Information needs of adolescents when a mother is diagnosed with breast cancer

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Abstract
This pilot study was undertaken to increase our understanding of the information needs of adolescents when a mother is diagnosed with breast cancer. In-depth interviews with 13 adolescents provided insight into the types of questions they had at the time of their mother’s diagnosis and how satisfied they were with the access they had to information. These adolescents had many questions about cancer and its treatment, specific questions about their mother’s disease and survival, and concerns about their own risk. Each sought information on their own in addition to conversations with one or both parents. They identified their most pressing concern as the need to know about their mother’s survival. All felt it was important to have access to information and to have someone to whom they could talk about what was happening. This person needed to be someone with whom they were comfortable and whom, in turn, had both credibility and comfort with emotions. Clearly, adolescents experience needs for information when their mother is diagnosed with breast cancer. Cancer nurses can assist women diagnosed with breast cancer plan how to support their adolescent children and meet the needs for information.

Introduction
In Canada, 21,600 women are diagnosed with breast cancer each year. Seventeen per cent of those women are under the age of 50 when they are diagnosed, and 18% of these women will die before they reach the age of 50 (National Cancer Institute of Canada, 2005). Breast cancer is the leading cause of death in women between the ages of 35 and 50.

These younger women face many unique psychosocial issues revolving around family, relationships, sexuality, and employment (Gould, James, Gray, & Fitch, 2003). Mothers who are diagnosed with breast cancer face the unique challenge of explaining a disease that disfigures and kills to their children. This challenge comes at a time the woman herself is feeling overwhelmed, vulnerable, and uncertain about her future. To find the right time and the right words, not only for the mother but also for the child, can be a daunting task and one for which the age and development stage of the child has an important bearing (Fitch, Bunston, & Elliott, 1999).

The diagnosis of breast cancer can be overwhelming as well for family members (Kristjanson & Ashcroft, 1994). The illness can have more than a physical impact on each and every one in the family and access to information is important for coping with the situation. Information needs of spouses and the process of communication with young children in this circumstance have been studied, but little work has focused exclusively on adolescents. Given that adolescence is an important time regarding body image, individuation, and identity (Quinn-Beers, 2001), communication and the provision of information could be crucial influences on teenagers coping with their mother’s diagnosis and treatment. Having a mother who is ill with cancer no doubt adds stress and uncertainty to a time that is difficult enough as the adolescents work to find a path for their own lives.

This study was undertaken as a pilot project to identify the information needs of adolescents when their mother is diagnosed with breast cancer. Much work has been done over the past decade to meet the information needs of the women who are diagnosed and a significant amount of information now exists in the public domain about the disease. It is not clear if any of this reaches adolescents in an appropriate or timely manner.

Background
During the past 15 years, there has been a substantial increase in the amount of quantitative information about the impact of a woman’s breast cancer diagnosis on a partner (husband) and family and a clear recognition that cancer is a family experience (Fitch et al., 1999; Hilton, 1993; Yates, 1999). The body of knowledge regarding the impact on husbands is quite large (Lewis & Hammond, 1996; Lewis, Woods, Hough, & Bensley, 1989; McGuire, 1981; Northouse, 1988; Wellisch, Jamieson, & Pasnau, 1978; Woods & Lewis, 1995).

The quantitative literature on children’s reactions to cancer in one of their parents (Issel, Ersek, & Lewis, 1990; Quinn-Beers, 2001) or the death of one of their parents from cancer (Berman, Cragg, & Kuenzig, 1988; Galloway, 1990) has also been growing over the past 15 years. Much of this work gathers the parent perspectives on the children’s reactions, particularly if the children are young (Fitch et al., 1999; Zahlis & Lewis, 1998). Relatively little work has gathered information directly from children. Nonetheless, it is evident that cancer in a parent does have an impact and the impact will vary by age and development of the child (Quinn-Beers, 2001).

The focus on adolescents, defined as 13 years old and older, has been relatively less than the focus on younger children. However, claims exist that the adolescents may have more difficulty coping than their younger siblings, responding with irritability, withdrawal, self-destructive behaviour, or a preoccupation with the illness (Armsden & Lewis, 1993).

When parent and adolescent perspectives are compared, adolescents rate themselves as more distressed than parents rate them (Welch, Wadsworth, & Compas, 1996). Children reported as well their distress declined from a high at the time of diagnosis over the next four months; parents, however, were not aware of this change. Compas et al. (1994) reported a significantly higher rate of symptoms of anxiety and depression among adolescent daughters of women with cancer when compared to their adolescent sons.
Qualitative work has also utilized parents to describe the needs of children (Barnes, Kroll, Burke, Lee, Jones, & Stein, 2000; Shrands, Lewis, & Zalhis, 2000) with relatively little work drawing on adolescent samples. Lewis, Ellison, and Woods (1985) conducted interviews with adolescents after their mother had finished treatment and learned about how these children felt pulled in two directions simultaneously – wanting to help their mother more and wanting to spend more time in individual activities. Berman et al. (1988) reported on semi-structured interviews with 10 adolescents who had lost a parent to cancer. The surviving parents reported they had kept the adolescents informed about the diagnosis, death, and funeral. However, the adolescents themselves described a sense of isolation. They thought they had little help from health care professionals and received more from family, friends, relatives and peers. Issel et al. (1990) studied how children (six to 20 years) coped with a mother’s breast cancer. They conducted interviews with 81 children, two to two-and-a-half years after the diagnosis. Themes concerning coping strategies included: acted as though they were in her shoes, carried on business as usual, tapped into group energy, and put her illness on the table. Specifically related to information, 20% of the older children (n=46) reported thinking about their mothers’ illness as a coping strategy. Of that group, 13% mentioned worrying about whether their mother would be okay, 16% talked about trying to understand the illness, and 7% worried about getting the illness. However, another 20% of the older group said they coped by putting their mother’s illness out of their minds and not thinking about it. Some of the older children claimed they did not worry (9%) while others plunged into work or homework (7%). In terms of who helped them cope, family and friends were cited most frequently. Twice as many older children (57%) than young children (23%) named friends as a source of support.

Regarding information and its role in coping with illness, strong evidence exists about the important role it plays for adults with cancer (Gray et al., 1998; Northouse, Cracchiolo-Caraway, & Appel, 1991). The role of information in the coping of children and adolescents has received less attention. Recently, Kristjanson, Chalmers, and Wood (2004) have made an initial attempt to describe the information and support needs of 31 adolescents using standardized measures together with semi-structured interviews and focus groups. The most salient piece of information adolescents wanted to know was whether their mother was going to survive. Adolescents have described support at school to be important because it allowed them to continue with their lives and feel hopeful (Chalmers et al., 2000).

Purpose of study

The purpose of this (pilot) study is to begin to document, in a qualitative manner, the nature of the information needs experienced by adolescents whose mother is diagnosed with breast cancer. Particularly, in light of more information about breast cancer being available and media discussions of breast cancer becoming more prominent over the past decade, the needs of adolescents for information may be shifting. It is also important to learn more about how adolescents would like to receive information related to their mother’s breast cancer.

Methods

This exploratory-descriptive study made use of in-depth interviews with adolescents whose mother had been diagnosed with breast cancer. The semi-structured interview guide allowed the participants to describe the type of information they were curious about or wanted to have, where they searched and found the information, what was missing for them in the information they found, and what they thought was the best method to use in providing information to adolescents at the time of diagnosis of a mother’s breast cancer. The guide was designed for use in this study with input from psychologists and social workers with expertise in working with adolescents.

To accrue participants for the study, invitations were sent to each member support group of the Ontario Breast Cancer Information Exchange Partnership (OBCIEP). The agencies distributed the invitation to members who were women survivors of breast cancer. Names of interested individuals were sent to the investigator through OBCIEP. The research assistant then contacted each person, further explained the study participation, and obtained consent. With little initial response to this approach, the invitations were then circulated to all breast cancer information exchange partnerships across Canada and the nursing staff at a large metropolitan cancer centre.

To be eligible for participation, an individual needed to be between the ages of 13 and 19 years at the time of their mother’s diagnosis of breast cancer, speak English, and the mother’s breast cancer must have been diagnosed in the last 10 years. The timeframe was established for the diagnosis for several reasons: many advances had occurred in breast cancer treatment and care during that time, especially with more information being available to the general public; use of the internet has escalated, particularly for young people; recall of the pertinent details more than 10 years ago would be a challenge.

Consenting participants were interviewed over the telephone and the sessions were audiotaped. The interviews lasted between 30 and 45 minutes. Each participant signed a consent form prior to the interview. The interview questions included demographic items (age now and at time of mother’s diagnosis, living arrangements, parental occupation), personal experiences during the time of the diagnosis (e.g., how they were told about the diagnosis, how it impacted them, satisfaction with the way in which they were told about the diagnosis), their informational needs at the time of diagnosis (e.g., who they spoke with, what they wanted to know, what information they obtained), and general opinions about how best to meet the informational needs of teenagers in similar situations.

The participants were asked open-ended questions initially to allow them the opportunity to speak about what was important to them. Subsequently, they were presented with a list of common responses built up from the preceding interviews with other adolescents and they were asked if they wished to add anything more to their own responses.

The interviews were transcribed and any identifying features removed from the transcripts. The transcripts were subjected to a standard content and theme analysis (Silverman, 2000). Fundamentally, two ideas or questions focused the analysis: what was it like for the adolescents when their mother was diagnosed, and what types of questions (information needs) did they have at the time. Each investigator read through the transcripts and made marginal notes about the content, where it fit within each of the broad questions, and how the content might be drawn together or categorized in each of these areas to describe the experiences of these adolescents. The investigators compared their notations, discussed their perspectives about the data, and agreed upon a categorization scheme. One investigator then coded all the interviews using this agreed-upon scheme while the other supervised the work to ensure consistency and use of all data. Once the content was categorized, each coded category was reviewed and key ideas identified. For example, under the broad topic of the experience of having a mother diagnosed with breast cancer we developed a content category called emotional reactions. The content coded into that category provided a range of descriptors about the emotions the adolescents experienced in learning about their mother’s diagnosis.

Findings

Selected characteristics

A total of 14 adolescents were interviewed for this study. However, one interview was subsequently removed from the study because the mother’s diagnosis was more than 10 years ago and the participant had very little recall of the details. Data from three males and 10
females are included in this report. They ranged in age from 16 to 25 years at the time of the interview and 13 to 19 at the time of their mother’s diagnosis. The mean age at the time of their mother’s diagnosis was 15.7, with six respondents between 13 and 15. Ten of the mothers were between 40 and 50 at the time of their diagnosis; two, between 30 and 40; and for one, age was unknown (respondent could not recall specific age other than below 50). Eight of the respondents were living with both parents and siblings at the time of the diagnosis.

Learning about the diagnosis

Without exception all the adolescents in this study talked about how shocking and upsetting it was to learn about their mother’s cancer diagnosis. The word cancer to them meant death and, as a result, their immediate thoughts were that their mother was going to die.

“I was, like, devastated. Really upset, like, at first, I really thought she was going to die.” (4)

The group was rather evenly divided in terms of when they were told about the diagnosis. Some found out before a definitive diagnosis was made because their mother had found a lump through breast self-examination and told them then. Others were told about the cancer at the time of the diagnosis, describing their family as “upfront and honest” (4) and “really kept us kids involved” (3). Others learned about the diagnosis later, but also learned their parents had reasons for not telling them earlier [e.g., “I was in the middle of examinations (9), I was just too young at the time (10)].

For the most part, these participants were satisfied with the manner in which they learned about the diagnosis. However, they also had ideas about how things could be improved. Their suggestions included: being able to talk to a doctor directly, knowing as soon as possible that something is wrong, being treated as an adult, not having the information “sugar-coated,” and being able to talk with other teens in the same situation.

These young people experienced a range of emotional reactions upon learning about their mother’s diagnosis. Anger and bitterness emerged as they struggled with questions about why did this happen to Mom? (10), and how it was unfair (5). Feeling overwhelmed was also a commonly expressed reaction.

“I felt like I just wanted to run away from it all, just get out of the house, there was so much crap to deal with. I just wanted to forget it all.” (2)

“I just didn’t want to face it, to even think about it. Like, cancer is, like, death.” (10)

In turning away from the reality of the cancer diagnosis, some turned to sports, or homework, or activities to keep busy and take their minds off what was happening.

“I was shocked, yeh, and really upset. But I didn’t want everyone at school to know. Like, I could go and do athletics and forget it. Like it was all so unfair and, well I guess I was pretty bitter about it.” (5)

Some were drawn to spend more time with their families and with their mom. Some wanted to help, others wanted to be in close touch with their other family members.

“I stayed home more. I wanted to be, well, I felt I had to be extra nice to Mom then.” (3)

Despite knowing the diagnosis and feeling there was openness to talking in the family, as well as a sense of being involved, these adolescents still experienced a sense of separation and uncertainty. The sense of isolation was heightened when information was not shared.

“I felt in some ways I was kept in the dark a lot. Really not told everything that was going on, I guess they didn’t want me to worry.” (6)

For some, the overarching recollection about the time around the diagnosis was of not really understanding what was happening. It was a time when there was much activity, of both parents being upset, and the usual things that happen around their home not happening in the usual way. It was a time of disruption and uncertainty.

“Mostly I just didn’t know what it meant. Like I knew cancer was bad, but really didn’t understand about it.” (8)

| Table One. Questions adolescents wanted answered at the time of diagnosis of their mother’s breast cancer. |  |
|---|---|---|
| General items | Items Specific to Own Mother | Questions about Own Risk/Self |
| What is cancer? | How serious is it? | Can I catch her cancer? |
| How common is cancer? | What is my mom’s smartest option? | What are my heredity risks? |
| What are the survival rates? | Will she die? | What is going to happen to me? |
| What is chemotherapy? | Will everything be okay? | |
Information needs

The types of questions these adolescents had at the time they learned about their mother’s diagnosis are listed in Table One. The questions include general ones about cancer, specific ones about their own mother’s situation, treatments for cancer, and their own future risk. When asked what was the most important information gap at that time, all these adolescents identified questions about their mother’s survival such as the following: will she be okay? (2), will everything be okay? (8), how long will she live? (3), when will she get better? (7), will she die? (10).

The participants were asked to identify what they needed most at the time of diagnosis of their mother’s breast cancer. Their answers focused on either information or support. The information they wanted to know most concerned their mother’s recovery and reflected an underlying desire for reassurance about the future.

“For me, what I needed most was to know everything was going to be okay… I wanted answers, you know, about how it was going to be.” (14)

As far as support, these adolescents talked about needing someone to talk to about what was happening. They wanted someone to be there for them. Preferably that person would be someone they knew and they were comfortable being around.

When encouraged to talk about other things that were important for them, these adolescents described wanting answers to their questions and wanting to be with others. They wanted to be able to spend time with family and spend time with friends, but experienced a struggle at times sorting out how to balance these two things. In most cases, they would spend more time with their peers but, under the circumstances, felt drawn back to their family. They felt they needed to be with the family to be included and involved in decisions about what was going to be done about managing day-to-day while their mother was on treatment.

“In some ways, you kind of grow up fast. Like you have to do stuff maybe you didn’t before, you know, clean your room and stuff…we all had to take turns doing stuff. Dad sort of organized it.” (9)

All the participants in this study had someone with whom they talked about their mom’s breast cancer. All talked with one or both parents. Some spoke with their close friends or siblings, or a close adult relative or family friend. Almost all also spoke with a professional in health care (doctor, social worker, psychologist) or school staff member (teacher, coach, guidance counsellor). Three were able to speak with another teen who had had a parent diagnosed with cancer. For the most part, their factual questions had been answered satisfactorily. However, the questions that were not answered to their satisfaction concerned the prognosis and survival. About two-thirds of this group sought information on their own. Although they received information from their mothers, they wanted to see what they could learn through their own efforts. They searched for information on cancer, treatments, side effects, survival rates, and how to protect themselves. Their search included a wide range of sources including people (other adult, parents, family doctor, other health care professional), library (books, textbooks), cancer society, internet and a support group for teens. Of the 13, only one struggled with his information search. Most thought a range of formats would be best, but emphasized the internet, videos/DVDs, and stories from other teens.

The teens who participated in this study thought there are reasons why adolescents might search out information on their own even though there has been some conversation with parents or others. Examples of these reasons are illustrated below:

“Well, you have privacy. No one knows your questions. No one can tell you they’re silly ones…or tell you don’t worry about that.” (9)

I can learn what I want to on my own time. (4)

You don’t have to show your emotions to someone. (13)

I just learn best this way. (12)

I don’t want to upset my mom asking certain questions. (3)

Sometimes I’m just not too comfortable talking to someone else. (11)

The participants in this study agreed that adolescents need information when their mother is diagnosed with breast cancer, although they thought age and personal preference needed to be considered. For anyone in high school, they thought the information needed to be provided. They talked about the information coming from a range of possible people including parents, relative, friend, coach, teacher or health care professional. They would only want a sibling or another teen involved if they were really informed themselves. Overall, they wanted someone who they trusted, felt safe with, and could confide in to tell them. They wanted accuracy, but they also wanted to have someone who could be okay with the emotions that might be shown.

“Your know, this information has emotions to it. It’s not just facts. So when you hear it you felt something, you know. Like you need to have someone who understands you.” (12)

Discussion

This study was undertaken as an exploratory study to begin to understand the information needs of adolescents whose mother has been diagnosed with breast cancer. The in-depth interviews provided insight into the nature of the adolescents’ responses to their mother’s diagnosis and how information plays a role in their reactions.

The accrual to the study took considerable effort and required a cross-country invitational approach. Even so, only 14 adolescents came forward. Two reasons likely contributed to this accrual challenge. Overall, the number of women diagnosed with breast cancer who have adolescents is relatively small in contrast to those without children. Also, parents may have been very cautious about suggesting the study participation to their children. One might assume that a very select group of adolescents actually came forward for this study. We found the adolescents who participated spoke rather easily about their experiences and thoughts and displayed rather good communication skills. The description of their experiences (i.e., open communication, involved in decisions) suggests they may be from selected family situations. Their families may have been unique in how openly they discussed the situation with their children and how much they involved these youngsters in decisions. One has to question how reflective their experiences are of all adolescents and families dealing with breast cancer.

Clearly, adolescents have needs for information at the time a mother is diagnosed with breast cancer. The actual topics are very similar to topics identified by adults (Gray et al., 1998; Fitch & Allard, in press). Although these adolescents knew about cancer as a disease and had heard about it on television, they did not know details about it or its treatment. Their primary issue was whether or not their mother would die, as their perception was cancer was equated with death. Conversation and information about outcome and prognosis is important.

To be uninformed leaves the adolescent isolated and alone with fears and worries. The actual telling about the diagnosis needs to be done by someone the adolescent knows cares for them and with whom they feel secure. Similarly, the option for ongoing exchanges/conversations ought to be offered together with encouragement to ask questions. Ideally, information packages for
adolescents could be developed with stories from other adolescents in the same situation and a list of internet sites with credible cancer information could be provided. These packages could be available through cancer centres, family physician offices, schools, public libraries, and community centres. It may also be useful to coach parents in how to share the news of the diagnosis and engage in open conversation with the teen about it.

The internet may actually be a useful tool for developing online support for teens. Online support groups, facilitated by a professional, have been successful for adults (Helgeson, Cohen, Schulz, & Yasko, 2001). Given the facility adolescents have with web-based communication, the approach could be useful and provide a way for teens to share experiences. Online support approaches are quite helpful if the target group is small in number or if there are privacy issues. Both issues are applicable to adolescents. Clearly, there is a need for program design, implementation, and evaluation.

Implications for cancer nurses

Cancer nurses who are caring for women with breast cancer need to think about the information needs of the adolescents in the family. Initially, it would be important to hold a conversation with the woman about her children and her plans for talking with them about the breast cancer diagnosis. She may benefit knowing about the informational needs of adolescents reported in this study and wish to explore how to approach the conversation with her teens. Cancer nurses may be able to support the woman in holding that conversation or may offer to speak directly with her adolescent child after the conversation if there are questions about the disease or treatment. Recommending reading resources or web-based resources could also be helpful.

References


