

VIEW FROM THE OBSERVATORY

Exploring the meaning of spiritual care in the Indian context: findings from a survey and interviews

Michael Wright¹, Reena George², Rosemary Mingins¹

¹*International Observatory on End of Life Care, Lancaster University, UK*

²*Department of Radiation Oncology and Palliative Care, Christian Medical College, Vellore, India*

In India, the hospice/palliative care movement began during the 1980s and led to the establishment of India's first service at Shanti Avedna Ashram (Mumbai) in 1986. Today, hospice/palliative care services may be found in 11/29 states in settings that include regional cancer centres, free-standing hospices, government and private hospitals, outreach clinics, and day and home care scenarios. Kerala features prominently (1) where around 46 of India's 75+ services are located.

A feature of palliative care provision is the integrated approach that focuses on physical, social, psychological and spiritual dimensions of care (2). India is rich in religious and ethical traditions that include Buddhist, Christian, Hindu, Jain, Muslim, Parsee and Sikh perspectives. Yet in this multireligious environment, 20 years after the beginning of the hospice movement, little is known about the nature or meaning of spiritual care.

At the 11th Conference of the Indian Association of Palliative Care (IAPC) at Chandigarh (2004), these considerations led to a call for more research in this under-represented area. This pilot study begins an initial exploration of the spiritual domain and aims to inform a larger project to be undertaken in 2005. Underpinning this investigation is the following question: how do hospice/palliative care workers in India perceive the spiritual care of patients?

Correspondence to:

The Revd Dr MC Wright
International Observatory on End of Life Care
Institute for Health Research
Lancaster University
Lancaster LA1 4YT, UK
Tel: +44 (0) 1524 593152
E-mail m.c.wright@lancaster.ac.uk

METHODS

Rationale

Researching the spiritual domain presents problems at both conceptual and practical levels. The lack of any generally accepted definition of spirituality has been long-regarded as a barrier to research; a factor that also renders spiritual conceptual frameworks open to marginalisation (3). Furthermore, the relationship between spirituality and religion is by no means clear and remains to be articulated fully. Health care literature abounds with the rhetoric of dislocation yet pays scant regard to the religiously integrated, whole-life perspectives found in many cultures and traditions. Significantly, the term 'spirituality' has arisen in a Western milieu. Its modern roots lie in the Christian Quietist movement of the 17th century. Dictionary definitions link it to the notion of 'spirit' as 'breath' or 'life-force' within the Judaeo-Christian tradition (4). Consequently, Markham urges caution when translating 'spirituality' into other contexts since, conceptually, the word may not be recognised equally by every religious tradition (5).

In the Indian context of a multireligious workforce caring for a religiously diverse patient group, these considerations give rise to the following methodological questions:

How can spiritual care activity be identified?

Can assumptions be made about a common understanding of spirituality among members of the multidisciplinary team (MDT)?

To what extent can spiritual care be a shared activity?

Do the spiritual concerns of patients arouse feelings of comfort or discomfort among members of the MDT?

Design

A mixed-method design utilised a cross-sectional descriptive survey supplemented by data from in-depth, recorded interviews. This was to balance the questionnaire responses with more detailed information relating to the lived experience of those interviewed. A self-complete questionnaire was devised, designed to determine:

1. The personal importance of spirituality.
2. The importance of addressing the spiritual needs of palliative care patients.

Table 1. Responses by role

Role	n	%
Doctor	35	54
Nurse	15	23
Social worker	3	5
Spiritual counsellor	3	5
Volunteers	9	13
Total	65	100

- How frequently respondents hear the spiritual concerns of patients.
- The respondent’s level of comfort/discomfort on hearing spiritual concerns.
- Perceptions about the appropriateness of personnel other than spiritual counsellors to give spiritual care.

With regard to goals 1 and 2, the assumption was made that respondents would have an understanding of the terms ‘spiritual’ and ‘spiritual needs’. To facilitate goals 3 and 4, a module of 19 items was devised across a range of religious and existential dimensions located in the spiritual domain. It was assumed that the expression of these items was indicative of a spiritual-related engagement between the patient and the health worker. Respondents were asked to report: (i) how frequently the items were heard; and (ii) their levels of comfort/discomfort on hearing these items.

Sample

A self-select sample among delegates at the IAPC conference held in Chandigarh (2004) and from members of the Institute of Palliative Medicine, Calicut, produced 75 responses. In view of the nature of this hard-to-research area, this type of convenience sample was considered appropriate for a pilot study.

Inclusion criteria focused on India-based health workers rather than foreign delegates which reduced the sample to 67. Among the roles that were disclosed, doctors formed the largest professional group (n = 35, 54%), whereas the smallest were the groups of social workers and spiritual counsellors (n = 3, 5%); the roles of two respondents were unknown (Table 1).

Among religious affiliations, the Hindu group was the largest (n = 26, 46%); the sole Buddhist was the smallest

Table 2. Responses by religion

Religion	n	%
Buddhist	1	2
Christian	16	29
Hindu	26	46
Muslim	8	14
Sikh	3	5
None	2	4
Total	56	100

(n = 1, 2%). Two respondents claimed no religious affiliation, and 11 gave no indication (Table 2).

Semi-structured, recorded interviews were conducted with 9 conference participants selected on the basis of convenience. These participants were all clinicians and several held IAPC positions. In a wide-ranging interview, participants were asked about the nature of spiritual care, with relevant supplementary questions. All interviews were transcribed in full.

Interview data were analysed with the assistance of NUD*IST software; questionnaire responses were analysed using SPSS.

RESULTS

The importance of spirituality

These items were scored on a 4-point scale – very important, important, slightly important, and not important. Aggregating the very important and important categories indicates that, overall, around 90% of respondents fell into this section (Table 3).

Frequency hearing items related to the spiritual domain

These items were scored on a 4-point scale – frequently, sometimes, rarely, and never. Aggregating the categories of frequently and sometimes indicates that the six items heard most frequently relate to (Table 4): (i) relationship with God, ‘It is God’s will’ (48, 75%), ‘Everything is in God’s hands’ (47, 71%), ‘I have faith that God will heal me’ (41, 63%); (ii) finding meaning, ‘Why did this happen to me?’ (46, 72%); and (iii) mortality, ‘I am not afraid of death’ (48, 73%), and ‘I am afraid of dying’ (39, 61%).

Table 3. Importance of spirituality: responses in the ‘very important’ and ‘important’ categories

	All*	Doctor	Nurse	Social worker	Spiritual counsellor	Volunteer
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Personal importance of spirituality	55 (87)	33 (97)	10 (71)	3 (100)	3 (100)	5 (71)
Importance of addressing patients’ spiritual concerns	58 (91)	34 (100)	11 (73)	3 (100)	3 (100)	5 (71)

*Any discrepancy between the figure in the ‘All’ column and the total of the subgroup responses is due to the respondents who answered the question but did not indicate their role.

Table 4. Respondents hearing spiritual items ‘frequently’ or ‘sometimes’

	All	Doctor	Nurse	Social worker	Spiritual counsellor	Volunteer
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Why did this happen to me?	46 (72)	25 (73)	10 (67)	3 (100)	3 (100)	4 (57)
Is God punishing me?	35 (54)	16 (47)	9 (60)	3 (100)	3 (100)	4 (50)
I have committed many sins	21 (33)	13 (39)	4 (29)	3 (33)	2 (67)	2 (25)
I have faith that God will heal me	41 (63)	24 (71)	10 (67)	1 (33)	3 (100)	3 (37)
Everything is in God’s hands	47 (71)	27 (79)	11 (73)	2 (67)	2 (67)	5 (56)
It is God’s will	48 (75)	25 (76)	11 (73)	3 (100)	3 (100)	5 (63)
Pray for me	30 (46)	15 (44)	7 (47)	0 (0)	3 (100)	3 (33)
Pray with me now	17 (27)	10 (30)	1 (7)	0 (0)	3 (100)	2 (25)
Give me a blessing	16 (25)	10 (31)	1 (7)	1 (33)	2 (67)	2 (25)
Read a spiritual passage for me	10 (15)	8 (24)	1 (7)	0 (0)	1 (33)	0 (0)
Is there a prayer room?	14 (22)	9 (26)	3 (21)	0 (0)	1 (33)	1 (13)
Can I see a spiritual counsellor?	14 (22)	11 (32)	2 (13)	0 (0)	0 (0)	1 (11)
Can you arrange a worship service?	12 (19)	9 (27)	1 (7)	0 (0)	0 (0)	2 (25)
Telling me honestly helps me to face the future	32 (49)	22 (64)	4 (27)	2 (67)	1 (33)	3 (37)
I am not afraid of death	48 (73)	27 (82)	10 (67)	3 (100)	1 (33)	7 (78)
I am afraid of dying	39 (61)	24 (71)	6 (43)	2 (67)	1 (33)	6 (75)
What will happen after I die?	17 (27)	14 (43)	1 (7)	0 (0)	1 (33)	1 (13)
What do you believe about death?	12 (19)	7 (21)	1 (7)	1 (33)	1 (33)	2 (25)
What would you do?	16 (25)	10 (31)	3 (20)	0 (0)	2 (67)	1 (13)
Total average – frequency	(42.0)	(47.9)	(34.2)	(38.6)	(57.8)	(34.7)

Levels of discomfort concerning items related to the spiritual domain

These items were scored on a 4-point scale – very uncomfortable, uncomfortable, comfortable, and very comfortable. Aggregating the categories of very uncomfortable and uncomfortable indicates that the six items which promote most discomfort relate to (Table 5): (i) mortality, ‘What will happen after I die?’ (35, 63%), ‘I am afraid of dying’ (34, 54%), ‘What do you believe about death?’ (27, 49%); and (ii) finding meaning, ‘Why did this happen to me?’ (29, 45%), and ‘Is God punishing me?’ (31, 48%).

APPROPRIATENESS OF SPIRITUAL CARE-GIVERS

These items were scored on a 4-point scale – very appropriate, often appropriate, sometimes appropriate, and not appropriate. Aggregating the categories of very appropriate and often appropriate shows that, overall, the three most appropriate roles for spiritual care-giving are (Table 6): (i) a spiritual counsellor of the patient’s own faith (53, 85%); (ii) a member of the patient’s family (49, 79%); and (iii) a friend of the patient (47, 76%).

NARRATIVE RESPONSES

These interview extracts give an insight into the lived experience of spiritual care among a widely distributed group of palliative care professionals. In the following extracts, Firuza Patel (6) outlines the inclusive approach

shown towards patients and their religion, and speaks of the practical support given to Chandigarh Hospice by a neighbouring temple (*mandir*):

We run this hospice as basically a homely atmosphere. For us, all occasions that we would celebrate at home, we make it a point that we celebrate them here as well: children’s birthdays, patients’ anniversaries, marriages, we’re very particular about that; and I think the patients appreciate that. The hospice is open to all religions and we have made a logo of a caring hand with a hospice hut on top of it; and then we have the four religious signs along with it – the Hindu, the Sikh, the Muslim and the Christian.

*The Temple is a big support, because what happens is, in the mornings and in the evenings we have what’s called an **arti** where everybody gets together to go and worship, in the temple or wherever; even at home, everybody does this. So what happens here is that in the evening-time when the **arti** is going on in the **mandir** they will go and stand out. Patients who can go – walk; they go up to the **mandir** every day; they go to the temple and they come back to the hospice, just because it’s next door. And they’ve been so kind: even they have been thinking of building a small ramp there, so that wheelchairs can go up. So that is a big help to us. And then they support us; the ration for the patients – for the kitchen – comes from them for the whole month. If our cook is not there for some reason, they will send their cook to cook for the patients.*

Table 5. Levels of discomfort related to spiritual items: responses in the ‘very uncomfortable’ and ‘uncomfortable’ categories

	All	Doctor	Nurse	Social worker	Spiritual counsellor	Volunteer
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Why did this happen to me?	29 (45)	12 (35)	9 (60)	1 (33)	1 (33)	5 (62)
Is God punishing me?	31 (48)	12 (35)	8 (57)	2 (66)	1 (33)	6 (75)
I have committed many sins	23 (39)	8 (25)	6 (55)	2 (67)	1 (33)	5 (62)
I have faith that God will heal me	15 (23)	6 (18)	5 (36)	1 (33)	0 (0)	3 (38)
Everything is in God’s hands	7 (11)	3 (9)	3 (21)	0 (0)	0 (0)	1 (11)
It is God’s will	9 (14)	2 (6)	3 (21)	1 (33)	2 (67)	1 (13)
Pray for me	16 (25)	8 (24)	4 (29)	1 (33)	0 (0)	2 (22)
Pray with me now	16 (25)	7 (22)	4 (29)	1 (33)	0 (0)	2 (22)
Give me a blessing	23 (43)	11 (38)	6 (60)	3 (100)	0 (0)	3 (47)
Read a spiritual passage for me	19 (35)	10 (35)	5 (42)	1 (33)	0 (0)	3 (50)
Is there a prayer room?	8 (14)	4 (13)	3 (23)	1 (33)	0 (0)	0 (0)
Can I see a spiritual counsellor?	8 (14)	3 (10)	2 (18)	1 (33)	0 (0)	2 (29)
Can you arrange a worship service?	12 (22)	6 (21)	2 (20)	2 (67)	0 (0)	2 (25)
Telling me honestly helps me to face the future	6 (9)	3 (9)	1 (8)	0 (0)	0 (0)	1 (13)
I am not afraid of death	9 (14)	4 (12)	2 (14)	0 (0)	0 (0)	3 (33)
I am afraid of dying	34 (54)	15 (44)	8 (61)	2 (67)	0 (0)	7 (88)
What will happen after I die?	35 (63)	16 (52)	9 (90)	2 (67)	2 (67)	5 (72)
What do you believe about death?	27 (49)	13 (43)	7 (70)	1 (33)	2 (67)	3 (43)
What would you do?	26 (46)	12 (37)	6 (60)	2 (67)	1 (33)	4 (57)
Total average – discomfort	(31.2)	(25.7)	(40.7)	(41.9)	(18.5)	(40.1)

From Chennai, Mallika Tiruvadanan (7) tells of the importance of training to help deal with spiritual distress around diagnosis:

I think as a [palliative care] trained physician I am able to do some spiritual counselling for our patients; but I think definitely a lot of us have to learn about the way spiritual counselling has to be done. Towards the end, many patients are left with a lot of spiritual distress. Many of them say: ‘We don’t take alcohol’. They’re not taking tobacco, and they’ve been going to the Temple every day, attending rituals, so many of them are unable to understand, especially in the younger age group – say 50s or 45, the bread-earner of the family – they are unable to digest the fact that they have got a life-limiting disease.

So, even though we believe in our Karmas, there is a large need for spiritual counselling, and I think people have to be really trained in that. Health care professionals need to be trained in providing answers or tackling situations where the patient’s asking you: ‘Why is this happening to me? Why did God do this to me?’ A lot of patients who have been very religious start getting angry. They say things like: ‘I don’t pray any more. I don’t believe in that God any more,’ and it takes quite a while to get them back into their own selves. But I think this is where the professionals have to be; even volunteers can have training in spiritual care. It’s very, very important.

In the following extract, a Christian religious sister (8) reveals the pain of her cancer diagnosis and recalls the

Table 6. Respondents’ perceptions of appropriate spiritual caregivers, by role

	All	Doctor	Nurse	Social worker	Spiritual counsellor	Volunteer	Buddhist	Christian	Hindu	Muslim	Sikh
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Sp C same faith	53 (85)	28 (82)	13 (93)	3 (100)	3 (100)	5 (71)	1 (100)	13 (87)	23 (92)	5 (63)	3 (100)
Sp C different faith	18 (30)	10 (30)	2 (14)	2 (67)	3 (100)	5 (71)		7 (47)	5 (21)	3 (43)	1 (33)
Doctor	35 (57)	22 (65)	5 (36)	2 (67)	2 (67)	3 (50)		10 (67)	15 (60)	2 (29)	2 (67)
Nurse	35 (58)	22 (67)	7 (50)	2 (67)	2 (67)	1 (17)		12 (80)	16 (64)	2 (29)	2 (67)
Volunteer	40 (63)	24 (69)	8 (57)	2 (67)	2 (67)	3 (38)		11 (69)	18 (72)	3 (38)	3 (100)
Social worker	35 (56)	22 (65)	4 (29)	3 (100)	2 (67)	3 (38)		10 (63)	15 (60)	4 (50)	3 (100)
Psychologist	35 (56)	22 (65)	4 (29)	3 (100)	2 (67)	3 (38)		10 (63)	15 (60)	4 (50)	1 (33)
Patient’s friend	47 (76)	27 (79)	11 (79)	1 (33)	2 (67)	5 (71)	1 (100)	12 (80)	17 (68)	7 (88)	3 (100)
Patient’s family	49 (79)	27 (82)	12 (86)	2 (67)	2 (67)	5 (63)	1 (100)	12 (75)	19 (79)	8 (100)	3 (100)

spiritual support she received from colleagues of a different faith:

In 2000, 6th of January, I felt something is wrong with me. I was not keeping so well. I went to the doctor, and I told him: 'I feel some pain on the right side of, the left side of my breast'. But deep down in my heart I knew I am maybe having something beyond what I think. So immediately he examined me and he said: 'Why did you wait?' So then he sent me for a test; then the test proved that it was cancer. It was very painful for me to accept that moment because I was very active, I didn't have any other problems; but to know that it was a cancer and the third stage, it was very, very painful. And at that moment I didn't think of myself, I thought of the others. I thought of my sister who was with me and all the others; I have my mother, so it was very painful, it was. The first moment I didn't have any reactions. It's very difficult to accept. I could not digest. I just asked bitterly: 'Why it's for me?'

Then the very next day the doctor told me: 'You get admitted. Tomorrow morning I'll operate you because I don't want to wait.' Somehow I was not prepared. I said: 'I have to go and hand over my responsibilities', because I was the administrator of a hospital. The most thing what I experienced from all the employees was, you know, such a support. They felt more than me. They were just weeping along with me: 'Why is this for you?' And they are not Catholics. They are all Hindus – so rather religious people – but they all came along with me to the church, they prayed along with me, and they came to the railway station to send me off for surgery.

Next, Stanley Macaden (9) speaks of the team's approach in Bangalore:

People in India are spiritual, you know; they do believe in a higher power, in a God – or in fact many Gods. Our patients know that we are from a Christian background and we get involved with them first as a friend. We listen to what gives them meaning, what gives them strength and support in a situation like a terminal illness; and in that course we hear about their faith. We encourage them in their faith, but we also share our faith, and a lot of our patients appreciate that. And we always pray with our patients, with their permission, when we go to their homes. And sometimes when we have kind of been busy and we have not got down to praying, some of them have reminded us that: "We would like you to pray", you know. So, we find that our patients are supported and helped by that and not burdened by [us] praying with them or for them. They are encouraged.

We overlap roles, you know, sometimes if the chaplain is not there, one of us would pray and one of us would

talk about God but generally the doctors and nurses, the chaplain, all of us are talking the same language, basically.

Finally, Suresh Kumar (10) speaks of the issues that led to a policy of excluding religious functionaries from the Calicut multidisciplinary team:

When you work in a multireligious community as we do, as a policy we have, from the very beginning, decided that when it comes to spiritual care or spiritual support, we won't mix religion with spiritual care. For example, we have decided that we won't employ, or we won't seek help from say, a Hindu priest, Muslim priest or Christian priest, because that can cause a lot of practical issues; and also we believe that when it comes to the realm of spirituality one can only act as an active observer and guide the patient to disclose his or her own spiritual dimension or spiritual problems.

There have been a lot of occasions where the patients particularly request some sort of religious help, in which case we are happy to direct them to a religious person or bring a religious person to the patient's place. But generally, we see spirituality as something beyond religious practice. It has its own problems, this practical way in which we approach it. There is a risk that we are taking an extreme position and avoiding the religious perspective altogether... In a way, I think this probably is still one of our weak areas, I must say. As doctors we sit with the patients and help them with problems in this area, but we are missing the clergy during the training and during work with the patients.

DISCUSSION

The finding that around 90% of palliative care workers attach importance to their own and their patients' spirituality suggests that the concept is generally unproblematic. A closer examination of the responses, however, reveals that the figure falls to around 70% among both nurses and volunteers. Given the small numbers in the sub-groups, little weight can be attached to this. Yet, in view of the forthcoming study, an interesting question arises: could this reduced importance be due to differences in training and experience?

The strong support for the spiritual counsellor of a patient's own faith is perhaps unsurprising, although the finding that spiritual care may be appropriately given by other personnel is significant. Both professional and religious groups favour members of the patient's family, a family friend or a volunteer – all members of the patient's community. This view has much to commend it. In this scenario the spiritual caregivers are well known to the patient, are aware of local provision and know where to access necessary support. It resonates, too, with the view, prevalent in Kerala, that the chronically ill are a community

responsibility. Suresh Kumar: 'we sort of believe that chronic illness is a social issue, so responsibility moves from the medical profession to the community' (10).

A counter to this argument could relate to the levels of discomfort broadly experienced by all but the group of spiritual counsellors. In some instances, these are particularly high among volunteers. Interesting, too, that despite finding favour among professional and religious groups, only around one-third of the volunteers nominate their own group as spiritual caregivers. In view of the community involvement of many palliative care services, the role of the volunteer is worthy of closer attention, while on the broader front, issues emerge about the handling of existential questions and the safeguarding of patient and staff boundaries (11).

The narrative data give a valuable insight into what is happening on the ground. Importantly, they reflect the lived experience of palliative care and its meaning to those closely involved with the service. From just a few interviews, key issues have emerged to be explored with future participants, including: relationships with religious functionaries; the nature of local support; dealing with spiritual distress; working collaboratively; and respecting boundaries. It is acknowledged that all except one of these participants were physicians, whereas in the following investigation, interviews will be sought from all sections of the multidisciplinary team.

CONCLUDING COMMENTS

This pilot study provides new information regarding the spiritual care perspectives of hospice/palliative care workers in India. While the small numbers preclude any far-reaching conclusions, a first step has been taken in an under-researched area. Important lessons have been learned and these will be incorporated into the main

study, scheduled to begin in 2005. This is likely to include a survey of the IAPC membership and will form part of a wider review of palliative care development in India funded by the Irish Hospice Foundation and the US-based National Hospice and Palliative Care Organization.

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