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Broadening our perspective on spirituality and coping among women with breast cancer and their families: Implications for practice

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Abstract

The purpose of this paper is to illustrate the role of spirituality in coping among women with breast cancer and their families. This phenomenological study was guided by family systems theory and the recognition that a family is a complex system whereby family members interact with one another as well as with the outside world. A change in any of these interactions/relationships can affect the rest of the system, and the diagnosis of breast cancer in mothers within the family system is no exception. Five families (five women, five men and six children) comprising a total of 16 participants took part in this study. The women in this study reported using a number of methods to cope with their illness, one of which was utilising their spiritual beliefs. Although they placed a great deal of importance upon their spiritual beliefs, their families did not. The implications of this reality upon nursing practice will be discussed here.

Key Words: Breast cancer, lived experiences, phenomenology, spirituality, women

*Hope is the thing with feathers
That perches in the soul.
And sings the tune
Without the words,
And never stops at all.*

Emily Dickinson (1830-1886)^[1]

Many women in North America will receive a diagnosis of breast cancer this year, as it is the most common cancer diagnosis among women.^[2,3] In fact, 22,300 women in Canada will be diagnosed with some form of breast cancer this year alone; of these 5,300 will die leaving countless loved ones behind. The statistics are equally staggering in the US, where 178,480 women will be diagnosed with breast cancer this year; of these, 40,460 will die of their illness. As a result, there are incalculable numbers of women, men

and children dealing with this diagnosis and trying to cope with it as part of a family system. It is important to understand the impact this diagnosis has upon these individuals and upon the family system itself.

Spirituality is an elusive concept that has been reported to be used by many families to cope with difficult circumstances.^[4] However, few studies have ever addressed this issue by looking at each of the individual family members and then comparing and contrasting their experiences with one another as a family system. In doing so, one can better understand how this system functions and how individuals within this system provide emotional support to one another. Armed with this knowledge, we can then identify where the gaps lie and determine ways in which formal supports on the periphery of this family system (such as healthcare providers) can address these areas of need.

Materials and Methods

This phenomenological study employed family systems theory to explore the lived experiences of women with cancer and their families.

Design

According to Patton,^[5] phenomenology addresses how “human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning” (p. 104). As such, this philosophical approach blends nicely with a family systems approach. Family systems theory acknowledges that, “the family [is] a complex interrelated group that derives meaning through interactions within and between the family and their world” (p. 1620). Both are concerned with meanings an individual within a system shares with other individuals within that system. A family coping with breast cancer is an important case to explore this relationship. To capture such meanings, van Manen^[6] advocates the use of personal interviews as a way of, “exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon” (p. 66); therefore, a semi-structured interview method was used in the present study. The key purpose of this study was to explore the lived experiences of women with breast cancer and their families, with an emphasis on how their relationships changed; how household responsibilities shifted; the stressors they faced and how they coped with it. Although spirituality was not a major theme addressed in this study, it did emerge as being a prominent factor in the lives of these women. This article will specifically address the role of spirituality in their ability to cope with their illness and how their family members' views did not necessarily reflect their own views.

Procedure

Participants were recruited from a community in southwestern Ontario, Canada, once ethics approval had been granted by the academic institution. Purposive sampling was the distinct sampling method used to recruit individuals because of its focus on information-rich cases (meaning those most likely to

be knowledgeable and informed with regard to the phenomenon under study).^[5] Recruitment posters were provided to a key informant, who in turn approached and provided information to women with breast cancer. These women were then asked to seek their spouses and children to see if they would be interested in participating in the study. In addition to this method of recruitment, snowball sampling was also used (whereby individuals learn about the study through word-of-mouth). Once these women identified themselves (and their families) as being interested in participating, the researchers ensured that they met the four study criteria: (1) that they had a formal diagnosis of breast cancer; (2) that these women were between the ages of 40 and 60; (3) that they had completed active treatment (i.e. surgery, chemotherapy and radiation) within the previous 4 years; and (4) that they were married/cohabiting with a partner and have at least one child who was 16 years of age or older. In total, five families participated in this study, including five women with breast cancer, five men (spouses) and six children (two males, four females).

Data collection

Upon consenting to participate, all study participants completed a background questionnaire, which collected information specific to their/their family member's diagnosis, treatments and other general demographic queries. Each participating member of the family completed this questionnaire independently. There were separate questionnaires for the mother with breast cancer, her spouse and her children. These questionnaires essentially sought the same information, but were geared toward the particular individual in question (e.g. the child's questionnaire inquired about the school they were attending, level of schooling, etc.). Once they completed and returned these questionnaires, an interview was fixed (at the time and place convenient to the individual in question) to conduct an in-depth, personal interview. The background questionnaire information for each participant was reviewed prior to the interview to provide some contextual information about the individual and to help guide the line of questioning. The audio-taped interviews were conducted either personally or on the telephone with each family member separately. The audiotapes were transcribed

verbatim to ensure that it accurately reflected the discussion that took place as part of the interview. Through the use of a member-checking process, the participants had the opportunity to review their transcripts and to remove or add information they felt pertinent. This process provided participants with a certain degree of control over any sensitive information they had revealed, and so it was viewed as an important part in this qualitative process. Lastly, the interviewer maintained field notes throughout the interview process to illuminate the contextual factors surrounding each interview. These were completed immediately after each interview by the interviewer in a private space. The content of these field notes focused primarily on the comfort level of the participants, distractions that may have occurred throughout the interview and any other notable circumstances surrounding the interview process. These field notes were used in the subsequent analysis of data.

Data analysis

The data were analysed using Patton's^[5] method of phenomenological analysis as well as Glaser and Strauss' method of constant comparison.^[7] Through multiple readings of the transcripts, themes emerged from the data and were then compared and contrasted by the research team. Any discrepancy in this analysis was subsequently discussed and resolved during follow-up meetings until consensus was reached by the researchers.

Credibility

A number of procedures were put into place to enhance the credibility of data. The first was the fact that an extensive literature review was done to ensure that the knowledge of our research team was most current and up-to-date. Next, the research team used two distinct forms of triangulation, the first being methods triangulation. It involves the collection of multiple sources of data throughout the study (i.e. background questionnaires, personal interviews, field notes and member checks). Secondly, investigator triangulation was also employed to enhance the credibility of our findings. The research team analysed the transcripts for common themes and then came together to discuss and evaluate these themes. Each

of these steps helped enhance the overall credibility of data analysis.

Results

Description of the participants

As previously stated, five families participated in this study including five women with breast cancer, five men (spouses) and six children (two males, four females). The number of children in the five families ranged between one and three, and their ages were in the range of 9-34 years. The men and women in this study were married/cohabiting for 16-34 years, with the average being 24 years.

The mothers ranged in age from 43 to 55 years, with the average age being 50 years. Each of these women had had a unilateral mastectomy and chemotherapy to treat their illness. In addition, four of these women had had radiation, one reporting the need for special wound care treatment as a result of radiation burns that she suffered. Although four of these women were taking Tamoxifen (used as an adjuvant therapy following primary treatment) at the time of this study, all had completed the active treatment.^[11] Only one woman sought a complementary or alternative form of treatment during her illness, which was Reiki (a Japanese relaxation technique involving the 'laying on of hands').^[12] All these women described their family members (especially immediate ones) as being a strong source of support throughout their illness. Only one woman worked outside of her home at the time of this study. This group of women had a high level of academic achievement, with all having at least some college education and three having attained a college diploma ($n = 2$) or a university degree ($n = 1$).

The fathers in this study ranged in age from 45 to 58 years, with the average age being 53 years. Only three of these men described their family members as a source of support, but all of these men listed a number of friends or colleagues whom they looked to for support. Three of these men worked full-time outside of the home, averaging 42 h per week in their jobs, and two of these men were retired. Four of these men had completed some college, including two with a college diploma and one with a university degree.

The children in this study ranged in age from 16 to 34 years, with the average age being 25 years. Three of these children were single, two were married/cohabiting with a partner and one was separated/divorced. Only two of these children were still living with their parents at the time of the study. All but one child described their parents as being a source of support to them and each listed a number of friends and/or extended family members whom they looked to for support. Two of these children were high school students at the time of the study, and one was a fourth year university student (all three children worked part-time outside of school); among the other children, two had achieved a university degree and one a college diploma (all three were working, two full-time and one part-time).

Description of the findings

Although only two women in this study reported regularly attending church, all of them reported that spirituality played an important role in their lives. Some described their spirituality in terms of a direct belief in God, while others were more comfortable subscribing to the notion of a non-specific, amorphous higher power who was present in their lives. When asked in their background questionnaire to describe the specific role spirituality had played in their lives, many of these women referred to the positive contributions it made to their lives and its ultimate importance.

One woman expressed, "Spirituality brings peace, calmness to my life. Prayer gives me strength and it helps me make decisions and gain direction in regard to personal situations. I trust that I am in God's hands and just have faith that things will work out and am determined to make the most out of my life. Even though I do not attend church as often as I should, I still believe your faith is important and even more so since cancer has entered my life."

One woman referred to the fact that her spirituality allows her to believe in the interminable nature of the human spirit. "I believe in a higher power and that our spirits live on after we are gone. This makes it easier to face my inevitable death which hopefully will be later rather than sooner."

Another woman referred to her beliefs in terms of how they guided the way in which she lived her life and her attitudes about others. "I am very spiritual but not in organized religion. I believe in helping others as much as I can and also being kind to others. I feel we share all the same fears and uncertainties. I feel very strongly about being open to other people's race, religion, sexual orientation and not judging others, etc."

It is evident that spirituality was believed to play an important role in the lives of these women.

This importance did not appear to be the case with either the men or the children in this study. In fact, none of these men reported that they currently attended church; however, one man acknowledged he tried to attend church four to six times per year. Only two of these men had commented on spirituality in the background questionnaire. One commented: "I'm not big on organized religion. In that aspect, spirituality plays a very limited role."

Another one referred succinctly to the things he believed related somewhat to spirituality. He stated simply, "Be kind and charitable," and these were the points that he carried through to the rest of his life. One of the six children in this study referred to the fact that she 'sometimes' attended church, however the rest did not. They were a bit more forthcoming than their fathers in their answers pertaining to what spirituality meant to them, although none referred to a belief in a higher power. Rather, they all referred to spiritual qualities that were based on the individuals themselves: "I believe that a strong, positive will can help heal and keep you healthier. For example, believing in yourself as a catalyst to a good life. Spirituality (non-denominational) represents equanimity that a person is perpetually approaching through their lifetime. Although I don't necessarily subscribe to the idea of organized religion, this doesn't mean I am an atheist - I believe people should be free to express their own spirituality in their own way and shouldn't be forced to follow rules, etc."

One child revealed that there was a complete absence of spirituality in her life. She stated, "I am a logical

thinker, spirituality plays no role in my life.” Despite the importance the mothers in these families seemed to place upon their spirituality, this belief was not reflected in the responses of their partners or children.

The women in this study also described the ways in which spirituality assisted them in their ability to cope with their illness. There were a number of ways in which spirituality helped achieve this. At times, spirituality and one's belief in a higher power was experienced in its perceived 'divine guidance', either providing a guiding voice or hand when they needed it most. One woman described the circumstances surrounding her hair loss and the fact that this was an extremely painful experience (both physically and emotionally) for her. While grappling with the decision of what to do about it, she decided to go for a walk, to clear her head. "I'm sitting there thinking about what I am going to do with my hair ... or my head, because I can't stand the feeling [of being bald]. So ... you know, of course um praying helped. So I'm sitting back there, you know, asking God what to do with my hair (laughs). So by the time I got back I decided that I was going to shave it off. So I shaved it. [My daughter] actually shaved it for me. Yeah, so she shaved my head. And it was a, it just felt like a, just like a blanket had lifted up, you know? Just felt like um the weight had lifted by getting rid of the hair."

Another woman described a situation in which she was feeling depressed during the hiatus between chemotherapy and radiation and how she felt that 'doing something' might help her rise out of her despair. She wanted to be needed and felt that this could make a world of difference in her attitude. Shortly thereafter, she received a call from a former employer asking her if she would return to work and help him out of a tight spot for a few days. She described this situation as being 'just what I needed'.

"And then, you know after that [completing the work], I was a bit tired from that and then a week later, I started my radiation or something. So it was just like an answer from somewhere, from God or whatever it would be, right?" She basked in the satisfaction of

having helped someone else out again, rather than being the person who was always receiving help.

When questioned about her background questionnaire response that stated her faith was more important now that she had cancer, one woman described: "That's right. Like I uh I don't get to church as often as, but I still feel I don't think you have to go to church to believe in something and I and I feel it just helps me get through my situation. [So is it something you're more aware of now than before?] Um yeah, because you think if they wouldn't have found this, then things would've gone further on and who knows what position I would have been in you know? You just look at it differently." She seemed to believe that her faith may have played a role in the discovery of her cancer and this thought had renewed or enhanced her faith.

Spiritual lessons in life were also experienced as simply a more positive way to conduct one's life and feel happy about it. One woman described: "I am spiritual, um and by that I mean it's my spirituality about being kind to others and the teachings of the Bible are important. 'Do unto others as you would like done to yourself.' And I think I've always tried to help people as much as I can, that kind of thing, respect other people's beliefs and opinions about how they feel um about religion and that kind of thing. Um so I have a God, but it's not (exhale), how can I say it, a Catholic God or that kind of thing. Um I believe in a higher power and being the best that we can be."

The sheer power of prayer, in and of itself, was also described by a few of these women.

"Just by somebody saying 'I'm thinking about you' meant a lot to me. Or 'I'm praying for you' meant a lot to me. And I'm not a religiously organized person but I'm spiritual in the fact that I think that you know, everybody has their beliefs and it means a lot to me if someone says to me you know, 'I'm praying for you'. Like I take that as a compliment, like I take that, I hold that in high regard."

Another woman simply stated: "Yep, church is important. Um that's, um, praying was important,

which it still is. It was just really important at that point.”

Spirituality was described as providing a source of strength and as ‘something to hold on to’ during a particularly tumultuous time: “Well I think you have to, you have to believe in something and you hold on to that to get you through something like that. Like your whole attitude changes once you’re in that position. Um and I look at things a lot different [*sic*] than I did before ‘cause life is short, like it can be short’. And when you’re told that you have cancer, it’s a scary word and you know if you don’t have something, if you don’t have things to believe in and you know you’re, it just helps you get through it.

One woman summed it up in a simple statement, “[Cancer] has confirmed my beliefs” and it was these beliefs that gave her the strength to carry on.

From the responses given by these mothers, it was evident that they derived a significant amount of strength and reassurance from their faith and spirituality and this was an important source of support that they relied upon. Despite the fact that the men and children in this study were described by these women as providing emotional support throughout their illness, it would appear that spiritual support was not fostered through these familial relationships.

Discussion

Spirituality emerged as an important coping modality used by these women, although it did not appear to be a type of support that was nurtured in their familial relationships. It is important that such women be able to nurture this spiritual relationship in a supportive environment, and the nursing relationship is one such environment that could offer these women an opportunity to foster their spiritual beliefs and help to nurture and expand these beliefs over time. It was also noted by the women in our study that spirituality did not necessarily pertain to any one organized religion, but rather was multi-faceted and much broader than any one faith could encompass.

Many have discussed the importance of spirituality on individuals with cancer,^[8-10] but none have evaluated its influence on individuals with cancer in relation to the beliefs of their immediate family members. Spiritual beliefs have been described as an important resource in coping with cancer,^[9] and prayer has also been described as a supportive and important spiritual tool,^[4] as was for the women in this study. Because family is a key source of support for these women with breast cancer, it is important to understand their spiritual relationship in relation to their significant others, and if spirituality is not shared they need another avenue through which they can nurture it.

Implications for practice

The implications of these results for healthcare practice are multi-faceted. Healthcare providers are in a unique position to provide the much needed guidance and support to individuals grappling with a diagnosis of breast cancer. By providing a supportive atmosphere characterised by openness and understanding, they can assist patients in utilising their spiritual coping tools to their fullest extent. As such, there are a few points that care providers need to consider in order to provide concrete assistance in this area. Firstly, they should recognise that we live in a multi-denominational (and oftentimes non-denominational) society. Being open to the beliefs of one’s patients (regardless of whether these beliefs reflect or conflict with that of one’s own) is critical. Secondly, they should recognise the importance of being non-judgmental and supportive in any way possible to these individuals. Healthcare providers are in an ideal position to provide a safe space for believers to practice their faith and spirituality. In addition, they can (and should try to) provide opportunities for these individuals to nurture this aspect of their being, for only the patients themselves know how this nurturance may affect their ability to heal and be at peace with their illness over the long term. Thirdly, healthcare professionals should recognise that those closest to the patient may not share the same belief system as that of the patient. Therefore, when providing assistance to these families, healthcare providers need to understand the beliefs of other family members as well in terms of their spirituality (or lack thereof) and be respectful to their beliefs. Above all, if healthcare providers strive to maintain

an open mind and an open heart, they will be able to provide necessary support to families dealing with a breast cancer diagnosis.

Conclusion

Spirituality is a largely misunderstood and yet extremely important concept for many individuals struggling with a diagnosis of breast cancer. A sufferer's family may not agree on the terms of spirituality, and so it is the responsibility of healthcare providers to recognize the importance of spirituality for their patients. They should attempt to foster its existence in their formal care-giving relationships, while respecting the needs of all family members. This will help to further the evolution of the formal care-giving relationship from a position of merely addressing the physical needs of patients to addressing, acknowledging and validating their spiritual needs as well.

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