

**Original Article**

# The Caregiver's Perspective on Existential and Spiritual Distress in Palliative Care

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**Abstract**

*There is a paucity of research relating to how palliative caregivers conceptualize, identify, and provide for spiritual and existential domains of care. Focus groups comprising experienced palliative care providers participated in three semistructured 2–2.5 hour interviews, which were transcribed and subjected to thematic analysis. Eight themes were revealed: conceptualization of spirituality; creating openings; issues of transference and countertransference; cumulative grief; healing connections; the wounded healer; sustaining a healing environment for the caregiver; and challenges and strengths for the spiritual and existential domains of palliative care. While the spiritual and existential domains were variously conceived by experienced care providers, their significance for both patient and caregiver was affirmed. Transference and countertransference issues and the “wounded healer” concept were considered fundamental to effective care. Strategies for promoting therapeutic depth discussion were suggested and the importance of self-awareness and staff support emphasized. J Pain Symptom Manage 2006;32:13–26. © 2006 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*Palliative care, existential suffering, healing, caregivers, spiritual care*

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**Introduction**

The goals of palliative care include the alleviation of suffering,<sup>1</sup> the optimization of quality of life,<sup>2</sup> and the provision of comfort and compassion in dying.<sup>3</sup> The existential or spiritual domain is an important determinant of quality of life in the palliative care setting.<sup>4</sup>

There has been a growing attention to empirical research on spirituality in the past 10 years. Publications have included systematic reviews of research about religion and health;<sup>5,6</sup> studies of spirituality, religious beliefs, and the existential and spiritual experiences of health care providers and patients;<sup>7–10</sup> and double-blind studies on intercessory prayer suggesting better clinical outcomes among prayed for patients.<sup>11,12</sup> Other publications have presented the results of surveys concerning patients' need for spiritual care<sup>13</sup> and observations on how spirituality relates to medical practice.<sup>14</sup> For example, patients who are depressed or are experiencing meaninglessness may have a lower threshold for pain.<sup>15,16</sup> Conversely,

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patients who experience a deep sense of meaning and purpose in life may be better able to cope with difficult symptoms<sup>17</sup> and live longer.<sup>18</sup>

Health care providers recognize suffering and healing as central concerns.<sup>4,7,15-20</sup> However, there is a paucity of research relating to how palliative caregivers conceptualize the existential and spiritual domains of care. It is also unclear how patient suffering impacts on the caregiver's own existential and spiritual well-being. The present study used a qualitative focus group methodology to investigate these issues from the perspective of highly experienced palliative care providers. This approach has been considered the optimal means of obtaining detailed understanding of lived experience in sensitive, multifaceted, subjective areas such as existential suffering.<sup>21</sup> Specifically, this project seeks to explore: 1) how spiritual/existential patient needs are identified and interpreted by palliative caregivers; 2) how caregivers identify and interpret their own experience of spiritual/existential suffering; and 3) how caregivers perceive the strengths of, and barriers to, the provision of spiritual care.

## Methods

Palliative care providers were recruited through personal contact and arbitrarily assigned to two focus groups, five members per group. Selection criteria included at least 10 years' experience in providing palliative care in a palliative care unit (PCU), home care (HC), or bereavement support (BS) setting; willingness to participate in three weekly focus group meetings, each session lasting 2-2.5 hours; willingness to discuss patient and caregiver spirituality and healing in a focus group format; and fluency in English. The two authors, a palliative care physician and a nurse educator experienced in qualitative research, psychiatric nursing, and palliative care, conducted the interviews. The questions in Table 1 provided a general context for the semistructured interviews and resultant discussions. This list was distributed to participants during their first meeting. The first focus group included two practicing nurses, one retired nurse currently working as a PCU volunteer, and two volunteers with extensive PCU and BS experience. The second group consisted of a music therapist,

a palliative care physician, a nurse with PCU and HC experience, a PCU and BS volunteer, and an academic family physician with a particular interest in palliative care. In focus group discussions, "healing" was viewed as a process involving movement on the quality of life continuum toward a sense of integrity and wholeness and away from anguish and suffering. Informed consent was obtained and participants were advised that they could withdraw from the study at any time. The study was approved by a McGill Faculty of Medicine Ethical Review Committee.

## Data Gathering

There was an attempt to foster an informal atmosphere during focus group meetings; refreshments were served and the opportunity for casual conversation was provided, both prior to and following the audiotaped interview part of each session. All six focus group interviews were held at a university location that provided privacy. Participants were asked to respect confidentiality. Field notes documenting the nonverbal aspects of these meetings were compiled by the interviewers.

## Analytic Process

Data analysis followed the analytic process described by Moustakas<sup>22</sup> The phases involved include: *immersion* (with the experience and data); *incubation* (drawing on researchers' insights, tacit inferences, new understandings, and awareness of the subjects' experiences and their meanings); *illumination* (recognition of expanding meanings and new clarity brought to the emerging themes); *explication* (new connections within the emerging themes); and *interpretation* (expression of new understanding). This methodological approach was chosen because of its emphasis on the dynamic involvement of the researcher as an active participant in the generation of data and its ability to probe the depths of human experience, meaning, and the "knowing" that is generated through personal experience.

The three transcripts generated by each focus group were analyzed and interpreted as a unique stand-alone case.<sup>21</sup> In addition, transcripts for both groups were subjected to thematic analysis; thematic categories were developed, and subthemes identified, through iterative review of the text. These were verified

Table 1  
Interview Guideline Questions

Experience	<ul style="list-style-type: none"> <li>• Can you tell us about a recent experience you had caring for someone who might have been experiencing spiritual/existential/inner life distress?</li> <li>• What went well with this experience?</li> <li>• What did you find difficult in your role as a caregiver?</li> </ul>
Opinion/value	<ul style="list-style-type: none"> <li>• What does spiritual/existential/inner life suffering/well-being mean for you personally?</li> <li>• What does it mean for patients?</li> <li>• How would you describe this type of distress?</li> <li>• How would you describe care aimed at relieving this type of suffering?</li> <li>• What are some of your own personal goals in relation to this aspect of care?</li> </ul>
Feeling questions	<ul style="list-style-type: none"> <li>• How do you feel when faced with a person who appears to be suffering due to spiritual/existential/inner life issues?</li> </ul>
Sensory/experiential questions	<ul style="list-style-type: none"> <li>• Describe a picture of what you might see or hear if a patient was experiencing spiritual/existential/inner life distress?</li> </ul>
Knowledge	<ul style="list-style-type: none"> <li>• What might be your own approach towards a person you believe is experiencing spiritual/existential/inner life distress?</li> <li>• What resources are available for this kind of distress?</li> <li>• How and when would you use them?</li> <li>• What kind of knowledge is needed to care for persons who are experiencing this kind of distress?</li> </ul>

(Adapted from Patton, 1990.)

by returning to the relevant transcriptions and field notes.

## Findings

Participants ranged in age from late 40s to mid-60s; each participant had 10–25 years of palliative care experience in inpatient and outpatient settings. A sense of openness, often bordering on an urgent need to “unburden,” permeated the focus group discussions, which appeared to be facilitated by the high degree of trust existing between all concerned. This enabled a depth of honesty and candidness, which was invaluable in carrying forward the overall research goal of deepening our understanding of existential/spiritual/inner life suffering and healing. The purposive sample of highly experienced, insightful colleagues whose wisdom had been hard won at countless bedsides over intervals measured in decades also proved to be an effective strategy. Table 2 documents the eight major thematic categories and respective subthemes that emerged during data analysis.

### Concepts of Spirituality

Concepts of *spirituality* and *spiritual care* varied from participant to participant. The boundaries between psychological, existential, and spiritual issues were not clearly drawn. For some, *spirituality* was equated with a *sense of meaning*.

“I asked (the patient) about his wife and he talked about how caring she was. She was a teacher and (he talked) about the impact that she had on the people she had worked with and on himself. That’s what gave him meaning—remembering how good she was and how she changed (his) life. He doesn’t believe there’s life after death...But he believes in the goodness that his wife taught him.” (p. 30, February 4, 2002)

Another caregiver described the spiritual and existential domains in terms of a *sense of alignment*, consonance as opposed to dissonance, an experience of wellness, and sense of purpose.

“I think of moments of well-being; there is a sense of alignment of all parts ...” (p. 36, January 31, 2002)

In another account, spirituality related to a *power of goodness* or *wisdom* within the self.

“If we have a practice of going deep within ourselves, we find that incredible power of goodness which is transpersonal and probably eternal.” (p. 31, February 4, 2002)

A palliative care nurse suggested that the spiritual domain has to do with “*the spirit*.”

“When physical deterioration occurs, patients who are attached to their physical being see themselves as no longer respected or valued because they no longer look like

Table 2  
Emergent Categories and Themes

1. Concepts of spirituality	<ul style="list-style-type: none"> <li>• Relationship with a higher power</li> <li>• Sense of connection with self, family, and community</li> <li>• Sense of transcendence through personal suffering and healing</li> <li>• Sense of “alignment”</li> <li>• Sense of purpose</li> <li>• Intimacy</li> </ul>
2. Creating “openings”	<ul style="list-style-type: none"> <li>• Sustaining dialogue concerning inner life issues</li> <li>• Awareness of existential issues at differing levels of intimacy</li> <li>• Recognition of healing process through meaningful caregiver-patient relationship</li> <li>• Sensitivity to varying stages of “invitation” concerning patients’ existential and spiritual concerns</li> <li>• Providing the space for “safe” meaningful caregiver-patient connection</li> </ul>
3. Issues of transference and countertransference	<ul style="list-style-type: none"> <li>• Unrelenting desire to heal existential suffering</li> <li>• Caregiver awareness of transference and countertransference issues</li> </ul>
4. Coping with cumulative grief	<ul style="list-style-type: none"> <li>• Reflective awareness of multiple losses</li> <li>• Awareness of need to heal one’s own inner suffering</li> <li>• Facilitating a “peaceful” death as a source of enhanced caregiver meaning</li> <li>• Experiencing a “burden” of trust in patient disclosures of inner life suffering</li> </ul>
5. Healing connections	<ul style="list-style-type: none"> <li>• Healing through inner-self reflection</li> <li>• Healing through connection with peers, family, and community</li> <li>• Healing through meaningful caregiving</li> </ul>
6. The wounded healer	<ul style="list-style-type: none"> <li>• Acknowledged vulnerability and suffering may enable healing</li> <li>• Ability to relate meaningfully to patients and transcend inner woundedness</li> <li>• Personal experience of suffering negates the illusion of a power difference in relating to the suffering experience of another</li> <li>• Awareness of healing possibilities through conscious reflection on one’s own past suffering</li> <li>• Acknowledgment of self as a “wounded healer”</li> <li>• Acknowledgment of woundedness permits risk and intimacy</li> </ul>
7. Sustaining an environment of healing for the caregiver	<ul style="list-style-type: none"> <li>• Authentic relational environment in palliative care</li> <li>• Maintaining informal and formal supportive relationships with peers</li> <li>• Awareness of a sense of purpose and connection through work, relationships, and self</li> <li>• Vocation and mission in care for the dying</li> <li>• Acceptance of personal success and failure as a caregiver</li> </ul>
8. Challenges and strengths for the spiritual/existential domains of palliative care	<ul style="list-style-type: none"> <li>• Variation of subjective healing strategies in spiritual/existential care</li> <li>• Need for self-awareness of personal vulnerability within the caregiver-patient encounter</li> <li>• Recognition of the open-ended, exploratory nature of spiritual/existential needs assessment</li> <li>• Importance of trust and authentic presence in the caregiver-patient encounter</li> <li>• Need to recognize that the patient’s experience of suffering and healing may differ from that of the caregiver</li> <li>• Awareness of creating the space for meaningful “safe” existential dialogue</li> </ul>

themselves. But if you think of people who have meant something to you, it’s not so much their physical being that has held that (significance) for you, but their spirit that defines who they are. ... I try to have people see that their spirit will never change, that it isn’t affected by illness, but is still alive and youthful.” (p. 34, January 17, 2002)

Participants also spoke about the difficulty they experienced in using words such as *spirit* and *spirituality* and the problem of not having

a shared language with which to discuss such concepts. Words such as *mindfulness*, *intimacy*, *consciousness*, *spaciousness*, and *transcending* were suggested as possible expressions of the *spiritual* domain. For some, the relationship between self and something that “happens” that lifts one out of the self was deemed an expression of spirituality.

“I actually think that to listen to Yo Yo Ma is a spiritual happening if you really sit and are mindful. I didn’t know anything about Yo Yo

Ma. I never heard of him. I'd never listened to his music...and yet I was mesmerized by him. He just went straight to my soul...I knew that this man is playing spiritually. For me that was an epic experience." (p. 43, February 4, 2002)

The inadequacy of words to express spirituality was a common theme. The music therapist contrasted her Jewish perspective to that of a Christian colleague.

"We're talking about something words are not really adequate for...I know that I can create intimacy quite easily with a lot of people and the music helps and that's also something of who I am and...I call it intimacy...but for Anne (a colleague) it just seems so simple and clear. For her, Jesus acts through her and she is a conduit for the love of Jesus. For me it's much more complicated and ambiguous." (p. 33, January 17, 2002)

The terms *spiritual* and *psychological* were sometimes difficult to distinguish. For one participant, the *spiritual* was encountered in the kind of relationship that allowed people to accompany one another into places of deep intimacy or pain.

"In all these stories of caregivers and patients, there is an element of personal grief, violation, loss or angst...We're calling it 'inner life'...inner life is also a personal story. What makes it 'spiritual'? Where is the spiritual element? I don't really have the answer to that...I suspect that when we forge a strong personal/professional relationship—the kind of containing relationship that goes into those places of deep pain—Hmm—Is that necessarily a spiritual act? To be spiritual I think is to support something to somehow 'move beyond'." (p. 26, January 21, 2002)

For another, *spiritual care*, at its best, is simply expressed.

"What about just the humility of knowing that we have maybe a small part to play and it could be a smile and it's not trying to decide which action you're going to take—it's just being respectful and loving." (p. 19, February 4, 2002)

In a similar vein, the family physician spoke of an experience of shared humanity.

"The issue of spirituality often comes up when you are dealing with somebody who is not of your religious background. As I think of the work I've done with dying people, the spiritual dimension becomes most clear when it is not an expression of our shared religion, but of the commonality of our humanity...a bond between my humanness and their humanness!" (p. 28, January 21, 2002)

### Creating "Openings"

The ability to create an "*opening*," which enables the patient to express spiritual/existential concerns, was viewed as important by participants in both focus groups. Participants varied, however, in the strategies they used to foster an invitation to this level of depth discussion. Personal discomfort in addressing spiritual/existential topics on the part of either the caregiver or the patient was noted as a potential barrier to discussing these issues.

It was also perceived that the ability to create an opening for dialogue was directly related to the severity of the patient's illness and the level of anxiety associated with the knowledge that the person was dying.

"I found that the sicker the person was, the more open they were to deal with spiritual issues—and I mean, even (in the absence of a significant) relationship!... I remember having to go to see somebody who was very ill—for a colleague who had the day off—and this woman was very close to death... She asked me if I would (help) her children to let her go, ... because she said she talked to God every day and he was her best friend and the thing that was slowing down her process was the children hanging on to her... But that all happened with (my) not ever knowing her name! ... She was so ill—all the barriers were down." (p. 17–18, January 17, 2002)

Similarly, a palliative care physician reflected on the special potential for healing at the end of life.

"When the chips are down, and a lot of garbage is out of the way, you're down to the essentials. ... There's less room for...neurotic stuff. I think some people have more resources and are more open to healing at that point." (p. 7, February 21, 2002)

One participant described two factors that influenced his ability to create an opening for spiritual/existential dialogue.

“One factor is whether there is any receptivity that I can sense from the patient—that they are going to allow me in. The messages that are conveyed when I try to get closer are pretty evident in many cases! ... The other (factor) comes from within me. ... I (am most effective) when something about the person hits me and is meaningful to me in some way.” (p. 15–16, January 17, 2002)

In other descriptions, caregivers recognized that difficulty in communicating at this level may arise out of personal discomfort with that particular patient. One caregiver was painfully confronted by identification with her Jewish culture when caring for a German patient.

“I didn’t feel like a good caregiver!! There was my own personal, emotional, religious background—spiritual really—on the one hand, and my role as a professional caregiver on the other. And it became harder and harder! It was clear that I was important to him; ... I became so freaked out by my own confusions around caring for this man! The six million killed (in Nazi concentration camps) were in the room with us!!—The experiences of the German soldiers were in the room!! And I regret now, looking back, that I didn’t—that I *couldn’t* find a way!—I felt absolutely stuck—that I couldn’t find a way to open that up for him, and talk with him, or (at least) open the door if he wanted to talk. (Our conversations) remained on the surface!” (p. 3, January 17, 2002)

When the “opening” is found and dialogue in depth occurs, it may be richly rewarding. The family physician described his discussion with a Holocaust survivor whose struggle had initiated their conversation and it became a collaborative learning experience.

“She was bright—in her early 70s; still working for the restitution of Holocaust survivors—(and) we struggled with issues together... I don’t think that’s particularly unique in caring for a dying person...but the depth was exceedingly satisfying for me.” (p. 11–12, January 17, 2002)

Other accounts illustrated how a language barrier or other external factors may influence the caregiver-patient relationship, and prevent the opening necessary for a spiritual dialogue. One experienced palliative care physician recalled identifying the existential nature of the suffering of one of her patients, yet she was unable to help because of difficulties with language and culture. Her frustration and sense of inadequacy intensified when a colleague who shared the patient’s culture was consulted for further in depth exploration only to have the patient’s suffering misunderstood as being due to what was being presented “on the surface.” The referring doctor was devastated.

“You know I could understand 75% of what he was attempting to express, and I could fill in the gaps because of context, but to work with what was *really* going on with him required much more than that! I did medically what was indicated in terms of (the) pain he was having, and the nausea, and other symptoms—(but) I thought ‘Okay, now where—*how*—does he get help?!’ Because I really felt it was not right to let him sit with—‘I don’t want anything more, thank you.’ I tried to refer it to some of the more language fluent members of the team, but ... I mean, some of them were not able to see beyond what presented on the surface. I felt myself totally inadequate to help him beyond the level of ... symptoms and—sort of a superficial level.” (p. 20, January 17, 2002)

Another caregiver, a bereavement counselor, suggested that recognition of personal vulnerability makes it easier to share deep levels of inner pain.

“Think of your own closeness to spirituality—I find when I’m vulnerable that I’m closer to that component of myself and I’ve found that any time that I was vulnerable—because of circumstances that were happening in my life—when I would visit patients there was a difference, because we started at a very different level—because we were both at the same level! And I found that there was a lot more shared as a result.” (p. 26, January 21, 2002)

### *Issues of Transference and Countertransference*

A third significant theme for these experienced caregivers involved transference and countertransference, that is, the unconscious attribution of one's own feelings, attitudes, or desires, positive or negative, to the other person in the caregiver-patient relationship. The challenge for care providers is to become aware of the aspects of their own suffering that they are projecting onto the patient and to reflectively work with these aspects of the self. A volunteer who had worked in the field for many years expressed her anger and frustration when she was unable to help a close friend, now living several thousand miles away, to die peacefully. She recalled:

"My friend was struggling with...death, to a point where she even sat up—she sat up in her bed—and went like this with her fists up, (gestures with fists)—like, 'I don't want to die, God! Like, leave me here!' Anger!—a lot of anger—and I didn't know what to do. But her suffering was enormous...her inner suffering, her existential suffering was horrible...It was a very bad death... and I felt helpless because I felt I should know better after all my experience. I've assisted so many people dying, you know. I've been able to really just be with them, and soothe them, and feel that I made a difference! ... My wish was to be there when she died. I wanted to really be with her...you know, at the moment of her death. Because I was always hoping I could do that ultimate thing for her." (p. 2, p. 8, January 21, 2002)

In another account, the family physician was conscious of his own countertransference while caring for a woman who reminded him of a vulnerable "little girl." The experience of her vulnerability evoked the feeling that he wanted to hug her in the way a mother would hug her own child. In recognizing his countertransference he refrained and in doing so enabled a healing encounter.

"I'd looked after (the patient's) late mother and (that) was a difficult thing for (her) to deal with. (My patient) had no siblings, no relatives. She was struggling with low grade depression and some existential issues; trying to keep her reserve. When I looked at

her, I saw her mother's face. And seeing her mother's face I could suddenly see and hear more in this woman and she looked very vulnerable. She looked like a bit of a girl and my countertransference was—'I want to hug her.' I looked at her—the right to hug her wasn't there. It would have been very uncomfortable. Fortunately I was awake enough to be aware of what I was feeling and my countertransference. (So) I looked at her and said, 'how long has it been since somebody's hugged you...' and suddenly it came out—her body sagged and tears flowed—which she had not been able to do before—and it was clear that I had reached her. But I had reached her courtesy of her mom—because I had seen her mother's face—thought about the relationship and her mother holding her—and then my countertransference of wanting to hold her—and so it all came full circle. And I had a moment of grieving for her mother, but (also of) recognizing that my grieving for her mother was helping her in a really neat way." (p. 18–19, January 31, 2002)

One participant described her experience of countertransference following her loss of both parents.

"I've experienced the death of both my parents in the past six years ...I felt so vulnerable—a motherless child, an orphan in the world. So I (felt I) must be grown up and all that entails for me. And then again, having my own small children, and the sense that something could happen to them—(could) stimulate that identification and fear, I try to be as conscious as possible so that I'm not doing too much countertransference and projecting my own stuff all over the place. I really try to stay conscious. But when I'm in the room of a mother, for example, who is leaving her young kids... um...I often will bring in my own experience. I might say, 'I too am a mother. I can only begin to imagine how you might feel.' And so I'll make it manifest and then we can talk about our kids and how one worries about (them). So my experience can be used as a way of connecting with people—and to increase sensitivity and connection. But I still have to deal with my own mortality

salience...my own feelings of terror.” (p. 7–8, January 31, 2002)

### *Cumulative Grief*

A further theme expressed by participants was the issue of cumulative loss while working in palliative care. Cumulative grief was experienced as an awareness of inner pain brought about by many losses sustained over long periods without satisfactory closure. One palliative care nurse who had retired from active duty described this challenging issue.

“I think that we absorb a lot of sadness that we can’t possibly acknowledge until we (leave palliative care). Because we are caregivers, we feel we should be able to handle difficult things. We encourage others to just spill their guts and say how they are feeling and yet we really deny ourselves that opportunity to really express the losses we’ve been through—thousands—that’s what I was thinking. I mean, you know, I was involved in an intimate way with probably 2000 people. It has to have had an effect! I’ve paid the price for it. I think my body was full of sadness. But we don’t realize that. ... We say we have a supportive environment (on the PCU)...but one person goes and another person comes in, and it’s just constant! ... I don’t think we had a lot of closure.” (p. 11, January 31, 2002)

The programs put in place by palliative care services to deal with this problem are not always effective.

“Some of us absorb it more than others, and then you start to hurt. We do have a staff support meeting but I don’t think we’re comfortable using it. I don’t think a lot of people really go with their material and use it as a way of getting closure. Because there’s constant death, there has to be a constant process in place to deal with it.” (p. 12, January 31, 2002)

In contrast to the palliative care experience, a general practitioner may have the advantage of a perspective born in a long-standing relationship. The family physician observed:

“My own practice is 23 years old and many of those people have been with me 20 years or more. We have the advantage of time.

Grieving as professionals is a gradual (process). We see the deterioration over time, the same way that we see the changes in our parents over time. So there’s a lot more opportunity for preparation.” (p. 14, January 31, 2002)

Palliative care may foster increased bonding with the patient and the possible risk of cumulative grief. One caregiver spoke of intimacy and her feelings of closeness to the patients when sharing her music with them.

“When I’m there, (within the patient’s spiritual space), in the intimacy, it feels great. Because it’s close, it’s connected, it’s authentic, it’s intense, it’s deep, it’s like all the things we thrive on—it’s sharing! I think what’s hard is to keep going there—to keep getting there and then to go from one patient to the other. So what do you do with it all? If you’re running from one to the other, and you don’t have time to process, and then you go home and there’s kids and homework—and you fall into bed and (then) you start over (the next day). And that’s where burnout starts to happen. So being there is great, but I think we have to process it. We have to do something with it and we have to find places where it’s not about (death.)...To do it all the time without allowing for a) the processing and b) the self-nourishment—is dangerous!” (p. 38, January 17, 2002)

### *Healing Connections*

Illness may present patients, family members, and caregivers with their existential aloneness and a sense of disintegration of the self.

“I think causes of suffering are very different for different people. What they experience is the essence of themselves disintegrating. For some it might be the loss of a role, for another that they won’t be there to see their children grow up, for others it might be having a sore throat—so I think the determinants are unique to each person. But the result is that sense of being overwhelmed, out of control; the very essence of the self, as one understands it, coming apart at the seams.” (p. 6, February 21, 2002)



This same participant went on to reflect on what happens when people experience healing.

"I think one thing that can help us experience a sense of wholeness is sometimes music—the beauty and perfection. Music might give one, even temporarily, a sense from the deep self of connecting with something whole, or beautiful. For others it might be a prayer or a connection with a God concept...So I think the experiences of healing can be quite different (from one person to the next)." (p. 6, February 21, 2002)

As she noted, healing connections may occur at the phenomenal level, experienced through the senses, as with music or the beauties of nature, and it may occur through a sense of connectedness with God, the cosmos—ultimate reality, however perceived by that person. It may also be experienced as occurring within the person, resulting in a new experience of integrity and wholeness. One participant commented:

"I had been raised in a house where I was really loved... I was really truly loved...and all of a sudden all that just went poof. Our life fell apart. We were thrown out of our house and my mother was deported to a forced labor camp. Then I would go to an old gorgeous church... I went because it was silent and there was nobody there to bother me and I could actually lie down on the pews and I could read my books...That's where I think I really learned that there was something rich and wonderful in the whole universe and it is inside myself...and it made me incredibly strong. That was the first time I knew that I was accepted. I didn't know yet that it was me accepting myself. It made a difference for the rest of my life. ... If you're thoughtful enough and silent enough you learn that there's an incredible pool of wisdom and goodness and transcendent power in each human being and it's the same power in all of us. ... It's love, ultimately. ... And it's all within us. I mean endlessly. Totally! And it's infinite; limitless. And we all have it and it has to make one joyful. You know if it doesn't, there's a block somewhere." (p. 20, January 28, 2002; p. 31, February 4, 2002)

The volunteer just quoted also described her relationship with a spiritual teacher who was dying, with whom she found a deep sense of connection. She recalled.

"This man was a brilliant monk; he had taught me to meditate and now he was dying with cancer. ... (He was) somebody I truly loved. ... It wasn't a crush. I truly had this wonderful relationship with him in the last month of his life. ... I read to him (and) I would sit in silence, and he would look at me and he would sleep. ... He said things to me—not much, but (they) changed my life forever. That's why I am in palliative care. It was an amazing closeness. ... Um ... One of the last things he said to me was, 'You'll never be alone. I'm taking you with me to be with me always, beyond time.' ... Everything I experience in palliative care, whether it's a meditation or sitting with a dying patient, or washing somebody—everything is in the light of that relationship that I had with this man, which was intense beyond belief, but very quiet—a seminal relationship which somehow infuses all my other relationships." (p. 31, January 21, 2002)

#### *The "Wounded Healer"*

Participants appeared to be in agreement that personal suffering increased one's awareness of the suffering of others. One physician explained:

"I certainly think that how you've suffered personally increases your sensitivity and your openness and awareness of suffering in other people. If we don't know what someone is going through, it's easy to treat (only) the physical symptoms...give more of a drug (and) just close your eyes to anything else." (p. 8, February 21, 2002)

In one vivid narrative of caregiver "woundedness," suffering and healing, a nurse explained how she was able to care for her dying patient following the suicide of her adult son. She recalled:

"I think what our patients feel when (they are) at the terminal stage is really a lack of purpose—that life has no more meaning. You want to give them back that feeling of purpose. ... My patient on the PCU had terminal metastases. She was starting to deteriorate day

by day and she was so angry at every loss she experienced. Her sister was trying to help her without much success. Many of the nurses felt very impatient with her but she was my primary patient so I had to give her care... Day after day passed and I felt like I was starting to progress a little bit in helping her, but it was really slow. Then my son died and I left the hospital for a few weeks, but I felt bad leaving her... So, after a few days, ... I went to see the patient even though I knew I wasn't going back to work... I felt I owed her something... I went up to the patient and I told her what happened to my son—with no secrets—I told her my son had committed suicide and I cried with her. Now, at that time she was not getting out of bed in the morning—and I told her that she would be (in heaven) soon and I wanted her to look after my son. And she responded 'When I die give me the picture of your son in my coffin.' And she cried and told me that she never had a son and that I could trust her, that she would look after him. And she took over right away I guess, because from that moment on she was calm. ... I think once you have discovered that you are vulnerable, that you are fragile, it makes you very humble. And I think from then on, you don't look at your patients in the same way. You see them—their vulnerability, their suffering—in a different way and I think you are more compassionate." (p. 34–35, January 28, 2002)

In another account, a nurse described taking care of a patient on the PCU when her husband died suddenly at their home in the country. She explained how her anger had consumed her in such a way that she felt unable to go back to work for a time.

"I was on the PCU and there was one patient who in his delirium could no longer speak English or French but reverted to his native Spanish. He was my primary patient. I spent the weekend... looking after him talking to him in Spanish, for whatever he could hear or understand... And my husband died alone up North that weekend when I had been spending my weekend taking care of patients. I was very, very angry after. I could not even step into the PCU." (p. 38–39, January 28, 2002)

She went on to recount how the comments of a colleague helped her to reframe her experience so as to find meaning and relief from guilt.

"Another nurse on the ward said to me, 'Do you remember what happened that weekend? You know, probably you were more useful at the bedside of this patient than you would have been at the side of your husband. He died of a massive heart attack and it happened in probably a few seconds, whereas your presence to your patient made a difference. It had purpose.' It really made me feel reconciled that I had been (with the patient) and that I had not been with my husband... I was more useful... My being at work had a purpose!" (p. 39, January 28, 2002)

#### *Sustaining a Healing Environment for the Caregiver*

A flexible, responsive system for palliative caregiver support is needed. One palliative care volunteer explained:

"The difficulty with regularly scheduled team support meetings as an answer to crisis intervention is one of timing. When you're in a crisis in the day-to-day kinds of issues in palliative care you want to get on with it right away! You know, a week later, it's something else that has happened!... I can remember a couple of weeks ago, one of the nurses breaking down and crying... She came to me and said, 'Can I talk to you?' She just needed to unload herself of all the issues she was dealing with. I think it was a series of deaths that had just simply overloaded her." (p. 10, February 4, 2002)

The pressures of a busy ward add an additional burden. As one nurse put it:

"At 2:30 PM you have to finish up what you are doing. (Maybe) you have an admission coming;... you have your group charting to complete; and the patients keep calling—the families come—and on it goes!! ... So it's very hard for nurses to liberate themselves to attend the team support meeting, even if they want to be there." (p. 11, February 4, 2002)

*Challenges and Opportunities  
in Existential/Spiritual Aspects  
of Palliative Care*

The factors facilitating or inhibiting a deepening sense of integrity and wholeness were not always clear. While a significant encounter with a caregiver was identifiable in many cases, in others, that was not the case.

"I recall a deeply anguished woman who was absolutely impossible. Nobody wanted to go into her room, because she was just terrible. I remember bringing her food tray one night and I moved a couple of her things and boy, did she let me have it! She said, 'You work around my things! My things stay where they are!' Now what changed the whole thing was our art therapist—a young girl...She started painting with her. She really got to her! From that moment on, she was a different person. Everyone wanted to go into her (room)." (p. 20–21, January 21, 2002)

In response to this account, a palliative physician commented:

"Actually, I have reviewed (the chart of that patient) in an attempt to identify what had turned things around. ... After months of consistent, florid suffering, a nursing note on one shift simply stated, 'a better day today.' That was dramatically different from anything that had been there before and from then on the notes documented continuing progress. The art therapist first saw her a couple of days later, so it appears that something in her had already shifted, enabling her to make something of what she was being offered. What the art therapist was able to bring helped, but the change had happened before that." (p. 21, January 21, 2002)

As in this example, it is not always clear how a patient's suffering is transformed. One nurse mused that the healing process might be dependent on a locus of control within the patient, but supported by caregiver relationships.

"So what (enables) the little miracles that can happen? What do we do—what do we do as caregivers to make that trigger? What happens? Do we help, or is it just a process that (the patient) goes through? Or are both these factors enmeshed?" (p. 22, January 21, 2002)

A volunteer explained:

"I know the aim is to fix everything...but (it) is helpful to just give them that space (that they need)—to be angry, or whatever. We must meet them where they are and when they need it!" (p. 12, February 4, 2002)

Some accounts related the difficulties of dealing with the vulnerabilities that both caregivers and patients encounter in palliative care.

"I remember a patient who was very angry and he said to the volunteers, 'You're all self-serving bitches'—He said those words. 'You're all self serving. Don't come and bother me with your kindness. When you have something positive to say—like a cure!!...*then* come and smile!'" (p. 6, February 4, 2002)

In response, a nurse reflected on the challenge of dealing with one's emotions in such a case.

"It (is) interesting—you know, you can say 'Good for him'—and even when we're talking about it, it's fine—'Good for him!' But to be face to face with someone and you're trying to be nice, and that person speaks like that—It's not easy to deal with!" (p. 6, February 4, 2002)

A further participant countered:

"I don't get angry if patients get abusive—I can really understand that...But when I really get angry is if I can see something going on that could be corrected. When I see the patient suffering and it would be easy to correct and some kind of stupid barrier—perhaps within me—keeps me from doing that." (p. 7, February 4, 2002)

As they considered barriers to healing connections, one member expressed the opinion of the others.

"I think if we acknowledge the fact (that) patients have many reasons to be angry, but if they know that we are here to care for them and to help—and, I mean, that we understand what they feel...It works! I think, when they see that we come back the next time that they call,...whatever their need,...they eventually express it in words,

that yes, it is just disgusting to be dying when you are 50 and having bags draining your stool on one side and your urine on the other side—it's very humiliating. And when they can say all that then...it seems to bring down the anger and then it brings sadness...and (a link has been established and) a process started that acknowledges what is really happening. The door has been opened." (p. 8–9, February 4, 2002)

## Discussion

Spiritual/existential concerns are important determinants of enhanced quality of life, the primary goal of palliative care.<sup>4,23–25</sup> They thus warrant the attention to detail paid to other aspects of palliative diagnosis and therapeutics. Cicely Saunders commented on this need in a letter to an American colleague written in 1965.

"I am interested that religion is never discussed or hardly at all under its own heading but only under the work of the chaplain. ... I think, however, that the religious attitude or, at least the philosophy concerning life as well as death of other members of the staff is extremely important and could perhaps be emphasized more. I do not mean that in most cases they would ever speak of it directly but communication with words of security based on that dimension is, I think, of immense importance in helping the patient to find his own meaning."<sup>26</sup>

The fact that these issues remain difficult to define and measure 40 years later, however, fosters their neglect, reinforces preoccupation with the more evident symptomatology concerns of the biomedical model, and enhances the risk that palliative medicine will be reduced to "just another specialty."<sup>27</sup> One's assumptions around the meaning of terms like spirituality and existential suffering may affect the way that caregiver-patient relations are structured, patient needs are expressed, and care is given.

Creating openings to dialogue at this intimate level is at the heart of the caregiver's art and a key to effective whole person care. It requires an understanding of the significance of existential/spiritual issues, discernment in

their inclusion in the differential diagnosis of the causes of suffering, and sensitivity in communication. Participants in this study suggest that such discussions may be facilitated by the caregiver's personal experience of suffering and by the imminence of the patient's death.

In accompanying the dying, palliative care team members do not pass unmarked, for they recognize the threat of their own mortality mirrored in their patients' experience. Their countertransference is likely to be influenced by this recognition of personal vulnerability, and cumulative grief underscores this risk. While the comments made by our focus group participants suggest a sense of privilege in being palliative care providers, there was also clear expression of the need for a space in which one can mourn multiple losses and find resolution in instances of perceived "failure." There is a need for continuous reflective assessment of the personal emotional cost of being a palliative caregiver and for the provision of informal and formal opportunities for personnel support.

The participants in this study work in settings that encourage the recognition and pursuit of opportunities for healing, both for their patients and for themselves, and they have the knowledge and skills, born in long experience, to identify such "therapeutic moments." Their accounts point to the importance of transference and countertransference, the notion of the "wounded healer," and the significance of "healing connections" in fostering integrity and wholeness.

When a person becomes sick, the *patient-healer archetype* is activated.<sup>28</sup> (An archetype, as postulated by Jung, is understood to be a specific inherited pattern of energy in the collective unconscious that is an evolutionary product of previous human experience; an inborn latent potentiality of behavior that is evoked by a typical, constantly recurring situation.)<sup>29</sup> Since the patient-healer archetype is activated in *both* patient and caregiver, as a result, both patient and caregiver have an inner patient *and* an inner healer as their relationship develops. Transference (the process by which a patient displaces onto his caregiver feelings and ideas which derive from previous figures in his life<sup>30</sup>) and countertransference (the caregiver's transference on his patient<sup>30</sup>—both as an unconscious, antitherapeutic product of the

caregiver's early life, and, as a reaction to the patient's transference<sup>31</sup>) are unavoidable components of all therapeutic relationships. While countertransference is primarily an unconscious process, it may be recognized by the quality and intensity of the feelings it arouses in the caregiver.<sup>31,32</sup> It can also be recognized by the patterns of behavior it may induce, including: avoidance, task-centeredness and aggressive treatment approaches, the development of "chronic-niceness," the development of survivor guilt.<sup>32</sup>

Guggenbuhl-Craig suggests that in the interest of avoiding ambivalence a splitting of the archetype tends to occur in this situation, such that one pole of the archetype is repressed in both patient and caregiver and projected onto the other person—the "healer" pole being repressed in the patient (thus handing over to the caregiver the power of healing), the patient pole in the caregiver (thus assuming the identification of a strong, healthy caregiver without wounds). The caregiver is now only caregiver and no longer able to constellate the inner healer in his patient; the patient is only patient. The only way out of this dilemma is for the caregiver to do the necessary psychological work, for it is only through recognizing the reality of oneself as a "wounded healer" that the caregiver can help to constellate the inner healer in the patient.

The thematic finding of the "wounded healer" in this study reveals the participants' awareness of the role played by their personal limitations in exercising their mandate as healers. This insight is not new. It has been expressed down the centuries, from the figure of the wounded centaur "Chiron"<sup>32</sup> in Greek mythology to the present-day poet's admonition:

Ring the bells that still can ring.  
Forget your perfect offering.  
There is a crack in everything.  
That's how the light gets in.<sup>33</sup>

Speaking of the caregiver's capacity to act as healer, Jung said, "It is his own hurt that gives the measure of his power to heal,"<sup>34</sup> and again, "The doctor is effective only when he himself is affected. 'Only the wounded physician heals.' But when the doctor wears his personality like a coat of armour, he has no effect."<sup>35</sup>

But why must we recognize our limitations if we are to be effective healers? Kearney<sup>31</sup> offers a clarifying synthesis in explanation. The caregiver who brings awareness of personal vulnerability to the bedside, yet is willing to accompany the patient, effectively lights a fire of possibility that otherwise lies dormant, by activating the patient's inner capacity to heal himself.<sup>28</sup> Kearney suggests that "being there" with another in his or her suffering promotes an ability to contain the primal emotions aroused in confronting the unknown. This containment by the carer enables the patient to feel heard, as well as to feel held and secure.<sup>31</sup>

"Healing connections," with their associated enhanced sense of meaning and of being part of something greater and more enduring than the self, are at the root of a deepening experience of integrity and wholeness for both patient and caregiver. The identified source of this sense of connection may be within (the individuation of Jung);<sup>29</sup> with others (the I-thou relating of Buber);<sup>36</sup> with the world around us, as experienced through our senses; and with ultimate meaning, God, "the More," however conceived by that individual. Each of these variants has been commented on by participants in this study. Caregivers clearly struggled with their desire to facilitate healing for their patients when their own suffering was acute. When a meaningful caregiver-patient bond existed, healing occurred not only for the patient but also for the caregiver.

The theme "Challenges and Strengths for the Existential and Spiritual Domains of Palliative Care" includes the need to address the emotions of the palliative caregiver through exploration of personal vulnerability, past experiences of unresolved loss, and the need to find a place of healing within the "self." The spiritual and existential domains of palliative care may be viewed as being richly rewarding and essential for any thoughtful pursuit of optimal quality of life for both patient and caregiver.

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