Shielding and being shielded: Children's perspectives on coping with their mother's cancer and chemotherapy

By B. Ann Hilton and Kris Gustavson

Abstract

*Little research has examined children's perceptions of what it was like when their mother was diagnosed and treated with chemotherapy for breast cancer. This research aimed to describe the children's perspectives and to suggest interventions to assist children to manage the experience with less stress. Qualitative naturalistic inquiry methods were used. Purposive sampling was used to recruit children whose mothers had chemotherapy for breast cancer in the prior two years. Eleven children were interviewed individually or with siblings. Children were between seven to 21 years of age. The major theme that emerged was **Shielding and Being Shielded**. Shielding refers to how children protected themselves from their thoughts and feelings and protected themselves from others. Being Shielded refers to what others did to protect the children. Shielding and Being Shielded each had components reflective of knowing/understanding, acknowledging/feeling, sharing, and shifting/helping. Recommendations directed towards assisting children, parents, and nurses and other health care professionals are suggested.*

A mother's diagnosis, hospitalization, and treatment for cancer are considered serious threats to children and often result in anxiety and detrimental effects on family life, school life, sports, and leisure activities (Hilton & Elfert, 1996; Nelson et al., 1994; Rosenfeld & Caplan, 1983; Zahlis, 2001). Although awareness of the impact of parental cancer on children is increasing, gaps remain. Parental cancer impact has often been studied from the parent's perspective (Howe, Hoke, Winterbottom, & Delafield, 1994; Hymovich, 1993; Lewis, Zahlis, Shands, Sinsheimer, & Hammond, 1996; Lichtman et al., 1984; Shands, Lewis, & Zahlis, 2000), but more research is needed from the child's perspective. In addition, studies with children have mainly involved older children and adolescents coping two to five years after the mother's treatment (Brown, 1992; McTaggart, 2000; Nelson et al., 1994; Rosenfeld & Caplan, 1983). Only two studies were found that focused on the diagnosis and treatment period (Hilton & Elfert; Zahlis). The current study aimed to describe children's experiences when the mother required chemotherapy for breast cancer. Greater awareness of children's perspectives can provide better understanding and guide the development of ways to assist children in coping with a mother's illness.

Relevant literature

Children must be included in studies in a meaningful way in order to understand their experiences. Interviews may contribute more to our understanding than structured questionnaires. Studies with children coping with parental cancer have mainly used interviews with children (Brown, 1992; Issel, Ersek, & Lewis, 1990; Nelson, Sloper, Charlton, & While, 1994; Rosenfeld & Caplan, 1983; Zahlis, 2001) and interviews with parents and children (Hilton & Elfert, 1996; McTaggart, 2000). Several others relied on structured interviews and questionnaires (Birenbaum, Yancey, Phillips, Chand,

& Huster, 1999; Compas et al. 1994; Wellisch, Gritz, Schain, Wang, & Siau, 1991 & 1992).

When a parent has cancer, children worry about many things, including what will happen, whether their mother will die, whether things will change, about their family, about talking to others, their own risk for cancer, and how their family will manage financially (Zahlis, 2001). Researchers have also learned something about children's awareness and understanding, their information needs, and whether they talk about the cancer situation. Awareness was a major theme in Hilton and Elfert's study (1996). The child's developmental level understandably influenced understanding and the nature of the demands. Parents thought preschoolers were too young to understand, so they gave them simple explanations. More information was shared with school-aged children who believed the situation was serious. Rosenfeld and Caplan (1983) also found that what children were told and understood varied considerably and that problems in parent-child relationships related to the extent children were kept informed about the illness. Most children did not want to or could not tell anyone at school because of family policies about not discussing the illness and they did not think anyone would understand. Children who were not given sufficient information became anxious and resentful and remained angry. Nelson and colleagues (1994) found that high anxiety was related to an inability to discuss the parent's illness with the parents.

Studies reflect the impact on children's patterns and routines. Dependence, a major theme identified by Hilton and Elfert (1996), reflected variation in dependence and independence across age groupings. Families with preschoolers focused on child care and scheduling. School-aged children showed concern for the mother and were more self-sufficient than young children, but were still dependent on parents. They usually helped with chores. Teens felt the threat and described increased emotional closeness. They saw themselves as very busy and over-committed at school, and they resented extra demands at home. The illness generated a blurring of roles with some giving hands-on care and taking on household duties. Rosenfeld and Caplan (1983) also described the extra domestic chores and responsibilities for sibling care and noted that many teens had to give up some sports and hobbies. They also spent less time with friends which was anxiety-provoking. Nelson et al. (1994) concurred and reported that high anxiety was related to having to spend less time with friends, less time for sport and leisure activities, deterioration in school work, and continuing anxiety over the illness.

Issel and colleagues (1990) identified four themes for how children dealt with the mother's breast cancer. "In Her Shoes" reflected what children wanted if they were in the mother's shoes and ways to anticipate what she wanted. Younger children were more considerate and took care of the mother, helped with chores, and tried to be nice. "Business As Usual" described how children downplayed

B. Ann Hilton, RN, PhD, is Professor, School of Nursing, University of British Columbia, in Vancouver, BC.

Kris Gustavson, RN, MSN, is Patient Services Director at The Children's Centre at Mount Saint Joseph Hospital, Vancouver, BC.

the illness by acting normal and doing regular things. "Group Energy" reflected how children sought comfort from others. "On the Table" described how children tried to understand the illness experience by problem-solving and interpreting information. This included getting their thoughts and feelings out in the open through family discussion and personal reflection. Older children were more likely to talk and reflect on the situation.

McTaggart (2000) explored the experience of breast cancer and the mother-adolescent daughter relationship. "Inhabiting Another Landscape" described a trajectory of experience and meaning from the diagnosis to the effects of treatment and into the present and imagined future. Mothers and daughters privately held concerns about cancer and the possibility of the daughter also being diagnosed with it. "Intending and Acting" described mutual caring and protectiveness to minimize the threat. Maintaining a sense of normalcy and limiting conversations on the cancer experience were common strategies. "Acquiring Wisdom" described personal change resulting from the experience. "Enduring Mother-Daughter Relationships" reflected the quality of mother-daughter relationships and the import of the cancer on the relationship.

Brown's (1992) study focused on teenagers living with a parent with advanced cancer. This situation had a profound emotional and physical impact and teens described "shielding" as a strategy to pursue the tasks of adolescence and to "get on" with their lives, despite the worsening home situation. They protected themselves from a reality for which they were not ready. An underlying theme related to the teens' drive to put their lives ahead of others and to "get on" with the work of adolescence. They shielded themselves by choosing not to think about the situation, staying positive, and trying to view their parents as they had been before becoming ill. Younger teenagers were more intent on not thinking about the possibility of the parent's death and felt more trapped and resentful, while older teenagers felt they had more responsibilities.

Common themes from these studies reflect that cancer is a major threat that affects many dimensions of children's lives, and that awareness and understanding vary as does talking about concerns. Down-playing the illness and decreasing disruption help children to keep things as normal as possible. These studies enhance our understanding of children's experiences, but little research has been conducted closer to the time of treatment and, particularly, when chemotherapy is the major treatment employed. The research question addressed in this study was: "What is the experience of children when the mother requires chemotherapy for breast cancer?" This study was part of a larger study where the investigators worked collaboratively with women, their male partners, and their children to understand what helped and hindered coping and to identify ways to assist them to manage the experience with less stress (Hilton et al., 1996).

Methods

The investigating team consisted of nurses, social workers, an oncologist, women with breast cancer, and a spouse. We employed qualitative participatory action research methods for the larger study because of the emphasis on collaboration and action and the development of strategies (Erlandson, Harris, Skipper, & Allen, 1993). In the investigating team, the women with breast cancer and the spouse were involved in proposal development and discussion of results. The emphasis in the children's component was only on the child's participation in the interview process. Semi-structured interviews were conducted with 11 children in their homes. Siblings generally preferred to be interviewed together. Because the focus of this study was not to differentiate views based on whether children were interviewed individually or not, their preference was respected. This may have influenced communication of their perspectives. The semi-focused interviews explored children's perceptions of their experience and what made it easier or more difficult for them to cope.

For example, children were asked what they thought about when they first heard what was happening to their mom, what they were told, and what it was like for them when their mother was going through chemotherapy. The emphasis was to understand the children's experiences when the mother required chemotherapy, but not to separate out the specific impact of the chemotherapy on their coping. The study was approved by the appropriate ethical review committees.

Children of women who had chemotherapy for breast cancer within the two years prior to the study and who had at least one child living at home were recruited through purposive, snowball sampling. Staff from the cancer agency first approached families who met the study criteria. If the families were agreeable, they were then approached by the investigating team. Others were recruited through personal contact with the investigating team. Eleven children from six families participated. The families consisted of one to four children ($M = 2.3$), with ages ranging from four to 28 years ($M = 12.3$ years). The children interviewed ranged from seven to 21 years of age with four boys and seven girls. Four children were young school-age (seven to nine years of age), two were older school-age (10 to 12), three were young teens, and one was an older teenager (17-19). Another 21-year-old male was also included, even though he was somewhat older, because the opportunity was available and we thought his contribution would be valuable. His mother had received several cycles of chemotherapy over many years and was coping with a serious recurrence of her cancer.

Most mothers were, or had been, employed as teachers, health care professionals, technicians, service providers, or homemakers. Six fathers had university preparation. Most families were two income earners and annual family income ranged from \$36,000 to over \$95,000. Six to 25 months had elapsed since the mother's chemotherapy [within six months (two), six to 12 months (two), 16 to 25 months (seven)]. One woman was in the palliative stage of her illness.

Interviews were audiotaped and transcribed, and transcriptions were read thoroughly. Open coding was used to identify ideas, and further analysis reflected higher order themes. Constant comparative analysis was used to assist in further clarification and refinement (Strauss & Corbin, 1990). Trustworthiness and rigour were supported by clarifying the decision trail (auditability), staying close to the informant's words, using quotations in presenting the results (credibility), and discussing themes as they were identified together with supporting evidence with the team and others (fittingness) (Denzin & Lincoln, 1994; Lincoln & Guba, 1985). This process facilitated identifying properties and dimensions and verifying the fit.

Findings

Shielding and **Being Shielded** emerged as major themes. **Shielding** refers to how open or protective children were about their thoughts and feelings and how they protected themselves or opened themselves to others. **Being Shielded** refers to what others did to open or protect the children from the situation and its stress. "Knowing/Understanding," "Acknowledging/Feeling," "Sharing," and "Shifting/Helping" were subthemes of **Shielding** and **Being Shielded**. Table One reflects these themes and the dimension of openness/protectiveness within each.

Knowing/Understanding

"Knowing/Understanding" reflects the children's level of awareness and understanding of the situation or lack thereof, their expectations for the future, and what they did to seek understanding or to protect/shield themselves from information. Understanding was highly influenced by if and what others told them. Some children shielded themselves from information, while others were active seekers. Some were shielded from information, while others were kept informed.

Children had various levels of awareness and understanding of the mother's situation. Younger children were generally less aware. "I was only in grade one so I didn't really know what would happen." Another young boy emphasized his lack of awareness, "I didn't really know how bad this was...so I don't think it bothered me." Even an older adolescent talked about not knowing what went on initially. In contrast, several children, some quite young, reflected moderate to full understanding of the situation and its potentially serious implications. Seven- and nine-year-old sisters said, "(Cancer) is sort of a cell that infects your body, infects the good cells...a little bit of cancer got into her ribs" and "I know that she might die." Their

mother had explained the situation to them in a very sensitive manner. "If mum dies, she said that God would probably give her a special star to sit on by me and (sister's) window." Adolescents were generally aware that the situation was something to be concerned about and that there was a possibility of their mother dying, "Cancer kills and she could die and you would be left alone." After taking a biology course, another adolescent gained greater understanding but "when she was talking about lymph nodes at first - I had no idea. It was a bad thing that's all I knew."

It was difficult to get a clear picture of a 21-year-old boy's understanding of his mother's recurrent cancer situation. She had

Table One: Patterns of Shielding* and Being Shielded**

Knowing/Understanding

The degree that children were aware and understood the situation or lack of, expectations for the future, and what they did to seek/resist information and understand or protect themselves from information. What others did to inform or not inform.

Shielding

1. Naive/oblivious, limiting understanding
2. Reasonable understanding/concern, open to information
3. Too much information/confusion/unrealistic; seeking too much information, not knowing what to do with it

Being Shielded

1. Not being made aware
2. Being adequately informed for developmental level
3. Getting too much information

Acknowledging/Feeling

The degree that children recognized and acknowledged strain on self and others (or lack of) and use/non-use of supportive strategies.

Shielding

1. Oblivious, self-focused, putting on a good face, pretending nothing is wrong
2. Recognizing feelings in self and others, acknowledging/expressing/sharing concerns, seeking and using comfort measures
3. Focusing on fears, little self-awareness, using ineffective strategies, acting out versus peacemaker

Being Shielded

1. Being protected from tension and family strain
2. Having reasonable exposure to stress/worry
3. No protection from tensions

Sharing

The nature and degree children talked to others about the situation and their concerns and how others talked with them

Shielding

1. Keeping to themselves, focusing on sadness
2. Reasonable sharing, connecting, humour
3. Unlimited talking, no boundaries, inappropriate humour

Being Shielded

1. Handling it alone
2. Having the way paved
3. No privacy of thoughts

Shifting/Helping

The degree children were impacted by changes in family patterns and how children were involved in helping at home.

Shielding

1. Rigidity in keeping normal patterns, putting self on hold, not knowing what to do/say
2. Reasonably normal patterns, accepting changes, balancing home-friends, getting guidance
3. Patterns upside-down, resenting change, feeling guilty, directed, controlled

Being Shielded

1. Life as normal, not being involved, being controlled
2. Making adjustments, working together, feeling helpful/recognized
3. Making major shifts, giving up things, growing up fast, feeling burdened/resentful, acting out

Meaning of the levels 1, 2, 3:

- Level 1 - large degree of protectiveness by children or others
- Level 2 - moderate protectiveness taken by children or others
- Level 3 - no protectiveness by children or others

*Shielding - how children protected themselves from their thoughts and feelings and those of others (and opened themselves)

**Being Shielded - what others did to protect the children from the situation (and expose)

recently been very ill and “had a lot of fluid build-up.” He wondered how she would be in the future, but would not elaborate, although he thought she was going to be “OK.” In the family interview that followed, his mother was adamant that only positive thoughts were acceptable, which likely influenced his lack of revelation of any major concerns.

Children were optimistic and hopeful that things would work out well, but they were still concerned and feared their mother might die. They found it hard to tell how sick she was and felt helpless to change the situation, “There’s nothing you can do to make it better.” One boy who was more pessimistic than others said that he had not been concerned about death at the time of his mother’s chemotherapy, but was now feeling more negative and thought his mother would die. He said he knew more now than before. “It’s (cancer is) all around...I just sort of worry about her being tired or doing things, lifting things she is not supposed to lift.” His worry and fear increased because others he knew with cancer had died.

Children’s understanding and responses were very much influenced by what and how others told them and what they read and heard. Some parents openly explained it to them in simple terms, while other parents shielded the children by limiting what they were told. Children generally found it difficult to hear the news of the mother’s illness, but when they were told that she was doing well and that “she isn’t going to die,” they felt relieved and often did not want to know more, thereby shielding themselves from further information. A young adolescent said passively, “I understood the things I was told....that she would be alright and she’ll be home soon (and wanted no further information).”

Parents used several methods to inform children, but pictures and videos about cancer and coping with cancer were particularly effective. A 10-year-old said watching videos as a family helped. Other families encouraged the children to be aware of what was happening. Some children went to the cancer clinic, and this was generally seen as helpful. Others were told by their father to “keep quiet” when they went to the hospital and they “just sat around.” Without guidance, the experience was not as helpful or as positive. Older teens recalled the tension of going to the cancer agency:

He (father) didn’t want us to go. I wanted to go. I was talking to her (mother) and playing with her hair. He got so mad at me. He said, ‘don’t touch her.’ He doesn’t know what to do...I don’t know if he didn’t want us to see her like that and he just didn’t want to say so.

Children with greater awareness were often extensively involved in keeping family routines going and, therefore, were constantly confronting reality. It was not unusual that children shielded themselves by controlling their knowledge. While some limited input by avoiding situations or people who might talk about it, others actively sought information. The adequacy, accuracy, and helpfulness of information, however, was not always useful and may have contributed to confusion. An older teenager got information at school, but generally felt “clueless.” Several children did not want to know more about the mother’s situation when she was diagnosed and having chemotherapy. They felt knowing more would make things harder, “I think if I knew more, it would have made it worse.” Another said, “I was not paying attention to what was going on, so I really don’t know.”

Children often did not want to talk and actively resisted any talk. “I tried not to talk about it. Dad did a few times. He started to say, ‘If your mom dies,’ but I said to him, ‘don’t talk to me about that.’ Dad talked about it so he could face it if it turned into reality; that’s why he talked about it.” Her younger sister said:

You can’t stop thinking about it but I would never say it... I couldn’t say that word ever. I don’t remember ever saying that word....I would probably start crying. I guess I was scared. It’s not going to happen. I can’t live without her. I was very dependent on my mother. I have always been very close to her

and the thought of not having her...then I’ll die too. I can’t do this by myself.

The older sister in this family said her mother, “told me what my sister was thinking because I’m much more independent. They thought I could deal with it better by myself.”

In contrast, some children sought information. Young daughters of a mother who was palliative were told about the situation and they in turn asked their parents questions. “He sort of tells us what’s going on and sometimes he doesn’t, but if we ask a certain question he’ll explain it because they tell us everything.” A daughter asked her father whether her mother would die and he said that she might die. They felt it was all right to ask questions. In another family, two siblings sought advice, “questions and stuff” from their older sister who they looked up to and saw as quite sophisticated and articulate. The sister did not recall their coming for information or advice. Children in another family wanted to “check that the doctor wasn’t a big loser.” Two teenagers in yet another family would have liked the family and doctor to get together to hear what was “going to happen” in order to feel more comfortable with him and be “able to go to him if you have any problems or need help to understand.” They felt that talking with a doctor would be quite different from talking with a therapist, “it’s not like the therapist where you share your feelings and everything – just the facts to see what is going to happen.”

A few children actively sought written information. A teenage girl looked up cancer in a dictionary, another read about it in the encyclopedia, and a young male adult got information from the library. He wanted to know what to do if something happened (but he would not elaborate). Only one older adolescent reflected on her cancer risk. “I read books on it. I wanted to find out about me and I watched a documentary. It was depressing so I stopped.”

In trying to make sense of the situation or put it into perspective, some children compared their situation to others. One teenager felt her mother was sicker than others, “for my mom compared to some other women, she had a really, really bad time. It would be like a really, really big deal when she came to the dinner table because it would mean she was having a good day.” Although children generally did not say whether they wondered why their mother got cancer, one teenager wanted to understand why it had happened to her mother. She was “angry, rebellious, and scared - constantly asking why. Why not someone else who was like way worse?”

Children therefore shielded themselves and were shielded by others. They were either receptive or not, and sought information out or preferred to be unaware. Parents and others were highly influential, especially for young children, in what they knew and how the news was taken.

Acknowledging/Feeling

“Acknowledging/Feeling” refers to the children’s recognition and acknowledgement of strain in themselves and others, and their use of comforting/supportive strategies. They talked about their worries and fears and how they coped with the stress. Their awareness and understanding influenced their emotional response. Many were shielded from the stress by what they were told or not told, and by the emotions they witnessed in others.

Some children were well aware of their anxiety, fears, and worries, while others seemed more oblivious. “Now I am just a little worried that something might happen, but not much.” Two teenage sisters worried when their mother went for a check-up, “I don’t want her to come home like that again - telling me that it’s coming again.” One young girl found it difficult to cope when her mother was in pain. Many children were well aware of their feelings. A young girl whose mother was palliative said, “When my mum first got it, I did cry, but like when I think of it at school, I don’t cry.” She and her younger sister were angry, “I get mad about cancer.”

Some children were very bothered by the mother’s hair loss and when people asked about it. “It’s hard when you look at someone with

hair for such a long time and then all of a sudden it's gone." One daughter told people it was a wig in order to hide the reality. A young boy found it "really strange because you usually see bald men." A teenage boy said his parents "took it (loss of hair) way more seriously than I did." A young adult male helped his mother with tying headscarves, something he learned from his peer group. He also helped his mother purchase and use the scarves in innovative ways to help draw attention away from the hair loss.

Several children recognized heightened family strain. "I think we got on each other's nerves more... like bucking each other... We didn't feel good so we would get on each other's nerves." Children recognized the increased stress and demands on fathers and how difficult it was for fathers to do unfamiliar tasks. "I think for my dad the hardest thing was making the dinner... putting it in the oven and putting it at the right temperature for a certain amount of time." They realized it was more difficult because fathers had not cooked much before. "My dad really can't cook." While some fathers stayed home more to help, others continued to work, although perhaps with reduced hours. Several children recognized the strain on fathers and the importance of their working and getting away from the home situation. "He was frustrated and confused and hurting inside but he's not the one to show his emotions. Work is a place where he can let it out....Work was a safe place where he didn't have to worry about all this stuff." Although some children were very aware of heightened stress on families, others were not, perhaps protected by what they were told and what they saw. Many families may have tried to keep the stress from children by hiding their fear.

Some children also tried not to communicate their fear and concern by putting on a good face. They did not want to think about it; they wanted to avoid the issue and "pretend that nothing was wrong." Two sisters did not discuss it, "putting on a face for everybody when you actually aren't inside." An older teenage girl said that:

I went through life as a routine. I wanted to pretend that nothing had happened. I'd always be with my friends. My dad said, 'why can't you stay home with your mom?' He wouldn't let me go to a lot of places.

One child found it annoying when people asked about her mother because "it made you think about it all the time" and another focused on school work to get away from it. Even though they tried not to think about it, many did dwell on the illness. An older adolescent said she was always trying to keep her mind off the cancer but:

It didn't really work because it was always occurring and you had to do so much at home that you were always anxious and you were always feeling that you didn't want to do anything anymore because it was always so hard to keep up with everything.

Children were very worried, felt "on edge," and some tended to explode. "Any little thing would get me really worried and I'd like blow up because it would be like the slightest little thing would tick me off." Another also said she had a bad temper:

I always take things out on people. I remember one time dad yelled at me for no apparent reason, but I guess I should understand he is going through a lot too, but I just didn't. I just got mad too and I just left and they didn't know where I went. I got mad a lot and I left a lot...I'd try to be more open and take things easier to take the stress off my family.

Some children, whether they recognized their stress or not, used comforting measures such as watching television, enjoying physical closeness, and using favourite cuddle toys. An 11-year-old said, "my old blanket and my teddy bear and I just watched TV and then I'd be OK." He seemed somewhat embarrassed about using cuddle toys. Two young girls said the baby in the family stopped crying when their mom was home and it was comforting for them to sit on their mom's lap and snuggle. Several used prayer or meditation. While some prayed on their own, others prayed with family. One daughter stopped

going to the nightly family prayer sessions. The young male adult used meditation and prayer because it "kept me from worrying and kept my mind open." A younger child believed her prayers were always answered:

Maybe not when you are expecting it, but they are answered, so I think it does help...you could actually trust someone and hopefully this person was not going to let you down, but mostly you do get let down, but this is the one person you could trust that won't let you down.

Children, therefore, recognized their stress and the stress of others to varying levels. While some families openly acknowledged and expressed stress, avoidance was prominent in others. Children shielded themselves or were shielded from the emotional impact of the situation.

Sharing

"Sharing" refers to the nature and degree that children talked to others about the situation and their concerns. Some were quite open, while others were more closed. They shielded themselves in how they talked, and others shielded the children by how and what they said.

Children generally did not talk about the situation or their concerns with anyone, including siblings, friends, and schoolmates. Not talking was a way to shield themselves. "I'm not comfortable expressing out loud. In my head, it's different." An older teenager talked to her closest friends to a limited degree because they were "family friends," but she purposefully hid her feelings at school. She confided in her boyfriend, but only later:

I was not cold but I didn't show anything. I tried to act normal. I didn't want to tell the whole world so I guess I was a different person at school. My two friends knew but they were the type of people I could express my feelings to...but there's certain things you can't do with your best friend. We never went into deep discussions. At the end, I had a boyfriend and I talked with him about it.

It was difficult to talk about the mom's illness and their feelings and they did not always think friends would understand. They kept concerns to themselves so as not to burden others. They often went out of their way to hide it, with some children staying physically and emotionally aloof from friends. "Sometimes it's very heavy and I didn't want to burden my friends and make them feel they're obligated to listen to all the problems." Others said:

I just kept it to myself. If I was upset I would either cry or punch a pillow...I didn't tell any of my friends until it was almost over so I didn't have anyone to talk to, but it was my fault because I wasn't comfortable talking about it with anybody.

I kind of like closed off to everybody. The only person I really talked to was my best friend at school. She's like the only one. We were like really good friends from grade six, not so much in grade seven and now in grade eight she is the only one that knows absolutely everything.

Another teenager also said she did not talk with her closest friend and her friend did not come to her house like before. She referred to her house as a "sick house" and said that when you walked into her house you could tell automatically that there was illness in the home.

School-age girls also said they were selective in who they talked with. "Sometimes we talked to our friends when we were over at their house and sometimes we talked to the grown-ups," but it was the adults who usually initiated the discussion by asking questions. The children would not have brought up the subject. One of the boys who did not like to talk about it did not talk to his friends and did not think his father or relatives talked about it. "I don't think I like to talk about it now (with this study). I don't mind now because I'm just helping." Even if children did not tell classmates, some friends and schoolmates may have been told by their own parents. One boy considered it "a bit nosey" when a classmate asked about his mother. He responded with

a very vague reply. Other children's parents may have told their children not to ask about the situation to try to protect the children's feelings.

In contrast, the youngest daughter of the mother who was palliative said, "the whole school knows." They "talk about it...we have a prayer time" and it helped her to talk about it. She had also told her two best friends. When the sisters went to see a counsellor, "we colour and talk about it and she brings out some books about feelings." Another child saw benefits from sharing with others in a more materialistic way. When he talked with more people he got "more presents." Some children were asked about whether they would have wanted to talk with a counsellor or be in a group with other kids who had a mother with cancer. Younger adolescents were a little more receptive, but older teenagers were not receptive at all. "Who wants to talk about it? My mom is feeling really crappy today. She looks really bad. The whole house looks like a disaster. My whole life sucks. It's not a good way to be united with other young people." Although this teen was adamant that she did not want to talk to a counsellor, she said she might talk to someone else. She had talked with a counsellor, but had not found it helpful:

It didn't really help that much 'cause I'm not one to talk to a person I don't know...it was informative but other than that it wasn't. I went along one time (to cancer agency) but doctors don't really talk to you. (She did not want to talk to a family member because) something might slip out and you would get angry if they can't keep it (quiet), but someone you feel comfortable talking to...and you can tell them what is bothering you and preferably someone who has even gone through this would be a lot better because they could actually relate to you. (She did not want to talk to a counsellor because) that's like talking to a total stranger - you don't usually open up or nothing like that 'cause you don't know this person and you are not going to trust them with your deepest darkest secret or your worries.

The young adult said that talking with peers would be helpful if it was part of a group close to home. Talking by phone with someone his age who had been in a similar situation might be helpful and it would be easier since he would not have to leave home. His peer supports were in another city, but it did not appear that he had talked with them about his mother's situation.

Children talked about whether cancer was discussed at home and how families talked about the cancer with others. Some families wanted to keep it in the family, while others shared. In one family, talking with people from the church was acceptable, but talking with others was discouraged. In another family, a young adolescent was encouraged to talk. "My mom said that if I feel something that I couldn't really talk with her that I can talk to my old teacher because she was one of my best teachers...I felt more comfortable talking to her than my mom. It was easier because now we are like best friends instead of teacher and student." This same girl had not talked with her friends. A teenager said this about their family communication:

I think most people just kept it to themselves. They didn't really express how they were feeling or what their fears were. They kept it bottled up and I think we should have talked about it more because now if you think about it, it is hard to talk about. Like if something is bothering you, you are not used to talking about it with other people - it's like your problem - deal with it, instead of being open and talking and telling people about what's bothering you.

Although breast cancer is serious, children found humour in it that created sharing opportunities. Two young girls "played with mom's fake breast - like a beanbag," and although their mom was not too excited about them doing that, she did not forbid it.

Some parents paved the way by talking to teachers and telling them what was going on. "My teachers knew at the time. They just kept asking me about her." This boy also thought that his mother had

written a note to the teacher and that his father had told his hockey coach. Children seemed to find it helpful when others knew and used the information in a helpful way.

Most children, therefore, did not talk to others about the situation in order to protect themselves and others. They did not think their friends would understand, and it was hard for them to talk. The sharing that took place in many families was minimal.

Shifting/Helping

The "Shifting/Helping" theme reflects the degree to which patterns changed and how children helped. The child's age, family support and resource availability, prior family patterns, family composition, and mother's illness level influenced pattern changes and how much children helped at home. Children were shielded from the impact if patterns did not change much. Some parents took extensive measures to minimize changes to routines, especially for the children.

Some children noticed little change in patterns. Others experienced a major impact. A young boy "just played" as he normally had and others who said they were not very aware of what was going on also continued their activities as before. They did not feel much impact or sense much concern. A teenager said "(life) just continued." On asking his mother how things had gone after her chemotherapy, she usually said "good" and "that was about it." He realized that his parents took the situation more seriously than he did, and said that he would be more supportive now.

While some children were quite flexible and recognized the increased demands and need for patterns to change, change was still stressful. Two school-age sisters said, "We can't do a lot of things with mum anymore...she's got to rest up a lot for our concerts and science fairs and everything." Grandparents came to help and they went to the grandparents' home. Although fond of them, they did not want to go. For other children, having father home more was not always easy. He "couldn't get the baby to stop crying and made us go to bed early." He would not let them watch television as they usually did, partly because he wanted to watch sports.

Changes in patterns were noticed, and even minor shifts were difficult and upsetting. Children were bothered when mother was not there to say goodnight, or snacks were not ready as usual. A child said "it was weird" when people other than his mom drove because she usually stopped at stores on the way home. In one family, it was difficult for teenagers to ask their father for money because "he never realizes about money - like why do you need money?"

Major efforts were made to keep patterns as normal as possible. Other family members and friends pitched in. "My grandma sort of took her place so that took care of it. (Because of her help) I'd say that things stayed the same." Some families hired help which reduced some of the burden. "My mom did everything and when she was sick the cleaning lady did everything so he [dad] didn't have to do anything." However, hiring assistance was not problem-free:

(cleaning lady) was overprotective...it wasn't our house anymore. She tried to help but it bugged me...the idea that she had to be there. You can't feel really comfortable lying around in your underwear...you get used to her. She made mom eat when she didn't want to eat.

A teenager talked about feeling good that she had adapted to the changes, but she was concerned that things would never be the same. She felt she had done well at "accepting and dealing with the changes and adapting to what your lifestyle is going to be like and noticing that your mom isn't the same and she isn't going to ever be the same."

Some children were not expected to help, while others took on major responsibilities and tasks. In some cases this was difficult, because of the competence and time required that took away from doing 'normal' things and being with peers. They did not always want to be home and preferred to be with friends, but many felt they needed to be there and felt guilty they were not home. "I really didn't go out

that often anyways because I wanted to stay with my mom and then the one time I go out and that happens. I think I should not go out anymore. So I felt really bad.”

In some families, children's help was essential. Rather than others rallying to keep patterns normal, children as young as seven years were expected to help keep life going. Other activities were curtailed and they had to help with or take over child-care and housekeeping tasks. Some children found the added responsibility difficult. Two young school-age girls said, “Sometimes it was hard because we had to take care of our little sister... Sometimes we couldn't get her to stop crying and he (father) would get kind of mad.” The young one had to clean and set the table, warm the baby's milk, and make her own snacks. If they said no, their father would get “real mad... We could barely play with our friends because daddy keeps saying no.” Some teens described their added responsibility. “The younger ones couldn't do as much, but being the oldest you had to assume responsibility.” A young adolescent who took on jobs her mom normally did gave up activities she enjoyed and her school work “took a beating”:

I grew up really fast because all of a sudden you are expected to do so much but you aren't used to it but you adjust... You don't act like a normal 12-year-old anymore. Your train of thought and everything is just totally different than others your age 'cause you have been through so much... Like everything else isn't like a big deal anymore.

An older boy also found the helper role awkward. He helped with housework, cooking, shopping, and driving his mother to treatments. “I have to spend the time at home and I'm not used to spending a lot of time at home.” He preferred that visitors stayed elsewhere.

Some children said that it was difficult when the focus was so much on the mother. “You are supposed to be concerned for this person, but it bothered me because no one ever asked how you are doing as opposed to the person who is sick.” It also bothered some children when people kept asking about the mother, “stop asking me.”

Children were, therefore, impacted in major ways when patterns changed. Although many families tried to minimize pattern shifts and to shield children and themselves, even subtle changes were significant for children. To keep things going, children were often expected to help out and to take on major tasks and responsibilities. They were not shielded from the impact.

Discussion and implications

Most children are considerably impacted by a mother's cancer and chemotherapy, particularly by what they see, hear, and read, by the emotional tone sensed in the family, and by changes in patterns. Shielding reflects ways to protect self and others. Protectiveness on the part of children and others, primarily the parent, to a minor or major degree, plays a major role in how children cope. Because of the stressful nature of cancer and chemotherapy and the implications of these circumstances, shielding to minimize the impact of the situation is common. It is not only children who *shield* themselves by whether information is sought or avoided and whether concerns are shared or not, but others *shield* children by whether and what they tell them and whether normal family patterns can be maintained.

Similar patterns of shielding in this study were reported in Brown's (1992) study of adolescents coping with advanced cancer in a parent. They used shielding to alleviate fear about the future and to allow them to get on with mastering tasks of separating from family and moving toward autonomy and independence. They shielded themselves by deliberately not thinking about the situation at home, by taking breaks away from home to be with friends, by trying to maintain the old view of their parent, by hoping that the parent would recover, and by maintaining a positive attitude that recovery could happen. Although not labelled as such, shielding and being shielded were also identified in other studies. Hilton and Elfert (1996) described how parents tailored what children were told to minimize

the impact and what major efforts were taken to keep children's patterns as normal as possible to decrease stress. McTaggart (2000) described the mutual caring and protectiveness of mothers and daughters in order to minimize the threat for themselves and the other. Maintaining a sense of normalcy and limiting conversations on the cancer experience, particularly related to prognosis and possibility of death, were common strategies. The theme “Business as Usual” in Issel et al.'s study (1990) emphasized how children downplayed the illness by acting normal and doing regular things.

Wide variations in shielding and being shielded were evident which were influenced by age and developmental level, how ill the mother was, and how the illness impacted on her activity, family composition, prior family patterns, availability and willingness of others to help, and the family's financial resources. A few children were strongly protected from being made aware of the situation through what they were told and what they noted about pattern shifts. Being shielded influenced the child's behaviour in a major way. If children did not sense stress or particularly note visible changes in the mother and the household, there was no need for them to shield themselves. Most children were made aware of the situation and few were exposed to overwhelming information. It was less common for children to actively seek more information than what they were told, unless they passively gained information from others or from school materials, television programs, and the internet.

Shielding is different from denial, which according to Kalish (1985) is an unconscious avoidance to insulate the self from the emotional impact that death is a reality. Shielding is a way to alleviate fear about the future and to allow children to get on with life. In itself, shielding and being shielded is neither positive or negative, particularly when used in moderation. If used too much or too little, issues can arise. When children feel uninformed or out of the loop because of excessive shielding or they feel ill-prepared and overwhelmed because of insufficient or inadequate shielding, problems can arise.

Elsegood (1996) describes opposing views about whether or not a child should be told bad news: the ‘protective approach’ which seeks to shield children from knowing bad news and the ‘open approach’ which recommends that children should be told. Decision-making is even more difficult when the bad news is associated with stigma or when it includes uncertainties. Elsegood emphasizes that disclosure does not have to be an ‘all or nothing’ situation and that honesty and complete openness are not the same thing. Furthermore, it is important to recognize that children become aware of bad news or that something is not quite right, even when they are not openly told about the situation or if information is concealed. Although it is distressing for children to hear bad news, it is likely that less distress will be experienced when information is given in a clear and honest manner (Jewett, 1994). The argument that children do not need to be told because they do not have the capacity to understand abstract concepts ignores the influence of the child's experience on his/her level of comprehension. Whittham (1993) emphasizes that children can become actively involved and can benefit from helping themselves when they are openly told about the situation. Disclosure is considered to be beneficial (Rosenheim & Reicher, 1985). Elsegood emphasizes that once bad news has been broken, then children can and should be given the opportunity to be actively involved in deciding what else they are told. Furthermore, he states that proponents of the view that children should be told only when they ask, or appear to want to know, rely too heavily on children being able to express themselves and depend too much on their own ability to recognize covert expressions. He goes on to say that these children would then be subject to isolation, confusion, and anxiety until they feel able to express themselves or until their disguised fears and concerns are recognized. Elsegood also describes how children often try to protect their parents from being upset and also try to protect themselves from what they think will be their parents' response.

Being shielded was also highly influenced by the nature and degree that children's patterns had to change. Needing to change patterns is highly stressful; children wanted to maintain their routines. The importance of keeping life normal has been emphasized by others (Hilton, 1996; Issel et al., 1990). Although some families minimized or decreased the disruption, major change was evident in others. When the mother was unable to function as usual in her normal roles, particularly at home because of the effects of chemotherapy, the impact on the family was considerable and the impact on the child significant. The children who had to take on major household responsibilities to keep the family going were significantly impacted. They did not feel protected or shielded, but felt stretched and often unprepared for the responsibility they had to take on. Although many girls tended to

take on more household and childcare responsibilities than boys, this was not always the case. School provided a normalizing environment or perhaps a refuge for the children. When mothers had chemotherapy during the summer months when children were likely out of school, the children were then exposed to the cancer's impact 24 hours a day. Although the flexibility of their time during the summer was helpful, they would then not have had the regular school pattern in which to escape.

Maintaining normalcy included trying to put the situation out of mind and not drawing attention to it. Children purposefully avoided talking about it with others. It was common that children shielded themselves by not talking with others about their fears, or by carefully monitoring what they said. They did not know what to say, but they also did not think their friends would understand and, therefore, did

Table Two: Recommendations for children, parents, and health professionals to help children cope with parental cancer

For children

Raise awareness and assist children to know/understand more about their situation

- have materials accessible to parents and children in various formats (video, print, computer, internet) with attention to age, developmental level and culture
- encourage attendance at cancer agency/treatment centres, e.g. art therapy, children's sessions

Assist children to emotionally cope with situation

- help them be aware that reactions such as anger, fear, and guilt are normal as is use of comforting measures, e.g. teddy bears and blankets
- encourage other ways to reduce stress
- assist children to balance home demands with "being a kid." This may require negotiation with parents to find a balance and reduce children feeling guilty when not at home
- encourage them to talk about their worries and talk with others who have gone through it
- development of peer cancer support groups can prove helpful

For parents

Assist parents to know how and what to tell their children

- identify suitable resource materials
- help parents work through own situation in support groups
- encourage reasonable openness: guide what is appropriate for different age levels
- help parents be aware of possible regressive behaviours in their children
- encourage parents to bring child/children to cancer agency

Assist parents to understand usual responses of children

- hold sessions that include information on frequent responses of different aged children
- increase awareness of children's dislike for change and how to distinguish what must change from what can be kept more stable

Assist parents in working with the child's emotional responses

- encourage them to provide quiet opportunities for families to work together
- increase parental awareness of resources for children, e.g. music and art therapy, counsellors
- encourage parents to discuss and work out practices that might be disturbing or meaningful to children, e.g. when mother is hospitalized, have a picture of her close by and have her call home each night to wish child(ren) goodnight

Assist parents in how to involve children and what is reasonable to expect of children at home

- help them realize what might be appropriate versus burdensome for children considering situation, past practices, family patterns, and beliefs
- help children understand their value and importance in doing what they are asked
- encourage parents to alert teachers to the situation so they can be better prepared.

For nurses and other health care professionals:

Assist health professionals to be more prepared to work with parents and children

- provide in-service programs focusing on family and children needs and ways to work with them
- encourage greater awareness of materials/resources and their quality that might be recommended for parents and children
- develop programs/systems that would be helpful to parents and children such as the creation of a "buddy" system where women can be supported by other women and where spouses/partners and children can talk with counterparts
- assess parents regarding their need for information and support for their children
- facilitate information access by identifying ways to help parents access useful information
- include children when appropriate and feasible
- help decrease disruption and increase continuity when possible by helping parents find out what resources are available that might decrease disruption such as the availability of childcare services at the cancer agency or in the neighbourhood
- further study is needed of children's responses to parental illness from the child's perspective as well as studies that test interventions as listed above

not talk with them about their concerns. They did not want to cause anxiety in others by bringing up the subject. Keeping silent was like an extension of some family patterns about not talking about the situation. Although they may not have shared their feelings or concerns, the stress was evident in their behaviour and the behaviour of their family. Some children were aware of their emotional and behavioral responses to the situation and to that of others, particularly in their family, and they may or may not have modified their own behaviours accordingly. Other children may have recognized heightened stress levels in themselves and others, but they continued to react to the situation and to others. This was also noted in other studies including McTaggart's (2000) theme of "Intending and Acting".

We cannot tell the long-term impact on children, but some children in this study were impacted by the illness situation long after treatment was over, particularly those exposed to the raw realities and intensities in the situation. For them, initial resentment was not unusual, and for others the mother's illness gave them new perspectives about themselves. Having to grow up fast was noted, particularly by children who had to take on major household tasks.

The findings should be viewed in light of the research limitations. The sample size was small and had little cultural diversity. Interviews

with a larger sample of children may have yielded additional information and fleshed out the themes. The findings suggest the importance of shielding to children and families and that inappropriate use or overuse and underuse of shielding and being shielded can be problematic. The findings also suggest implications for clinical practice and research. As health professionals, we have a responsibility to make a difference in the lives of children and families. Several recommendations for children, parents and health care providers are offered that illustrate how children can be appropriately informed and involved in situations where mothers require chemotherapy (see Table Two).

Acknowledgements

The authors want to express appreciation to the other co-investigators who assisted with the planning, implementation, and analysis of the large study (J. Brown, A. Ho, G. Heaps, E. Holwerda, M. Rechner, S. Sample, and G. Tennant), the other research assistants (L. Esson, P. Fisher, A. Lee, and L. Unger), and to the women, men, and children who participated in the study. This study was supported by the Canadian Breast Cancer Foundation.

References

- Birenbaum, L.K., Yancey, D.Z., Phillips, D.S., Chand, N., & Huster, G. (1999). School-age children's and adolescents' adjustment when a parent has cancer. *Oncology Nursing Forum*, 26(10), 1639-1645.
- Brown, J. (1992). **The experience of teenagers living with a parent with advanced cancer.** Unpublished Master's thesis, University of British Columbia, Vancouver, BC.
- Compas, B.E., Worsham, N.L., Epping-Jordan, J.E., Grant, K.E., Mireault, G., Howell, D.C., & Malcarne, V.L. (1994). When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychology*, 13, 507-515.
- Denzin, N., & Lincoln, Y. (Eds.). (1994). **Handbook of qualitative research.** Thousand Oaks, CA: Sage.
- Elsegood, J. (1996). Breaking bad news to children. In B. Lindsay & J. Elsegood (Eds.), **Working with children in grief and loss** (pp. 32-55). London, UK: Bailliere Tindall.
- Erlanson, D.A., Harris, E.L., Skipper, B.L., & Allen, S.D. (1993). **Doing naturalistic inquiry.** Newbury Park, CA: Sage.
- Hilton, B.A. (1996). Getting back to normal: The family experience during early stage breast cancer. *Oncology Nursing Forum*, 23(4), 605-614.
- Hilton, B.A., Brown, J., Ho, A., Holwerda, E., Rechner, M., & Sample, S. (1996). **Creative intervention report: Developing creative interventions to assist young families to meet the challenges of chemotherapy for breast cancer.** Unpublished manuscript, University of British Columbia at Vancouver.
- Hilton, B.A., & Elfert, H. (1996). Children's experiences with mothers' early breast cancer. *Cancer Practice*, 4(2), 96-104.
- Howe, M.J., Hoke, I., Winterbottom, M., & Delafield, D. (1994). Psychosocial effects of breast cancer on patient's children. *Journal of Psychosocial Oncology*, 12, 1-21.
- Hymovich, D.P. (1993). Child-rearing concerns of parents with cancer. *Oncology Nursing Forum*, 20, 1355-1360.
- Issel, L.M., Ersek, M., & Lewis, F.M. (1990). How children cope with mother's breast cancer. *Oncology Nursing Forum*, 1(suppl.), 5-13.
- Jewett, C. (1994). **Helping children cope with separation and loss.** London, UK: Batsford.
- Kalish, R.A. (1985). **The final transition.** Farmingdale, NY: Baywood, Publishing Co.
- Lewis, F.M., Zahlis, E.H., Shands, M.E., Sinsheimer, J.A., & Hammond, M.A. (1996). The functioning of single women with breast cancer and their school-aged children. *Cancer Practice*, 4, 15-24.
- Lichtman, R.R., Taylor, S.E., Wood, J.V., Bluming, A.Z., Dosik, G.M., & Leibowitz, R.L. (1984). Relations with children after breast cancer. The mother-daughter relationship at risk. *Journal of Psychosocial Oncology*, 2(3/4), 1-19.
- Lincoln, Y., & Guba, E. (1985). **Naturalistic inquiry.** Beverly Hills, CA: Sage.
- McTaggart, D.L. (2000). **Breast cancer experience: Mothers, adolescent daughters and the mother-daughter relationship.** Doctoral dissertation, University of British Columbia, Vancouver.
- Nelson, E., Sloper, P., Charlton, A., & While, D. (1994). Children who have a parent with cancer: A pilot study. *Journal of Cancer Education*, 9(1), 30-36.
- Rosenfeld, A., & Caplan, G. (1983). Adaptation of children of parents suffering from cancer: A preliminary study of a new field for primary prevention research. *Journal of Primary Prevention*, 3, 244-250.
- Rosenheim, E., & Reicher, R. (1985). Informing children about a parent's terminal illness. *Journal of Child Psychology and Psychiatry*, 26, 995-998.
- Shands, M.E., Lewis, F.M., & Zahlis, E.H. (2000). Mother and child interactions about the mother's breast cancer: An interview study. *Oncology Nursing Forum*, 27(1), 77-85.
- Strauss, A., & Corbin, J. (1990). **Basics of qualitative research: Grounded theory procedures and techniques.** Newbury Park, CA: Sage.
- Wellisch, D.K., Gritz, E.R., Schain, W., Wang, H., & Siau, J. (1991). Psychological functioning of daughters of breast cancer patients: Part I: Daughters and comparison subjects. *Psychosomatics*, 32(3), 324-336.
- Wellisch, D.K., Gritz, E.R., Schain, W., Wang, H., & Siau, J. (1992). Psychological functioning of daughters of breast cancer patients: Part II: Characterizing the distressed daughter of the breast cancer patient. *Psychosomatics*, 33(2), 171-179.
- Whittham, E.H. (1993). Terminal care of the dying child. Psychosocial implications of care. *Cancer*, 71, 3450-3462.
- Zahlis, E.H. (2001). The child's worries about the mother's breast cancer: Sources of distress in school-age children. *Oncology Nursing Forum*, 28(6), 1019-1025.