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# Women Undergoing Breast Diagnostics: The Lived Experience of Spirituality

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**Purpose/Objectives:** To explore perceptions of spirituality in women who had undergone a breast diagnostic experience.

**Research Approach:** Qualitative, phenomenologic study using Giorgi's approach.

Setting: An outpatient comprehensive breast assessment center.

Participants: 20 Caucasian women, aged 30–89, who had just completed the diagnostic process, including definitive diagnosis, regarding a breast abnormality.

**Methodologic Approach:** In-depth, semistructured, tape-recorded, and transcribed interviews analyzed using the Giorgi method of coding, transforming, and synthesizing data.

Main Research Variables: Descriptions of spirituality, spiritual needs, and supporting spirituality.

**Findings:** Two themes emerged: creating a focused isolation and seeking connections. Women created a private mental world in which to concentrate on the stressful diagnostic process. Within the isolation, women explored their personal strength and their connection to God or their spiritual beliefs. When the stress began to overwhelm, they sought out loved ones for support and diversion. Women found the center's staff to be supportive; however, many did not wish to speak to an agency chaplain during the uncertain period.

**Conclusions:** Women needed to handle the stress alone, with reliance on spirituality and God that was balanced with a need for specific connections to family members or close friends.

Interpretation: Nurses can support women's need to focus and can assist family members to understand their role during the diagnostic period. The diagnostic period can be used to talk with women about their spiritual beliefs, their needs, and possible referral to a chaplain.

reast cancer is the most common cancer among women, excluding nonmelanoma skin cancers, and more than 275,000 new cases occurred in 2004 in the United States (American Cancer Society, 2004). In Canada, breast cancer is the second leading cause of cancer death in women, exceeded only by lung cancer (National Cancer Institute of Canada, 2004). Women have reported that a diagnostic work-up for a breast abnormality is extremely distressing (Halstead & Hull, 2001; Heckman et al., 2004). Moreover, women have found themselves lacking the support and care they require during this phase of the disease continuum (De Grasse & Hugo, 1996), and they have expressed a need for spiritual support when undergoing diagnosis (De Grasse, Hugo, & Plotnikoff, 1997; Highfield, 1997). However, little is known about the spirituality of women during the diagnostic process for a breast abnormality. Knowledge of women's perceptions of their spirituality and spiritual needs may help nurses provide support during this stressful time in the cancer continuum. The current study explored the lived

# **Key Points...**

- Women undergoing breast abnormality diagnostics rely on their spirituality to support them during the period of uncertainty.
- ➤ During the diagnostic process, women create a focused, reflective isolation that is balanced with specific close relationships.
- ➤ Staff can help support women by establishing a warm, open environment and initiating dialogue on the role of spirituality in their lives.

experience of spirituality for women who had undergone a breast diagnostic experience.

## Literature Review

Interest has increased in the spiritual and religious aspects of health and positive outcomes (McSherry & Ross, 2002; Miller & Thoresen, 2003; Zinnbauer et al., 1997), yet various interpretations of spirituality exist in the literature without consensus (Tanyi, 2002). Tanyi found through concept analysis that "spirituality is an inherent component of being human, and is subjective, intangible, and multidimensional" (p. 500). Spirituality includes a person's search for existential meaning in life (King, Speck, & Thomas, 1994). In an attempt to bring more clarity to the issue, McSherry and Cash (2004) provided an emerging taxonomy of the language of spirituality and a caution that if the concept takes on too broad a meaning, any real significance may be lost. Spiritual beliefs narrowly reduced to denominational affiliation or frequency of religious observance undermine the strength and value of a personal belief system that may not be rooted in a particular religion yet may contribute to an individual's response to a diagnosis (King et al., 1995).

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Digital Object Identifier: 10.1188/06.ONF.121-126

Research demonstrates that spiritual values positively affect the health of patients (Highfield, 2000). Spirituality has been correlated to a number of health issues, such as loneliness (Miller, 1995), self-esteem, assertiveness, coping, hope and finding meaning (Mickley & Soeken, 1993; Mickley, Soeken, & Belcher, 1992; Post-White et al., 1996), quality of life and adjustment to cancer (Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Flannelly, Flannelly, & Weaver, 2002), and uncertainty (Landis, 1996).

In addition to identifying outcomes of spiritual values, studies have examined spiritual needs in diverse groups. Several studies have examined religious and spiritual needs in medical-surgical patients (Grant, 2004; Stephenson & Wilson, 2004), older adults (Fehring, Miller, & Shaw, 1997; Narayanasamy et al., 2004), African Americans (Conner & Eller, 2004; Holt, Clark, Kreuter, & Rubio, 2003), and people with terminal illness (Kub et al., 2003; Mueller, Plevak, & Rummans, 2001). Albaugh (2003) explored spirituality in individuals facing life-threatening illness, including some with breast cancer. Spiritual needs of patients with cancer include the need to review beliefs, the need to have meaning, and needs related to religiosity and preparation for death (Taylor, 2003).

Spiritual care sometimes is deemed more valuable to patients with cancer than counseling, support groups, peer support, or spousal support (Flannelly et al., 2002). Research on quality of life in women with breast cancer has revealed that spirituality is an important factor (Cotton et al., 1999; Spagnola et al., 2003). Although these and other studies exist on spirituality in women diagnosed with breast cancer (Gall & Cornblat, 2002), not many studies have focused on spirituality and spiritual needs in those who were newly diagnosed. Coward and Kahn (2004) examined the resolution of spiritual disequilibrium by women just diagnosed with breast cancer, and Levine and Targ (2002) found that spirituality and spiritual well-being were important correlates of functional wellbeing in women recently diagnosed. Only a small number of studies examined spirituality during the actual diagnostic process. Studies looked at mammography screening (Kinney, Emery, Dudley, & Croyle, 2002) and discovery, diagnosis, and treatment for African American women (Lackey, Gates, & Brown, 2001). The latter study found that women follow physical and emotional trajectories from finding a breast abnormality to definitive diagnosis.

Given the positive outcomes associated with spirituality, the lack of studies focused on the large number of women who undergo a diagnostic experience for breast abnormality is a serious issue. Prior to developing appropriate supportive care, an understanding of women's perceptions of their spirituality is required.

#### Methods

The current study used a phenomenologic design as described by Giorgi (1997). The approach enabled an exploration of the participants' perspectives of their spirituality.

#### Sample and Setting

The sample was comprised of 20 Caucasian women who had undergone a breast diagnostic investigation and had received a definitive diagnosis. Women whose primary language was French were included if they spoke English also.

The setting was a regional women's breast health center in a city in eastern Canada. At the center, a multidisciplinary team provides comprehensive breast health services to women and their families. At the time of the study, about 4,000 visits and more than 8,000 diagnostic imaging procedures were conducted annually.

#### **Procedure**

After approval from the institutional review board, the study was explained to members of the multidisciplinary team. Patients' primary nurses approached the women and asked whether they would be interested in the study. Afterward, the chaplain investigator, a resident in the pastoral care program, approached patients to explain the study in detail and obtain consent. The primary nurse explained that the investigator was a nondenominational, clinically trained chaplain who was available to people of any faith and others with spiritual concerns.

#### **Data Collection**

Data were collected in semistructured interviews conducted by the chaplain investigator. Interviews lasted about an hour and took place in a private room during a return visit to the center. The interview focused on the woman's spiritual experience throughout the diagnostic phase. Figure 1 presents examples of interview questions. Data collection was extended to 20 participants to achieve saturation because some women also talked about other pressing personal concerns during interviews, which made analysis more complex. Interviews were recorded on audiotape and transcribed; identifying information was removed.

#### **Data Analysis**

Data were analyzed according to steps noted by Giorgi (1997). All transcripts were read to get a sense of the whole. Each interview was coded to identify essential meaning. The meaning units were discriminated on the basis of relevance to the study and were defined for consistent application throughout. Similarly coded data were examined and probed to make the disciplinary value of each unit more explicit (Giorgi). Phenomenologic categories were derived as patterns emerged, and their essential properties were defined. The essential categories were synthesized into themes to provide a broad, comprehensive, and holistic narrative structure of the phenomenon. Throughout the analytical process, memos and diagrams were constructed. The visual representations of the categories permitted an overview of the emerging results. Subsequent to the main analysis, comparisons using the essential categories were made between the youngest five participants and the oldest five participants, because the range was large.

- · Can you describe some of the thoughts or feelings that you experienced when you came to the breast center?
- · What would you say helped you to face any challenges during your diagnostic experience?
- Please describe what gives your life meaning.
- What is your understanding of spirituality?
- Please tell me what faith means to you.

Figure 1. Examples of Interview Questions

### Study Rigor

Credibility was achieved by several means (Holloway & Wheeler, 2002), including interviews that were long enough to allow participants to voice their experiences and meanings, open-ended questions with probes to achieve thick data rich in the essences of the experience, and coding performed jointly by two of the investigators. The third investigator periodically participated in the analysis as a content expert in supportive care during the breast diagnostic experience. Consensus resolved any differing interpretations. Periodic debriefing to ask thoughtful questions about the emerging results was performed by the third investigator and a peer who was experienced in qualitative research but had no direct involvement in the study. To achieve confirmability, investigators kept an audit trail in the form of memos during the project, providing the analytic process with an element of transparency (Rodgers & Cowles, 1993). Personal thoughts and feelings, as they influenced the project, were discussed and recorded prior to and during the study (Beck, 1994).

# Results

Table 1 provides the participants' demographic information. Two themes were derived from the data: creating a focused isolation and seeking connections. Analysis revealed no differences between the youngest and oldest participants with regard to the themes.

### Creating a Focused Isolation

The women attempted to isolate themselves as a strategy to diminish distractions during the diagnostic process. The desired isolation permitted women time to concentrate on their diagnostic experiences and to reflect on their lives. One participant explained, "While I was in diagnosis, as I say, I almost pulled myself back from anything that I felt was going to interfere with me getting on with what I had to do." Women concerned themselves with options for treatments and the potential for death, given a worst-case situation. The brush with their own mortality triggered an increased awareness of spirituality for some of the women. However, for others, the experience was incorporated into their usual, active spiritual lives. One woman said spirituality "helped me through, well, this whole issue of cancer, and varied dealings with relationships with the family."

Many saw life entwined with the notion of woman as nurturer, including those who were mothers and those who were not. Inherent in the notion were the values and actions of caring for others, kindness to others, or not hurting others. The nurturing actions were linked to their spirituality, which, for some women, arose in part from the belief that God nurtures. Many women held an image of God as a guide, as all-knowing, one who watches over, cares, heals, and helps. During the diagnostic process, the idea of self as nurturer had to be set aside at times. Essentially, the women physically withdrew and put up an emotional barrier to protect themselves during the vulnerable time. When physical withdrawal was not possible, isolation took the form of emotional and mental distancing by being present and active in normal routines but also operating in a private world. One woman said "I know when I was having my core biopsy, I think the girls thought that I was . . . because I was doing inner-self and really talking to myself and really shutting them out."

Table 1. Demographic Information

Variable	n	%
Age (years)		
30-39	1	5
40-49	6	30
50-59	6	30
60-69	4	20
70–79	2	10
80-89	1	5
Language spoken most often at home <sup>a</sup>		
English	17	85
French	4	20
Other	3	15
Marital status		
Single	1	5
Married	14	70
Separated	2	10
Divorced	2	10
Widowed	1	5
Present religious affiliation		
Protestant	6	30
Roman Catholic	10	50
Jewish	2	10
Other	2	10
Current living situation		
With partner or spouse	12	60
Alone	6	30
With family	2	10
Breast diagnosis		
Breast cancer	16	80
Benign or normal	4	20

N = 20

Women spoke of their personal inner strengths, including humor and a sense of optimism. Inner strength was guarded and maintained by the focused isolation. Participants avoided associations that required them to talk about the situation because they had the potential to provoke unwanted emotional public display, possibly robbing inner strength and control. "Definitely while I was in the process, I wouldn't have felt comfortable sharing. I was too emotional. Much too emotional; I needed my strength." Women found that thoughts and prayers to God rather than going to church or to church activities, such as Bible study group, supported focused isolation. Contact with others also required the women to deal with the reactions of the other people, that is, to provide support rather than receive it. The women who were at the end of the diagnostic process had plans to resume former associations, for example, a return to church.

#### Seeking Connections

Although the women preferred to deal with the diagnostic situation alone, at times they sought out their close relationships because they needed to prevent overwhelming sadness or depression. One woman said, "I never really got a chance to go down enough [get depressed] before I was pulled up again . . . because I have support around me. My husband to start with, who is always with me, and then my sisters. I am not alone, not alone in this." In this time of enormous stress, the goal was to get support from family and others; however, the participants were aware that those who could provide comfort

<sup>&</sup>lt;sup>a</sup> More than one language could be selected.

also needed increased comfort, such as spouses, children, close friends, and other intimates. A woman shared, "So he was worried, you know, if anything happened to me, what is he going to do with the children?"

The women also valued distractions to take their minds off the potential of cancer and death. They selectively sought out sources of enjoyment, such as music, nature outings, shopping, or things considered treats.

Other connections were of a religious or spiritual nature. Women who had firm beliefs in God actively spoke with God. As one commented, "Oh, well, I go around talking to God all day." Another said, "Prayer is an ongoing thing. And you're not praying for the same things that you would normally pray for. I guess it's being rather selfish actually. You're praying for yourself and that everything is going to be alright." Their own prayers and those of others aided the women. As noted by one of them, "So many people are saying, 'Well, we're praying for you,' and I know they are. And it's a comfort to me." For others, the spiritual connection was a questioning or puzzling about the nature of things and the right to ask for God's help in a crisis if they did not regularly engage in prayer. A typical comment was, "Oh, well I prayed a lot, and I figured, you know, why should I be saved when somebody else isn't? Why? So I prayed, but with that sort of ambiguity there." Another woman said, "Sometimes I don't know how to pray, so sometimes you stumble around prayer." Some participants felt a spiritual connection not associated with religion. One saw nature as source of spiritual comfort, and one participant said "[God] is for other people. I can't believe in that sort of thing.'

Women found that staff at the breast health center provided helpful connections. One participant summed up the idea: "Because people here are all very loving and caring. It's the whole atmosphere; it's just functional. It has a soothing effect." When asked about speaking to an agency chaplain during visits, some women said that they would not wish to do so. The primary reasons were that it was not necessary or that they feared that religious beliefs would be imposed on them. Many believed that they were overwhelmed and just needed to concentrate. For those who said maybe or that they would like to speak to an agency chaplain, many expressed the desire that the chaplain be female, "like a woman would understand another woman." Some found the idea positive because "it was when I could first cry and start to talk about it with someone other than someone who was suffering with me." When speaking about sorting through events to create meaning, a woman said, referring to staff at the center, "Someone needs to ask the questions."

#### Discussion

Results of the study suggest that spirituality is important for women who are undergoing diagnostics for a breast abnormality. The experience of spirituality, as revealed by study participants, included a spiritual need to engage in an intense period of isolated reflection about themselves, their families, their own spiritual nature, and their beliefs about God. The isolation was balanced with a need for connections. The current study findings are consistent with Reed's (1992) definition of spirituality as meaning created through a sense of relatedness experienced intrapersonally and interpersonally. The reflection on personal self and spirituality that occurred during the period of isolation supported women and helped them to cope with the uncertainty of diagnosis. Humphreys

(2000) found a similar link between a greater connection to self and a higher power and decreased distress in sheltered women who had been battered. The study's findings that spiritual needs exist during the diagnostic process support Kub et al.'s (2003) findings, which demonstrated that spiritual needs are often as great in the outpatient setting as in the inpatient setting. Although Coward and Kahn (2004) found that women felt compelled to seek information and support at the time of diagnosis, the current study suggests that such needs start prior to diagnosis.

Most women in the current study used prayer and links to God as a strategy to meet their spiritual needs. Social strategies were used when women's inner strength was weakening. Halstead and Fernsler (1994) found that cancer survivors used spiritual coping strategies such as prayer or belief in God and social strategies such as frequently talking the problem over with family and friends. The current study supports the finding and reveals that drawing on spiritual and social strategies also occurs during the diagnostic process, the difference being that the social strategies alternated with focused isolation. Shifting from focused isolation to seeking social connections is similar to a finding by Heckman et al. (2004) that women used cognitive approaches and cognitive denial to cope during the diagnostic process. The personal control sought in focused isolation was diminished when women were feeling extreme worry or sadness; at such times, they drew on their personal resources. Johnson (2002) described a relationship between humor and spirituality in breast cancer survivors, and the current study indicates that humor and optimism are used during the diagnostic process as well.

Grant (2004) found that nurses view spirituality as efficacious to health outcomes and implement a number of spiritual therapies when caring for patients. He also suggested that establishing a culture to support spiritual care is important. The finding that participants found the staff and ambience of the comprehensive breast center to be very supportive reinforces the notion that culture can support spirituality. The finding is congruent with that of Taylor (2003), who found that nurses, by showing kindness and respect, supported spirituality. Fitchett, Meyer, and Burton (2000) demonstrated that, given the opportunity, some patients request spiritual care, whereas others who may need it more do not. The participants in the current study indicated that most would not wish to speak to a chaplain, which fits with their desire to reduce all but close, essential relationships.

#### Limitations

One limitation of the study is that the sample was quite homogenous. Although it reflected the community from which it was sampled, it was a white, middle-class group. The needs of other groups may be quite different. Some women required considerable time to answer during the interview. This may have been because of an inability to articulate the abstract ideas of spirituality, or it may be attributed to women using the interview to reflect on their lives and spiritual nature. The final concern is the possibility that only women who thought in spiritual or religious terms volunteered to participate.

# Implications for Practice and Research

One nursing implication from the study is the need to recognize and support women's desire for focused isolation during the diagnostic process. While providing information and explanations in a supportive atmosphere, nurses should note whether women wish to discuss aspects of their spirituality. This could facilitate women's attempts to find meaning in the diagnostic experience. At the same time, it may provide an opportunity to identify inner resources that contribute to personal strength and hope in such a time of crisis and uncertainty.

A second implication is to provide opportunities for families and intimates to discuss their needs with staff to avoid burdening women while they work through the diagnostic experience. Petrie, Logan, and DeGrasse (2001) noted that spouses benefit from an opportunity to discuss their concerns during the breast diagnostic period. Identifying who will be available to support women and providing information about the intense need for women to concentrate during the period of diagnosis will alert family and friends and encourage them to respect the need for isolation. In addition, staff can provide resources to assist women and their families in their spiritual journeys.

Because nurses act as the initial screen for spiritual needs, they need to recognize that some women may be experiencing spiritual distress even though they do not request, or even decline, chaplain visits. Informing women that chaplains are available to them if they wish could be part of the care process. Nurses should be cognizant that many women may be uncomfortable with speaking to chaplains. Providing a female chaplain, if possible, or a nurse with spiritual care training may make women more willing to accept help with spiritual matters. McEwen (2004) found that little nursing

education centers on spirituality. A clinical chaplain, as part of the team, is a resource to staff wishing to learn more about addressing patients' spirituality. By "asking the questions," a chaplain or a knowledgeable nurse could help women begin their spiritual exploration.

Implications for future research include studies to determine how best to support the need for focused isolation. In addition, studies are needed to explore the spiritual concerns of women's support systems and the effects of spiritual interventions to help families during the diagnostic period. Also, studies are required to examine the effects of program structures that include a multidisciplinary approach of a chaplain and nurses addressing spiritual needs during the diagnosis of breast abnormalities. Ultimately, research to determine the most effective allocation of spiritual resources (e.g., during diagnosis, during treatment, at the end of life) should be conducted.

The current study adds to a small body of work on spirituality of women undergoing diagnostic work-up for a breast anomaly. After exploring spirituality as perceived by the participants, as well as how spiritual needs were being addressed, the authors determined that spiritual support would be helpful to women during the breast diagnostic process. Nurses can play an important role for women exploring their spirituality during the breast diagnostic process.

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