

# The Impact of the Hospice Environment on Patient Spiritual Expression

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**Purpose/Objectives:** To understand how hospital inpatients express their spirituality and to investigate the impact of hospice environment on this expression.

**Research Approach:** Qualitative.

**Setting:** Two metropolitan hospice centers in southern Australia.

**Participants:** 12 inpatients (7 males, 5 females) who were residents for at least four days.

**Methodologic Approach:** Influenced by Heidegger's Phenomenological Hermeneutics, semistructured interviews were conducted. Interview transcripts and field notes were analyzed to reduce data into codes and themes. Data were coded by extracting verbatim phrases used to describe spiritual expression and the impact of hospice environment on it.

**Main Research Variables:** The nature of spiritual expression and the impact of the hospice environment on the spiritual expression of hospice inpatients.

**Findings:** Participants were comfortable discussing their spiritual expression within the context of four main themes: Relationships, That Which Uplifts, Spiritual Practice, and Having Hope. Finding meaning was a common link among these themes. The impact of the hospice environment was variable. Most believed that it facilitated their spiritual expression to some degree.

**Conclusions:** Spiritual expression is important but is facilitated by individualized spiritual care. Nurses play an important role in the provision of spiritual care within a hospice setting.

**Interpretation:** Nurses are significant in assisting in patients' spiritual expression. Nurses' needs for training in listening skills, confidence in discussing spiritual issues, and time to provide individualized spiritual care should be assessed to ensure optimal patient expression.

Since the 1990s, the literature has placed considerable emphasis on the importance of spiritual care for palliative patients (McGrath, 1999; Spiritual Care Work Group of the International Work Group on Death, Dying and Bereavement, 1990; Thomson, 2000; Wright, 2002). However, little, if any, research has investigated the impact of the hospice environment on the spiritual expression of inpatients. Some studies have been carried out among palliative care staff members, such as nurses, as well as caregivers (McGrath, 1997; McSherry, 1998; Strang & Strang, 2002; Wright), whereas others have involved homecare palliative patients and survivors (Benzein, Norberg, & Saveman, 2001; Bolmsjo, 2000; Carroll, 2001; Gall & Cornblat, 2002; Hermann, 2001; McKinlay, 2001; Thomson).

The provision of spiritual care is complicated by the nature of spirituality itself (McGrath, 1997). Although the literature

## Key Points . . .

- ▶ Spiritual expression is important, an individual matter, and not necessarily related to religion.
- ▶ Nurses are seen as significant others in the inpatient hospice environment.
- ▶ Assessment of how nurses can further facilitate patients' spiritual expression may be needed.

has differentiated between spirituality and religiosity (Koenig, McCullough, & Larson, 2001; McGrath, 1999; Walter, 2002; Wright, 2002), this division is not universally accepted (Gall & Cornblat, 2002; Rumbold, 2002). Numerous attempts have been made to define spirituality and the essence of spiritual care (Breitbart, 2002; Koenig et al.; McGrath, 1999; Rumbold; Walter; Wright). The most commonly mentioned themes are those of forgiveness and reconciliation; relatedness to self, significant others, and, for some, a divine being (Mickley & Cowles, 2001); transcendence (Benzein et al., 2001); hope (Benzein et al.; Kellehear, 2000; Parker-Oliver, 2002); and remembering (Strang & Strang, 2002). Elements of each of these are encompassed in the theme of "searching for meaning" and so, for the purpose of this article, spirituality is defined as a search for meaning. This search is enabled and motivated by relationships with a higher power, with significant others, with nature, and in transcendental experiences. Spiritual expression may include religion.

Apart from the difficulty of defining spirituality, a number of challenges are associated with research in the spiritual domain

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of patient care that have been identified in the literature. The individual's search for meaning is difficult to quantify; as a result, it tends to be marginalized in a healthcare system that functions in an environment with heavy emphasis on quantitative data (McGrath, 1997; Millard, 2002; Rumbold, 2002). Many patients, as well as staff members, lack the language to express spiritual needs and discuss spiritual issues (Byrne, 2002; McGrath, 2002; Mount, Lawlor, & Cassell, 2002). Identifying precisely who is responsible for the provision of spiritual care has been debated in the literature. Traditionally, chaplains have accommodated this need; however, many nurses have accepted a role in spiritual care (Carroll, 2001; Ronaldson, 1997). Literature embracing the broader understanding of the nature of spirituality promotes the notion of spiritual care as a team responsibility (Carroll; Kellehear, 2000; Walter, 2002), although complications such as lack of training in specific listening and counseling skills and lack of facilities and opportunity for staff to address their own spirituality also have been described (McSherry, 1998; Wright, 2002).

Extensive research still is needed in the area of spiritual assessment and patients receiving palliative care. A deeper understanding of this type of care may lead to greater quality of life for family members living with a dying loved one.

## Methods

This qualitative study was influenced by the premises of Heidegger's Phenomenological Hermeneutics, described by Crotty (1998) as a circular process. Heidegger's Phenomenological Hermeneutics combines the concept of phenomenology, which, according to Becker (1992), studies situations from the perspective of the person experiencing them, with hermeneutic analysis in which the "interpretations of the observer and the observed are repeatedly interwoven until a sophisticated understanding is developed" (Ezzy, 2002, p. 25).

The researchers used a number of procedures to ensure the current study's rigor. The interviewer ceased volunteer work as a counselor and pastoral care worker in a participating hospice prior to commencement of the study so that she was not known to any of the participants other than in the role of researcher. Prompt questions were constructed carefully to focus on an area for discussion but avoided suggesting individual responses (Rice & Ezzy, 1999). An audit trail, consisting of typed and coded transcripts, field notes, memos, and data reduction and analysis notes, was established (Ezzy, 2002; Fontana & Frey, 2000; Rice & Ezzy). Ethical approval was given by the human research ethics committees of the University of Adelaide and the two participating hospices.

In this qualitative study, semistructured interviews (Kellehear, 1989; McCracken, 1991; Silverman, 2000) were conducted with participants drawn from inpatients who had been residents for at least four days in two local hospices. Participation was limited to those who understood that they could withdraw at any time and had been assessed independently by medical staff and found to be medically and emotionally able to participate in a semistructured interview conducted in English. Those referred were approached by the principal researcher and given a prepared information sheet and a full explanation of the project. Following receipt of informed, written consent, relevant demographic details for each participant were obtained from their records.

Theoretical saturation, defined as the point at which no new themes emerge in the data (Ezzy, 2002; Glaser & Strauss, 1967), was used to determine the number of participants. Twelve participants were interviewed. All patients who gave consent were interviewed unless rapid deterioration of their health prevented it ( $n = 1$ ). Each participant was supplied with a list of professionals such as chaplains, social workers, and counselors who were able and willing to speak with them should issues arise during the interview with which they needed assistance. Interviews were audiotaped with the participants' prior consent. Care was taken to establish a friendly rapport with the participants and to be conscious of their comfort and well-being throughout the interview (Fontana & Frey, 2000; Wright & Flemons, 2002).

The semistructured interviews had two aims: (a) to understand how the participants expressed their spirituality and (b) to investigate how they viewed the impact of the hospice environment on that expression. Every interview began with the following question: "[In the area of spirituality], what has been most important to you since the diagnosis of your illness?" When the notion of spiritual expression had been explored as fully as possible, a transition statement was made: "Now I would like you to think about the time you have been here in the hospice. Would you like to tell me how that has affected the things we have been talking about?"

The design of the prompt questions in Figure 1 was influenced by the aspects of spiritual expression discussed in the literature review and by the researchers' knowledge and understanding of the concept of spirituality (McCracken, 1991). The questions were reviewed prior to use by two experienced palliative care nurses and tested in a small pilot study.

Data were evaluated using thematic analysis (Crotty, 1998; Ezzy, 2002; Glaser & Strauss, 1967; Silverman, 2000), which involves coding the data to identify themes or concepts. In this study, the computer software QSR NUD\*IST (Qualitative Solutions and Research Ltd., 2002) was used to assist in coding.

## Findings

Twenty-one of the 28 patients referred to the study were approached for participation. The others died ( $n = 1$ ), were discharged ( $n = 3$ ), or deteriorated rapidly ( $n = 3$ ) before being

### **Understanding how participants expressed their spirituality**

- What has influenced the way you have been able to cope with your illness?
- What is it that can make you despair?
- What gives you hope?
- How do you make sense of what is happening to you?
- Do you have any beliefs that have helped you?
- What uplifts you?

### **Understanding how the hospice environment impacted spiritual expression**

- What has happened here that has helped you most with \_\_\_\_\_?
- Have some unhelpful things happened?
- Are there some things that you wished had happened here?
- How has the hospice staff fit in with \_\_\_\_\_ that you have said is most important to you?
- Has the way you make sense of things changed since you have been in the hospice?

**Figure 1. Sample Prompts**

approached. Sixty-two percent of those approached agreed to be involved (n = 13); however, one patient died before being interviewed. Demographic details about the participants who were interviewed are in Table 1.

Following coding, participants' responses fell into four main themes: Relationships, That Which Uplifts, Spiritual Practice, and Having Hope. The themes were united by a common thread—finding meaning and purpose—that was identified as an important outcome. The main aspects of each of the themes, including subthemes, important outcomes, ways in which the hospice was seen to facilitate these outcomes, and what may have helped, have been summarized in Table 2 and are illustrated in the participants' comments. None of the participants had difficulty discussing spiritual expression in terms of at least three major themes, and nine of the participants discussed all four themes. However, the ways in which the participants interpreted and experienced these themes varied dramatically, suggesting that spiritual expression is a very individual matter.

### Relationships

All of the participants consistently rated relationships with significant others as very important and frequently considered these individuals to be the most important aspect of their spiritual expression. Two participants made a very direct connection between spirituality and relationships when they said, "I don't go to church. I just have a very strong love for my family" and "I am not a religious person. I enjoyed my work, and I enjoy going out [with friends] to meals, movies, partying—all sorts of things."

Ten participants discussed the importance of their relationships with their spouses and families, and five spoke of this in terms of the relationships being the purpose of their life, giving them meaning and support: "My grandson is a marvelous boy. He is a marvelous human being, and to me, that is absolutely sufficient. You can't beat that." Another patient said, "They mean everything, absolutely everything."

Not being abandoned and receiving support from family were important to others. For example, according to a participant, "A lot of people who have [my disease] end up

being abandoned by their spouses, but my wife has stood by me."

A significant aspect of the role of friends and family was their importance in helping participants to maintain some sort of ordinariness in life and in the face of death by being able to talk about daily events and common interests.

I don't want them to come here and say, "poor old fellow," you know. . . . When my friends come to see me, they just talk about the everyday things, things which you like, which in my opinion is what you are [talking about].

Although relationships with nurses were not mentioned initially as an aspect of spiritual expression in this study, they clearly were particularly important in the context of the hospice environment. Participants said, "They are wonderful" and "He is just made for this work. I have often told him he is more like an angel. There are a lot of them though and you don't get the same one." However, not all of the participants had such positive experiences: "[The nurses] were probably having a hard time at home and they take it out on the patient."

### That Which Uplifts

Although a number of modalities were mentioned, in this study, the most commonly described means of being uplifted was through music.

Music is the key to souls. I suppose you could [have a CD player], but I don't want to bother people. I can hear it just as well without it. I can hear it in my head.

The last thing you are left with is music. I know that for sure. Your mind might go in all different directions, but you will still hear music. It is very calming.

Participants' experiences with music provided by the hospice were quite variable. Some found that no one helped them play the music they wanted or they were obliged to listen to music they did not enjoy.

Three participants cited having a sense of humor, having friends with a sense of humor, and being able to joke as very important in lifting their spirits above the problems of their situation. For example, one participant said, "I'm always making jokes and things like that." Another felt that patients need "a bit of bravado to throw off the enemies—knowing the fact that [death] is going to happen—a bit of bravado is all that you have got."

The expressed need for humor or laughter is an area in which nurses were seen to have both positive and negative impacts. According to one patient, "Sometimes I make these jokes and things. [The staff members] think that that's all right and cheers things up . . . just a little bit."

Attempts at humor can be a way of masking fear, pain, and guilt that are easily overlooked by nurses who then are perceived as being insensitive.

Yes, sometimes it has been staff. They come out and don't let me start [to say anything]. They make jokes. . . . They take it as a joke and think, "Oh, I can get a bit of fun out of this bloke even if he is not going to last long."

For half of the participants, their relationship with a higher being, mostly referred to as God, was important to their ability

**Table 1. Demographic Data**

| Characteristic               | n |
|------------------------------|---|
| <b>Age (years)</b>           |   |
| X = 73                       | — |
| Range = 54–92                | — |
| <b>Gender</b>                |   |
| Male                         | 7 |
| Female                       | 5 |
| <b>Religious affiliation</b> |   |
| None                         | 7 |
| Roman Catholic               | 2 |
| Protestant                   | 2 |
| Pagan                        | 1 |
| <b>Country of birth</b>      |   |
| Australia                    | 7 |
| United Kingdom               | 3 |
| Italy                        | 1 |
| Romania                      | 1 |

N = 12

Table 2. Hospice Influence on the Main Themes, Subthemes, and Important Outcomes

| Theme              | Subthemes   | Important Outcomes  | How Hospice Facilitated Spiritual Expression   | What May Have Helped Patients Express Spirituality   |
|--------------------|---|---|--|--|
| Relationships      | Spouse or partner<br>Family<br>Friends<br>Spiritual family<br>Palliative care team                                | Nonabandonment<br>Inspiration<br>Purpose or meaning<br>Support<br>Hope for the future<br>Bringing ordinariness  | Deepened relationship through facing death together<br>Bond with dead wife who died in the same room<br>Freedom of family and friends to come and go at any time<br>Freedom to worship with spiritual family<br>Staff recognizing their “significant other” status | Single room option for all patients<br>Greater sensitivity to patients’ need for time-out from visitors<br>More facilities for entertaining larger groups (e.g., party)<br>Greater recognition by nurses of their “significant other” status<br>More continuity of nurse with same patient |
| That Which Uplifts | Music<br>Garden, nature, or pets<br>Sense of fulfillment<br>Religious practice<br>Spiritual beliefs<br>Humor      | Rising above the mundane and painful<br>Beauty still exists.<br>Thankfulness or meaning<br>Acknowledging something higher<br>I am more than physical.<br>I am cared for.<br>I have a code for living and dying. | Provision of music or gardens<br>Allowing pets to stay or visit<br>Spiritual beliefs reflected in compassion and caring of staff and volunteers<br>Staff appreciation of and participation in humor  | Greater sensitivity to patient needs for music of their choice<br>Greater awareness that humor can be used as an attempt to hide pain and fear.  |
| Spiritual Practice | Group meetings<br>Prayer, meditation, or quiet time<br>Forgiveness  | Meaning<br>Connection with spirit beyond or within<br>Closure   | Interdenominational service<br>No evangelizing<br>An atmosphere of peace and quiet<br>Own priest can visit   | More training for nurses in listening skills and in dealing with views that are very different to their own<br>More time for nurses to just listen   |
| Having Hope        | Of cure<br>Of end to suffering<br>Of finding meaning<br>From spiritual beliefs<br>From relationships or listening | Resume normal life<br>End to lack of meaning<br>Acceptance or peace<br>Sense of control<br>Future for grandchildren<br>Finding meaning<br>Being cared for   | Giving the impression of hope when needed<br>Willingness to listen<br>Giving patients some sense of control<br>Providing normality   | More training in awareness of individual needs   |

to transcend the negative: “I just really and truly feel that [my physical life] is not all of it. This could even be hell on earth.” For some, their relationship with a higher being helped them in finding meaning and purpose in their suffering.

I think the journey is very difficult. I think perhaps getting to the end is not as hard as the journey itself. I think perhaps we are meant to find a meaning in that journey. I hope I will be able to do so. So far I think I have.

Nine participants made reference to the compassionate, nurturing attitude of most of the nurses and volunteers, such as, “It’s the little things. Like if you get in the shower and you say, ‘I’m wobbling on my legs. Will you dry my back?’ they will. I couldn’t say that to my sister.”

However, this perspective was not unanimous among the participants. One man who had a very strong pro-euthanasia stance that was a spiritual issue for him, said, “I think it is a bit cold to go on feeding and looking after you. It’s like a ship on the rocks. You let it go and don’t bother about getting it off the rocks.” Another man also felt his value as a human being, which he felt was a spiritual belief, was not respected when he was moved to a different room twice and then moved from a single to a double room: “I felt double crossed. . . .

Perhaps I didn’t deserve that room; perhaps I didn’t work for it in the right way.”

A sense of being fulfilled, of having lived a useful life that had achieved something, was very important, not only in reaching a state of inner peace and acceptance but also in finding meaning while living through a terminal illness. Among those who spoke of fulfillment was the youngest participant at 54 years of age: “So that’s so incredibly gratifying to know that you have helped people along the way.”

Spiritual Practice

For some participants, spiritual practice associated with established religion was part of spiritual expression; however, they seemed to attach varying degrees of importance to these activities. For example, participants said, “It doesn’t take over everything” and “We go [to church] every Sunday.”

Five participants claimed to have no religion, yet spoke of what could be classified as spiritual practice. “These days I enjoy silence and being on my own, quiet. I’m glad I found this room. It’s quiet. No one disturbs you in here.” The atmosphere of peace and the opportunity for a quiet space were important to their process of making sense of things and finding meaning in their experience.



Unlike the others, one participant believed the hospice was inappropriate for spiritual practice: "It is a sort of a death house, isn't it—a house where people are going to die. The atmosphere is all wrong for it here." This comment perhaps reflects the participant's personal view of death as a time when one was ready for recycling—like a dead plant going back to the earth to eventually become another form of life—rather than as a spiritual transition as most others saw it.

Four participants specifically appreciated that the hospice supported their spiritual practice or their decision not to have any. One patient said, "I think one of the good things here is that they don't evangelize. I think that is very important."

In this study, the word "forgiveness" was mentioned by only one participant who considered the process of working with forgiveness to be part of her lifelong spiritual practice. Nevertheless, the concept of forgiveness seemed to underlie issues raised by two other participants. The most poignant was expressed by a participant who had been a gunner in World War II and now considered himself a murderer: "And then came the war and I saw what happened. I went through what happened. I participated in what happened and I very brutally killed a lot of people."

## Having Hope

In this study, the participants spoke of experiencing hope in two ways: the hope for a cure and, for most participants, hope related to finding meaning in some way. One participant spoke of hope exclusively in terms of cure. When discussing current scientific research, he said, "I think the main thing, I think, I anticipate that something will turn up. . . . I don't get involved with any other views of my situation."

Hope, even when it is not based on an expectation of cure, can be quite fragile. Two participants found the staff too blunt in discussing their prognosis and insensitive to their need to slowly adjust to reality.

They are very straightforward here in the hospice. They don't pull any punches. . . . If you are not up to it, you don't [find it helpful]. When you first come across it, oh yikes, you know! Dr. Ice Blocks, you know. It's "what do you mean I only have two weeks? What are you talking about?"

For some participants, hope was associated very closely with finding meaning in life. For one participant, life now had no meaning, thus he had no hope except to die. Another found that the meaning of his life became clearer as he spoke with the researcher, and as a result, his sense of hope grew.

Three participants found that being able to talk about death and the process of dying with family or staff was important in maintaining hope because it gave them a sense of being more in control of things and less fearful of the process. According to a participant, "You have to know what is going to happen with the rest of your life." Of course, if talking is going to be beneficial, the hospice needs staff members who are able and willing to listen. For some participants, this need was met by friends, family, or a spiritual community. Half of the participants stated that they were certain that the nurses would be willing to listen if they felt the need to talk about issues such as hope, how they felt about dying, and how they were making sense of the process. Three, however, had some reservations or negative experiences in this area (e.g., "There

is not really anyone [to talk to about the important issues]. They are busy I guess.").

Despite the contrast expressed in the participants' comments, among hope of cure, hope independent of cure, and despair of having no hope, being in control (i.e., experiencing hope by having some say in shaping the future) was described frequently. For some, the nurses brought a sense of ordinariness, normality, and security into an abnormal situation, which gave the patients a sense of hope. One participant said, "I was talking to a nurse and saying that if you tried to improve [the hospice] it would seem artificial somehow," and another stated, "They treat me as if there was hope. They haven't written me off, and although I know I will die soon, we meet each day as it comes." Here again, participants describe connection with meaning. These examples show that everyday interactions with nurses and significant others, based on respect and some control over daily functions and activities, can be vital in assisting patients to maintain a level of hope that is independent of cure and life expectancy.

Another important contributor to hope, for eight participants, was spiritual beliefs. In three cases, the beliefs were related partially to the idea of some sort of reincarnation and the hope of evolving spiritually: "I am looking forward to coming back as a more evolved human being and continuing on the journey, giving, but knowing that there is a reward. Yes. I expect that to happen." For others, hope lay in the anticipation of a spiritual existence after physical death.

## Discussion

The relational role of nurses, although recognized in earlier studies (McGrath, 1997), was not initially raised by any of the participants in this study. However, the importance of nurses as significant others in an inpatient hospice environment became very apparent as each interview progressed. Three main areas emerged that were relevant to spiritual expression and on which nurses, as well as other important individuals in the life of the participant, had a significant impact. These were listening, sensitivity to individual needs, and creating ordinariness for the participant.

Within the context of all four themes discussed in the findings, having someone who has the time and ability to listen was considered important by the participants. In fact, half of the participants were anxious to tell their life story even though it was not the focus of the interview. Other researchers have noted the importance of a life-reviewing process commonly undertaken by the ill and dying (Frank, 1995; Murphy, 1999). In this study, the reviewing process affected the areas of forgiveness, reconciliation, hope, spiritual beliefs, and finding meaning in life. Not all participants felt that their need to have someone listen without judgment was met.

The ability of staff, both doctors and nurses, to be sensitive to individual needs was another important factor that emerged in this study and was found to have particular impact in the themes of Having Hope and That Which Uplifts. The task of being sensitive to individual needs is made more difficult because patients residing in hospice often are reluctant to bother anyone and frequently give verbal responses that do not necessarily match their true feelings; for example, the participant who felt degraded when moved to different rooms is one such case. The difficulties in assisting palliative patients

to have hope that were documented by McSherry (1998) also were evident in this study.

The importance of nurses in creating ordinariness for the participants emerged in this study. Kellehear (2000) noted that spiritual expression was facilitated by maintaining a sense of ordinariness, continuity, and connectedness to the familiar. In this study, evidence suggested that this was especially important in the areas of facilitating relationships with family and friends and in engendering a sense of hope and meaning. Clearly, one challenge for staff is to determine what is ordinary for each individual patient.

The entire palliative care team, particularly nurses, impact the spiritual expression of hospice inpatients. Although nurses traditionally have accepted some role in the provision of spiritual care, considerable debate has ensued regarding who should be responsible for this sensitive matter (Carroll, 2001; Kellehear, 2000; Walter, 2002). The current study was very small and involved a relatively demographically homogenous group of participants; therefore, its results cannot be generalized. However, findings do suggest that the ability and time to listen and be sensitive to individual needs are very important when creating an environment in which patients in the hospice setting are able to express their spirituality.

## Conclusions

The hospice environment was found to impact the spiritual expression of the participants in this study. The palliative care team and, in particular, the nurses were “significant others” in the life of inpatients, so not surprisingly, their words and actions were found to affect the important areas of spiritual

expression among the participants. Although all participants were comfortable discussing their spiritual expression within the context of four common themes, their individual needs differed. Being sensitive to individual needs and acting on them can be challenging for all those involved in the care of inpatients in the hospice setting.

If the conclusions of this small study are found to be more generally applicable, further research is needed in several areas. For example, does the consistent provision of individualized spiritual care to hospice patients place inappropriate burdens on nurses within current operational systems? Is extra training needed for nurses to assist in developing listening skills and a greater sense of ease in discussing spiritual issues? If additional training is needed, how could the effectiveness of such training be assessed?

## Recommendations for Practice

Several recommendations for practice are suggested by this study, including increased awareness of nurses’ important role as significant others in the lives of inpatients in hospice and assessment of nurses’ needs for more training in listening skills. When nurses listen to their patients, especially patients’ stories, they can derive important assessment data in relation to patients’ spiritual expression. Finally, assessing nurses’ needs for more opportunity in dealing with their own spirituality and having confidence in discussing spiritual issues with patients may be helpful.

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