Reflecting on spirituality in the context of breast cancer diagnosis and treatment

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Abstract
In this first part of a longitudinal study, women were asked to reflect on the meaning of spirituality in the first year following diagnosis of breast cancer. Twenty-two women were interviewed at approximately one year post-diagnosis. This paper reports on a thematic analysis of these interviews. Participants’ responses reflected three higher-order themes: relationship with a higher power, a deepening sense of self, and spiritual connection with others. The findings provide an enhanced understanding of how spirituality frames and impacts (both positively and negatively) the experience of breast cancer immediately following diagnosis and treatment. Most participants in this study found strength and support in their experiences of spirituality. They also spoke at times of feeling disconnected from or abandoned by God. The paper concludes with a discussion of how cancer health professionals might respond to the spiritual needs expressed by women living with cancer.

Background
Breast cancer and spirituality

In Canada in 2006, an estimated 22,200 women were diagnosed with breast cancer and 5,300 were expected to die from this disease (Canadian Cancer Society, 2006). Since 1993, incidence rates for breast cancer have stabilized and there has been a decline in mortality rates (Canadian Cancer Society, 2005). The most recent Canadian data for 2001 demonstrated the death rate from breast cancer to be at its lowest since 1950 (Canadian Cancer Society, 2005). The numbers of women who will survive this disease are expected to increase as the population ages and as diagnostic and therapeutic techniques continue to improve (Mandelblatt, Schechter, Lawrence, Yi, & Cullen, 2006). Nevertheless, breast cancer can be life threatening. People diagnosed with cancer find the experience stressful and suffer from uncertainty about the future, fear of recurrence and worry about the side effects of treatment (Wonghonkul, Dechaprrom, Phumivichuvate, & Losawatkul, 2006; Lauver, Connelly-Nelson, & Vang, 2007). At least one-third of those living with cancer experience some form of distress (Vachon, 2006). This fundamental uncertainty regarding illness and possible death may provoke a search for meaning (Thomas & Restas, 1999). Spirituality might play a part in that search.

Over the last two decades, there has been an increased interest in the role of spirituality and religion in managing serious illness, as reflected in health care journals. Flannelly, Flannelly and Weaver (2002) documented the extent to which this interest increased in the nursing literature in the 1990s. Stefanek, McDonald and Hess (2005) noted a 600% increase in journal publications on spirituality and health (compared to a 27% increase for publications on religion and health) between 1993 and 2002. Recent review articles have explored ways spirituality is defined and used in health research (Chiu, Emblen, Hofwegen, Sawatzky, & Meyerhoff, 2004) and documented ways spiritual well-being has been found to enhance the ability to cope with the emotional distress of chronic illness (Lin & Bauer-Wu, 2003).

Spirituality and religiosity are often used interchangeably in studies related to health, although there has been some effort to differentiate and clarify the two concepts (Baldacchino & Draper, 2001; Hill, Pargament, Hood, McCullough, Swyers, & Larson, 2000; McGrath, 2004). Pargament (1997) defines religion to include “feelings of spirituality, beliefs about the sacred and religious practices” (p. 4). Generally, spirituality is understood to be a broader concept not necessarily related to religious practice. In most definitions, spirituality includes the search for meaning, transcendence and connection with self, others and a higher power, although some (including Baldacchino, & Draper, 2001) argue that spirituality can describe the feelings of those with no belief in a higher power.

Spirituality can be an important support for people with chronic illness (Hampton, Weinert & Bozeman, 2006). Finding meaning in the face of illness is an important part of adapting to changed circumstances. Spirituality has been found to be associated with greater adjustment to living with prostate cancer (Krupski, Kwan, Fink, Sonn, Maliski, & Litwin, 2006). Australian men and women living with hematological malignancies used the metaphor of a spiritual journey to help make sense of their experiences (McGrath, 2004). These journeys illustrated comforting, as well as painful aspects. Cancer may provide an opportunity for spiritual growth – regardless of prior spiritual or religious beliefs (Baldacchino & Draper, 2001; Walton & Sullivan, 2004).

A number of studies have focused specifically on spirituality and breast cancer. Levine and Targ (2002) found a significant correlation between spiritual well-being and physical and functional well-being among women diagnosed with breast cancer. Another correlational study found that higher psycho-spiritual well-being scores were related to lower distress following treatment for breast cancer (Manning-Walsh, 2005). Similarly, Romero, Freidman, Kalidas, Ellidge, Chang and Liscum (2006) found a positive relationship between spirituality and better quality of life during treatment for breast cancer. Gall and Comblat’s (2002) study of women with breast cancer found a link with God or a higher power to be important in establishing meaning and those who understood cancer to be part of a divine purpose were better able to accept the
diagnosis. A positive relationship with God also helped women maintain hope and optimism in dealing with breast cancer (Gall & Cornblat, 2002).

A time of spiritual disequilibrium or spiritual anguish may also follow a breast cancer diagnosis (Coward & Kahn, 2004; Gall & Cornblat, 2002). This might be followed by a period of transformation wherein women find hope and positive meaning in their illness. Coward and Kahn found that attempts to resolve spiritual disequilibrium begin soon after diagnosis and include reaching out to church communities, family or friends, or God. Introspection and determining new priorities also help establish a feeling of control and meaning (Coward & Kahn).

Methods

The purpose of this study was to explore women’s reflections of the meaning of spirituality in the first year following a breast cancer diagnosis. An examination of the meaning of spirituality in the context of a breast cancer diagnosis provides a greater understanding of the spiritual context within which women make sense of this kind of health crisis. Given the lack of conceptual agreement about the terms spirituality and religiosity, the authors asked that women provide their own descriptions. The authors chose a qualitative descriptive design to stay close to the words of the participants and to provide a retrospective summary of events over the course of the year since diagnosis (Cresswell, 2003; Sandelowski, 2000).

This study was conducted in Ontario, Canada, between January 2003 and June 2004. The protocol was approved by the Ryerson University Research Ethics Board and the Sunnybrook and Women’s College Health Sciences Centre Research Ethics Board. Participants were selected from women who responded to advertisements of the study in flyers distributed through hospital-based and community-based support programs in Southern Ontario, and notices in the Ontario Breast Cancer Information Exchange Partnership newsletter, which has a circulation of 4,400 distributed across Canada. The flyer and the announcement in the newsletter invited potential participants to contact the research co-coordinator if they wished to be involved in a study about spirituality and breast cancer. Participants were offered a small honorarium.

The initial interview was timed at 12 to 15 months following a first diagnosis. In total, there were 22 respondents who were diagnosed for the first time within the requisite timeframe, who were available for an interview and who spoke and read English. One of these women had metastatic breast cancer at first diagnosis.

Once participants agreed to an interview, they were mailed a consent form and a brief demographic questionnaire. Interviews were conducted at a time and place convenient to the participant. Interviews lasted from one to five hours. All researchers involved in the data analysis also facilitated at least two interviews. Fourteen interviews were conducted in person, and eight were done on the telephone. All participants living outside southern Ontario were interviewed by telephone.

During the interviews, participants were asked to describe their breast cancer experience, their sense of spirituality in general, and how they understood their spirituality in the context of their breast cancer diagnosis. The interview guide included questions such as, “What does spirituality mean to you?” “How do you experience spirituality?” “What stories/moments come to mind when you think about spirituality in the context of your breast cancer diagnosis?” Before answering questions about their spirituality, many women prefaced their remarks with caveats such as, “I know this might sound weird” or “I’m sure this is different but…”

All interviews were recorded and later transcribed verbatim. Each participant was sent a copy of her transcript to verify. Three participants requested small editorial changes. After receiving and incorporating this feedback, the research team began the coding process. All three authors carefully read and reread half of the transcripts before meeting to formulate the coding framework. Over the data collection period, the team continued to meet monthly to review and modify its understanding of the themes and to modify the coding framework. Detailed codes were developed following an analysis of initial themes. All codes and subcodes were applied to all transcripts using the NVivo 2 qualitative software package. Once the detailed coding was completed, the research team categorized and documented meaningful patterns of higher-order themes and subthemes found in the data. During this period of analysis, the team was invited to present initial results at cancer support events, at a cancer support centre and at oncology rounds at a major hospital-based cancer centre. Feedback from these presentations was used to further refine the authors’ understanding of the emerging thematic structure although these presentations did not bring forth new data. Rather, many audience members who had also been cancer patients expressed that the findings resonated with their experience. Preparing for these presentations also encouraged us to narrow the scope of the findings from this large data set. In addition, a report was prepared and sent to participants to solicit additional feedback. None of the participants responded to this request. This process of establishing member validation adds credibility to the thematic analysis developed here (Mays & Pope, 2000).

The sample

The 22 participants ranged in age from 37 to 64 years. The average age at diagnosis was 49.5 years. While the authors did not restrict the sample to women, breast cancer is a disease that disproportionately affects women, so it was not surprising that no men volunteered to take part in the study. Eleven women were married or cohabiting, five were separated or divorced, and five were single. Fourteen women had children. Fourteen participants indicated their ethno-cultural group to be Caucasian, three said they were Jewish, two African-Canadian and one indicated First Nations. Thirteen of the 22 women in the study were born in Canada. Most of the participants lived in southern Ontario, although four participants lived in eastern and western Canada.

Not all of the study participants were aware of the staging of their cancer at diagnosis. Of the 18 who identified a stage, six said they were Stage I, eight Stage II, three Stage III and one stage IV. They were treated with a combination of surgery, radiation (14), chemotherapy (13) and hormone therapy (16). Ten participants had lumpectomies and 11 had mastectomies.

Fourteen women said they belonged to a religious organization. Of the seven who were not then members, all but one participant said that they had been affiliated in the past. Most of the participants, whether or not they were actively involved in religious organizations, identified themselves as spiritual long before receiving their diagnoses. Only three of the 22 women in this study were propelled into a spiritual search following their diagnosis.

Defining spirituality

Participants’ definitions of spirituality sometimes included a reference to nature, a deity or higher power, a sense of personal growth, loving others, and interconnectedness. Some women described spirituality in terms of an experience such as an awakening and others as a deep focus on the present moment.

Spirituality to me means loving, love. It doesn’t matter what church or institution you belong to, or it doesn’t even matter what building you’re in, it could be outside. It’s caring about the environment, people, animals, plants, respecting and loving. (That to me, is spirituality. (Eloise)).**

Women spoke about their sense of spirituality as unfolding or changing over time. To indicate this fluidity and evolution when defining spirituality, they used words such as “searching”, “responding”, and “emerging”.

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Overall, the participants’ reflections of their spirituality and breast cancer experiences were organized into three higher-order themes and subthemes: 1) Relationship with a higher power including sub-themes, methods to engage, qualities of engagement and qualities of disengagement; 2) A deepening sense of self including the sub-themes, integrating beliefs with a diagnosis of cancer and transformational experiences after a cancer diagnosis; and 3) Spiritual connection with others, including the subthemes the hand of God, the faith community, cancer support groups, and giving back.

Findings

Relationship with a higher power

The majority of the women in the study sample spoke about having a relationship with “something bigger” before, during and after their diagnosis and treatment. Some women held multiple images of a “higher being” and, for a few women, those images changed over time. One participant said:

I found the strength in something, but I can’t really give it a name. But it’s something bigger than I am. It’s sort of like taking me by the back and holding me up. (Lisa)

Others used words such as something beyond, something greater, mystery, loving presence, God, universe to describe this sense of a higher power in their lives. One participant said:

…I don’t think that I buy into that whole God and heaven and all… not in a churchy kind of way, but I do feel there is a higher being. (Lena)

Methods to engage

Women discussed several means or practices for engaging with “God” including reading scripture, attending religious gatherings, listening to choral music, actively disregarding distractions, and praying. For the most part, women did not perceive that their relationship with a higher power needed to be mediated by a third party such as a priest, rabbi, minister or other spiritual leader. Women described their spiritual relationship as personal, real and accessible.

Qualities of engagement

Participants ascribed particular qualities to their relationship with their “higher power” such as trust, commitment, love, accessibility, anger and fear. They utilized this relationship to cope with very strong fears under difficult circumstances. The participants also spoke about how this relationship assisted them to endure specific treatments and to deal with recurring fears of death following treatment.

I think the experience of being faced with cancer… that you know death is possible and that we’re not here forever… with God it’s an invitation for me to trust and also to be… without fear… I’ve been at peace… I experienced times where I was freaked out with the (cancer treatment) procedures, but I really wasn’t fearful. (Leslie)

This active relationship could also be fraught with difficulties, especially in light of facing cancer diagnosis and treatment. Women had different ways of illuminating and then understanding conflict in this relationship. For example, one woman spoke about her need to negotiate with her deity and work through impasses.

(at) first… it is sort of natural that you go through this negotiating mode. “Well, okay God, I’ll do this and then you get rid of the cancer”… because you’re under such incredible stress that you would do anything to get yourself out of this situation… (Sophia)

Qualities of disengagement

A few women also shared stories of feeling disconnected/abandoned/in crisis with/from their God after receiving their diagnosis. One woman described her crisis as if her “faith had a hole in it”. In order to attempt reconnection, women described requiring space and time away from the distractions of daily life to work through their anger and the pain of the severed connection. Another woman spoke of the disconnection that remained a year after diagnosis.

To me (the diagnosis) was that deep dark night kind of thing of “what does any of this mean”, “is there a God”, to me there isn’t… the treatment and the not knowing… it took away from having a connection. (Angeline)

A deepening sense of self

The following section includes descriptions of how participants conveyed a search for meaning in the context of having been diagnosed and treated for breast cancer.

Integrating beliefs with a diagnosis of cancer

Some women shared their perspectives about how their religious or spiritual beliefs were related to reasons for developing cancer. For most participants, spirituality was part of early religious experiences and associations, although they described how their current sense of spirituality was quite different from the religious affiliation and/or spirituality of their childhood. For three participants, spirituality emerged in response to their cancer diagnosis. Some women saw their diagnosis as a message from “God” (or “higher power”). While none of the women interviewed felt that this “higher power” had caused their cancer, it was clear that some of the participants struggled with how to integrate beliefs around sinning/punishment with their diagnosis.

There’s this huge sense of blame… self-blame and you go through… “I think I must have done something” …it crosses your mind… “maybe God’s really punishing me… God’s up there like okay, you need a tune-up, so bing, we’re going to get you.” And it’s like “OK, God, you’ve got my attention, hello”, and I don’t even really feel that way, but it was a fleeting… like you do, suddenly, you go through every sin you’ve ever committed in your life. (Sophia)

Transformational experiences after the cancer diagnosis

Some women described their spirituality as arising from a deepening sense of self. Some women also felt the changes they experienced would be permanent while others viewed them as part of an ever-changing process. Many women construed these changes as positive. For example, several women noticed a sense of a spiritual awakening, transformation or shift following the cancer diagnosis.

(The cancer diagnosis time period) was rather a dark time for me and the dark time is over and it has meaning and so, because of that, there’s a positiveness there, and I think I’m moving into that… I (am) sort of sens(ing) my own power again… (Annette)

Women spoke about the very personal and unique process of using visualizations and images to experience transformative moments. The images that emerged for some women were religious symbols. Others experienced images from the natural world.

Finally, the women spoke about how the experience of transformation and engagement with themselves rendered them more aware and more appreciative of life.

Spiritual connection with others

The previous section quoted participants who were enduring great stress as a result of diagnosis or who recalled feeling very “freaked out with the (cancer treatment) procedures”. Many
participants described feeling fearful and worried during this period. For example, Margaret said she was terrified of the treatment.

So I actually avoided going to the doctor for a long time because I thought the treatments were going to be more horrible than dying of cancer.

Shannon was worried about loss of income.

You know, my biggest fear was having to be out of my house and what am I going to do with my life? It wasn’t so much that I wasn’t concerned about my health, but I was more concerned about being the first bag lady in [name of town].

In the face of feelings of fear, most participants welcomed the practical and emotional support of family and friends, their faith community and the cancer support community to see them through the distress of diagnosis and treatment. The most frequently mentioned need for support was simply having someone with whom they could talk. Neve longed for the kind of psychic or spiritual help that remained elusive:

What would have been wonderful is if there had been someone waiting to catch me the minute I walked out the door (of the doctor’s office).

The hand of God

Women in this study told us stories of the support and gratitude they felt for doctors, nurses, family, friends, the church community and work mates. Many described the support they received as a spiritual experience. Participants also expressed both surprise and gratitude for the support they received from unexpected sources, or from people they did not know well.

I think people can be led by God or spoken to by God, and given a little nudge to do a nice thing because it seemed too coincidental that someone I barely knew through church or through school would show up at my doorstep with a meal, but it just seemed like such an incredibly kind thing to do. (Fiona)

The faith community

Some of the women interviewed for this study found support from their church communities. The following participant described being lifted from an immobilizing fear by the practical support and prayers of her church community.

I had to do chemo… I was going to have to live through it, okay, and I was just freaking. I was trying to write and my older son came in the door. The sun is behind him, and he comes in with an envelope, a blue envelope with a ribbon (and) a bow… it was from the church, a card from the church filled with gift certificates from (names restaurants and movie vendors) organized by my friend who had had cancer. It was incredible because I was so low and it was their community that I could just feel, lifting me up and I went ‘whoa’… And I’m sure that was everybody out there praying and I said, ‘okay, I can do this’ and I settled down and went through it. (Ava)

The opportunity to talk about spiritual concerns is also important for people who are not part of a religious community. One participant in this situation longed to be able to approach someone and simply say:

…you know I had some spiritual concerns and I don’t belong to any particular denomination and no, I don’t go to church, but I would like to discuss this with somebody. (Katelyn)

Cancer support groups

Because some of the participants were recruited through hospital- or community-based cancer support groups, it is not surprising that many participants mentioned the importance of Toronto-based centres such as Wellspring and programs like The Healing Journey. They particularly liked that centres offered what one respondent referred to as a “smorgasbord” of options (i.e., meditation, yoga, support groups, retreats). Often, the group experience created an opening for a renewed sense of spirituality. Not all women were comfortable with the notion of support groups. One stated that she thought they would be too depressing to attend.

Giving back

Many participants talked about opportunities to give back. For some this was a reaction to having been through the experience without support and not wanting others to face treatment alone. For others it was the need to share the good feelings they experienced and the support they received during treatment.

I found myself… kind of doing the same thing, mentoring someone through a similar experience… I felt like I was doing the same thing that had been done for me, you could tell somebody yes, there’s life at the end of the tunnel. (Katelyn)

Some already found themselves in a support role. Others expected that they would look for opportunities to volunteer in the future. Coward and Kahn (2004) argue that the process of reaching out to others can itself be spiritually healing.

I feel, too, that it’s just, it’s what I’m meant to do, I don’t know, I just have this feeling that God is always saying to me that there’s some way that I can help. (Francis)

Discussion

A diagnosis of breast cancer thrusts women into what Williams (2004) calls the “line dance of cancer” (p. xiii); mammograms, surgery, chemotherapy, radiation, clinical trials and alternate therapies. The women in this study shed light on the ways in which the management of the treatment regimen is altered in both a positive and negative way when viewing this experience through a spiritual lens. The management of cancer is also greatly assisted through the experience of connection.

Women in this study talked about connecting to spirit (God or a higher power), to self and to others when asked about spirituality in the context of their breast cancer diagnosis. Personal fulfillment and knowing oneself, along with tapping into a larger source of power (however it is construed) and seeking and finding spiritual support in friends, family, religious and spiritual communities were common to the participant’s conceptions of spirituality in the context of breast cancer diagnosis and treatment.

The diagnosis of cancer can be a stimulus for spiritual exploration and a search for meaning (Thomas & Tetsas, 1999). Three women in this study were spurred towards spiritual exploration following their diagnosis. For the rest, their religious faith or sense of spirituality existed long before they experienced a cancer diagnosis. These women were able to draw on religious practices or spiritual understandings as they struggled to make sense of their feelings and fears. Participants in this study, including those new to spirituality, experienced both support and disconnection in the first year post-diagnosis. Cancer professionals should not assume that spiritual issues are new to individuals with a life-threatening illness or that people will experience spirituality in a unilateral way. Individuals will at some times feel spiritually supported and at other times fearful, worried and even abandoned.

For the study participants, the primary way of trying to understand what the cancer diagnosis “is doing to me as a person” was to turn to the spiritual, to find meaning in the experience. Spirituality provided a frame for moving between overwhelming existential concerns, anger and blame and more comfortable periods of peace or acceptance. Women in the
The present study talked about spirituality as a dynamic process—at some moments a support—at other moments they felt angry with or betrayed by God—or had fleeting thoughts of having caused their cancer through some past sin. Feeling spiritual is not usually perceived in the literature as being both positive and negative for a single person. For example, Pargament, Smith, Koenig and Perez (1998) describe how both negative and positive patterns of religious coping with illness are possible—but not how individuals move between the two experiences. Coward and Kahn (2004), who studied spiritual disequilibrium, describe the process as moving from disequilibrium to equilibrium, but not back and forth between the two. In contrast, McGrath (2004) describes the movement between spiritual comfort and spiritual pain as a (non linear) struggle. The participants in the present study also conceptualized the struggle in non-linear terms.

According to Jenkins and Pargament (1995), as many as one-third of cancer patients report unmet spiritual and existential needs. Indeed, the greatest need voiced by women in this study was having someone with whom they could talk. The study participants who spoke about spiritually meaningful images and symbols often did so with a sense that the content of their talk might be considered unusual or “weird”. That the research participants typically felt their understandings were unique or odd might indicate the highly personal nature of this experience. It might also point to the lack of spirituality discourse between individuals in general, and as the subject of a research interview in particular. Narayanasamy (2002) found that patients with a chronic illness were apprehensive about talking about spiritual feelings with caregivers and family because they were afraid of ridicule.

Cancer professionals who are able to create trusting contexts wherein women can talk freely about their experiences (that might or might not be associated with religious dogma) provide an important component of care to women with breast cancer in the first year following diagnosis. As the results of this study show, effective spiritual support must be offered at several junctures over the cancer trajectory as the timing and valence for spiritual assistance will vary for each woman. If oncologists, nurses, social workers and chaplains provided an opening for spiritual discussions to occur, then women would be free to initiate discussion about their most essential spiritual concern at that particular moment. Responding to the finding that cancer survivors desire a person with whom to talk about their fears following diagnosis and treatment, oncology nurses are in the best position to provide information about community-based cancer support groups and support centres.

Spirituality has increasingly become a focus of research interest in health studies. As more of these studies are published and read by health care professionals, spiritual supports will increasingly become part of the cancer care discourse. The more oncology nurses can openly dialogue with patients about, for example, spiritual supports, the less likely it will be that women like the participants in this study will feel it “weird” to express their spiritual experiences and concerns.

Limitations

There are a few limitations to the present study. The sample was non-random and was self-selected, in that it included women who responded to the recruitment posters. Thus, these participants were typically women who were already members of cancer support groups and centres. These women also already held an explicit interest in the role of spirituality in their cancer experience. Had the study participants had minimal access to spiritual resources, the findings might have demonstrated an even greater existential resource gap. Alternatively, the findings could have revealed that those who do generally access these resources do not need them.

The authors chose not to include the interview text of women who had experienced a recurrence as a second diagnosis and, therefore, were not able to reflect in the findings the descriptions of spiritual meaning for women who might have greater existential needs.

Because the sample is mainly Caucasian, the findings did not reflect how spiritual meaning is contemplated by women from a variety of ethnicities. Women of colour for example, have offered that spirituality is a central aspect of coping with cancer (Ashing-Gwa, Padilla, Tejero, Kraemer, Wright, Coscarelli, et al., 2004; Musgrave, Allen, & Allen, 2002).

Finally, the sample size was small, although adequate for this exploratory study.

Future research:

Spirituality and survivorship

Moadel, Morgan, Fatone, Grennan, Carter, Laruffa, et al. (1999) found that proximity to diagnosis was related to greater spiritual and existential needs. This heightened concern following diagnosis has been referred to as the “existential plight in cancer” (Weisman & Worden, 1976, p. 1). Yet, studies exploring cancer survivorship find that many women experience anxiety and depression and the fear of recurrence once adjuvant treatment has ceased (McKenzie & Crouch, 2004; Rabin, Levanthal, & Goodin, 2004). Participants in this study spoke of fear of dying, anxiety about treatments and fear of recurrence. Some also spoke of experiencing a crisis of faith as they grappled with these fears. The Canadian Cancer Society (2005) offered that: “The cancer experience... presents many physical, emotional and spiritual challenges to patients... These challenges may persist beyond the point of physical recovery from the cancer itself, often requiring extensive use of rehabilitation and supportive care resources.” (p. 61)

As more women are surviving a breast cancer diagnosis, understanding the emotional impact of diagnosis and treatment is of increased importance (Rabin et al., 2004). To understand when patients experience the greatest existential needs, Moadel et al. (1999) suggested that research systematically assess the needs of a cohort of newly diagnosed people and track them over time. This research has begun to address this need. Results from interviews with these same participants three years post-diagnosis are forthcoming.

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* Mays & Pope (2000) also discuss the limitations of member checking. For example, accounts collected from multiple participants that are then analyzed and summarized are not likely to have relevance to an individual and his/her recollection of his/her account.
** All names appearing with quotes are pseudonyms.
References


