

# A Family-Based Program of Care for Women With Recurrent Breast Cancer and Their Family Members

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**Purpose/Objectives:** To evaluate the FOCUS Program (family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management), a family-based program of care for women with recurrent breast cancer and their family caregivers.

**Data Sources:** Randomized clinical trial.

**Setting:** Midwest region of the United States.

**Data Synthesis:** The family-based program of care consisted of five components: family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management. The program was delivered in three home visits and two follow-up phone calls over a five-month period of time.

**Conclusions:** Patients with recurrent breast cancer and their family members reported high satisfaction with the FOCUS Program. Although the FOCUS Program had a number of strengths, limitations of the program also were identified that need to be addressed in future family-based interventions.

**Implications for Nursing:** A need exists for family-based programs of care that enable both patients and their family members to manage the multiple demands associated with recurrent breast cancer.

## Key Points . . .

- Breast cancer recurrence can be stressful for patients and their family members.
- A brief, time-limited program of care, the FOCUS Program (family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management), was developed to assist women and their family members to manage the stressful effects of illness.
- Facilitating communication, encouraging optimism, teaching coping strategies, reducing uncertainty, and managing symptom distress are key interventions to assist women with recurrent cancer and their family caregivers.

family-based program of care for women with recurrent breast cancer and one of their family members, which was offered as part of a large, randomized clinical trial. The results of the clinical trial will be reported elsewhere. This article will describe the (a) theoretical and empirical underpinnings of the program, (b) program design and sample, (c) program delivery, (d) program components, (e) program evaluation, and (f) the strengths and limitations of the program.

Although early detection of breast cancer has improved treatment and survival outcomes, recurrence of the disease remains a major threat for many women and their families (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Ganz et al., 1996; Spencer et al., 1999). Patients have reported being significantly more burdened by activity restrictions, symptom distress, and uncertainty about the future and less hopeful during the recurrent phase than during the initial phase of cancer (Cella, Mahon, & Donovan, 1990; Frost et al., 2000; Gotay, 1984; Weitzner, McMillan, & Jacobsen, 1999). Despite these difficulties, few programs of care are available for women and their family members during the recurrent phase of illness.

The purpose of this article is to describe the FOCUS Program (family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management), a

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## Theoretical Framework

Stress-coping theory (Lazarus, 2000; Lazarus & Folkman, 1984) and family stress theory (McCubbin & McCubbin, 1996) provided the theoretical basis for this program. According to stress-coping theory, a series of personal and environmental factors initially can affect how individuals appraise and cope with illnesses and subsequently affect their quality of life over time. In keeping with the stress-coping framework, a supportive and educative family program was envisioned to reduce patients' and family members' negative appraisal of the recurrent breast cancer (e.g., decrease threat, hopelessness, uncertainty), enhance participants' coping ability, and minimize the effects of some of the illness-related factors (e.g., symptom distress) on patients' and family members' quality of life.

Family stress theory (McCubbin & McCubbin, 1996) contends that the family is a social system; hence, stress in one family member has a reverberating effect on other family members. The theory suggests that patients and their healthy family members may experience stress reactions in response to illness. As a result, the family needs to be viewed as a system that may be in need of supportive care. The theory also suggests that in times of illness, families must adapt to both normative (e.g., developmental) and non-normative (e.g., illness-related) changes and that a combination of these stressors can accumulate and exceed the family's coping resources. Family stress theory emphasizes the importance of identifying family strengths that can be used to help families adapt to hardship and strain.

The tenets of stress-coping theory and family stress theory were relevant to the current study of women with recurrent breast cancer and their family caregivers. Stress-coping theory provided the rationale for targeting the interventions to reduce negative appraisals and symptom distress and to enhance active coping strategies. Family stress theory provided the rationale for including family members in the program of care, working with the family as a team, identifying family strengths, and helping families to manage multiple stressors in their lives.

## Literature Review

### The Nature of Cancer Recurrence

According to the research literature, cancer recurrence is one of the most stressful events in the overall course of illness for both patients and their family members (Cella et al., 1990; McEvoy & McCorkle, 1990; Silberfarb, Philibert, & Levine, 1980; Weisman & Worden, 1985). More than 78% of the patients in one study reported that learning their cancer had recurred was more upsetting than learning of their initial diagnosis, particularly because the recurrence damaged their sense of hope (Cella et al.). Frost et al. (2000) found no difference in emotional distress in patients with breast cancer at various stages of disease but did find that women in the recurrent phase had poorer health perceptions, more physical problems, and more difficulty interacting with medical staff. Bull et al. (1999) assessed the quality of life of women with recurrent breast cancer prior to recurrence, at the time of first recurrence, and six months after recurrence. They found significant decreases in women's perceived quality of life, general health, and emotional and social functioning from

prerecurrence to initial recurrence. Emotional distress was especially high at the time of initial recurrence; 43% of the women reported high distress at that time, and 28% reported high distress six months later.

Family members also are affected by recurrence. In one study, husbands of women with recurrent breast cancer reported as many adjustment problems as their wives did (Northouse, Laten, & Reddy, 1995). They also reported more uncertainty about the illness and perceived less support than patients did. Some family members had difficulty discussing the cancer recurrence (Chekryn, 1984) and others reported having difficulty working together to manage the illness (Barg et al., 1998). Some research suggests that when partners of women with advanced breast cancer have difficulty adjusting to the illness, it has a detrimental effect on patients' adjustment (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Northouse, Dorris, & Charron-Moore, 1995). According to Lewis and Deal (1995), even though couples try to balance their lives as they face recurrent breast cancer, they still are troubled by depressive moods and stress in their marital relationships. These findings suggest that patients and their family members both must be included in programs of care.

### Factors Related to Quality of Life Following Recurrence

Several investigators have tried to determine whether certain factors explain why some women and their family members experience more problems adjusting to recurrent illness than others do. Findings from these exploratory studies identified key factors that were built into the current program of care. Support from family and friends was related to better adjustment (Giese-Davis et al., 2000; Northouse, Dorris, et al., 1995; Worden, 1989), whereas aversive support or criticism was related to more negative mood among women with breast cancer (Koopman, Hermanson, Diamond, Angell, & Spiegel, 1998). In addition, greater optimism or less hopelessness (Carver et al., 1993; Northouse, Dorris, et al.; Worden), less uncertainty about the illness and treatments (Mishel, Hostetter, King, & Graham, 1984; Northouse, Dorris, et al.), less symptom distress (McCorkle & Quint-Benoliel, 1983; Northouse, Dorris, et al.; Weisman & Worden, 1985), and the use of more active coping strategies (Hack & Degner, 1999) were associated with better adjustment outcomes. These findings pointed to the importance of including content in a program of care that facilitates family support, enhances optimism, and encourages active coping, and also reduces uncertainty and symptom distress. As this article will discuss, these key factors became the core content areas of the FOCUS family intervention.

### Intervention Studies

Although a number of intervention studies have been conducted among women with breast cancer during the initial phase of illness (Badger, Braden, & Mishel, 2001; Helgeson, Cohen, Schulz, & Yasko, 1999; Marcus et al., 1998; Maunsell, Brisson, Deschenes, & Frasure-Smith, 1996), few have been conducted during the advanced stage of breast cancer (Classen et al., 2001; Spiegel, Bloom, Kraemer, & Gotthel, 1989), and fewer still have included family members (Donnelly et al., 2000). In addition, several investigators have focused on the caregivers of patients with cancer, including some patients with breast cancer (Jepson, McCorkle, Adler,

Nuamah, & Lusk, 1999; Pasacrete & McCorkle, 2000; Toseland, Blanchard, & McCallion, 1995). These intervention programs have assessed various psychosocial outcomes and have been of varying duration, delivered by various methods (e.g., telephone, home visits), and offered either to caregivers alone or to patient-caregiver dyads. Although few significant effects were found, some of the studies were limited by a small sample size (Donnelly et al.) or low response rate (Toseland et al.) or they were offered at a time when patients and caregivers were not experiencing adjustment difficulties (Toseland et al.); hence, only limited improvements could be attained.

The FOCUS program was offered (a) at the time of recurrence because of the difficulties experienced by patients and family caregivers during this phase, (b) for patients and family caregivers to facilitate their communication about the illness and its effect on one another, (c) through home visits to increase participants' comfort during the intervention sessions and limit additional travel demands, and (d) as a brief, time-limited program that may be transportable to patient care.

## FOCUS Program: Study Methods

### Program Design and Sample

Based on stress-coping theory, as well as on the findings from the research literature, a family-based program of care was developed for dyads of women with recurrent breast cancer and one patient-selected family member. The program consisted of five core content areas that formed the acronym FOCUS: family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management.

A longitudinal, randomized clinical trial was used to test the effects of the program on patient and family outcomes (these results will be reported elsewhere). Each dyad was comprised of one patient and one of her family members; they were assessed at baseline and randomly assigned to either the control group (i.e., standard clinic care) or the experimental group (i.e., standard clinic care plus the FOCUS Program). All dyads were reassessed three and six months later. In addition, a program evaluation tool was administered to all dyads following completion of the protocol.

Women were eligible for the study if they had a recurrence or progression of their breast cancer within the previous month, were aged 21 or older, had a life expectancy of at least six months, and had a family member who was willing to participate in the study. Patients identified selected family members as the people most involved in their care. Although most of the family participants were spouses (64%), a number of sisters, adult children, or other relatives also participated in the study (36%). Two hundred dyads completed baseline data and were randomized to either the FOCUS Program or the control group. The average age of participants was 54 years for patients and 52 years for family members. Most of the patients had either stage 3 or stage 4 breast cancer (95%). Even though a sizable number of women died during the course of the study, 73 patients and their family members completed the FOCUS Program. An additional 71 patients and their family members were retained in the control group.

### FOCUS Program Delivery

The FOCUS Program was comprised of an initial phase and a booster phase. The initial phase consisted of three home visits with a master's-prepared nurse scheduled when

patients and their participating family members could be present, with each home visit lasting approximately one and a half hours. Home visits were spaced about one month apart, thus covering the immediate postrecurrence period. The booster phase consisted of two follow-up phone calls, with each phone conversation lasting approximately 30 minutes. The phone follow-ups were conducted at one and two months following completion of the home visits. Overall, the FOCUS Program covered a five-month period of time (three months for home visits, two months for phone follow-ups).

To ensure standardization of the intervention program, a 17-page protocol manual was developed that outlined specific interventions for each home visit and telephone session. The interventions for each session were structured around the five core content areas of the FOCUS Program. The protocol manual was created in a checklist format, allowing the intervention nurses to indicate when each core content intervention was completed. Although the protocol manual outlined core content, the program also had some flexibility that enabled the nurses to tailor the program content to the specific needs of individual dyads (e.g., some pairs needed more help with optimism, others with symptom management). The researchers also developed additional handouts, such as information cards on managing side effects and pamphlets on maintaining optimism and talking with children about recurrence. Intervention nurses kept detailed notes and recorded the tailored information that was provided in each session (e.g., medication information discussed). The nursing notes were transcribed and analyzed for specific themes.

Intervention nurses recorded the percentage of time (0%–100%) they spent on each of five core content areas during each session. Because the program was tailored to the individual needs of families, the researchers wanted to determine whether intervention nurses were spending similar amounts of time on the core content areas. The researchers averaged these percentages across each nurse's caseload for a subset of patients and made comparisons across intervention nurses. As shown in Table 1, the intervention nurses did demonstrate consistency in amounts of time. For the most part, they spent the largest percent of their time on core content related to the area of family involvement and the least amount of time on the area related to symptom management. In most cases, it appeared that the women's symptoms were being managed adequately in the clinic settings. Furthermore, because these women all were dealing with recurrent cancer, many of them had acquired ways of managing fatigue, nausea, and other symptoms when they were receiving their initial treatment for breast cancer. However, family communication, optimism, and coping were addressed less often as a part of their standard clinic care; thus, more time was spent on these issues during the FOCUS intervention sessions.

To further standardize the implementation of the program, intervention staff met regularly with the principal investigator to discuss their caseload of families. The staff also met regularly with one another to discuss their families using a case presentation method that covered the five core content areas. These presentations and the discussions that ensued provided the intervention staff members with opportunities to compare their approaches to dyads' individual concerns and to ensure that each of the intervention staff was intervening in a similar way with patients and their family members.

**Table 1. Percentage of Time Spent on Five Components of FOCUS Program**

Program Components	Intervention Nurse							
	Nurse 1 (n = 7 dyads)		Nurse 2 (n = 28 dyads)		Nurse 3 (n = 20 dyads)		Total (N = 55)	
	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD
Family involvement	26.4	7.5	27.0	6.9	25.5	4.8	26.4	6.2
Optimistic attitude	22.1	4.9	20.9	3.2	21.8	4.1	21.4	3.9
Coping effectiveness	19.3	3.5	18.0	4.6	24.0	5.0	20.4	5.3
Uncertainty reduction	16.4	4.8	18.4	8.5	17.5	3.8	17.8	6.7
Symptom management	15.7	3.5	15.7	5.2	11.3	7.2	14.1	6.2
<b>Total</b>	<b>100</b>	<b>24.0</b>	<b>100</b>	<b>28.3</b>	<b>100</b>	<b>25.0</b>	<b>100</b>	<b>28.3</b>

## FOCUS Program Components

The FOCUS Program consisted of five core content areas that were individually tailored to the needs of patients and their family members (see Table 2).

### Family Involvement (F)

The first core component emphasized family involvement, which included promoting open communication, encouraging mutual support, identifying family strengths, and helping children in the family to deal with the effects of the illness.

**Promoting open communication:** Dyads varied in the degree to which they communicated openly about the illness. Some families communicated well with one another about the recurrent illness; intervention nurses reinforced their effective communication and encouraged them to continue with their current level of openness. Other families, however, had more difficulty communicating and supporting one another. These dyads often had preexisting communication difficulties that were exacerbated by the stress of the recurrent cancer. For many dyads, the intervention sessions were enough to open communication and ease tensions. However, dyad members who had long-standing communication problems that interfered with their ability to manage the illness were encouraged to seek counseling.

Some patients or family members were afraid to share their feelings about the recurrent illness because they did not want to burden others with their fears. One husband said he was uncomfortable with his wife's desire to discontinue her current treatments. He thought this meant that she was "giving up." His wife, on the other hand, shared her frustration with the side effects of her treatments and the lack of quality in her life. With the help of the intervention nurse, each partner was able to gain a better understanding of the other's perspective. For this couple and many others, discussions about quality of life lead to discussions about death, dying, and fears related to losing a partner. Many dyad members expressed gratitude for the support that they received to deal with these difficult issues.

**Encouraging mutual support and team work:** The effects of cancer on the family and the importance of mutual support were discussed with each dyad. Patients and family members were asked questions such as "What specific things does your partner do to show support?" and "In what ways has your partner been helpful during this time?" The inter-

vention nurses encouraged frank discussions of what each member needed from the other and the degree to which those needs were being met. Dyads were encouraged to work as a team to help one another manage the stress associated with the illness.

**Identifying family strengths:** Family strengths were identified and reinforced. One couple talked about the enjoyment that they used to have when splitting wood together. The patient said that she no longer had the energy to help her husband but now sits in the backyard while her husband splits wood and "gives him moral support" [smiled]. The intervention nurse said that this wood-splitting example illustrated one of the strengths that they had as a couple: They were able to adapt to the demands of the recurrent disease and continue on with one of their enjoyable, leisure activities. The nurse also pointed out that this was an example of a patient giving her healthy partner support and working together as a team.

**Helping children in the family:** The researchers discovered early on that many family dyads communicated reasonably well with one another but often felt ill-equipped to discuss the cancer recurrence with their children. For many families, being asked to discuss cancer in their families opened the opportunity for more in-depth communication and sharing. One patient told of her son's anger related to her illness. She admitted that she hid her feelings from her son and did not discuss her illness with him. The intervention nurse discussed the benefits of open dialogue and explained that the son's imagination could be far worse than the facts.

To meet families' needs for information, the researchers designed a pamphlet that gave parents guidelines on how they could discuss the return of the cancer with their children. The pamphlet also provided parents with information on how to recognize and differentiate normal behaviors in their children from behaviors that might require professional evaluation. Families wanting more comprehensive information were provided with copies of two books, *When a Parent Has Cancer: A Guide to Caring for Your Children* (Harpham, 1997) and *How to Help Children Through a Parent's Serious Illness* (McCue, 1994).

### Optimistic Attitude (O)

The second core component of the FOCUS Program helped families maintain an optimistic attitude. This included practicing optimistic thinking, sharing negative thoughts, maintaining hope, and staying hopeful in the face of death.

**Table 2. FOCUS Program Components and Examples of Nursing Interventions**

Program Component	Interventions	Examples
Family involvement	Promoting open communication	<ul style="list-style-type: none"> <li>• Encourage open discussion of concerns.</li> <li>• Use "I" statements to express feelings.</li> <li>• Encourage participants to share their perspectives on an issue or concern.</li> </ul>
	Encouraging mutual support and teamwork	<ul style="list-style-type: none"> <li>• Discuss that cancer can affect both patient and family, making mutual support essential.</li> <li>• Recognize the contributions of both members of the dyads and encourage expression of appreciation.</li> </ul>
	Identifying family strengths	<ul style="list-style-type: none"> <li>• Help patients and family members identify individual and family strengths.</li> <li>• Identify resources the family has to manage the recurrent illness.</li> </ul>
	Helping children in the family	<ul style="list-style-type: none"> <li>• Discuss benefits of open communication versus concealment.</li> <li>• Give names and contact numbers of support groups for children of parents with cancer.</li> </ul>
Optimistic attitude	Practicing optimistic thinking	<ul style="list-style-type: none"> <li>• Discuss the importance of optimism.</li> <li>• Teach dyads that optimistic thinking can be practiced.</li> </ul>
	Sharing fears and negative thoughts	<ul style="list-style-type: none"> <li>• Encourage airing of fears and negative feelings so they can be addressed.</li> <li>• Allow dyads to vent frustration and disappointment about the recurrent illness.</li> </ul>
	Maintaining hope	<ul style="list-style-type: none"> <li>• Assess each partner's level of optimism on a scale of 1–10.</li> <li>• Encourage dyads to practice optimism strategies daily.</li> </ul>
	Staying hopeful in the face of death	<ul style="list-style-type: none"> <li>• Give permission to maintain hope in spite of progressive disease.</li> <li>• Help dyads to appreciate the present.</li> </ul>
Coping effectiveness	Dealing with overwhelming stress	<ul style="list-style-type: none"> <li>• Encourage day-to-day efforts to cope.</li> <li>• Allow opportunities to discuss death and dying issues or concerns.</li> </ul>
	Encouraging healthy coping and lifestyle behaviors	<ul style="list-style-type: none"> <li>• Discuss benefits of active versus passive coping strategies.</li> <li>• Educate about the importance of healthy lifestyle behaviors for patients and family members: eating and exercise, sleep and rest patterns, use of chemical substances, and support networks.</li> </ul>
	Helping caregivers manage the demands of illness	<ul style="list-style-type: none"> <li>• Encourage caregivers to accept offers of help from others.</li> <li>• Help caregivers identify activities to restore their mental and physical energy (e.g., hobbies, recreational activities).</li> </ul>
Uncertainty reduction	Obtaining information	<ul style="list-style-type: none"> <li>• Educate about disease process.</li> <li>• Answer questions about current or experimental treatments.</li> </ul>
	Learning to be assertive	<ul style="list-style-type: none"> <li>• Discuss assertiveness techniques and role-play as needed.</li> <li>• Validate that requests for information are reasonable.</li> </ul>
	Learning to live with uncertainty	<ul style="list-style-type: none"> <li>• Help dyads set short-term goals so they can feel satisfied when accomplished.</li> <li>• Normalize feelings of uncertainty.</li> </ul>
Symptom management	Assessing symptoms	<ul style="list-style-type: none"> <li>• Assess symptoms experienced by patients and family members.</li> </ul>
	Teaching self-care strategies	<ul style="list-style-type: none"> <li>• Review patients' and their caregivers' symptom management and educate as needed.</li> <li>• Provide information about community resources and support services.</li> </ul>

**Practicing optimistic thinking:** Many dyads found it difficult to maintain optimism in the face of recurrence. A number of patients admitted having a sense of diminishing hope as they attempted to deal with further progression of their breast cancer. Some patients and family members were devastated by treatment failures, their difficult daily struggles, and interrupted life plans of growing old together. Dyads were taught that optimism was an attitude that could be learned

and practiced. They were given an optimism brochure that the researchers developed that listed a series of strategies dyads could use to promote and maintain an optimistic attitude. Dyads were asked to review the list of strategies, pick two or three that they would be willing to try, and practice them before the next session.

**Sharing fears and negative thoughts:** The family members were asked to share any fears that they had about recurrence

because their fears could interfere with their attempts to stay optimistic. Many patients expressed their frustration and sadness at having to shorten time frames when planning for the future. Women with young children described their anguish over their fear of dying before seeing their children attain important developmental milestones. Women often held these thoughts like private secrets, reluctant to disclose them to their mates because they did not want to give the impression that they were giving up. Family members, in particular, benefited from these discussions because they gave everyone the opportunity to share thoughts that often were not spoken.

**Maintaining hope:** Dyads were helped to focus on the positive aspects of their situations and encouraged whenever possible to reframe negative events. Dyads were encouraged to view hope as “contagious” and surround themselves with positive people. Families were encouraged to do the activities that they enjoyed and spend time together. Women who were depressed because they no longer could do what they enjoyed were asked to explore alternatives. One woman who loved to hike the nature trails in northern Michigan was encouraged to find a trail that was wheelchair accessible so that she could continue to enjoy the outdoors. Families were encouraged to make short-term goals, focus on the quality of their lives rather than the quantity of future years, and enjoy the moment. Furthermore, if hope for a cure was not reasonable, then families were encouraged to strive for a series of extended remissions.

**Staying hopeful in the face of death:** Women who were nearing death were given permission to maintain hope in spite of their grim circumstances. Women with young children wanted to be sure their children would remember them. One woman who was divorced was particularly concerned that her two small children may forget about her. She was encouraged to develop a journal for each child, detailing each child’s individual characteristics and stating how special each child was to her. Dyads were helped to recognize the small blessings in their lives. Women were encouraged to set aside a small amount of time daily to identify the joy in their lives. A core aspect of the optimism interventions was to help families learn how to live for and appreciate the present.

## Coping Effectiveness (C)

The third core component of the FOCUS Program was coping effectiveness, which included dealing with overwhelming stress, encouraging healthy coping and lifestyle behaviors, and helping caregivers cope with demands of the illness.

**Dealing with overwhelming stress:** The chaos of being thrust back into cancer treatment was a challenge to most and overwhelming to some. One woman described her situation this way. “I often wanted to go to bed and pull the covers over my head. . . . I couldn’t see an end to my suffering.” A number of women reported that the nighttime was especially difficult; they experienced trouble sleeping and described mental demons that made it difficult to relax. Intervention nurses discussed the emotional aspects of the cancer experience, the sense of helplessness that many families experience, the pressing feeling that one should do something or fix something, and the normality of these feelings when facing such life-threatening events.

Some women were struggling with the probability of imminent death; they expressed the need to talk about this difficult subject. Many women felt emotionally fragile. Nurses discussed issues such as facing death yet living and appreciating life with these women. These discussions allowed some dyads to take care of unfinished business between them or others.

**Encouraging healthy coping and lifestyle behaviors:** Women and their family caregivers were asked to describe what they did to cope with the stress that they were experiencing. Intervention nurses discussed the importance of active coping strategies and healthy lifestyle behaviors with all patients and family members. Mild levels of physical activity were encouraged, as patients’ pain and energy levels would allow, to decrease stress. A handout on the benefits of walking was given to patients who were interested. Nutritional information and weight management information was provided as needed. Relaxation methods were discussed, and a relaxation tape was offered to all dyads as another means to manage stress.

In many families, the members were functioning very well. They were encouraged to persevere and continue their effective coping strategies. One woman described her feelings about the intervention during the last session. She said, “You always made me feel so much better. You helped me feel like I can do this.”

**Helping caregivers manage the demands of illness:** During the intervention sessions, partners or other family members discussed the stress that they were experiencing in their caregiving roles. Frequently, they felt overwhelmed and experienced distress related to the changes in their lives. Some family members said that they were afraid to leave their patients alone, even for brief periods of time. One husband described his feelings this way: “There is no textbook to deal with it. Sometimes I’m just grasping at straws. I don’t know what to say or how to help her. I get a knot in my muscles and feel helpless. I don’t like that feeling.”

These family caregivers were encouraged to use the support offered by family and friends. The benefit of regular respite was discussed as a way to increase their ability to endure over time. Family members were encouraged to continue with their hobbies, even if only for brief periods of time. They also were encouraged to practice healthy lifestyles as much as possible to maintain their mental and physical health and ability to care for their patients.

## Uncertainty Reduction (U)

In the fourth core component of the FOCUS Program, the intervention nurses strived for two outcomes. The first was to provide women and their families with information that may reduce their uncertainty caused by knowledge deficits and teach them how to be more assertive in asking for that information. The second was to help them learn to live with inevitable uncertainty, given the nature of recurrent breast cancer.

**Obtaining information:** The researchers offered women and their families factual information about breast cancer, cancer recurrence, and the treatments the patients were receiving. Questions about bone marrow transplants, new chemotherapeutic agents (e.g., vinorelbine tartrate, docetaxel), and common side effects of new treatments were addressed. Given the experimental nature of many of the treatments, families often looked ahead to the next treatment option should the current one not be successful. They asked questions about

new research developments and treatments they had read or learned about on the Internet. Families also were given a toll-free number for cancer information and encouraged to increase their understanding about the disease.

**Learning to be assertive:** Some families felt that their questions were answered inadequately by their healthcare providers, which added to their uncertainty. They were encouraged to use more assertive approaches with healthcare professionals and to call their physicians' offices with their questions. Families were told that asking for information was not bothersome but a legitimate request for services. Families were encouraged to use the office nurses as advocates who could answer questions and help them access their physicians. Families also were helped to make a list of questions and encouraged to take the list to their next office visit. If family caregivers were not available to accompany the patients to office visits, patients were encouraged to take someone else who could help them remember what was said.

**Learning to live with uncertainty:** Uncertainty has an emotional component that evolves from the fear that the treatment may not be successful and the cancer will be terminal. Intervention nurses talked with patients and family members about their need to live with uncertainty in the presence of cancer. Families discussed the difficulty of living with the day-to-day worry that the cancer would return. One woman said, "It's like living with a time bomb. I'm on pins and needles all the time wondering if the cancer will get worse." Another said that the uncertainty was different than any she had experienced in her life, because one possible outcome was death. These women understood the fragility of life in a profoundly real way.

Some families wanted the opportunity to discuss what dying would be like for them as a way to reduce uncertainty. Intervention nurses discussed the dying process with these families, exploring their knowledge of the disease and helping the patients identify what the cancer trajectory might be for them.

The goal of this component of the intervention was to manage uncertainty but not necessarily eliminate it. For some patients and family members, uncertainty was preferable to known certainty that was thought to be negative. To these participants, an unknown future offered more hope than a future of certain death. In these circumstances, intervention nurses supported patients' wishes to view uncertainty as positive. Intervention nurses also guided these families toward the understanding that, like everyone else, they could do no more than live life one day at a time.

## Symptom Management (S)

The last component of the FOCUS program addressed symptom management, which included assessing patients' and family members' symptom distress and teaching them self-care strategies.

**Assessing symptoms:** Patients and family members were asked to describe the physical and emotional symptoms and side effects that they were experiencing and the degree of distress that these symptoms caused. Patients most frequently reported fatigue, pain, nausea, anorexia, altered sleep patterns, and leukopenia, according to the nurses' notes. Family members reported fatigue, altered sleep, and emotional distress most frequently. Intervention nurses wanted to help participants minimize the level of distress that these symptoms

caused. At the same time, they encouraged participants to practice self-care whenever possible.

**Teaching self-care strategies:** Patients and family members were given a preprinted symptom management card for each symptom they had from a list of 39 possible symptom cards (Mood & Bickes, 1989). Many women reported overwhelming fatigue that caused them frustration—they had things they wanted to do, but they felt too tired to do them. Women were encouraged to pace their activities, rest when they were tired, seek assistance from others, and eliminate activities that were less important to prevent fatigue from overwhelming them. For many patients, pain was a constant companion. Intervention nurses attempted to dispel myths of addiction and emphasized the benefits of liberal yet safe pain medication use. They also discussed the importance of scheduling routine administration of pain medication to control the pain before it became intolerable. Family members were encouraged to maintain their own health and continue to receive their own routine health checkups so that they could remain healthy to care for the patient. Families also were given information about community resources and support services that could assist them following completion of the FOCUS Program.

## Program Evaluation

A short program evaluation was built into the study and completed by patients and their family caregivers at the end of the randomized clinical trial. The evaluation questionnaire was given only once; however, the original randomization of dyads in the context of the larger study was considered adequate to control for possible baseline differences.

The purpose of the brief evaluation questionnaire was to determine the extent to which participants could validate the consistency of the intervention and assess their satisfaction with the specific elements of the FOCUS Program. The evaluation questionnaire consisted of six items; the first five items evaluated each of the five core content areas of the FOCUS Program, and the last item asked about the empathic skills of the nurse. Although the items were geared toward dyads that participated in the FOCUS Program, researchers also asked dyads in the control group to complete the questionnaire to determine to what extent they might have received this content as part of their standard clinic care. Researchers assessed the psychometric properties of the questionnaire and found it to have adequate content validity by a panel of nurse researchers as well as adequate internal consistency using Cronbach's alpha (0.89 for patients, 0.93 for family members).

The items and mean scores obtained for dyads in the control and experimental groups are listed in Table 3. In general, the satisfaction scores for participants in both the treatment and control groups were high, which often is typical in satisfaction with care surveys. However, patients in the FOCUS Program reported significantly higher satisfaction with each of the five content areas of the FOCUS Program than patients in the control group. More specifically, FOCUS patients reported more satisfaction than control group patients with their family members' involvement in discussions, the assistance they received to maintain an optimistic attitude, information they were given on how to cope, answers to their questions, and information they were provided on symptom management. FOCUS patients also rated understanding of

**Table 3. Patients' and Family Members' Mean Scores on the Satisfaction Questionnaire**

Items	Patients				Family Members			
	Treatment (n = 62)	Control (n = 55)	t	p	Treatment (n = 62)	Control (n = 55)	t	p
Family involvement in discussions	4.76	4.42	2.45	0.020	4.53	4.18	2.05	0.04
Assistance in maintaining positive attitude	4.65	4.04	3.94	0.001	4.23	4.00	1.13	0.26
Information on how to cope	4.58	3.85	4.31	0.001	4.18	3.87	1.55	0.12
Way in which questions were answered	4.68	4.18	3.65	0.001	4.34	4.04	1.72	0.09
Information on symptom management	4.52	3.87	3.71	0.001	4.15	3.85	1.48	0.14
Extent to which nurse seemed to understand	4.90	4.33	4.84	0.001	4.56	4.28	1.77	0.08
<b>Total satisfaction score</b>	<b>28.1</b>	<b>24.7</b>	<b>4.69</b>	<b>0.001</b>	<b>26.0</b>	<b>24.2</b>	<b>1.80</b>	<b>0.08</b>

their nurses higher than control patients. Family members in the FOCUS Program reported somewhat higher mean scores in all areas than family members in the control dyads, but this difference reached significance only on the family involvement item.

In general, patients and family members reported high satisfaction with the FOCUS Program. Additionally, these high satisfaction responses validate the consistent implementation of the intervention. The satisfaction ratings and comments made by the dyads randomized to the intervention group indicated a high level of recognition of the core elements of the FOCUS program.

### Program Strengths and Weaknesses

A number of strengths emerged for the FOCUS Program. First, the program promoted family communication about the recurrent illness and its effects on each person and the family as a whole. The sessions were very interactive. Patients and family members were encouraged to share concerns, offer support to one another, and identify what they needed or had already received from the other person in the dyad. Families were able to explore these issues with empathic nurses, who not only provided feedback to the dyads but also new information and ongoing support. Second, program content was tailored to the particular needs of each family. Although each family received established core content, the extent to which each topic was addressed depended on the particular needs of that family. Third, the program content emphasized family strengths. Illness management often operates out of a deficit mode that points out what families are lacking to meet their needs. In this program, family strengths were identified and reinforced as resources the families could use to manage the illness.

The FOCUS Program also had limitations. One of the weaknesses was that all program participants received the same amount of the intervention, even though their need for

the intervention may have differed. Some families could have benefited from a longer program of care, especially as patients' cancer continued to progress. Other families were managing very well and may have needed only one or two sessions and not the full program. Rather than apply a "one-size-fits-all" approach, future use of the program could identify families at higher risk for poorer adjustment and offer them a more extended FOCUS Program. Families that are at lower risk may benefit from an abbreviated FOCUS Program.


Another limitation of the program was that the final session ended with a phone call rather than with a home visit. The intervention staff reported difficulty in terminating with families by phone; they would have preferred to complete the program with a final home visit. Based on the staff's feedback, the researchers have revised the delivery of the FOCUS Program to three home visits with two phone contacts interspersed between the home visits, enabling the intervention staff to complete the program delivery during a face-to-face visit with the family. Another weakness was that a cost analysis was not included in this study. Face-to-face home visits are more costly than programs of care that are delivered in the clinic or by telephone. Although the original plan was to deliver the FOCUS Program in the clinic setting, the pilot study suggested that the clinic setting was very hectic for research purposes, and the decision was made to deliver the program in the home. Future studies will need to examine cost and its ratio to benefit according to delivery mode and outcomes. Given that the stressful effects of cancer are shared by patients and their family members, a continuing need exists to develop and refine a program of care that can help patients and families manage the multiple demands associated with recurrent breast cancer.

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