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Spiritual pain: A comparison of findings from survivors and hospice patients

Pam McGrath, BSocWk, MA, PhD

Abstract

The article presents comparative research findings on the notion of "spiritual pain." The findings from interviews with hospice patients affirm the previously published, preliminary conceptualization of spiritual pain from interviews with survivors. However, while the survivor findings highlight the potential for spiritual pain associated with life after high-tech curative treatment, the hospice patient data emphasize the protectiveness of the hospice experience for deflecting the possibility of spiritual pain. It is anticipated the discussion of comparative findings will affirm the importance of researching this "ignored dimension" and, in so doing, will enrich our understanding of the spiritual dimension of healthcare. The work is part of a program presently developing a language of spirituality through research.

Key words: spirituality, hospice patients, survivors, spiritual pain, psychosocial

Introduction

The comparative findings presented in this discussion are taken from a recent and ongoing program that seeks

to examine through research the notion of spirituality for those coping with serious illness and its relevance to healthcare. The hope and expectation is that such findings will go some way to addressing the hiatus in research on spirituality that has, for many decades, been articulated in the healthcare literature.¹⁻⁹ Only in recent years has the notion of spirituality been explored through the medium of academic research^{4,5,10-14} since most of the literature to date has been anecdotal.¹⁵

As an exploratory, qualitative research program, the *modus operandi* is to bracket preconceived assumptions about spirituality and explore the dimension through the phenomenological insights of those coping with the impact of serious illness. The conceptual starting point has been to build on, or challenge, the definitional assumptions about spirituality found in the literature. Although there is, as yet, no agreement,¹⁶ recent definitions posit "meaning making" and "experience as person" as the starting point for the exploratory research on spirituality.¹⁷⁻²⁵ To quote Taylor and Ferszt,²⁴ "spirituality is defined as that part of the self where the search for meaning takes place." Or as Hodder and Turley¹⁹ indicate, it is "the organizing centre of people's lives." A clear distinction is made in the literature between religion and spirituality. The

latter is seen as broader than religion and relates to the universal quest to make sense out of existence,^{26,27} a characteristic of human "being."^{28,29}

Preliminary findings from the research program indicate that there is a need for a new language for articulating spirituality. The findings indicate that the language of a secular spiritual journey, rather than a conventional religious or theological conceptual framework, was used for meaning making by the majority of participants interviewed.^{30,31} Such results affirm the recent definitional move away from conflating religion with spirituality, while pointing to the richness, complexity, and contradiction that individuals bring to their meaning making. The results indicate that maintaining the intimate connection with life through family, home, friends, leisure, and work is just as spiritually important to individuals as transcendent meaning making (religious or otherwise).³²

The preliminary findings from survivor data indicate that individuals need a strong sense of meaning making and connection with life in order to deal with the challenge of serious illness, including the demands of aggressive, invasive treatments.³¹ Such a connection can be threatened by a break with the normal or expected relationships and satisfaction with life through physical, identity, relational, and existential losses. When the disconnection is acutely painful (a

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subjective phenomenon depending on the individual), it is then experienced as spiritual pain, creating a void that challenges the individual's ability to make meaning from his or her existence.³³ If the spiritual pain is sufficiently severe, it can lead to suicidal ideation.³¹

This article presents additional comparative data, taken from interviews with hospice patients, that affirm the preliminary conceptualization of spiritual pain by the survivors from the program published elsewhere.

The core etiological factors for "spiritual pain" include a sense of diffuse emotional/existential/intellectual pain directly related to the meaninglessness created as the result of a break with the expected/normal network of relationships that function to connect one to life. A key ingredient in that pain is the sense that the normal network of relationships and experience *with* life are failing to meet the individual's needs, and thus the expected satisfaction and *meaning making from* life are not forthcoming.³³

Although the similarity in the two findings affirms the language of spiritual pain, the contrasts in the content and emphasis between the two arms of the study provide important insights into the differences between survivors and hospice patients on this topic. The aim of this discussion is thus twofold. First, it seeks through the publication of detailed findings on hospice patients to continue reporting the work of developing and testing a language for spiritual pain. Second, by reflecting on the contrasts between the findings of survivors and hospice patients, it seeks to provide insights into differences between cross-sectional samples of individuals in different stages of the serious illness trajectory. It is anticipated the discussion of comparative findings will affirm the importance of

researching this ignored dimension⁷ and, in so doing, will enrich our understanding of the spiritual dimension of healthcare.

The research

The research project represents the first time substantial funds have been provided by a major Australian cancer research organization for work on spirituality. The study, funded by the Queensland Cancer Fund for two years and conducted at the University of Queensland, examines the relevance of the notion of spirituality and spiritual pain for hospice patients (arm A) and their caregivers (arm B), and the health professionals who look after them (arm C), as well as cancer survivors (arm D) and patients undergoing curative care in a hospital setting (arm E). The findings reported in this paper are presented from the arm of the research that explores aspects of spirituality in relation to hospice patients (arm A).

The participants in this arm of the study were consecutively enrolled through the Karuna Hospice Service. Prospective participants were contacted and told of the study and invited to participate in an interview. Participants were informed of their ethical rights (such as informed consent, confidentiality, right to withdraw) before agreeing to participate, and a written consent was obtained prior to the interview. The university ethics committee has approved the study, and the ethics committee has ratified project descriptions and consent forms.

Target population

All the participants met the criteria for the community-based hospice in that they had a terminal diagnosis with less than six months to live, had a general practitioner who would be involved in their care, and had a caregiver who was able to look after them in their home environment.

Most of the participants were female (female, $n = 10$; male, $n = 4$). The diagnostic groups included breast cancer ($n = 4$), bowel cancer ($n = 3$), lung cancer ($n = 3$), prostate cancer ($n = 1$), ovarian cancer ($n = 1$), and two CCF noncancer. The ages ranged from 47 years to 97 years. Most were married with adult children ($n = 8$), with four widowed, one divorced, and one never married. All resided in the suburban area on the north side of Brisbane that is the geographical district serviced by the hospice. All were Anglo-Australians and, with the exception of one (English), all had Australian citizenship. The majority ($n = 8$) indicated no specific religion on the admission sheet. Five nominated a religion (Church of England, $n = 1$; Anglican, $n = 2$; Uniting Church, nonpracticing, $n = 1$; Catholic, $n = 1$), and one recorded Theosophy.

Methodology

The meaning patients are making from their illness experience has been documented through qualitative research using an open-ended interview with each participant. The interviews were conducted by a psychosocial researcher with a counseling background, experience in conducting and publishing in spirituality research, and many years' experience working with families coping with a member with serious illness. The time and location of the interviews were of the participants choosing and were all conducted in the patients' homes. The participants were encouraged to tell their stories from the point of prediagnostic symptomatology up to the present, with the opening prompt question: "Could you tell me of your experience, in your own words and in your own way, from the time you became aware that you were ill and how that has changed how you see the world and what you believe is important?"

The interviews were audiorecorded and transcribed verbatim. The language

texts were then entered into the NUD*IST computer program and analyzed thematically. A phenomenological approach was taken to the recording and analysis of the data. All the participants' comments were coded into free nodes, which were then organized under thematic headings. Ninety-seven free nodes were created for the full analysis of the patients' transcripts, of which the 11 directly related to the topic, spiritual pain, are presented here.

As inductive, phenomenological, qualitative work, the reporting of findings is based on a commitment to the participants' point of view, with the researcher playing the role of coparticipant in the discovery and understanding of what the realities are of the phenomena studied.³⁴⁻³⁷ Thus, a narrative account dominates, with a clear separation between the presentation of the exact words of the participants in the findings section and the interpretation in the discussion section.³⁸ For economy of presentation, the selected nodes have been organized under categories that, when juxtaposed, build an outline of the issues.³⁹⁻⁴⁰

Findings

Although there were many similarities between the findings of the hospice patients and the survivors, on the issue of spiritual pain there were considerable differences.

Spiritual pain

No paradigm example was expressed by any of the hospice patients that would fit all the characteristics of spiritual pain. As the following discussion of findings will show, the challenge of facing death per se, though highly stressful, did not create the degree of spiritual pain that makes the individual desire the ending of life, as was evident in the survivor data. In the cohort of hospice patients, spiritual pain

of a suicidal intensity was not reported in the present tense as relevant to the hospice experience.

However, there were statements of anger, frustration, and a sense of unjustness reported retrospectively about the experience in the curative system. Such issues were reported as tangential to, or an outcome of, serious illness but not from the fact of the terminal diagnosis itself. As can be seen by the following texts, experiences associated with callousness related to misdiagnosis, surgical mutilation, and unfounded hopeful promises during curative treatment were the cause of considerable angst to some of the participants:

- *Misdiagnosis and uncaring treatment in hospital system.* "I felt they had completely let me down. . . . Oh, it was shocking. The hardest part. Oh cripes yes. The things I went through and put my wife through was unreal. And probably shouldn't have gone through that."
- *Mutilating breast reconstruction.* "They had to take the reconstruction out anyway. So I am left with a weakness in the bowel because of that. And I was so angry because I'd never agreed to having that. Oh I was. He knew I was angry. And just cost us a phenomenal because I was in a private hospital and the bill came to \$86,000. Very unjust. Very unjust."
- *Difficulty of accessing expensive drugs that were meant to extend life.* "Then when I got the tablets, they [scoffs and laughs] . . . they had so many effects, that was probably the first time I felt down. That I'd tried so hard to get onto these that had a much better cure rate and all they did was make thing 10,000 times worse. . . . So probably that was

the lowest time, apart from being in the hospital."

Although, painful, frustrating, and unjust, the experiences did not challenge the hospice patients' sense of connection with life and the meaning making from life. Indeed, the data indicate the participants reported a strong connection with the here and now, and were making meaning from their satisfying relationships with significant others. This finding affirms the notion that etiological factors cannot be listed independently as assured prerequisites to spiritual pain. It is the degree of discomfort or the intensity of the pain level experienced, because of the impact of the factor in the unique life story and circumstance of the individual, that defines the etiological importance.

It is posited that the opportunity that the hospice experience provides for patients to remain in their own homes, within the supportive network of family relationships, affirms meaning making and deflects the possibility of cumulative spiritual pain and the void of meaninglessness.

Life satisfaction: The opposite of spiritual pain

Not only was there a "loud silence" on indications of spiritual pain but the antithesis, that of a strong sense of gratitude for a life full of meaning and satisfaction, was strongly stated. As can be seen by the following examples, the participants spoke at length about their varied and satisfying life experiences and fulfilling family relationships:

- "I've had a good life in the last 10 or 12 years [since I met my present wife]."
- "I've worked hard, raised six children, always helped the community [a 98-year-old's recipe for long life]."

- “I have had an incredible life; I’ve lived at least three lifetimes. I have had an incredible life. My life has been quite difficult [childhood problems, problems with first marriage], but I have had this wonderful time. You know what you have got. I can appreciate what I’ve got because I know how bad it can be.”
- “I have traveled a lot. The last count 36 countries I’ve been to”

As demonstrated later in the discussion, the sense of life satisfaction was coupled with statements that indicated that the participants could speak about and accept the fact that they were dying. The experience with terminal illness makes sense, and there is a privileging of the notion of normalcy: as one participant summed up, “well life should just keep going on, you know; it [dying] is normal.”

The satisfaction and acceptance evident in the hospice patients’ data contrast with the findings from the survivors. The survivors articulated a painful existential struggle to make sense of an existence where multiple losses associated with the sense of self had the potential to cumulate in a sense of disconnection and meaninglessness. On this point, the data seem counterintuitive since the original assumption was that those facing the ultimate challenge of the end of life would have been more vulnerable to experiencing spiritual pain than those facing survivorship.

However, as the following findings demonstrate, this is not to argue that hospice patients do not have to face quite extraordinary losses with regard to their sense of self during the terminal stage. Rather, the data indicate that sadness, frustration, and to some degree fear, rather than meaninglessness, accompanies such losses.

Loss of self

The data from the hospice patients resonated with the findings from the survivor target group on the issue of “loss of self” (physical, identity, relational, and existential). However, there was considerable difference in both the emphasis and content of the comment on this issue between the survivors and patients interviewed.

The stress of physical changes. The participants reported that changes to the physical condition of their body, particularly caused by the treatments, left them with an altered, less satisfying, and at times painful, sense of self. Such distress can be seen by the following statement:

- “My stomach, my husband laughs at me for saying this, I’ve got like two bottoms now. Because of the operations, I’ve got like a split down the middle, which makes it look as if I’ve got a bum at the front and a bum at the back [laughs]. And I don’t think anybody wants to see me like that. I wouldn’t frighten people.”

The participants also reported having to come to terms with a severe decline in their body’s ability to perform quite ordinary physical tasks such as walking and breathing. The physical decline was described in terms of a downward spiral of loss of previous abilities.

- “I certainly can’t do the same things that I used to. I tried to do a bit, but I got so tired I just dropped it.”
- “If I can’t change it, because I’m going to have to go on oxygen soon, because I get puffy. I wake up in absolute terror at night because I can’t breathe. And that is a bit hard to cope with. I try to hang off doing those things. I

don’t want to have the oxygen until I really have to . . . because to me that is another downward step, and I don’t want that to happen yet.”

- “Taking it gently, as soon as I do something, any exertion I’m gasping for 5 or 10 minutes after it. . . . Just going to the toilet and coming back, walking back here that sets me back a little bit.”

The downward spiral was exacerbated at times of having to deal with the unpleasant and debilitating side effects of treatment.

- “The chemo tables they had so many effects, problems, that was a bit, probably the time I felt the most down.”
- “The after effects with the feet that I couldn’t put down, you know, and I hated having to go into a wheel chair every time I had to go over for chemo.”

Fatigue is an important debilitating condition that accompanies the downward spiral associated with disease progression and the side effects of treatment, as can be seen by these examples.

- “I could lie on the floor, just exhausted. I’m so tired, and that’s a horrible feeling.”
- “I said, I need help with getting around like with a bit of shopping and that I’m just getting so tired. I am just so worn out. I came back from the doctor today, and I am still recovering from walking from the doctor.”

For many of the participants, an important dimension of the loss of self caused by severe physical limitations was the forced dependency on intimate others.

- “It has just affected my whole life. Like my husband has to lift me to go to the toilet and help me shower and cook all the meals, look after the whole house. So my life has just changed over . . . totally.”
- “It was only my family coming and worrying about me. She would have to lift me up herself, sit me up like that, and she’d wash me, give me a body wash, and if she let me go a little bit to reach a towel, bang, I’d just go on my face. So she’d have to push me up again. . . . couldn’t walk. Now a paraplegic and can’t do that.”

The distress of loss of previous identity. As with the survivors, a sense of loss accompanying the physical and emotional changes from the disease and treatments forced the survivors into a new definition of self.

For some, the very fact of having to face a serious illness after a previously healthy life challenged their previous notion of self.

- *Getting a serious diagnosis.* “In my case, it was out of character. I wouldn’t have thought that I could ever experience anything like that. Any kind of illness. Just shake them off. Because I always believe it couldn’t happen to me. Maybe the man next door but never me. . . . I have always considered myself a fit person.”
- “I’ve always been the one everyone has relied on, and I don’t like it being the other way around.”

The frustration of loss of leisure and pleasure

All participants reported a loss of self in relation to leisure and recreational activities. These activities were not only important in defining who they were as

individuals but also provided an important framework for the meaning they were making from their experience with life. As can be seen by the following selection of texts, the sense of loss extended over a wide range of activities such as reading, home care, singing, golfing, swimming, walking, carpentry, fishing, and gardening:

- “I am not reading as much as I’d like. I tend to lose my concentration.”
- “I’ve always sung. I love singing. I can’t do that now.”
- “I think a thing that does upset me is my home. My home is not clean compared to how I like it.”
- “A tremendous change. I can’t do the things that my husband and I used to enjoy doing, like golf. We were both golfers.”
- “I miss swimming. I used to love swimming. But I couldn’t put a costume on now.”
- “I think it is just the limitation of things I miss. I mean I used to love walking. I know I can’t do that.”
- “I cannot do the things that I always wanted to do. Well, I’ve got tools down in the workshop and I can’t use them. I’ve got money to buy tools or instruments that I need for myself. It is a waste of time buying them. I won’t be there to do it. Doing woodwork is very important. It was a big part of my life.”
- “Not being able to go fishing. I’ve got a boat sitting down the back yard I can’t use.”
- “I can’t look after the garden like I should. I’ve got a lovely bit of ground that I can’t use.”

For many participants with partners, there was a concern about how the sense of loss involved and affected the life of their loved one.

- “There is no quality of life. . . . I’m worried about my wife’s quality of life, too. . . . She is more or less bound to me. To do what I’m capable of doing.”

The frustration of loss of work

Having to give up work was another stressful change that participants reported as an important loss. The loss was not just in relation to the meaning they were making through being a physically capable and able person, but also through their sense of connectedness created by relationships with colleagues.

- “The work that I did entailed a fair bit of fitness, demanded a lot of physical. Loading, unloading trucks by hand. So it was fairly heavy, fairly heavy work. . . . Tiredness, yes, and I couldn’t lift as much as I used to be able to lift.”
- “[Giving up work] for me it was difficult. . . . It was something that I never want to happen, but I had no alternative because of the doctor’s prognosis. . . . It was a little bit hard to accept that at first, and then again you have to be real about it.”
- “I miss work. I miss the companionship of other people and the money. But certainly the companionship was the hardest thing.”

The painful void of the ultimate loss of self

The expectation was that the hospice patients, to an even greater extent than the survivors, would record the distress of facing the possible ultimate extinguishment of the self through

death. The data challenged this assumption with the findings that indicated a high level of acceptance of dying couched in calm, nonstressful language. Examples of such accepting language include the following:

- “So I know the end is coming.”
“You seem very accepting of that. Is that right?”
“Yes, yes, I’ve got used to it.”
- “I am not afraid of death. I’m a little bit afraid of dying. You know of lingering.”
- “I was speaking to a doctor, and he said to me, ‘It looks pretty hopeless.’ And I said, ‘Okay.’ ‘How do you feel about that?’ he said. And I said, ‘Not bothered.’”
- “Well I don’t know how long. But I think it is inevitable that it is going to happen this year. . . . It is something that happens; it is like taxes.”

The distress of relational pain. The participants spoke at length about their strong connection with the here and now. For all participants, meaning making centered on satisfying connections with family, friends, and the richness of daily life in the home environment. Although there was definite evidence of the distress of relational pain and sense of abandonment, the patients’ texts on the topic were more limited than the survivors’, both in terms of the number of participants who commented and the extensiveness of the comments. The opportunity provided by the hospice to remain in their own home supported by significant others offered a strong buffer to an exposure to relational pain. In spite of this comfort zone, however, there were still strong indications of the relational pain of rejection or avoidance caused by the difficulty others have in dealing with the idea of

serious illness. The relational pain was particularly associated with hospital stays, in relation to both the “production line” relationships with hospital staff and the friends who do not remain in contact during the hospital stay.

- “From what I am hearing, it is not the medical intervention, it is that they don’t seem to care?”
“Yep.”
“We’ll do this, the next one do this?”
“Yes, that is it exactly. That is exactly what it is. It’s the hospitals. That is what you feel. They just pass on.”
- “Is it a bit hard to make sense of?”
“Yeah, and when you just need somebody . . . just need somebody to come and spend five, ten minutes. Especially when I was in hospital for the eight weeks and they were just across there. And it wouldn’t have taken much to walk across and do it. Because that eight weeks were the loneliest time I’ve ever had.”

For some also, there was the sense of neglect and abandonment from friends in the home setting.

- “I wish they would just come and have a drink with me one day. . . . (It is) as though you’re being snubbed.”
- “When they know you’ve got cancer, you’ve got secondary, they all shy away from you. They don’t have a clue how to talk to you. And you can feel it just in their body motions as they are coming to you that they don’t want to say anything. And people that I was really depending on for support . . . who had helped so much for many years, didn’t even come over. And it really hurt.”

In the patient data, the notion of relationship did not just cover the here and now, but also embraced a sense of the future. Consequently, one important difference between the findings of the survivors and the hospice patients is the projected sense of relational pain that is associated with not being around in the future to experience the satisfying, normal, and expected relationship with intimate family members such as partners, children, or grandchildren. The distress or pain associated with this phenomenon motivates individuals to survive for their loved ones and is also reported by those who have a clearly stated acceptance of death and dying.

- “I just came to the conclusion one day I’d do the best I could, hang around the longest I could with the grandchildren and just take each day as it comes.”
- “I don’t feel cheated in that sense I feel sad that I won’t grow old with my husband and I am sad I will not know my grandchildren, but beyond that I don’t feel cheated at all.”

However, it needs to be noted that such relational pain is different from the idea of acceptance of death. Both participants who made the preceding statements expressed quite profound and calm acceptance of the fact of their own dying. The phenomenon is more closely related to the sense of protective connection that the terminally ill individuals expressed about their family members.

The pain associated with existential loss. As with the survivors, there were some statements from the hospice patients indicating that the confrontation with serious illness changed their existential perspective of life. The following example from one participant indicated that the strain of coping with the challenges of a life-threatening illness introduces cynicism and loss of innocence as part of the new lens on life:

- “I went back to work for four months (in drug and alcohol counseling). All these people coming in giving all the reasons for them drinking and disasters and I thought, I’ve got worse problems than that. So I got really fed up with listening and I thought, no this isn’t fair. Because that was the job I was doing. So I felt as though I wasn’t being fair in that ... so I did give it up.”

Change values

As with the survivors, most of the hospice patients reported a change of values as one outcome of the experience with serious illness. The change in values was about reinforcing and affirming the connection with life through a move away from materialism to embracing the significance of the here and now, and valuing the daily pleasure of family life and relationships.

- “I think it has [changed my values], you know money and possessions. It doesn’t worry me any more, if I don’t have it. Life is more important. I think it is more sentimental, sentimental value. That we sort of cherish more than monetary value. And we can all say, well, you know, money is handy to have, but if you haven’t got it. . . . It is not everything.”
- “Does it change how you view life?”
“Ooooooh, yes. Oh yes, it does, oh yes. Every day is a very special day. I used to struggle sometimes with work and everything. And I just think my life and my grandchildren’s lives are more important.”
- “We wouldn’t have taken that trip without that.”
- “I am getting closer to my sister;

it is something that has come out of that, that wouldn’t have happened. We are making efforts which we hadn’t bothered before.”

However, it should be noted that even though money and materialism are no longer a priority, financial distress can still be problematic.

- “So you know I try not to [worry about money] . . . but money is a big problem. . . .”

One participant noted no change from their prior value system.

- “Has the experience changed your values?”
“Oh, I don’t know about being different. No I don’t think anything’s different to me. No.”

Coping strategies: All about maintaining the connection

All the participants described in detail the coping strategies they used to deal with the challenge of terminal illness. In view of the findings on the strong meaning making and connection with life indicated by this group of hospice patients, it is interesting to note that most of the coping strategies incorporated a focus on maintaining a satisfying and meaningful connection with the here and now (which is the antithesis of conditions conducive to spiritual pain). These findings on the coping strategies of connectedness juxtaposed with an absence of descriptions of acute spiritual pain in the hospice patients affirm the preliminary theoretical notion of spiritual pain³³ posited by the initial data collected from the survivor arm of the study. These strategies of connectedness are as follows:

Strategy 1: Keeping the focus on the here and now. All the participants indicated that an important strategy in dealing with the challenge of terminal illness is to focus on the meaning and satisfaction they are making from life.

As one participant summed up the situation, it is important “to get on with life.”

Keeping busy either through working or daily activities is seen as both distracting the mind away from worry and as therapeutic.

- “Worked for so many years, just getting on with life and not worrying about it.”
- “Busy doing things I liked.”
- “Going to work was a good thing, cause it kept my mind on other things.”

However, for one, the distraction of work had an element of denial.

- “Couldn’t believe it . . . had to talk myself into fact that I had cancer . . . wanted to forget anyway because I was going off to work.”

As the hospice patients faced a decline in their capacities, they found less physically demanding activities on which to focus.

- “Trying to pull myself out of it, so do things like crossword puzzles.”
- “Tried to read books . . . just escapism . . .”
- “A little bit of exercise.”

Strategy 2: Valuing relationships with family and friends. Participants spoke about the importance of focusing on family relationships, both as a means of emotional and practical support and as a center for meaning making.

- “Just having the family around.”
- “Everyone is popping in.”
- “I am coping well. I am helping myself and my families helping to help myself.”

A great deal of the data were on the issue of the richness of family life and the importance of being at home surrounded by family and friends. Because the detail is too extensive for inclusion here, it will be reported elsewhere. However, it needs to be noted that on this issue the findings resonate with that of the survivors who prioritized the importance of the meaning they were making from relationships with family and friends as a "spirituality quintessentially of the ordinary."³²

Strategy 3: Rely on own inner strengths. As with the survivors, the hospice patients reported a strong reliance on their own inner strengths. As the following descriptions demonstrate, such strengths included self-reliance, strong will, positive outlook, open mind, and independence.

- "Armed forces experience . . . like to keep myself prepared for anything."
- "Feeling of being more self-reliant."
- "Being strong willed is also a help."
- "Being positive and healthy minded about things."
- "Keeping an open mind."
- "No use sitting there moping."
- "I have always been pretty strong in my ideas and things."
- "I haven't felt the need to go to a counselor."

There was a sense in which the hospice patients saw the challenge of remaining positive as a type of mind game that would ensure that they would not lose control of the situation.

- "If you let it get you down, you are gone."

Strategy 4: Accepting the situation. All the participants reported a strong degree of acceptance of the fact that they were dying, as can be seen by the following texts:

- "It is no use crying about it."
- "I will try to beat it and if I don't well."
- "I can't do anything about it."
- "The questioning element is there . . . this is what we've been given . . . so just deal with it."
- "Have to be real about it."
- "And you can't fight; you just go along day to day."
- "Just go with the flow."

The participants indicated that they had come to acceptance over a period of time, often unaware of the process happening.

- "I don't really know how you come to that [acceptance]."

Acceptance is described as an ongoing process vulnerable to further challenges during the progress of the disease condition.

- "That is just my way of dealing with what I can't change I've just got to accept . . . if you had come a few days ago when I had bone scans I wasn't too happy. And then I thought well there is nothing I can do."

Strategy 5: Planning or finishing off. The acceptance of death laid the foundation for coping strategies associated with planning or closure. Patients described plans to enjoy the most of the here and now (e.g., holiday trips), completing "unfinished business," or even in the

case of one participant, planning for the afterlife (which included plans for euthanizing the dog as company for the journey to the afterlife).

- "We have been planning."
- "Dog put down . . . coming with me."
- "My mind has been going fast [planning], I tell you."
- "Practically finish things off."
- "Said who I'd like my jewelry to go to."
- "I don't want to leave things difficult for anyone; it is painful enough for them."
- "A bit of a control freak writing my own funeral service"

Strategy 6: Scaling down. Underlying all these strategies for coping was an ongoing process of letting go of previous abilities and coming to terms with the continuous decline in physical capacities. This was described as a continuous process that progresses in small steps, with each step needing to be negotiated individually and incorporating an element of grief and adjustment.

- "Just gear down a bit."
- "One of the lobes of the lungs is totally solid. So the air entry is a bit limited so I get really puffy doing things. So I just gradually drop down what I'm doing."

There is a resistance described to each stage of decline, with the cycle of acceptance being re-enacted at each stage, and a sense of determinism and remaining positive used as strategies to deflect the speed of the decline.

- "I am still fully determined to do

as much as I can myself. Because I feel if I give up any bit of it that is another bit I mightn't get back again."

- "Try to be as positive as I can knowing in the back that going down but determined not to go down as fast as everybody thinks I might."

Religious beliefs

As will be described in detail elsewhere, for some participants these coping strategies were accompanied by the comfort of a reassuring belief in a personal God. For these individuals, the pastoral care reinforces and affirms their ability to cope.

- "And Father . . . comes and visits me once a week. And I love that. And he gives me Communion."
- "They come in and give me Holy Communion once a week. Yes, it did help. I'm certainly regaining my calm, that is how I say it is, that I'm actually regaining my calm, which I felt I'd lost!"

However, even for those who report a religious faith, active involvement in pastoral care is not a necessary coping strategy.

- "I have considered talking to a minister of religion as part of my process of going through this. But I haven't done it as yet."

Discussion

Although the findings from the hospice patients resonate with those of the survivors, there are significant points of difference. As Figure 1 shows, while the survivor findings highlight the potential for spiritual pain associated with life after high-tech curative treatment, the hospice patient data

emphasize the protectiveness of the hospice experience for deflecting the possibility of spiritual pain.

Both survivors and hospice patients indicated that they faced quite severe losses in their sense of self (physical, identity, relational, and existential) as a result of their confrontation with serious illness and its treatments. However, although the survivor texts privileged the presence of spiritual pain, the hospice patients provided detailed reports of their satisfying connection with the here and now, and a strong sense of meaning making from life experiences. The challenge for survivors is to create meaning for a future life in the face of devastating losses. Examples of these losses include infertility, severe educational and employment disadvantage, altered physical self, loss of prior identity, family and relationship pain, fear of relapse, and loss of naivete about life. For hospice patients, however, the challenge is to make sense of the losses through an acceptance of death and the processes of dying. This group of hospice patients recorded strong acceptance of death, a high degree of life satisfaction, and coping strategies that allowed them to accept and find meaning in the dying trajectory. Such strategies included keeping the focus on the here and now, valuing relationships with family and friends, relying on own inner strengths, accepting the situation, planning to gain the most of what was left from life or for bringing a satisfying closure, and scaling down in activities. This focus on the here and now resonates with the work of Chiu.⁴¹ For a small minority, there was a reliance on a sense of a personal God who provides a protective sense of comfort and a satisfying notion of an afterlife. Underpinning all the texts is a meaning making that was posited on a strong sense of the normalization of death.

First, then, the findings respond to the ongoing call for definitional clarity in work on spirituality,^{11,42} by affirming the definition of spiritual pain as posited by the preliminary survivor data.³³ Second,

the findings highlight the importance of understanding spirituality in relation to serious illness in holistic terms.^{43,44} The data indicate that both survivors and hospice patients describe their spirituality in terms of meaning making and their connections with life, rather than with religion per se—a direction evident in the literature.^{12,44-46} The appropriate response to such a notion of spirituality is not to split spirituality off as but one aspect of care, but rather to understand it in the context of overall service provision. It is not a matter of incorporating spirituality as one dimension in the plan of care,⁴⁷ but rather understanding that for community-based hospices spirituality actually is expressed as the plan of care. The opportunity to handle serious illness supported within the comfort of the network of meaningful relationships within the home environment thus becomes the *raison d'être* of spiritual care. This has direct implications for the importance of community-based hospice services and the holistic, supportive role of healthcare services. Third, the findings affirm the need for, and further the development of, an evolving language for spiritual care through research. As preliminary findings from the research indicate,⁴⁸ most individuals faced with serious illness have a need to talk but as yet there is not a suitable language in which they can express their non-theological spiritual notions.

Limitations

It is important to acknowledge that self-selection has affected the findings. Referral to Karuna Hospice Service is not an automatic process but rather one chosen by the participants from a number of alternatives. By the very fact of being a client of a community-based hospice, the participants are highly likely to have an awareness and acceptance of the fact that they are dying, a supportive family situation, and a meaning-making framework that values remaining in the home situation.

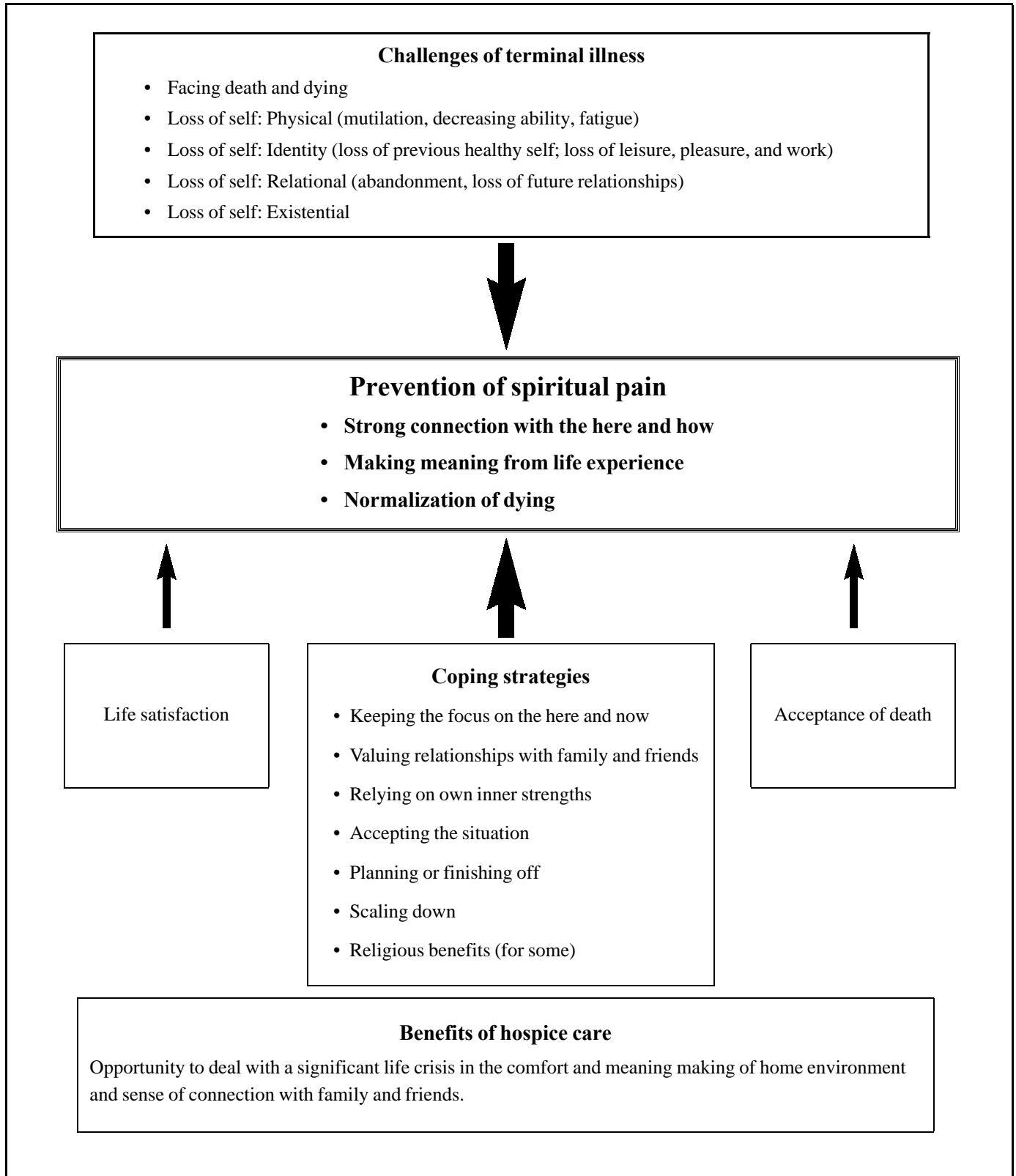


Figure 1. Outline of findings from hospice patient arm of research.

Conclusion

The findings presented in this article both affirm earlier work on the notion of spiritual pain and provide important insights into the holistic nature of spiritual care within the healthcare system. In so doing, the findings contribute to furthering the ongoing process of the development of a language for spirituality through research.

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