

Information and Support Needs of Adolescent Children of Women With Breast Cancer

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Purpose/Objectives: To elicit detailed descriptions of adolescents' information and support needs in response to their mothers' breast cancer.

Design: Exploratory, qualitative.

Setting: Four different outpatient and inpatient oncology settings in western Canada.

Sample: 31 adolescent children of women in five illness phases.

Methods: 27 semistructured interviews and two focus groups were conducted. Interviews were audiotaped, transcribed, and analyzed using constant comparison techniques. The Communication Subscale of the McMaster Family Assessment Device also was administered to assess family communication patterns.

Findings: Information needs were sources of information, information content, degree of helpfulness, and information timing. Support needs were type, degree of helpfulness, form, and source.

Conclusion: Most of the adolescents reported that their needs were poorly met.

Implications for Nursing: Women with breast cancer have a need for family-focused care. Further research is required to develop interventions that can assist nurses in providing care that meets the needs of adolescent children and other family members of women with breast cancer.

Key Points . . .

- The emotional impact of a mother's breast cancer on adolescents is significant.
- Assessment of the needs of adolescents of women with breast cancer and their families is minimal.
- Specific individualized interventions are indicated to address the needs of these adolescents.

programs designed to assist children of patients with cancer suggest that children find these programs effective and evaluate them positively (Adams-Greenley, Shiminisky-Maher, McGowan, & Meyers, 1986; Berger, 1984; Christ, Siegel, Mesagno, & Langosch, 1991; Taylor-Brown, Acheson, & Faber, 1993). However, very little systematic research has been conducted on adolescents' support needs and the formal and informal supports they consider helpful as they cope with their mothers' breast cancer experiences.

This study was designed to describe the information and support needs of adolescent children of women with breast cancer. Three specific research questions guided the study.

- What are the information and support needs of adolescent children of women with breast cancer?
- Do adolescents' needs for information and support vary according to the stage of their mothers' illnesses and the gender and developmental stages of the adolescents?
- To what extent do adolescents perceive that their information and support needs are met?

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Although many studies on the impact of cancer on adult family members have identified the importance of information needs (Kristjanson, 1986, 1989; Wright & Dyck, 1984), little is known about the information needs of adolescent children of women with breast cancer. Much of the existing literature covers parents' perspectives of their children's needs (Barnes et al., 2000; Shands, Lewis, & Zahlis, 2000). Some evidence can be found in the empirical literature that children's information needs vary according to age (Lewis, 1990; Lewis, Ellison, & Woods, 1985). However, specific knowledge about the type and amount of information helpful to adolescent children of women with breast cancer is limited.

The social support network within which individuals manage life crises has been shown to influence adaptation (Berman, Cragg, & Kuenzig, 1988; Kirschling, Tilden, & Butterfield, 1990; Maunsell, Brisson, & Deschenes, 1993; Morrow, Hoagland, & Morse, 1982). Adolescents have a developmental need to feel separate and independent from their parents, and peer relationships play a critical role in their daily lives. As a result, adolescents may have unique support needs as they cope with their mothers' illnesses (Bowen, 1976; Lewis, 1990; Lewis et al., 1985). Anecdotal reports of support

Background Literature

Although research related to children of women with breast cancer is limited, what does exist focuses primarily on the adjustment and coping behaviors of school-aged children. Researchers have reported behavioral problems and difficulties at school and with peers, as well as changes in sleeping and eating patterns among children (Birenbaum, 1995; Birenbaum, Yancey, Phillips, Chand, & Huster, 1999; Buckley, 1977; Lichtman et al., 1984; Northouse, Cracchiolo-Caraway, & Appel, 1991; Zahlis & Lewis, 1998). Children's reactions to the cancer experience vary with age, although strategies that all ages commonly use include avoiding the illness, maintaining normalcy, and spending more time as a family (Hilton & Elfert, 1996; Issel, Ersek, & Lewis, 1990). Variations in children's responses to their parents' cancer also have been reported by gender (Grandstaff, 1976; Lichtman et al., 1984; Wellisch, 1981). Daughters have additional concerns about their risks for breast cancer and may experience anger toward their mothers for their genetic vulnerability (Buckley; Hilton & Elfert; Lichtman et al.).

Findings specific to adolescents indicate that their lives are complicated by their mothers' illnesses. Adolescents experience conflict because they have a need for separation from home yet, at the same time, are drawn closer to the family unit in response to the illness demands (Lewis, 1990; Lewis et al., 1985). The duration of the mothers' illness and treatment requirements disrupt parent-child relationships and influence the adolescents' abilities to cope and their needs for helping resources (Buckley, 1977; Hilton & Elfert, 1996; Lichtman et al., 1984).

Some evidence indicates that children adjust better to the cancer illness of parents when they receive information that is appropriate to their level of cognitive development (Grandstaff, 1976; Hymovich, 1995; Northouse & Swain, 1987; Vess, Moreland, Schwebel, & Kraut, 1988). Furthermore, the process of sharing information may be more important than the actual content (Northouse & Swain). Parents, though, may avoid discussing the cancer experience with their children, resulting in children feeling isolated and unsupported (Grandstaff; Maguire, 1981). Before healthcare professionals can offer meaningful interventions to help adolescent children cope, further understanding of their informational and support needs is necessary.

Theoretical Framework

Two theories guided this study: family systems theory and symbolic interactionism. Family systems theory emphasizes that the whole is greater than the sum of its parts (von Bertalanffy, 1968) and that illness in one family member sends reverberations throughout the entire system (Bowen, 1976; Minuchin, 1974). In addition, the family is linked to other systems (e.g., extended family, school, support networks, healthcare system). This theory holds that the quality of these relationships influences the information and support available to the family members. Nursing practice employs family systems theory in the development of family nursing frameworks and assessment guides, such as the Calgary Family Assessment Model, the Calgary Family Intervention Model (Wright & Leahey, 2000), and the Friedman Family Assessment Model (Friedman, 1998; Friedman, Bowden, & Jones, 2003).

Symbolic interactionism also was incorporated into the guiding framework of this study. Symbolic interactionism postulates that people respond to other people, events, and activities based on the meanings that things have for them; further, these meanings have been shaped during past and current interactions in their social world (Blumer, 1969; Mead, 1934). Symbolic interactionism kept the investigators sensitized to the adolescents' perspectives throughout the study.

These frameworks guided the development of this study's whole research process, including the objectives, interview schedules for the individual and focus group interviews, and analysis procedures. Together, these frameworks facilitated the exploration of the meaning of a mother's illness within a family context and the role that information and support has for an adolescent child.

Methods

Design

An exploratory, qualitative methodology was used to elicit rich and detailed descriptions of adolescents' information and support needs in response to their mothers' breast cancer. The theoretical underpinnings of the methods were informed by grounded theory (Glaser & Strauss, 1967). However, this was used as an aid; the investigators did not intend to develop a substantive theory in this study.

Sample

The study population consisted of adolescent children, ages 12–18, of women diagnosed with breast cancer. Investigators used a purposive sampling approach within subjects to maximize variation in the data (Bogdan & Bilken, 1982; Patton, 1990). This sampling approach enabled the investigators to uncover and describe key information and support needs of the subjects rather than generalize the findings to a wider population.

The sample was drawn from four different sources: outpatient oncology clinics, inpatient medical and surgical units, a palliative care program affiliated with a tertiary teaching hospital, and a hospital-based support group for children whose parents had cancer. This sampling approach facilitated the inclusion of adolescents whose mothers were at various phases along the cancer care continuum.

The sample consisted of 31 adolescents. Sample sizes required to uncover and describe phenomena in qualitative research are usually small. Previous qualitative research has indicated that in-depth interviewing beyond a small number (estimates ranged from 10–60 participants) results in no new information and creates redundancy in the data (Glaser & Strauss, 1967; Lofland & Lofland, 1995; Swanson, 1986).

To determine if the sample of adolescents might reflect sampling bias by overrepresenting families whose communication patterns were more open, the Communication Subscale of the McMaster Family Assessment Device (FAD) was administered to the children (Epstein, Baldwin, & Bishop, 1983; Miller et al., 1994). The FAD was developed to measure six dimensions of family functioning based on the McMaster Model of Family Functioning. The Communication Subscale is a 12-item measure to assess family members' views of the family's communication style. Extensive review of the FAD has demonstrated consistent sound psychometric properties (Tutty, 1995), including internal consistency estimates of Cronbach's alpha of 0.90

and above (Miller et al.). Information about the families' communication styles was deemed important to facilitating data interpretation. The FAD, with its roots in family systems theory, was congruent with this study's theoretical framework.

Recruitment: Names of mothers with adolescent children who met study criteria and who agreed to have their names released were referred to a research nurse. The research nurse contacted the mothers by telephone, gave them a detailed explanation of the study, and asked those who were interested to discuss the project with their children. Prior to the interview, parents provided written consent for their children to participate. Adolescents were provided with written disclaimers, and their verbal consent to participate was secured. In total, 43 women were approached about participation, and 31 agreed to discuss the study with their children. In three families, the adolescents chose not to participate. Some families had more than one adolescent who agreed to participate, which resulted in a total of 31 adolescents in the study.

Data Collection

Data were collected using a semistructured interview guide specifically developed for this study. Initial questions were developed from the empirical literature on the impact of breast cancer on adolescents and from the theoretical perspectives taken in this study (family systems theory and symbolic interactionism). The research instruments and data collection process were pilot-tested with the first five participants. Interview questions elicited specific data, such as the length of the mothers' illness and the participants' own perceptions of the information and support they believed to be helpful as they coped with the breast cancer experience. Open-ended, "grand tour" questions (i.e., very broad, initial questions) (Schatzman & Strauss, 1973) were used to explore the illness experience. As the interviewing progressed, questioning became more focused. Probes were used to clarify the meaning of responses and pursue all topics until no new information was elicited. Congruent with qualitative research, the interview guide was revised during the data collection period. New questions were added to pursue themes that emerged during the analysis in more depth.

A nurse with an extensive background in pediatric nursing and nursing research conducted the interviews. At the time of data collection, the nurse interviewer was a doctoral student who had experience interviewing children and adolescents from several previous research studies. The research team provided ongoing support and debriefing opportunities for the research nurse during the course of the project. All interviews were audiotaped and fully transcribed. The nurse made field notes describing contextual information (e.g., nonverbal gestures, family circumstances) that may have influenced the data. Mothers completed a demographic questionnaire. Information about the mothers' breast cancer was obtained from medical records.

Twenty-four interviews were conducted with individual adolescents. In families with two or more adolescents, children were given the option of being interviewed alone or with their sibling(s). Two interviews were carried out with two sibling pairs and one with three siblings. As well, two focus group interviews of adolescents previously interviewed (one group with three males and one group with five females) were conducted at the end of the study. The group interviews were conducted to determine whether additional data that had not been elicited through the earlier interviews would be revealed and to assist in validity assessment.

All interviews were conducted in private locations at convenient times for the participants. In most cases ($n = 23$), interviews occurred in participants' homes. The interviews, including the introduction and debriefing periods, lasted between 1.5–2 hours; the focus groups lasted approximately 2.5–3 hours.

Data Analysis

Data collection and analysis were conducted concurrently. Data collection continued until no new information was forthcoming. Descriptive statistics were used to describe the sample in terms of the demographic and disease-specific variables and to summarize results of the FAD. All interviews were transcribed fully and converted to Ethnograph files (Seidel, 1988). Data were analyzed using constant comparison techniques (Glaser & Strauss, 1967). The unit of analysis was the unit of meaning in the data (i.e., words, phrases, sentences, or paragraphs of data) (Lincoln & Guba, 1985). Analysis proceeded through the stages of open coding in the transcript margins, input of sorting codes using The Ethnograph computer software program (Seidel), and category development and refinement (Schatzman & Strauss, 1973). As data analysis continued, codes were revised and previously coded data were recoded. The final analysis had 52 codes. Analysis continued until all categories were saturated and no new information on the categories was forthcoming. Operational definitions were written for all major categories and subcategories.

Measures to Enhance Rigor

Several measures were undertaken to enhance the rigor of the research process. These procedures followed the recommendations of qualitative researchers to increase the credibility, fittingness, auditability, and confirmability of the research findings (Altheide & Johnson, 1994; Denzin, 1978; Glaser & Strauss, 1967; Lincoln & Guba, 1985; Sandelowski, Davis, & Harris, 1989; Schatzman & Strauss, 1973). Credibility was enhanced by the extended period in the field (18 months), regular debriefing of the data collector with the research team, triangulation of data sources and methods (individual and focus group interviews) (Denzin), and "member checks" with study participants (Schatzman & Strauss). In addition, to ensure the credibility of the analysis, experts in the areas of cancer care social work and child development reviewed selections of transcripts and the developing analysis. Their feedback confirmed the interpretation of the data. The fittingness of the analysis to the original data and the applicability to other contexts were enhanced by detailed, line-by-line analysis of the transcripts and by providing extensive examples of the data to enable the reader to assess the fit of the interpretation. Auditability was demonstrated through the detailed coding procedures that resulted in consistency of coding among the three investigators. Through these processes, confirmability was established.

Protection of Human Subjects

Approval from participating institutions to access subjects was obtained following ethical approval for the project from the University of Manitoba. Attention to consent procedures, confidentiality issues, concerns about vulnerability of the population, and sensitivity of the topic were considered carefully because of the participants' ages.

Results

Descriptions of Participants

The demographic characteristics of the adolescents are outlined in Table 1. The typical adolescent at the time of the interview was a 16-year-old female. At time of the cancer diagnoses, a bimodal distribution of age of adolescents existed: six children were under age 12 and six were age 16 (see Table 1).

Demographic and disease-specific information related to mothers is shown in Table 2. At the time of interview, most mothers were 41–50 years old ($n = 22$) and married ($n = 27$). Twenty-three of the 31 mothers (74%) had at least some college education or higher, and 19 (61%) reported a family income of more than \$40,000. All but one mother was employed outside the home. The most frequent ethnic affiliation reported by mothers was European ($n = 10$), followed by “other” ($n = 9$), and British Isles ($n = 7$). At the time of interview, most mothers’ cancers were in remission ($n = 12$) (see Table 2).

A Cronbach’s alpha coefficient of 0.86 was obtained as an estimate of the internal consistency reliability of the FAD Communication Subscale. The mean score was 2.44 ($SD = 0.21$). According to Miller et al. (1994), this score is consistent with mid-range normative scores reported for “healthy” families. Therefore, the sample obtained represented families who were “typical” in terms of family communication. Analysis of variance was used to determine differences in family functioning according to demographic (e.g., age of adolescents) and disease-specific (e.g., stage of mothers’ diseases) variables. No significant differences were found.

Table 1. Demographic Profile of Adolescents

Characteristic	n	%
Age at interview (years)		
12	3	10
13	1	3
14	5	16
15	5	16
16	6	19
17	5	16
18	4	13
19	1	3
20	1	3
Age at diagnosis (years)		
< 12	6	19
12	4	13
13	2	6
14	4	13
15	2	6
16	6	19
17	5	16
18	2	6
Gender		
Female	22	71
Male	9	29
Number of families	27 ^a	–

^a In four families, two siblings participated. In one family, three siblings participated.

N = 31

Note. Because of rounding, not all percentages total 100.

Table 2. Demographic Profile and Illness-Related Characteristics of Mothers

Characteristic	n	%
Age (years)		
20–30	1	3
31–40	4	13
41–50	22	71
51–65	4	13
Occupation		
Professional	13	42
Clerical	8	26
Management	3	10
Homemaker	1	3
Other	6	19
Education		
Eighth grade or less	1	3
Some high school	2	7
High school diploma	5	16
Some college	8	26
College degree	9	29
Graduate degree	6	19
Ethnicity		
European	10	32
British Isles	7	23
Asian	3	10
French	2	7
Other	9	29
Marital status		
Married	27	87
Divorced	2	7
Single or separated	2	7
Annual family income^a (\$)		
11,000–20,000	3	10
21,000–30,000	4	13
31,000–40,000	4	13
41,000–50,000	9	29
More than 50,000	10	30
Mother’s illness at time of interview		
Recently diagnosed at stage 1 or 2	9	29
Recently diagnosed at stage 3 or 4	2	7
First recurrence	4	13
Remission	12	39
Advanced or terminal	4	13

^a One respondent did not provide income data.

N = 31

Note. Because of rounding, not all percentages total 100.

Findings Related to Study Questions

Results from the three research questions are summarized in Figure 1.

Information and support needs of adolescent children: Adolescents reported a number of information and support needs, which were described in terms of types, sources, forms, and effects. In addition, information needs were described according to content, sources, the importance of timing, and the ways that information was communicated.

Content of the information included knowing whether their mothers were going to survive. This was the most salient piece of information the adolescents could receive, regardless of their age. For example, one comment was “[if] something bad happens . . . to do with Mom . . . I don’t know what I’d do . . . if we ever . . . lost her or anything.” Other content that adoles-

- The emotional impact of the mothers' breast cancer on adolescents was significant.
- Needs assessment of adolescent children of women with breast cancer and their families was minimal.
- Adolescents reported a number of information and support needs.
- The most salient piece of information that adolescents wanted, regardless of their age, was knowing whether their mothers were going to survive.
- Adolescents perceived their needs as individualized, based on their own personal and family situations.
- Adolescents considered support from the school network to be important because it allowed them to continue with their lives and feel hopeful.
- Adolescents' needs extended beyond the direct impact of their mothers' illnesses.
- Adolescents deemed providing a sense of hope to be a significant component of support.
- Specific individualized interventions are needed to address adolescents' needs.

Figure 1. Summary of Findings

cents found most helpful included information about the seriousness of the illness, potential side effects of treatments, alternative therapies, medical "facts" associated with the disease, and how to assist their mothers with challenges. Adolescents appreciated information about the feelings and changes in their mothers (e.g., mood changes). They stated that knowing that their mothers might be moody or tired would have been especially helpful. They also valued information about normal feelings of adolescents. For example, they appreciated knowing that certain feelings (e.g., anger, guilt) were normal. Adolescents reported problems when misinformation was provided.

Needs for type of information content varied for each teen and seemed to be characterized by the phrase "it depends." Teens saw their information needs as unique and dependent on their own personal and family characteristics, what they already knew about breast cancer, the stage of their mothers' illness, and their ages. They reinforced the importance of professionals "checking out" needs individually, rather than assuming that all adolescents would want particular information.

Sources of information included parents, support groups, physicians, school classes (e.g., biology class), school counselors, books and library resources, brochures, and media. Parents were the most frequently used source of information. Mothers tended to be the "guardians of the information" and disclosed information according to their own views about what and how much was appropriate to share. One teen noted that her parents "didn't want us to be worried. So, they really didn't inform us. And, I think, well, I can handle the truth, you know. I think that the parents should tell them exactly what's going on, exactly what might happen. It's logical."

Depending on their relationships with their children, fathers served as "information interpreters," reinforcing information provided by others and clarifying the meaning of information already given. For example, "Me and my dad would basically talk about it. I think my dad would usually talk to my brother and sister too, when we were by ourselves or whatever. We'd just talk about chemotherapy and how many more treatments she had to go through."

Participants valued healthcare professionals who were straightforward, treated them "as adults," and offered information in clear and simple language. Adolescents also ac-

knowledge the benefits of access to an individual who could provide follow-up information or respond to their emerging questions. They stated that having a healthcare professional's phone number to call was helpful, even if they might never use it. Adolescents appreciated healthcare professionals who knew "the facts." However, few adolescents had direct access to a nurse or social worker. No adolescents reported having direct access to a physician.

Adolescents identified the importance of the timing of information and sharing information at an appropriate pace. They valued healthcare professionals and family members who were sensitive to the timing and their readiness for information. One participant noted, "Well, my dad was sitting at the head of the table, as usual, and kind of broke it to us slowly. He pretty much said, well, she has breast cancer, and that we're gonna have to take it like, slowly, and help her out a lot and be very supportive."

In addition, the ways that information was communicated were important. Most often, information conveyed in private was perceived as easier to receive and understand. For those who attended support groups, adolescents did not want the information shared if it was "too personal." Adolescents talked about the importance of not receiving too much or too little information.

Adolescents described different types of support offered, components of a supportive relationship, and various sources of support. The adolescents perceived support as either helpful or unhelpful, depending on what was offered and by whom. They valued positive, verbal, and nonverbal supportive gestures (e.g., hugs). However, they were sensitive to what they perceived to be insincerity. As one adolescent said, "Sometimes when someone says they are sorry, it doesn't sound right. It sounds phoney. Insincerity. Even if they did mean that they did want to help, they just came over as being a bunch of fakes. It was such a turn off I was like . . . go away."

Adolescents also reported the importance of relationships that were reciprocal, rather than feeling that they were always the recipient of support.

Adolescents discussed the importance of family, friends, and the school system in providing a sense of normality about their life, which helped them to cope. Individuals in these networks were perceived as helpful when they would invite the adolescents to participate in "normal" activities. They also reported the helpfulness of knowing that someone was there to talk to when they needed to call. For example, one teen stated the following.

I think just knowing the people were there for me. Cause, usually like before, I didn't have any big, huge problems. Before, friends were friends, people were people. But now . . . they say "Here's my number, give me a call . . ." and people were there for me. When I have a real big problem or I was really upset about some things, there would be people that would come pick me up . . . "Let's go for coffee, and we'll discuss it."

Support from a school network was essential to the adolescents' sense of continuity by allowing them to continue with their lives and feel hopeful. Participants felt supported when they were treated normally and when teachers and counselors were available, but not too probing. Adolescents appreciated compassionate and positive staff members. Although sensitiv-

ity of teachers was important, students did not want teachers to “overreact,” coddle them, or treat them differently because their mothers had breast cancer. However, the teens did want the teachers to realize that they may be moody. They also stated that allowances should be made at times when they were going through difficult periods (e.g., not to burden them with homework) (Chalmers et al., 2000).

The adolescents described their friends as supportive when they tried to be close, asked about their mothers, were “there,” and offered hugs and jokes. However, friends’ jokes (e.g., related to mother’s illness) sometimes were perceived as inappropriate or hurtful. Family relatives were described as helpful and supportive when they offered pragmatic assistance (e.g., meals, cleaning). Family members also were seen as supportive when they did not “bug” the adolescent. Adolescents who were participants in support groups described the groups as helpful because group members were caring, did not pressure the adolescents to participate, allowed them opportunities to relate to others who had similar experiences, shared stories about what they had experienced, and offered them opportunities to have fun.

Although this occurred less often, the most helpful support that healthcare professionals provided was specific, individualized support. Adolescents reported benefits of support from professionals (e.g., physicians, nurses, social workers) when offered one on one, with an honest, positive approach and an understanding, nonjudgmental tone. Adolescents reacted negatively to professionals who were perceived as “pushy” or not respectful of the adolescents’ personal boundaries. One teen stated,

“[It is important for professionals] . . . to be, just to be there and be supportive and not to think that any of [the teen’s] views are wrong, like ‘how could you say that!’ or whatever. Just to be there to listen . . . if they need to talk at all, they’ll talk and everything. It’s just—it’s always good to have somebody there to lend an ear.”

Adolescents also described support as helpful when the correct amount was offered. This varied from adolescent to adolescent. For some, too much was a problem; for others, too little was a complaint.

Effects of stage of their mother’s illness, gender, and developmental stage: Adolescents reported that timing of information in relation to the stage of their mothers’ cancer was important. They stated that they required detailed, understandable information soon after the diagnosis. As well, adolescents reported the importance of receiving information as the illness progressed.

A critical time for adolescents was when their mothers’ disease recurred. This event reinforced to teens that their mothers could die. However, adolescents reported the importance of hope regardless of severity of the illness. They also stated that their needs for information and support were greater when their mothers were sicker.

Gender did not appear to influence needs for information and support, with one exception. Daughters reported fears about being diagnosed with breast cancer at some time in their own lives. All of the daughters, regardless of age or stage of mothers’ illness, mentioned the sense of vulnerability related to this genetic risk. One said, “I worry that I will get it and, like, it’s obviously very hereditary or whatever. And I worry that my sisters will get it.”

These young girls reported that no one had spoken to them about their own risk of having breast cancer. Consequently, fears about this risk often were not supported by accurate information. Some female teens felt a special bond with their mothers because of the nature of the illness.

Developmental stages of the adolescents did not appear to influence information and support needs identified. However, the younger the child was at the time of diagnosis, the more difficulty the child had in remembering what happened in the early phases of illness. This was frustrating for some teens. Younger children expressed more guilt about their mothers’ illnesses (e.g., asking “Did I do something wrong?”). However, this perception appeared to be influenced by the mothers’ explanations of the illness.

Perception of needs being met: Adolescents reported that most of their information and support needs were poorly met both within the family and outside the family. They also reported feeling that they were outside the information “loop” and were not included in illness-related discussions. One obstacle to adolescents’ access to information was the degree of control that mothers exercised as “guardians of information.” Mothers frequently managed adolescents’ access to information and access to people and resources that might be information sources. At times, adolescents perceived this management of access to information to be too controlling and protective. As well, children could create their own obstacles to information. For example, one child said, “I didn’t panic in front of her, but it is really . . . really hard, like, I, I just . . . I kept my strength up in front of her . . . to protect her. . . .”

Fathers could facilitate or limit access to information as well. Fathers often were reported to be useful sources of information (information interpreters). Their willingness to be open with their adolescent children was an important factor in determining whether the adolescents’ information needs were met.

Adolescents mentioned community support (e.g., churches communities, neighborhoods) as helpful to their mothers or families in general, such as in providing food or flowers. However, adolescents did not perceive that their communities offered them personal support. The teens perceived that their community networks (e.g., churches) seemed more concerned with their mothers than the children in their families.

Adolescents’ needs for information and support extended beyond the direct impact of their mothers’ illnesses. Also, other needs, not directly related to the cancer experience, were important but not usually attended to. For example, one 12-year-old boy expressed fears and concerns that were more concrete. “The other problem that we are having is financially . . . now it is a lot because now they are saying the medical won’t be covered [teary] and my mom’s work is going on strike . . .”

Discussion

Three conclusions arose from this study.

- The emotional impact of breast cancer on adolescents is significant.
- Assessment of the needs of adolescent children of women with breast cancer and their families is minimal.
- Specific interventions are needed to address the needs of adolescent children of women with breast cancer.

The adolescents clearly reported fears, uncertainties, and feelings of isolation in response to their mothers’ cancer diagnoses. They expressed worries about their mothers’ survival

and concerns for the continuity and stability of their families. All adolescent girls identified fears about their increased health risks because of their perceived genetic susceptibility to breast cancer. Adolescents were sensitive to the suffering of their mothers and reported guilt about the contrasting “normalcy” of their own lives. This finding is similar to results reported by Christ, Siegel, and Sperber (1994) who found that adolescents empathized with their ill parents’ distress while, at the same time, expressing guilt about their own situations. Contrary to other reports, subjects in this study and the Christ et al. (1994) study did not report severe, acting-out behaviors. The healthy communication patterns of the families, as indicated by the FAD subscale scores, may have influenced the coping approaches of the adolescents. Adolescents from families with less functional communication patterns may have demonstrated other behavior patterns.

The absence of a systematic or focused assessment by healthcare professionals regarding the needs of adolescents was notable. For the most part, adolescents reported that healthcare professionals did not assess their information or support needs. Consequently, access to information and support was uneven and disjointed. Adolescents reported that the primary focus of care of healthcare professionals, family members, and community networks, such as churches, was on their mothers’ needs. Assessment of the family unit or individual adolescents was not usual. This lack of assessment made expressing concerns about their perceived genetic vulnerability to breast cancer difficult, as was getting their questions about the illness answered, and identifying resources that they might use to cope.

Findings also suggested that interventions (either individual or group) must acknowledge adolescents’ personal boundaries. The individual and variable nature of personal boundaries requires healthcare professionals and others to assess carefully the extent to which adolescents appreciate invitations for disclosure and closeness. Some evidence in the literature indicates that family boundaries are relatively enduring and not readily discarded in response to health or illness disruption (Stetz, Lewis, & Houck, 1994). Assessment of family and individual boundaries is an important part of a beginning therapeutic relationship.

Welch, Wadsworth, and Compas (1996) reported that, in a study of 76 families in which a mother or father had cancer, adolescent girls whose mothers had cancer reported the highest levels of distress. They also found that when children reported elevated levels of psychological symptoms, their parents did not appear to be aware of their distress and rated their children as asymptomatic. These results suggest that healthcare professionals may need to assist parents to assess and recognize the psychological distress of their adolescent children.

Prior literature (Lewis, Hammond, & Woods, 1993; Woods & Lewis, 1995) reported that the ability of children to cope with a parent’s chronic illness or cancer diagnosis is associated with the emotional state of the ill parent, the degree of marital conflict, and the extent to which the non-ill parent interacts with the children. Although this study did not focus specifically on the emotional state of parents or degree of marital distress, the findings did confirm that the information and support role of fathers was important to adolescents. This result points to the need to provide fathers with information about how to communicate with and support their adolescent children.

Study results confirm reports that interventions helpful to adolescents must take into account the age, gender, and developmental stage of the child (Quinn-Beers, 2001). Literature specific to different age groups is not widely available. Information specific to concerns about genetic risk is not routinely provided. As healthcare teams become more adept at genetic screening, programs may be developed and directed toward high-risk adolescents. Although this is appropriate, adolescents who may not be at high risk may, nevertheless, perceive that they are vulnerable to breast cancer. Therefore, the concerns of lower-risk adolescents should not be overlooked.

The question of how much to offer and how to intervene is a challenging one, captured by the adolescents’ consistent statements that “it depends.” The lack of clear guidelines about how much to offer circles back to the importance of individual assessments. As well, this finding points to the importance of creating a balance between attending to the illness and maintaining the “normalcy” of the adolescent’s life. Aamodt, Grassl-Herweke, Fairell, and Hutter (1988) reported this tension in a prior study. They studied children who had experienced alopecia as a result of chemotherapy treatments and identified a category called, “treat me special, treat me same.” This category captured the children’s need to have others be sensitive to the fact that they were coping with a cancer illness, yet also have others not respond solely to them as ill individuals. This theme was consistent with the stories that adolescents in this study told. Although a mother’s breast cancer illness creates special needs and concerns that require attention, the importance of the continuity of the adolescent’s life (e.g., normal school relations, friendships) was valued. Support groups may provide adolescents with a helpful way to contain their concerns about a parent’s cancer by allowing them a safe place in which to discuss concerns while keeping the experience of cancer from “contaminating” the more normal areas of their lives and development (Stuber, Gonzalez, Benjamin, & Golant, 1995). The challenge remains, though, to provide sensitive care that meets individual adolescent needs.

This study is an initial attempt to uncover the needs of adolescents whose mothers have breast cancer. The sample of adolescents indicated communication patterns within the normal range of family communication styles. The study does not capture the experiences of adolescents from families with communication difficulties or from those adolescents whose mothers did not consent to the study. Future work should be conducted in these areas as well as in addressing the needs of adolescents from families experiencing other cancer diagnoses and adolescents from diverse cultural backgrounds. These findings cannot be assumed to transfer across other family, illness, and cultural contexts.

Notwithstanding these limitations, the findings from this study have important implications for nursing practice. Nurses working in breast cancer clinics, genetics clinics, community care, and inpatient care facilities all have a role to play in providing information and support to adolescents of women with breast cancer. Nurses must see individual illnesses through a family lens regardless of their clinical focus. However, for the most comprehensive and efficient services, healthcare systems will need to develop systematic approaches to ensuring family-focused care, including the care of adolescent family members of women with breast cancer. This will necessitate development of structures within the healthcare system that support a detailed and care-

ful assessment and reassessment of all family members' needs at the time of diagnosis and as the patients progress through the illness trajectory. Family systems theory and symbolic interaction theory, as used in this study, highlight the importance of the interacting web of meaning when a major illness affects a family member. Sensitized by these frameworks and supportive agency policies, nurses can play an important role in providing care that increasingly meets the needs of family members.

Conclusion

Results from this study have identified the information and support needs of adolescent children of women with breast

cancer. This group of individuals had many needs that, to date, are not addressed systematically in many healthcare contexts. Further work is needed to refine assessment approaches to help identify adolescents who may have particular needs and to identify interventions that can more specifically address concerns of this group of family members. Further research is needed to develop and test interventions to assist nurses in providing care that meets the needs of adolescent family members of women with breast cancer diagnoses.

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