HELENE HUDSON LECTURE

Young mothers’ engagement with the cancer care system

by Judith T. Strickland

ABSTRACT

For young women who are mothers, the cancer experience is distressing, not simply because of their age or concern for themselves, but also because they are worried about the potential loss of years with their children and ability to mother them. While nurses are engaged with young mothers who are cancer patients, these mothers are engaged in taking care of their children. They juggle the demands of diagnosis and treatment with fulfilling their role as mothers.

The aim of this paper is to report selected findings from a grounded theory study involving 18 young mothers, and to promote dialogue with nursing colleagues about strategies for care that may make young mothers’ journey through cancer a little easier for them and their families.

Young mothers are frequently the principal caregivers of their children (Fitch, Bunston, & Elliot, 1999; Rayson, 2001). For young women diagnosed with cancer who are mothers, the cancer experience is distressing because they are concerned about their children, the potential loss of years with their children, and their ability to mother them (Billhult & Segesten, 2003; Coyne & Borbasi, 2006; Dunn & Stenginga, 2000; Elmberger, Bolund, Magnusson, Lützén, & Andershed, 2008; Helseth & Ulfsaat, 2005).

When mothers become cancer patients they are unintentionally placed in the difficult situation of trying to be good patients, as well as good mothers (Thorne, 1990). What it feels like for young mothers to be cancer patients and how we can support them during this frightening, difficult time is important to know. At present, young mothers fall outside of the more frequently recruited oncology samples. Furthermore, research suggests that the cancer care system does not adequately address the needs of young women and mothers as patients (Barnes et al., 2000; Elmberger, Bolund, & Lützén, 2000; Elmberger, Bolund, & Lützén, 2005; Elmberger et al., 2008; Gould, Grassau, Manthorne, Gray, & Fitch, 2006).

Usual cancer care services do not match or fit the needs of young mothers and women (Gould et al., 2006).

Being diagnosed with cancer can be devastating. The uniqueness of the situation for young mothers is related to their role in the care of their children and relationship to them. This paper is based on a research study conducted with young mothers who were diagnosed and treated for cancer in Atlantic Canada. I am from the province of Newfoundland and Labrador. I was living in another part of Atlantic Canada for a part of the time of this study.

The purpose of the study was to expand our understanding of the experiences of mothers, as a patient population in oncology, by focusing on their experiences with cancer, especially within the first two years after their diagnosis. The impetus for this research study was twofold; it was personal and it arose out of a long-standing clinical practice issue—how to support mothers diagnosed with cancer.

Research question

The research question for this study was, “What are the experiences of young mothers recently diagnosed with cancer?”

Research method

A qualitative research approach was used employing the Glaserian Grounded Theory (Glaser, 1998) method to investigate how young mothers manage their roles and responsibilities to their children while dealing with their cancer diagnosis and treatment. Ethics approvals and assistance to recruit from within the cancer care system in the study region were obtained.

The young mothers

The mothers were between the ages of 27 to 45 years at the time of their cancer diagnosis. Sixteen of them were diagnosed with breast cancer, and two with non-ovarian gynecological cancer. All of the mothers had surgery as the primary treatment modality. The majority of them had mastectomy as opposed to lumpectomy; some had a bilateral mastectomy. A few of them already had breast reconstruction, and almost all of them were planning to have this surgery done. Fifteen of the 18 mothers received chemotherapy, 11 received radiotherapy, nine received both chemotherapy and radiotherapy, two were found to have triple negative breast cancer, and one was in a clinical trial.

Sixteen of the mothers were married. One mother was divorced, and one was going through a divorce. One mother’s husband was working in another province and a few other husbands travelled for work, but returned home in the evenings. Three of the mothers had experienced fertility problems prior to successfully having their children.

Each of the 18 mothers had between one to four children. The children ranged in age from infancy to emerging adulthood. The majority of children were pre-school or school age.

Three of the young mothers had mothers who had been diagnosed with cancer in the past and were doing well since...
diagnosis. However, these mothers were diagnosed at an older age in contrast to their daughters. One of the young mothers was quite adamant that being diagnosed when one's children are raised is quite different from being diagnosed when one has young children at home. She was an adult when her mother was diagnosed with cancer. She explained the difference this way:

Mom would say, I know how you feel, and I would say, no mom you don't because when you had breast cancer your daughters were, you know, 31 and 34. We were grown adults. It is completely different for me, I had babies. So it is not the same, in some ways it is the same, but it is not the same experience.

**FINDINGS (SELECTED)**

The following discussion of findings is more focused at the descriptive than conceptual level of interpretation, as presented at the lectureship given last October at the 2014 Annual Scientific Conference of the Canadian Association of Nurses in Oncology. A conceptual representation of the findings, as well as detail about the Grounded Theory method, will be available in a separate publication.

The main concern of the young mothers, who were also now “cancer patients,” was how the cancer situation was going to emotionally and psychologically affect their children. They want to be there to raise their children. One of the mother’s first thought reflects the care and concern all of the participants displayed toward their children. “My first thought, as soon as I was told I had cancer was, ‘I can’t, I can’t, I have three small kids. You know, I have to be there for them.’

The following headings represent categories that provide a beginning understanding of how the young mothers address concern about their children and deal with their own feelings about being diagnosed with cancer. Nurses are ideally situated to support young mothers when they engage with the cancer care system for diagnosis and treatment and this understanding can help them provide appropriate support.

**Emotional protecting**

Emotional protecting emerged as the overall way in which the mothers addressed their concerns about their children possibly being emotionally affected by their cancer. Emotional protecting means, in this situation, to buffer the effects of the cancer on children and family, and for mothers to stay emotionally strong themselves. Even immediately at diagnosis, the mothers began to protect their children. For example,

That day, the first thing was the kids, and actually my first thought, I found out on June 8, and my oldest son was in grade 7 at the time; he is in grade 8 now. He had exams the following week for the first time in his life and he finished exams June 18. So the first thing I looked at my husband and said, ‘We don’t say anything to anybody until June 18, because there is no sense letting the kids know about this until he finishes exams.’

In order for young mothers to be able to emotionally protect their children, they have to come to terms with the diagnosis of cancer. They face this life-threatening diagnosis.

**Facing a life-threatening diagnosis**

Facing a life-threatening diagnosis refers to mothers coming to terms with their own mortality. Also, it suggests that mothers do tremendous mental work in order to stay emotionally strong, despite their fears, so they can emotionally protect their children.

It is kind of hard to believe initially. Right. Sometimes I feel like I am going through the motions, but I don’t know how well it sunk in. Sometimes I feel like I am not coping too well, but yeah, it is just like it is unbelievable for me… I can’t believe that it is happening to me, right. You know you hear the stories, but when it happens closer to home and it hits you exactly... you kind of... it’s wrong and I guess that I would say that sometimes I sit back and think... Jesus, this is me and it is not good.

Mothers are fearful that they might not get to see their children grow up; they might leave their children motherless. “The fear, you know, it never goes away. You know, I keep saying that if I can just get another 10 years and get them all through grade 12 I could breathe a little easier.”

Part of facing cancer is being able to control one’s emotions. Mothers immediately began to work to control their emotions. They controlled their emotions because they did not want their children to see them crying and upset.

The night before I saw my family doctor (to get the biopsy results) I was going to bed and I stopped at my kids’

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bedrooms, as a mom I guess, and you know, saw them sleeping and I had my cry that night. I kind of sat on the edge of their bed without my husband and I probably cried for about two hours, and just kind of felt, I know I have it and I just can’t even go there to imagine. And I think that was the only time that I let myself go... I didn’t let myself lose it after that.

Mothers decided how to tell their children about their cancer and when they would tell them. Mothers considered the ages of their children and used age-appropriate language such as “being sick inside.”

**Undergoing treatment**

When mothers undergo treatment, they engage with the cancer care system in an intensive way. This is the case primarily when they are receiving chemotherapy and/or radiotherapy. When patients have their first form of treatment, which is typically surgery, they may or may not be admitted to hospital.

All but one mother in this study were admitted to hospital for at least one night. For the mother who was not admitted, she has a health care professional in her immediate family, and this played a part in the decision to allow her to go home after having her surgery as a day patient.

Chemotherapy is associated with side effects such as nausea and fatigue. Such effects can be distressing for any patient. However, in the context of mothers, it can suggest to their children that mommy is very sick, and cause the children to worry. For mothers, it can make it difficult to mother their children in their usual way, which can be upsetting for the mothers themselves and reinforce to children that mommy is very sick.

Chemotherapy also necessitates taking precautions. For example, in the case of neutropenia, one mother explained:

*When you were kind of on those 7 to 14 days, you had to kind of keep away from him because of kids with bugs and whatever. He was four, so you had to keep telling him to wash his hands, and you had the sanitizer everywhere, but kids are kids. They are picking their nose and you know, whatever.*

It is important to reinforce with children the importance of good hand hygiene and to provide help for them to carry out the task.

One of the biggest issues these mothers described about going through chemotherapy is suffering hair loss. All 15 mothers who received chemotherapy lost their hair. One mother described her reaction this way:

“When I lost my breasts I did not cry. When I shaved my head I did. I felt like my breasts betrayed me and they were going, but my hair was just incidental or a victim or collateral damage.”

Often, hair loss is a visible sign of cancer. One mother said, “When you look sick, people treat you differently, too.” Another mother explained:

*I didn’t want other kids coming up to the [my] kids and saying, oh, your mom is going to lose her hair. That was really important to me that they never had to go through that. And they didn’t... I didn’t want the kids singled out having a sick mom.*

Findings from this study suggest that children can be a great source of support to their mothers throughout the cancer experience, including the time when the mothers were losing their hair or deciding to shave their heads.

*They knew that I was going to get my hair shaved, and when we came to (place) it was done at one of the hair technique places, and my daughter was there when I had it done. She watched and of course she was positive. And my son was just kind, he kind of thinks it is kind of cool, you know what I mean, at that teenage age. So, they are comfortable with it... but he does want me to put on my wig when his friends come.*

Eleven of the mothers received radiotherapy. In some ways, the mothers found radiotherapy easier than chemotherapy. For example, the side effects of radiotherapy were milder than those for chemotherapy. The hardest part about having radiotherapy was the need to travel to receive that treatment. It was difficult for the mothers to be away from their children, especially when their children were in school. The mothers continued to mother their children by distance and returned home on weekends or as often as possible.

Eight of the mothers lived too far away from the cancer centre to return home every evening. They had to temporarily relocate to the provincial capital city for their radiation treatment. Remarkably, five of the eight travelled home every weekend to be with their children and husbands. Some of them got a flight and others drove by themselves for a minimum of three hours one way. Three of the participants were able to have their children and husbands accompany them for the duration of their treatment.

*I used to get up Monday morning, I used to come in on the weekends and I would get up and drive in Monday mornings and get my treatments in the evenings by myself. Then I would do my treatment in the morning on Friday and I would drive out for the weekend by myself. So I travelled all by myself and I stayed by myself.*

**Maintaining family routines**

It is very important to these mothers to maintain family routines, as much as possible, because it provided a sense of normalcy and emotional security for their children and family. Keeping family life as routine as possible, however, required significant effort, which may go underappreciated. Receiving treatment can interfere or challenge efforts to maintain a sense of routine in family life. Mothers diagnosed with cancer arranged it so their children could continue to do the things they normally do. They pushed against fatigue, got up and got their children ready for school, went to sporting events, etc. “I don’t know if God only gives you what you can handle... because there would be days when I couldn’t think that it was possible to get up and I got up and took care of them.”

These mothers went to great lengths to make sure their children’s needs were met. Maintaining family routines involved mothers continuing to be active in their mothering role despite cancer. One mother explained that, while her husband and parents were very helpful in taking care of the children and keeping the house tidy and clean, she wanted to carry out her mothering role during treatment.
families. It was important to them because it was part of tak-
as something important and routine for them to do for their
be challenging. Mothers described how they and their children
hugging, lifting up, and bathing children can
interfere with a mothers' ability to be as physically close to
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cancer normally involves having surgical drains, sometimes
invoking emotions. Often there is a sentimental feel-
ing about being ill with a life-threatening illness such as cancer.

Taking care of children and dealing with treatment-related
fatigue made mothers feel very tired, yet, at the same time, they were reluctant to ask for help.

I guess one of the challenges that I had is, it is hard to ask for
help sometimes... I mean she [child] wants your attention all
of the time. So, I mean, it is hard to call somebody and say, I
am not doing well right now, can you help me?

Birthdays, holidays, and other special times are important
aspects of family life. One mother said it was really impor-
tant to her to keep her treatments on schedule because she was
planning her daughter's birthday party and didn't want to end
up needing to receive her chemotherapy on that day. Another
mother described making sure her children had what they
needed for a Christmas activity at school.

Like, even when I went in Christmas time, the week I was
in hospital, they had 12 days of Christmas at school for the
younger two, for primary and elementary. So one day they
had to wear red and white, then they had to wear a Christmas
hat, and you know, every day there was something on the go.
So before I went in, I made sure, especially if there was some-
ing different or something like that. And people said, like,
your husband, he can do that, and I am like, yes, he can, but
he has to work full-time, and I am in hospital and there are
three kids, and whatever I can do to help him, and especially
when there is something like that, like being every day.

Finding new ways to be close

Cancer invokes emotions. Often there is a sentimental feel-
ing about being ill with a life-threatening illness such as cancer. Being close feels very important at such an emotional time.

Finding new ways to be close is particularly relevant in the context of receiving treatment. For instance, surgery for breast
cancer normally involves having surgical drains, sometimes
for weeks post-operatively. The surgery itself and/or drains
can interfere with a mothers’ ability to be as physically close to
their children. Hugging, lifting up, and bathing children can
be challenging. Mothers described how they and their children
had to find new ways to be close and show affection. Mothers
may need to teach their children to hug more gently while
mommy’s “boobie is broken” as some children referred to it,
and create a new way to give kisses (e.g., on the forehead).

Chemotherapy is commonly associated with episodes of
neutropenia. When patients are receiving this type of treat-
ment, usually they are advised by their cancer care profes-
sionals to follow precautions. Young children may need to
be reminded to wash their hands and helped to do it. In this
study, many of the mothers said they placed bottles of hand
sanitizer in the kitchen and porch to remind everyone to clean
their hands often.

There were times, however, when following precautions
took a toll on being close. For example, one mother described
feeling torn between being physically close to her daugh-
ter and having to protect herself during chemotherapy. Her
daughter was 11 years old and had developed a strep throat
infection. It was not only the issue of having to distance her-
self from her daughter, it was the fact that she could not attend
to her daughter who was sick. This is her account:

I felt bad at the times when my daughter did have strep
throat and that, because I would say you know, mommy is
going to go in and lay down on the bed and watch TV, rather
than kind of be sitting next to her, you know that kind of
thing. So that was kind of, that was hard because like, I want
to be there, as a mother, to nurture her when she is sick, and
here I was feeling like oh my goodness, I don’t want to get too
close to her, because you know, I don’t want to get really sick
myself, you know. I was kind of torn that way.

Mothers of pre-school age children described their chil-
dren staying physically close to them while they were sick.
Furthermore, their children showed affection to them. For
example, “I mean ___ [name of son] would come to bed and
just (say) mom I want to cuddle, or let me rub your back, let
me rub your legs; let me rub your arms right. I mean that is a
five year old”.

She further explained with pride that her children were
“glued to my hip.” She did not mind her children being so
close. They had been like it before her cancer, but she noticed
that it occurred more often since her diagnosis. She said,
“Everything is mom, mom this and mom that. I mean the
youngest; he wouldn’t even get out of my arms”.

Travel for radiation treatment was a frequent reason why
mothers had to find new ways to be close to their children. The
physical distance incurred because of travel made it prohibi-
tive for some mothers to return home to their children every
evening after radiation treatment. Finding new ways to stay
close during radiation treatment involved returning home as
often as possible and staying connected by cell phone while
they were away for treatment. Mothers stayed in touch with
their children every day while away for radiation treatment by
talking on the telephone. One participant used Skype® so she
could see her children every day.

Creating a new normal

Creating a new normal coincides with the cancer care phase
referred to as follow-up or post-treatment. Usually, this occurs
when patients have fewer appointments with their cancer care
team because treatment is finished. It is a time to make the
transition to follow-up care, to assess for lingering side effects from treatment, and to check for signs of cancer recurrence. For the participants of this study, this phase began when they completed treatment or finished the most intensive treatment (e.g., chemotherapy and/or radiation), and were taking longer-term therapy (e.g., Tamoxifen®) such as in the case of breast cancer.

Mothers continued to protect their children during this time of transition. For instance, one mother said she refers to her Tamoxifen pill as a vitamin, so as not to worry her daughter. Another mother described that when she received a message from her family doctor’s office, she had to reassure her sons that the message was only about the flu vaccine.

Mothers expressed the desire to get life back to normal. However, they realized the old normal is gone. Cancer had changed their worlds. They felt like there was no going back to normal-normal because it was not possible. Yet, most of the mothers indicated an optimistic attitude about life, despite cancer. For example, one mother said, “I have a different attitude. I was kind of like a person who was always worried and high strung. You know everything had to be perfect…but now it is kind of like I don’t care...” In contrast, another mother said she feels almost pessimistic since her cancer treatment finished because she is worried about the cancer recurring. “I don’t know if I want to say pessimistic, but almost more pessimistic than I was before now. I am a little nervous about stuff.”

All of the mothers stated or implied that they worry about their cancer recurring. However, they enjoy taking care of their children and moving past having had cancer.

IMPlications foR oncology nURsing

When young mothers engage with the cancer care system, one of their very first contacts is usually with a registered nurse. Nurses working within or outside of cancer centres all have valuable contributions to make to the care of young mothers and all patients diagnosed with cancer. In the case of young mothers, it is important for nurses to be aware of their unique needs, as patients diagnosed with cancer. For instance, mothers want to emotionally protect their children, as they deal with the diagnosis of cancer and side effects of treatment. They want to be good patients and good mothers. However, they may put the needs of their children above their own. This approach could put mothers at increased risk for infection or worsening of nausea and vomiting and/or fatigue, for example. Nurses should be sensitive to young mothers’ efforts to take care of their children, and explore with them ways they can ensure their children’s needs are met without compromising their own health and safety.

When nurses support young mothers, they help support their children and families. Young mothers may not want or need much help. They may simply need some accommodation when appointments are being scheduled. Nurses can assess for problems, provide support and counselling, recommend resources, and make referrals (such as to a social worker), as needed. It is important to make mothers’ cancer experiences as favourable as possible for their sake and their families, most especially their children.

Acknowledgements

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References


