Spiritual issues and needs: Perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study

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ABSTRACT

Objective: Health care professionals and policy makers acknowledge that spiritual needs are important for many patients with life-limiting illnesses. We asked such patients to describe their spiritual needs and how these needs may impinge on their physical, psychological, and social well-being. Patients were also encouraged to explain in what ways their spiritual needs, if they had any, could be addressed.

Methods: We conducted two qualitative interviews, 3 months apart, with 20 patients in their last year of life: 13 patients with advanced cancer and 7 with advanced nonmalignant illness. We also interviewed each patient's general practitioner. Sixty-six interviews were tape-recorded, transcribed, and analyzed.

Results: Patients' spiritual needs centered around their loss of roles and self-identity and their fear of dying. Many sought to make sense of life in relation to a nonvisible or sacred world. They associated anxiety, sleeplessness, and despair with such issues, which at times resulted in them seeking support from health professionals. Patients were best able to engage their personal resources to meet these needs when affirmed and valued by health professionals.

Significance of results: Enabling patients to deal with their spiritual needs through affirmative relationships with health professionals may improve quality of life and reduce use of health resources. Further research to explore the relationship between spiritual distress and health service utilization is indicated.

KEYWORDS: Spiritual needs, Palliative care, Cancer

> *Man is not destroyed by suffering; he is destroyed by suffering without meaning.*
> VE Frankl

When confronted by serious illness most patients search for meaning (McClain & Rosenfeld, 2003). The persistent social attitude that denies death and the medicalization of death hinder patients in expressing existential questions about life and death.

Physicians (Emanuel & Emanuel, 1998), palliative (Byock, 1996) and primary care specialists (Aldridge, 1991), nurses (Narayanasamy, 1991), chaplains (Stoter, 1995), and sociologists (Walter, 1997) increasingly recognize the importance and commonality of this search for ultimate meaning and the desire for a good death (Smith, 2000; Clark, 2003). Spirituality has become an important "end of life" issue incorporated in quality of life measures (World Health Organization, 1998), textbooks (Lynn

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et al., 2000), and clinical guidelines. Some national health services provide spiritual care as a necessary part of service provision (Scottish Executive Health Department, 2002).

Research indicates that patients' spiritual beliefs influence clinical outcomes, and that spiritual distress is a factor in depression, demoralization, and end-of-life despair (Kissane & Clarke, 2001; Lloyd-Williams, 2003; McClain & Rosenfeld, 2003). An understanding of the mechanisms that cause and exacerbate spiritual distress is fundamental to the provision of effective care.

Defining and assessing spiritual needs is difficult (Puchalski et al., 2003). Narrow definitions that lend themselves to research tools may be restrictive. For this study we adopt a broad definition: "the needs and expectations which humans have to find meaning, purpose and value in their life. Such needs can be specifically religious, but even people who have no religious faith or are not members of an organized religion have belief systems that give their lives meaning and purpose" (Institute of Medicine, 1997).

We set out to describe the range and context of spiritual issues and needs that patients with advanced cancers and nonmalignant illnesses experience, and the extent to which such needs may impact on their well-being. We wanted to see how such needs and issues could be addressed and whether general practitioners recognize spiritual needs in their patients with advanced illness.

This article adds to the current debate on the role and place of spiritual care by exploring spiritual need rather than religious practice, and raising the question of whether spiritual distress increases the demand on health services. Between the extremes of ignoring the role of religion within health and actively promoting it there lies "a vast uncharted territory in which guidelines for appropriate behavior are needed urgently" (Sloan et al., 1999).

METHODS

Participants

We purposively recruited 20 patients with a range of advanced malignant and nonmalignant illnesses from a variety of religious and social backgrounds. General practitioners approached 29 patients from three contrasting practices in the Edinburgh area of South East Scotland. Exclusion criteria were dementia and serious mental illness. Twenty-five agreed in outline to participate, but 5 were not recruited because of death before the first interview, severity of illness, or hospital admission. The average age of the 20 patients was 75 years (range

57 to 100), 11 were female, 13 had cancer, 4 had cardiac failure, 2 had chronic obstructive pulmonary disease, and 1 had motor neurone disease. Eight claimed strong religious contacts, 4 nominal, and 4 had no religious affiliation. Eight lived alone. Appendix 1 details the participants. The local research ethics committee and Primary Care Trust approved the study.

Data Collection

Building on previous experience, we used in-depth qualitative interviews to capture highly personal and sensitive issues (Mays & Pope, 1996; Murray et al., 2003*a*). With informed consent, E.G., a social scientist, conducted 20 first and 13 second interviews (3 to 5 months later) in the patients' homes, using a flexible open-ended schedule (Appendix 2). Interviews followed patient cues and lasted from 40 min to 2 h. Following each patient interview, we asked the general practitioner to describe any spiritual needs or issues they felt their patient had, and whether such issues were having any impact. In total, 66 interviews were conducted. Five patients died, and 2 were too ill for a second interview. Five died shortly after the second interview.

Analysis

The interviews were tape-recorded, transcribed (together with field notes), coded, and analyzed, facilitated by use of the qualitative package NVivo. Analysis was guided by the research questions and was ongoing throughout the fieldwork to allow emergent themes to be fed back into the continuing data collection and coding strategy (Coffey & Atkinson, 1996). Regular review and discussion of the evolving themes by the multidisciplinary steering group contributed to data synthesis and interpretation. Consideration was given to how patients might express or display signs of spiritual needs, accepting that these are often interwoven with descriptions of physical, social, and psychological concerns.

RESULTS

1. What Spiritual Issues Concern Patients with Advanced Illnesses?

Searching for Meaning and Identity

At the crisis point of diagnosis, or as their illness incapacitated them, patients searched for meaning: "What is the point of life—years of happiness followed by a few years of misery and then out?" (Pt. 5) Patients had difficulty in constructing meaning

within their illness, which in turn diminished their ability to bring a measure of control to what was happening, and fed into a sense of uselessness and lack of purpose. Some wondered about judgment or divine indifference: "Where is God in all this, has God forsaken me?" (Pt. 3) "I think I have to be punished for the wrongs that I have done" (Pt. 9).

Patients asked: "who am I now?" as autonomy and control of who they were slipped away. Their sense of imprisonment: "I feel as if I am in a cage" (Pt. 2) was exacerbated by relatives who unintentionally focused on the "invalid." "People immediately think 'Oh she is poorly, we can't ask her to do that.'" (Pt. 2) Displacement within the family echoed a sense of displacement within a greater scheme of things and left patients questioning their value and place in the world.

Searching for Peace

Patients desired peace of mind, and freedom from a "dark" and often nightly fear of dying: "Fear and dread come over you, it's a horrible feeling, absolute total fear, because nobody wants to know when they are going to die" (Pt. 14).

They knew doctors could provide analgesia, but who could help them face death? "I fear death, a wee bit, not the pain you know, it can be controlled. No it's the unknown really" (Pt. 17). As patients sensed the imminence of death they asked more explicit questions: "Is it real; is there life after death, where am I going? What happens if I am wrong and there is something after all?" (Pt. 5).

Searching for a Guide into the Unknown

Many wished that someone, a doctor or nurse, who had cared for others as they died, would explain what was happening and help them make sense of it. Some talked of how when they were giving birth they had so much support, information, and guidance, but now they had so little.

Not Searching: No Spiritual Concerns

Two patients explicitly stated that they did not have spiritual needs. They associated spiritual needs with religion and explained that they had no connection with the church and no need for it.

2. Do Patients Think Spiritual Issues Affect Their Health?

Physical and Psychosocial Problems

Spiritual distress presented as physical discomfort: "I feel down, like an emptiness in my stomach. I get this dead feeling in my stomac" (Pt. 13).

Anxiety, insomnia, and panic attacks were often precipitated by fears about death: "I lie awake and think; it's not my eventual demise particularly but the slow road down to being a skeleton in a bed" (Pt. 14).

"I was shaking, literally—my clothes, my nightdress, just trembling away . . . every moment in bed at night getting worked up about it" (Pt. 4).

Losses experienced throughout their illness were interrelated, creating intense feelings of sadness and lack of purpose: "I feel useless. When the quality has gone, life isn't your own" (Pt. 4).

"I'll say 'God just let me die tonight.' There must be somewhere that's better than this" (Pt. 12). "I was very depressed this morning, it just seems to come in a wave. I am so conscious of being so useless" (Pt. 11). Loneliness was common: "People that were my friends will not even take a cup of tea" (Pt. 16).

Service Usage

Frequent panic attacks and an overwhelming sense of uncertainty prevented patient 12 from staying at home. Some routinely contacted health services for reassurance, and described medical problems to legitimize the call: "He gave me two tablets to get to sleep; at that point I really did feel as though I wanted some kind of help." (Pt. 3). Though patient 8 recognized the hurt that suicide would cause her family, she phoned the out-of-hours service: "I think I more or less says to the doctor, 'well if you don't come,' I say, 'there's an easier way.'"

Patients recognized the difficulties of explaining their emptiness and searching: "I'm not really (depressed) and yet the doctor gave me antidepressants" (Pt. 4).

3. How are Spiritual Needs Addressed, and by Whom?

Personal Resources

Patients utilized a range of techniques and enormous personal resources. Some accepted the inevitability of death, and spoke of a universal allotted span of life: "I've had my three score years and ten" (Pt. 17).

Being able to talk about illness was important: "Unlike the old days, at least now we can say the word cancer" (Pt. 14). Many found meaning in family relationships: "Let's face it, we have had a good life, we've brought up our family, now we've got our grandchildren, now what more?" (Pt. 18).

Others adopted a resilient, almost stoical approach: "It's going to be what it's going to be the

rest of time I've got left. I'm just taking each day as it comes" (Pt. 7).

Some found strength and hope in their beliefs and in the promise of a life after death, frequently interpreting their illness within their belief system: "It's quite difficult to put into words, but God is always near me. There's somebody there" (Pt. 3). "I am hoping that we will meet again" (Pt. 8). Reading the Bible, meditating, attending religious services, or sitting in the garden brought comfort and reduced angst. Even some nonreligious patients found prayer therapeutic and some felt it lessened their physical pain: "I just think, have a little chat with him up there [God] and I do and I just go to sleep after that" (Pt. 1). "When the going gets tough, it's [prayer] the only thing that gave me peace" (Pt. 2).

The Role of Professionals

Patients who felt valued and affirmed by their doctor described being more able to come to terms with their life and retain a sense of worth and meaning. Being treated as individuals who were important, rather than diseases, made the most difference to how people felt on a day-to-day basis: "My G, the most important thing that he does—well he assures me that I'm not away yet. He always listens" (Pt. 3). "She (her GP) believes in me" (Pt. 10).

One patient described their family doctor praying: "That wee prayer, that is more valuable than all the pills" (Pt. 9). Another talked of wishing that her doctors would say a "quiet prayer" for her, to give her hope for the future. Those who had experienced hospice care perceived a difference in the quality of care, which they connected with the holistic concern of the hospice staff.

4. Do General Practitioners Recognize and Respond to Spiritual Need?

Recognizing Need

General practitioners recognized the importance of the spiritual dimension, and its effects: "It's an inherent part of the whole person, spirituality" (GP 1). "If it's unmet then that will impact on their overall health" (GP 2).

They felt spiritual needs were most prominent during periods of crisis: "Times of illness are fairly focusing really because they make us ask 'What's it all about? What am I all about?'" (GP 3).

Assessing and Meeting Needs

Although a few GPs felt it would be inappropriate to raise such intimate issues, most felt that the life-limiting nature of the patient's illness provided them the opportunity and the permission to pursue spiritual inquiry: "Respect is a core value of general practice, [it] means valuing their soul qualities—it's impossible to practice appropriately without caring for the spirit" (GP 5).

All accepted that if spiritual issues or questions were raised they should be responded to but most felt they did not have the time nor the skill to "do spiritual care." GPs described it as an extra, though very important component.

GPs identified those who were spiritually well supported: "Pt. 1 has a very strong faith and that has helped her during many stages in her illness. I've acknowledge that and you know complimented her on the fact that that is helping her" (GP 4).

They also recognized those in significant spiritual need, describing them as "unreachable," "vulnerable," "difficult to get in touch with" patients, who often displayed a strong façade of coping, covering a refusal to accept their mortality.

DISCUSSION

Many patients were as distressed by existential issues and the imminence of death as by physical pain and disability. They associated anxiety, sleeplessness, and despair with such distress. They were best able to cope with their spiritual questioning when they were affirmed by family and professionals.

Strengths and Limitations of the Study

Most previous studies have used structured questionnaires to identify specific spiritual issues. Our qualitative approach allowed us to identify recurrent themes in the material, spontaneously provided at interview (Daaleman et al., 2001; King et al., 2001). Patients were able to describe spiritual needs and distress in their own language, using their own constructs and stories, grounding them in their everyday life struggles. Patient's voices captured the intensity of the themes. Return interviews facilitated the exploration of deeper, private themes. Separating spiritual themes from emotional themes is challenging (Murray et al., 2004). Authenticity was achieved, as far as was possible, by allowing patients themselves to separate psychosocial issues from concerns about how they felt in the face of a much greater whole or higher power. Though both religious and nonreligious patients were represented in this study, all came from the same geographical and cultural area in South East Scotland. The extent to which these findings are applicable to a wider range of patients from differing age, social, ethnic, and religious groups is not determined.

Effect of Unmet Spiritual Need: Spiritual Distress

Our study focused on spiritual or existential need rather than on spirituality or religiosity per se as this may impact more on other dimensions of health (King et al., 2001). We suggest that unmet spiritual needs may give rise to spiritual distress in some individuals that may worsen physical and emotional symptoms and the ability to cope with them (Fig. 1). Expressing spiritual distress through physical symptoms resulted in symptomatic treatment without care for the underlying spiritual distress. More work is needed to understand a possible cyclical effect of unmet spiritual need. The construction of the invalid role by family members and the reliance on health services effected disempowerment and reduced patients' sense of control and ownership of their health and of their identity. As these diminished, spiritual needs increased, and they in turn appeared to create demand for health service interventions.

This would correspond, in the preterminal phase, with the findings that in terminal care, psychospiritual interventions may decrease analgesia required (Murata, 2003).

Preventing Spiritual Distress

This study found that patients not only recognized their spiritual needs and their consequent distress but were able, when supported, to use a variety of personal strategies and resources to respond to these needs. Being able not only to construct the meaning of their illness in the context of life experience, as the coping literature suggests, but to construct meaning in the context of a greater whole is important in order to retain a sense of self-worth (Rideout & Montemuro, 1986).

A patient centered approach, supporting patients in their worldview, and providing openings for expression of fear, doubt, and anxiety may help patients in their search for meaning and prevent spiritual need amounting to disabling spiritual distress. Mount and Kearney (2000), echoing the work of Cecily Saunders, suggest that this whole-approach can activate the innate healing principle within the patient. Further research is needed to compare this approach with other methods, such as meaning-centered group psychotherapy (Greenstein & Breitbart, 2000), and to differentiate spiritual distress from clinical depression, which may also be underdiagnosed in palliative care (Hotopf et al., 2002).

Implications for Spiritual Care

Patients facing death long for a guide, and often look to health professionals. General practitioners consider that they have a role in responding to the spiritual needs of patients, but are constrained by lack of time and training (Murray et al., 2003*b*). Varying approaches to recognizing need, such as those reported by family physicians in the United States, were also found (Ellis, 2002). Chaplains and pastoral care workers have time and training to deal with spiritual issues. The tendency to see spiritual care as a specific task contrasted with patients' experience of finding support to meet their own spiritual needs through valuing and affirming relationships with carers. Professionals often unintentionally offered good spiritual care. The comfort conveyed when a physician supports the core that gives the patient's life meaning and hope is what many patients miss in their encounters with caregivers (Koenig, 2000). Care for the dying would benefit from a more thorough incorporation of pastoral-care principles and practices (McClain & Rosenfeld, 2003).

CONCLUSION

Patient perspectives on spiritual need provide evidence that such needs are common and give rise to spiritual distress that may impact negatively on well-being, and may increase health service usage. Patients have the capacity to respond to their own spiritual needs, if given support. Professionals who developed a positive relationship with patients inadvertently reduced spiritual distress.

AUTHORS' CONTRIBUTIONS

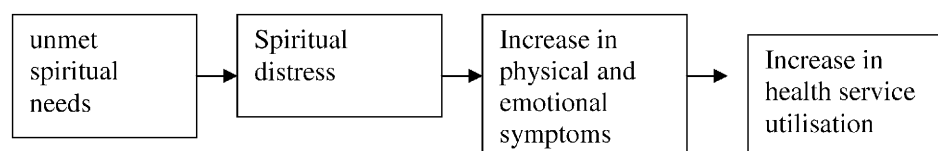E. Grant, S.A. Murray, M. Kendall, K. Boyd, S. Tilly, and D. Ryan conceptualised and designed the

Fig. 1. Possible effects of unmet spiritual needs.

study. Data collection was carried out by E. Grant. All investigators contributed to the interpretation of the data. E. Grant and S. Murray took the lead role in preparing the report, with all authors contributing to and commenting on drafts. The final version was approved by all authors.

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CONFLICT OF INTEREST STATEMENT

None of the authors has a conflict of interest. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

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APPENDIX 1

Table A1 gives details of the study participants.

Table A1. *Details of study participants including their WHO function score (World Health Organization, 1998)*

Patient number	Age	Sex	Informal carer or lives alone	Diagnosis	WHO score		Status at end of study	No. of interviews	Religious contacts
					1st interview	2nd interview			
1	70	f	Partner	Breast cancer	2	3	Dead	2	Yes
2	78	f	Family	Liver cancer	2	2	Dead	2	No
3	77	m	Partner	Cardiac failure	1	1	Dead	2	Yes
4	68	f	Alone	Cell lung cancer	2	3	Dead	2	Yes
5	78	f	Alone	Cardiac failure	2	3	Alive	2	No
6	80	m	Alone	Lung cancer	2	2	Alive	2	Nominal
7	91	f	Alone	Cardiac failure	3	3	Alive	2	Nominal
8	71	m	Partner	Lung cancer	2		Alive	1	No
9	83	f	Family	Ovarian cancer	4	Died	Dead	1	Yes
10	57	f	Alone	Renal carcinoma	3	Died	Dead	1	Nominal
11	90	m	Partner	Prostate cancer	3		Alive—v.ill	1	Yes
12	75	m	Alone	Lung cancer	3	Died	Dead	1	Nominal
13	59	m	Partner	Motor neurone disease	3	4	Alive	2	No
14	62	f	Partner	Breast cancer	2	2	Alive	2	No
15	68	m	Partner	Stomach cancer	3	Died	Dead	1	No
16	78	f	Alone	Bone cancer	3	3	Alive	2	Yes
17	73	f	Family	Breast cancer	3	3	Alive	2	Yes
18	77	m	Partner	Chronic obstructive pulmonary disease	3	3	Alive	2	No
19	77	m	Partner	Chronic obstructive pulmonary disease	3	3	Alive	1	No
20	100	f	Alone	Cardiac failure	3	3	Alive	2	Yes

APPENDIX 2

Figure A1 shows the interview outline for patients.

Appendix 2: Interview outline for patients

Interview strategy. The interview, of necessity, will be flexible and sensitive, and it will be critical to establish good rapport and to use the patient's own language to explore their concepts of spirituality, rather than imposing any already established frameworks.
A series of open questions will be asked – however recognising the difficulties of discussing spirituality, the unclear frame of reference for discussion and the potentially wide and varied vocabulary use in talking about spirituality, the interviewer will use patient cues to move the interview forward:

A. Beginning with setting the scene and establishing comfort in discussion –
How are you feeling in yourself today?
Can you tell me a little about how your illness started and what has been happening to you since that time? (*During their story the interviewer will look for cues to spiritual needs and issues, and working within the patients own framework, will seek to explore these various cues*)

B. Moving to centre the discussion on change and response to change:
How has your illness affected your life? What are the most difficult changes?
How do you cope with these changes?

Depending on the answers to this – examine with the patient if these mechanisms are very new, are a repeat of established mechanisms or are mechanisms from a time past in their lives. (e.g. many talk of praying – is this a new thing, something one did years ago in the family, or something that patient has always done)

C. Focussing on issues of searching for and receiving help in finding meaning and value–
Are there things that bother you about the wider meaning of life, eg why we are here, why me, what is the point of it all?
Do you sometimes find it difficult to explain to others what is on your mind?
Do you find that you are looking for a different sort of help than the help that you are actually getting?
Do you ever find you have tried to raise these questions and no-one wants to listen, How did that make you feel?

D Impact of spiritual needs
Do you find that this makes you feel physically worse or does it not really affect how you feel in your body?
If yes – how does it affect how you feel?
Are you more likely to use medicine, call GP, call a carer.
What is the best way for you of coping with days like these, and thoughts like these?
Are you worried that if you talk to your family about these things it will upset them more?

E Who could help?

Could anyone outside the family help?
Who do you think could offer the best help, I mean, what sort of person would you feel most comfortable talking to?

F. Focus on the future.

If patients mention death, the interviewer will encourage them to express their concerns about death.
What do the professionals say about the future?
How do you see your future?
Are you scared of dying (*if death and dying are talked about in any way*)
What do you think about the most?
Have you ever shared these thoughts with anyone?
Are there days when you worry/ more than others about these things? (*depending on what issues the patient has highlighted*)

Fig. A1. Interview outline for patients.