

Family-Focused Oncology Nursing Research

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Purpose/Objectives: To analyze five common assumptions about a family's adjustment to breast cancer and to suggest needed future directions for family-focused research.

Data Sources: Published research in nursing, psychiatry, behavioral medicine, and psycho-oncology about families' functioning with breast cancer.

Data Synthesis: Evidence from published research is that family members do not modify their coping behavior in response to illness-related pressures, do not appear to learn over time how to manage illness-related concerns, are not responsive to each other's thoughts and feelings about cancer, experience tension in the marriage from cancer, and neither understand nor assist children affected by a mother's breast cancer.

Conclusions: Current assumptions about how families function with breast cancer need to be replaced with a more informed, data-based view that guides the development of better programs and services for assisting families.

Implications for Nursing: Future research and interventions need to address the impact of breast cancer on the primary relationships in a household, the impact of the illness on the family's core functions, and the family members' competencies to manage the illness.

Key Points . . .

- ▶ Commonly held assumptions about a family's functioning with breast cancer have delayed the development of informed intervention studies and services in oncology.
- ▶ Future research with families needs to include a healing paradigm that addresses the core functions of families, the impact that the illness has on family member relationships, and the family's cancer-related management competencies.

Members of a family experiencing breast cancer must balance two lives—their life as part of a family and their life with cancer (Lewis, 2002). Despite this reality, most intervention research to date has focused on the index patient or on a family member as a caregiver. Research has not focused on the family as a family (Lewis, 1997, 1998). The goal of this article is to critically examine prior published studies on the impact of breast cancer on the family to challenge assumptions that many people hold about how families function and manage breast cancer. Recommendations are made for needed future directions of research. This article is organized into two sections: (a) a critique of five common assumptions about how families function with breast cancer that have been challenged in completed research and (b) a proposed new paradigm for future family-focused research in oncology nursing.

Assumptions About How Families Adjust to Breast Cancer

Five assumptions about a family's adjustment to breast cancer have been challenged by completed research (see Figure 1).

Assumption 1: Family Members Modify Their Coping Behavior in Response to Illness-Related Pressures From Breast Cancer

Results across multiple studies with families experiencing breast cancer have documented that illness-related pressures occur but families do not significantly modify their coping

behavior as a function of these pressures (Lewis, 1998). Path analyses calculated on data obtained from households with women diagnosed with breast cancer and their spouses or partners consistently have documented a nonsignificant relationship between patient- or spouse-reported illness-related pressures and family member coping behavior (Lewis & Hammond, 1992, 1996; Lewis, Hammond, & Woods, 1993). Evidence is that family members modify their coping behavior in response to family system changes, including tension in primary family member relationships, especially the marital dyad (Lewis & Hammond, 1992, 1996; Lewis et al., 1993).

The absence of a significant relationship between illness-related pressures and family member coping behavior runs counter to prediction in stress and adaptation theory and its extensions to families (Lazarus & Folkman, 1984; Manne, 1994; Manne, Pape, Taylor, & Dougherty, 1999; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1983; Wenzel, Glanz, & Lerman, 2002). Given these results, healthcare providers cannot unconditionally assume that family members modify their coping behavior in response to the illness-related pressures. Assumption 1 is not substantiated in the research literature.

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Assumption 1: Family members modify their coping behavior in response to illness-related pressures from breast cancer.

Assumption 2: Family members learn over time how to cope with breast cancer.

Assumption 3: Spouses are responsive to each other's thoughts and feelings about breast cancer.

Assumption 4: Tension in the marriage from breast cancer is a private matter between the patient and spouse.

Assumption 5: Families are able to understand and assist the child with the mother's breast cancer.

Figure 1. Five Unsupported Assumptions About the Family's Functioning With Breast Cancer

Assumption 2: Family Members Learn Over Time How to Cope With Breast Cancer

Common sense and learning theories suggest that family members learn over time ways to modify their behavior in response to changing and relatively stable illness-related conditions. In clinical settings, nurses often hear words such as, "Just give them time and they will figure it out," "They just need a little time to learn how to cope," and "Over time they will learn how to manage this."

Empirical evidence in longitudinal research with families with breast cancer runs counter to this assumption. In a study of 111 families of women with breast cancer, study participants were measured every four months at three time periods using standardized measures of illness-related pressures, coping behavior, and household functioning (Lewis & Hammond, 1992). Results revealed that family members did not appear to learn how to cope over time. More specifically, coping behavior did not significantly change over time, even as the number of illness-related demands changed (multivariate $F = 6.70$, $p < 0.01$). Instead of altering how they coped with the changing illness-related conditions, the family members' coping behavior remained stable, regardless of the illness issues the family members faced. In addition, in cross-lagged analyses involving these same 111 households, families' coping behavior did not diminish their illness-related pressures over time. In fact, how the family coped at one point in time did nothing to change the illness-related pressures that were reported at subsequent points in time.

Additional evidence suggested that these same families did not "learn over time." By the third data-collection period, suggestive evidence of burnout existed. The more diligently the families had coped at time 2, the less well they functioned as households at time 3 (Lewis & Hammond, 1992). Assumption 2 is not supported by the research literature.

Assumption 3: Spouses Are Responsive to Each Other's Thoughts and Feelings About Breast Cancer

Spouses may claim that they want to be responsive to each other's thoughts and feelings about breast cancer, but evidence from research with couples runs counter to this assumption. Evidence suggests six plausible sources of this nonresponsiveness: functioning in survival mode, dysynchronous illness trajectories, different explanatory models about the cancer, divergent views about support, gender-related frames of reference, and the wife's intense emotions. Following, each of these plausible sources is described briefly. Also, see Manne, Alfieri, Taylor, and Dougherty (1999), who argued

that patients' functional impairment also may lead to spousal nonresponsiveness.

Being in survival mode: In the early diagnostic and treatment phase, couples are in survival mode in which competing demands for obtaining, clarifying, and managing illness-related information directs their attention away from each other and toward the cancer. This sorting of information does not always involve helping each other emotionally process what is happening to each of them. Instead, emphasis is on getting information and making treatment decisions. Emotions and feelings appear to be given a "back seat."

Dysynchronous illness trajectories: Each spouse's illness trajectory is not typically synchronized with that of the other. Not uncommonly, a husband wants his wife to return to normal well before she is emotionally ready (Quint, 1963). Even though she may be physically recovered from the surgery, she claims she is not ready to return to normal or to resume her prior lifestyle. Nonconvergent trajectories may partly explain why spouses' or partners' scores on standardized measures of adjustment over time are not the same as the diagnosed wives' patterns of adjustment (see seminal studies by Baider and DeNour, 1984, and Northouse and Swain, 1987).

Holding different explanatory models: Couples have different explanatory models about the illness, including what helps women recover. These differences are demonstrated in overt as well as subtle ways, including what they allow each other to talk about the breast cancer (Lewis & Deal, 1995). For example, wives report needing to be able to talk about sad thoughts and feelings with their husbands as part of their recovery. They find, however, that their husbands do not want them to express negative thoughts. As one husband reported, "... I think ... if you're going to survive ... that you've got to have that will, that, 'Hey, yeah, I'm fine,' 'cause I think that really helps ... I'm sure those good feelings, positive feelings, help." (Zunkel, 2002, p. 51).

Differing views of supportive behavior: Spouses differ on what they consider to be supportive to each other. For example, the wife's need for one type of support can be discordant with the type of support the spouse thinks she needs or that he is able to give. When she wants him to sit quietly next to her or to hold her, he may want to do the dishes or clean the house. Spouses also report trying to support their wives by cheering them up or telling them that they will be okay (Samms, 1999). This optimism or attempt to see the positive in the illness may not be well received by wives.

Gender-related issues: Gender-related issues may influence a spouse's ability to be emotionally responsive to his diagnosed wife. Husbands work to protect themselves from their own feelings rather than find ways of dealing with them (Sabo, Brown, & Smith, 1986). They report riding their feelings out, stuffing them, or trying to forget them (Samms, 1999). A spouse's understanding of "being a man" or "being strong" is sometimes in conflict with being responsive to his wife. This struggle is evident in face-to-face case-intensive confidential interviews with spouses of women diagnosed with breast cancer. One spouse offered, "You have to be strong; you can't really let your feelings show on the outside" (Zahlis & Shands, 1991, p. 88).

Wife's intense emotions: The intense emotions of a diagnosed wife can make being responsive difficult for the spouse. Spouses reported feeling "jerked around" by their wives' emotions, which can be constant and unrelenting, and

say they want help dealing with them (Samms, 1999). During these emotional times, a spouse can find that being empathetic is difficult when his wife is emotionally undone. Given the published evidence, assumption 3 cannot be accepted.

Assumption 4: Tension in the Marriage From Breast Cancer Is a Private Matter Between the Patient and Spouse

Tension in the marital dyad is not a private matter when the wife is diagnosed with breast cancer. Although family systems theory posits that subsystems within a family have the potential to contain dyadic tension so that it does not diffuse to other subsystems (e.g., to the parent-child subsystem) or to the total household, this is not substantiated in data obtained from families affected by breast cancer.

During acute and long-term adjustment to breast cancer, marital tension has diffuse negative consequences on the household members' functioning (Lewis, 1998; Lewis & Hammond, 1996; Lewis et al., 1993). In child-rearing households, lower marital quality negatively affects family members' coping behavior (Lewis & Hammond, 1996; Lewis et al., 1993; Woods & Lewis, 1995), child self-esteem (Lewis & Hammond, 1996), and the quality of the parent-child relationship (Lewis et al., 1993; Woods & Lewis). Assumption 4 is not supported by research evidence.

Assumption 5: Families Are Able to Understand and Assist the Child With the Mother's Breast Cancer

Family members, including mothers, have little if any understanding of what a child is dealing with, thinking about, or feeling when the mother has breast cancer (Shands, Lewis, & Zahlis, 2000; Zahlis, 2001; Zahlis & Lewis, 1998). What mothers do know often is limited to what their children have asked about breast cancer. When a child is quiet or does not ask questions, parents may have limited exchange with them about the cancer (Shands et al.). Without questions from their children, some mothers do not initiate discussion.

Evidence is that children hold back their worries, fears, and concerns about the mother's breast cancer from the mother in an attempt to protect her or to avoid causing tension in their relationship (Issel, Ersek, & Lewis, 1990). Furthermore, the school-age child's developmental stage reinforces the child's silence (Armsden & Lewis, 1993). Asking for help or putting pressure on the mother, particularly a symptomatic or distressed mother, is not what a school-age child is likely to do.

During the acute phase of breast cancer, mothers claim they want to help their children but often are too distressed, symptomatic, or pressured to be the parent they want to be (Fitch, Bunston, & Elliot, 1999). Even as they are aware of the children's emotional needs, mothers knowingly give the children's needs second place to their own; they simply do not have enough energy to listen (Lewis, Zahlis, Shands, Sinheimer, & Hammond, 1996).

In studies that offer evidence of limited interaction about the breast cancer with the child, the content and form of that interaction is not always developmentally appropriate (Shands et al., 2000; Zahlis & Lewis, 1998). In telling their children about the cancer, mothers sometimes disclose overly charged messages and details in an attempt to not hide anything from their children (Shands et al.). Assumption 5 is not supported by completed research with children and breast cancer.

A Needed New Paradigm for Future Research: Healing the Family

Five commonly held assumptions about family functioning and breast cancer have received insufficient support in completed research to date. These assumptions need to give way to a more informed, evidence-based understanding of how families actually function with breast cancer, not how theories say they should function.

If families are not modifying their coping behavior in response to ongoing or changing illness-related demands, then nurses need to ask in what ways they can assist families in better managing these demands (Lewis & Hammond, 1992, 1996; Lewis et al., 1993). In the absence of outside assistance, not only do these illness-related demands not go away, but they also cause the family to wear down over time (Lewis & Hammond, 1992). Instead of the breast cancer stimulating coping behavior, it results in heightened tension in the marriage. This tension in the marriage, not the illness-related pressures, affects the family members' coping behavior; the greater the marital tension, the less the family members cope (Lewis & Hammond, 1992, 1996; Lewis et al., 1993). If this is true, nurses need to ask in what ways they can minimize the transfer of marital tension onto the family member's coping behavior.

If spouses want to but are not able to be responsive to each other's differing thoughts and feelings about the breast cancer, then nurses need to ask how they can enhance their responsiveness to each other. In the absence of intervention, tension in the marriage is diffusing into other primary relationships in the family, including the total household's functioning and the quality of parent-child relationships.

Families do not typically know, understand, interact with, or support children in coping with the mother's breast cancer (Issel et al., 1990; Shands et al., 2000; Zahlis, 2001). The child's journey often is unknown, even by caring mothers who want to better parent their children but are not able to do so. If this is true, then nurses need to ask in what ways they can enhance the quality of the mother's relationship with and support of her child during the breast cancer. Given this research evidence, nurses need to ask how they can assist families in healing from breast cancer.

What is healing in a family? To heal is to make whole or sound (Simpson & Weiner, 1989). Healing a family from breast cancer involves helping the family to stabilize and maintain its core functions; sustain or enhance relationships among members; nurture the development of individuals in the family despite the cancer, especially the children; and add to the family members' competencies to manage the illness (Fisher & Weihs, 2000; Lewis, 1998; Lewis et al., 2000; Weihs, Fisher, & Baird, 2002).

Healing involves reorganizing family routines around treatment, symptom management, long-term care, and survivorship while protecting and savoring time as a family away from the cancer. Healing includes reconfiguring, stabilizing, protecting, and enhancing the relationships among family members, even as the illness causes pressures that increase marital tension or distance between the diagnosed mother and her child.

Healing includes creating ways for members to safely express thoughts and feelings about the cancer during the entire course of the illness and over time (Lewis, 1997; Samms,

1999). Part of healing involves the family members in emotionally processing the changes in the family that are brought about by the cancer (Lewis, 1993). Healing involves generating a new identity as a family, not a "sick" family identity (Casey, 2002; Feldman, 1974).

If nurses adopt a healing paradigm to guide their research with families, they will leap forward in three ways. First, a healing paradigm moves nurses into relational-focused interventions at a time when they mostly provide patient-focused interventions (Fisher & Weihs, 2000; Lewis, 1997, 1998; Weihs et al., 2002; Yates, Bensley, Lalonde, Lewis, & Woods, 1995). Second, as soon as the research paradigm shifts to healing, nurses no longer focus on a family only as a caregiver; rather, nurses focus on interventions for the family as a family. Third, if this definition of healing is accepted, future interventions will try to enhance the family's functioning, including their threatened core functions and relationships, not just offer interventions that add to their cancer-related management competencies.

Dodd's and Lorig's research programs are seminal in adding to a diagnosed patient's abilities to self-manage, but nurses have much to do in extending self-management interventions to families dealing with cancer (Bandura, 1997, 2001; Goepfinger & Lorig, 1997; Lorig et al., 1999; Lorig, Gonzalez, Laurent, Morgan, & Laris, 1998; Meyerowitz, Heinrich, & Schag, 1983; Miaskowski et al., 2001; Parcel et al., 1994; Weihs et al., 2002). If nurses adopt a healing paradigm for the family affected by breast cancer, they cannot merely teach patients or caregivers how to manage symptoms and the breast cancer. Skills and competencies need to include skills for nurturing members affected by cancer, sustaining and enhancing the relationships among family members during particularly challenging times, and systematically structuring ways to help family members nurture and balance their lives as a family, not just their lives with cancer (Baranowski, Perry, & Parcel, 2002; Lewis et al., 2000; Zunkel, 2002).

Much of the family's healing can be enhanced with delimited psychoeducational interventions and does not always require face-to-face contact (Lewis, 2002). The World Wide Web is one channel that holds promise for reaching out to and delivering family-focused interventions (Kirsch & Lewis, 2004). Web-based instruction has high start-up costs but should be considered as an alternative to reach multiple family

members. Telephone-based interventions also hold promise under certain conditions (see, for example, Dougherty, Johnson-Crowley, Lewis, & Thompson, 2001). Interventions with family members need to use community-based and public service channels, not just service-based settings (Lewis, 1997; Longman, Braden, & Mishel, 1996, 1997; Roberts et al., 1995).

Whatever the content or form of family-focused interventions, they must be sustainable. Family-focused scientists cannot afford to develop intensive or expensive interventions that have no future in cost-sensitive environments. Scientists need to be able to develop and test interventions that cross the threshold of effect but still are deliverable and sustainable over the long run. Scientists do no good, and perhaps they do harm, if they develop expensive interventions that are efficacious but costly and not sustainable (Cochrane & Lewis, in press).

Science must match nurses' caring, and caring must match reality. Science and reality should be equal partners, not lone journeyers. In all, the focus should be on healing the family from cancer.

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