disease may mitigate against their participation in such a program. None of these studies reported formal evaluation. More recently, Davis Kirsch et al. (2003) have reported on a pilot study of a home-based intervention to enhance the communication of four mothers with early breast cancer, with children aged 8 to 12 years. Mothers reported being cautious and not wanting to frighten their children, but were more able to engage in active listening about cancer-related topics after the intervention.

Other interventions have focused on group support for children. The earliest of these discussed 32 support groups that had been designed to provide children with school-based, time-limited group support when coping with a life-threatening parental illness, usually cancer (Call, 1990). These groups aimed to provide support for the expression of feelings, encouraging children to recognize their capacity to deal with the crisis. Another intervention, "Kids Can Cope," has been designed to assist children aged between 5 and 18 years, with a parent with cancer, usually metastatic or with poor prognosis. This project aims to educate children about the cancer and its treatment and to provide a supportive environment in which children can express their feelings and share their experiences, themes being tailored to the developmental age of the child (Taylor-Brown et al., 1993). Another group intervention described has similar aims—provision of age-appropriate information and provision of a safe environment in which thoughts and feelings can be shared and questions answered (Bedway & Smith, 1996). Another intervention reported concurrent group support sessions for children and parents with metastatic cancer (Greening, 1992). In addition to the aims of support and information common to the above interventions, this author emphasizes the need to empower parents by helping them recognize their own strengths, thereby increasing their sense of control. In contrast, the Massachusetts We Can Weekend was for families with a member with early cancer. This weekend intervention for families aimed to explore the role of communication in the coping of 14 families (Walsh-Burke, 1992). The majority of participants reported positive changes in communication after the inter-

vention. The most recent family-based intervention reported (FOCUS) has been developed for families of women with recurrent breast cancer (Northouse et al., 2002b). Key themes are promotion of open communication, encouraging mutual support and teamwork, identifying family strengths, and helping children in the family. Preliminary analysis of results indicates that women who participated in the intervention reported significantly less hopelessness and less negative appraisal of their illness than control patients (Northouse, 2003, pers. comm.).

One study has examined the effectiveness of training student and practicing teachers about ways of responding to children experiencing cancer-related life stress (Cleave & Charlton, 1997). Participants described improvement in their listening skills and encouraging children to speak (in contrast with the usual teacher role of imparting information).

Overall, it appears that facilitating age-appropriate understanding and honest communication are key tasks in interventions to assist families coping with cancer (Sherman & Simonton, 2001; Rauch et al., 2002), along with enhancing family cohesion and confronting mortality (Sherman & Simonton, 2001).

CONCLUSIONS

Although the emotional burden for families and children of young women with advanced breast cancer is considerable, it appears that parents may fail to recognize or respond to this distress. A critical factor affecting adjustment is the developmental stage of the child: Younger children need reassurance that they are safe and will be cared for and middle-age children need specific information. Adolescent children, particularly daughters, appear to be especially vulnerable. Breast cancer in the mother may represent a challenge to self-esteem, identity, and social relationships, but perhaps more critically it may result in role reversal, and erosion of those “normalizing” activities that might promote optimism and a sense of competence in the face of adversity. For parents struggling to cope with disease burden and the confrontation with mortality inherent in the diagnosis of advanced breast cancer, these findings are far from intuitive, and parents require detailed appropriate information about the needs of their children.

Adjustment is also influenced by a number of other factors: the extent of disease and treatment burden, the marital relationship, the quality of relationship of the child with the well parent, and background issues of financial strain and premorbid adjustment of the family. The adjustment of the woman herself appears to exert a major influence

on family coping. However this is of concern as the women who have young children are themselves young, and thus more vulnerable to experiencing emotional distress in the context of breast cancer. A pervasive theme throughout the literature is the distress of parents who attempt to “protect” their children from sadness by avoiding or limiting discussion about the disease, only serving to compound the distress and uncertainty of their children.

Evaluations of interventions to assist children and families facing advanced breast cancer in their mother are limited. Overall, children of young women with advanced breast cancer need opportunities to express emotions, to have access to information that is developmentally appropriate, and to engage in at least some activities not related to the cancer to provide a sense of being “grounded” and to maintain self-esteem. Women and their partners require information about ways to talk with their children and facilitate more open communication; however, given the enormous grief inherent in their diagnosis, it is not simply a matter of giving information to parents. It is essential that women and their families have the support of health professionals who themselves model the capacity to “share the space” with them, and bear their pain, rather than avoiding such discussions because of the personal distress they necessarily engender.

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