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ORIGINAL PAPER

What Spirituality Means for Patients and Families in Health Care

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Abstract
This research focuses on the spiritual care experiences of patients and families at a hospital in Australia. Twenty-four patients and 10 family members were interviewed. Results indicate the importance of relatedness: being treated as a person, reminded of your capabilities and conversations about what matters. Maintaining contact with friends and family, sustaining religious and spiritual practices, music therapy and pet therapy were also significant and contact with the natural world and shared activities. The results indicate the importance of spirituality offered through pastoral care, and that all those involved in health care can contribute to the spiritually nurturing environment that reinforces healing.

Keywords Spirituality and health care · Patient and family experience of spirituality in health · Roles in spirituality in health care

This research seeks to strengthen understanding of the value of spiritual care offered in health settings. There is currently interest in developing and testing an Australian model that could evaluate whether and if so how spiritual care makes a difference to clients of health services, including acute and palliative care. Spiritual Health Victoria and La Trobe University in partnership with a number of Melbourne Health Services and St John of God Bendigo Hospital are aiming to facilitate the development of evidence-based spiritual care practice. We need then to identify what consumers, providers and their managers see as important and useful about spiritual care. More specifically, this includes:

- facilitating the development of appropriate data collection about spiritual care provision within health care systems, recognising that spiritual care may be carried

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out by all staff with specific specialist roles for those designated as spiritual care practitioners;
- ensuring appropriate and rigorous ways of collecting consumer outcomes data from the consumer perspective and
- encouraging the support (financially and otherwise) by line managers and CEOs for the provision of evidence-based spiritual care.

For an evidence-based perspective, this research seeks triangulated data: i.e. to request participation from staff (including staff such as nurses and allied health practitioners as well as those with a specific spiritual care role), patients and families/carers and managers. Each health care agency was asked what data should be collected to demonstrate outcomes, i.e. what do they think is significant about the provision of spiritual care? The immediate research goals were scoping how differently spiritual care is perceived and carried out, and researchers focused on different groups within the participating institutions, i.e. patients and families, providers and managers. This particular research then focuses only on one site as part of the bigger study; researching the experiences of patients and families was related to spiritual care and was carried out at St John of God Bendigo Hospital (SJGHB).

Background

Spiritual care generally named as pastoral care or chaplaincy has always been part of health care in some form, but the particular role spiritual care plays has changed as community norms have shifted to include greater secularisation and individualism (Zock 2008). This is reflected in how the specific role is named with some continuing with chaplaincy or pastoral care, others moving to spiritual care or well-being. The intent is generally similar: spiritual or pastoral care 'provides a supportive, compassionate presence for people at significant times of transition, illness grief or loss. …most often delivered through attentive and reflective listening and seeks to identify the person's spiritual resources, hopes and needs…. Spiritual care is a collaborative and respectful partnership between the person and their health care provider and is an integral component of holistic care' (Spiritual Health Victoria 2015, p. 2).

This reflects the meaning of spirituality we are using here: a broad and inclusive definition of 'that which gives life meaning, in a way that connects the inner sense of meaning with a sense of something greater' (Gardner 2011, p. 19). Spiritual need is met by anything that keeps you in touch with yourself, or connects you with people and ideas that matter, or keeps you going when life seems difficult and the future uncertain. It can then be provided across disciplines in the health care system, as well as through specialists in pastoral and spiritual care (Rumbold 2013). Puchalski et al. (2014a, p. 13) suggest the increased interest in spiritual care is 'a movement, culminating in a field called spirituality and health, which aims to restore the balance between the scientific and humanistic sides of health care. Grounded in core principles of service, compassion, dignity, and the interconnectedness of all people, the field is a commitment to making patients' search for meaning and relationship an essential focus of medical education, patient care, and the health care system.' This is reflected in the literature related to including spirituality in practice in such disciplines as social work (Holloway and Moss 2010), nursing (Clarke 2013) and allied health (Carey and Mathisen 2018). How spiritual care is practices varies considerably including greater use of narrative approaches including life reviews (Grossoehme 2015), listening presence/mindfulness (Parameshwaran 2015), hopeful presence

(Nolan 2012), compassionate presence (Puchalski et al. 2014a), prayer (Maddox 2012), advocacy (Morgan 2010) or dreams (Stranahan 2011).

What remains unclear is how to assess best practice in spiritual care, particularly the outcomes: what difference does spiritual care make? Clarity becomes more imperative as funding becomes more limited across health settings including faith-based health agencies which are also significantly dependent on government funding at least in Australia. Some studies do demonstrate outcomes: Jankowski et al. (2011, p. 111) reviewed past literature and concluded that patients 'believed that chaplains have met their emotional and spiritual needs, thereby improving their health care.' However, it isn't clear what chaplains did that was helpful or how they impacted on health outcomes. Studies tend to divide into those focusing on satisfaction—usually methodologically strong and showing positive effects compared to studies on interventions and outcomes which are not so strong methodologically (Lichter 2013). Snowden et al.'s (2013) use of patient reported outcome measures specifically related to chaplaincy (PROM) found that chaplains and patients agreed about the aim of pastoral care and their interactions were positive and enabling for patients. Overall, it is argued that there is a need for more systematic ways of ensuring that spiritual care is effective, from the perspective of both education and research (Puchalski et al. 2014b) although some writers would suggest that there are dangers in trying to overly define spirituality which is by its nature 'thin and vague' (Swinton and Pattison 2010).

Research Methodology

The overall research questions were:

How does spiritual care contribute to the overall quality of care provided in the health care setting? Specifically, what perceptions and experiences of spiritual care do patients and families see as contributing to the quality of their health care? Given that SJOGB has a pastoral care department, we have continued to name their workers as pastoral care workers, while using 'spiritual' care in the research question.

We decided to use semi-structured interviews where patients and their families were asked about the value of spiritual care, specifically: what kept you going through your experience of being in hospital? What sustained you? It was decided to use this very general question initially in order to encourage noting anything that the participants perceived as spiritual care. We were conscious that patients and families could experience spiritual care from all those on the health care team. Other prompt questions were used as needed to encourage further exploration such as: what made a difference to how you felt? Were there particular people who kept you going and how? Were you supported to make sense of your experience? And if so how?

A complex process of finding participants ensured they were both voluntary and felt able to participate. One of the pastoral care staff visited the designated ward/s and checked with the nursing staff which patients were well enough to be contacted. Two trained SJGHB pastoral care volunteers, then visited these patients, explained the research briefly and left the information letter. This included that the interviewer would be a social work lecturer at the local university, not employed by the hospital system and so more able to be objective. The volunteers visited the following day to ask if there was interest in participating, to answer queries and if appropriate set an interview time. Author A as the researcher then completed the consent form and carried out the interview. Some flexibility was needed: occasionally interviews needed to be re-scheduled because the person no longer felt well enough, had visitors or was seeing another health professional. One person

withdrew soon after the interview started. However, most participants were able and keen to participate. Interviews took between 14 and 43 min and were audio-recorded and transcribed, and then the data analysed for themes. Patients were asked whether they wanted to see their transcript to make changes but no one accepted this offer. About a third did request a summary of the results. Altogether, 24 patients and 10 family members were interviewed. Most family members chose to be interviewed with the patient, which may of course have influenced their responses. However, there was a high degree of consistency between those interviewed on their own and those interviewed together as well as a high degree of consistency between family and patient responses, so the emerging themes have been summarised together in the next section.

Results

The results were remarkably consistent and supported the view that all the health care team provided spiritual care, with the specialist pastoral care workers contributing both generally and specific care often but not always connected to supporting religious practices.

More specifically, the following were common responses:

Being Treated as a Person What was significant to nearly all patients was being treated as a person, someone to relate to and make a connection with rather than just a problem or another patient in a bed. Several mentioned feeling they were treated as 'part of a family'; others the friendliness of staff. While they acknowledged that they connected more to some staff than others, what was important was that generally staff actively sought a friendly interaction and sometimes to develop a relationship that allowed for sharing of more significant experiences. This applied generally to volunteers and staff, pastoral care workers, nurses, doctors and allied health staff to cleaners, to people bringing meals or tea and coffee.

> And they're very interested in, who you are and they share quite an amount about themselves, like without asking… And I think that that helps to…make you feel that you're a part of the family.

Being Reminded of Who You are, What You are Capable of For many of the patients this connected with being reminded that they were capable individuals. Many mentioned that they valued their independence and wanted to return to it as soon as possible. The staff managed well the balance between acknowledging when people felt simply too ill or in too much pain to do anything with actively encouraging patients to build their capacities for walking or exercising, for example.

> freedom… being able to make up your own mind and make your decisions, our own choice… And you feel independent
> there's a dignity about everything that is done here. we're not just blobs in the bed, we're people.

Part of this was being actively encouraged, having someone believe in you. One person, for example, doubted her ability to manage a book of crossword-type exercises brought in by a grandchild, but with the spiritual care worker's encouragement began to enjoy it. Another talked about the physiotherapists encouraging you to work harder than you really think you can.

Being Able to Have Conversations About What Matters to You Some people were fortunate in having many visits from family and friends and for some also from their faith tradition. However, both for them and more particularly for others, it was important to have relationships with members of staff or volunteers where they could talk about what really mattered to them. The pastoral care team were often specifically mentioned here, as people who would take time to initiate the kind of conversation where a patient could talk about whatever they wanted to.

Pastoral care are 'just fabulous, you know we talk about everything.'

Frequently, this would include talking about both life inside the hospital and what was important to sustaining the person by remembering their life outside the hospital. For some, a pastoral care staff member talked about family issues or what was worrying then; others asked a volunteer to talk about something like football—which was very restoring for that particular person.

The Importance of Maintaining Contact with Family and Friends and Related Networks This was one of the key aspects of maintaining a positive sense of self: being able to have visitors, see family and friends, have easy access by phone. Flexibility was a significant aspect of this, not having restricted visiting hours. Several family members mentioned being able to bring and eat their lunch at the same time as the patient, which fitted with their working day or other family commitments. Others valued being able to come when they could, and staying as long as needed. They accepted that this flexibility meant the work of the hospital came first, allowing for the patient's care or rehabilitation activities.

Some people also mentioned the importance of staying in contact with other networks: their community, through getting newspapers, for example, or with their gold club or craft groups. Church communities were frequently mentioned:

Religious Affiliations and Practices Just over half of the patients valued their connection to their religious tradition, perhaps a surprisingly high number given the decline in Australians seeing themselves as religious. Many of these were Catholic and appreciated both the visits from the pastoral care team and being able to have Holy Communion daily. Others from a variety of Christian denominations appreciated visits from the pastoral care team and either their own religious leaders or fellow church members and/or the religious leader from their tradition appointed to see people at SJGBH. More generally, people in this group valued the sense of connection or validation in the hospital for their religious beliefs: this partly came from visits from the pastoral care team, but also from symbols of the hospital's connection to a religious tradition such as having a highly visible chapel.

The pastoral care team were also valued by others not from a faith tradition, partly for how they communicated: one patient commented: 'the pastoral care people would talk to you about whatever you wanted to - everyone loves them.' Others named specific activities they valued: for example, the pastoral care team distribute a weekly Sunday leaflet that included writings that patients found sustaining. One commented on a quote in a leaflet—'you never know how strong you are, until being strong is the only choice you have' and said she had been thinking about this ever since. Two others had borrowed crocheted rugs the pastoral care team had had made and commented how comforting these were,

reinforcing feeling cared for and at home. Another had been given a wooden dove for prayer that she also found comforting. Related to this was:

Valuing Music Music therapy offered in a spiritual context is a strong focus of the pastoral care department, and the music therapist is very intentional about this with patients. Many mentioned her playing a harp or piano both individually and with groups. The music from the harp could sometimes be heard along the passageways and in other rooms and many patients commented on how heartening and sustaining that was for them. Others valued being able to join other patients in singing, or to have music to accompany some exercise classes, or access to a variety of other musical activities to suit particular individuals and groups. What this means for people varies of course:

> one said 'having a little sing, hymns and that, makes it more homely'
> another commented: 'And you really see them (older people) start to come to life when they sing those old songs. Well I'm the same, it really lifts you up'
> another: 'she was playing when we were at gym this morning, like you know marching sort of music and it was absolutely wonderful. Would love to get to the singing group, lovely hearing harp along passage.' Another patient felt reconnected to his church community and to his love of music generally through joining the singing group.

Nature/Being Out in the World Some of the patients had views out over the car park and beyond; the sense of being part of the outside world reinforced their connection to it and desire to return to it. Two particularly mentioned enjoying the liveliness of change in the car park and their enjoyment of seeing the trees changing from winter to summer. This was often particularly important for people used to living in a more rural setting, such as those from farming families with a wider, broader sense of the landscape: 'seeing out in the world, sky, trees, remembering there is a world out there.'

For them but also for others it was very helpful to be able to sit somewhere outside, somewhere sheltered where they could feel the sun and the air around them. Two mentioned the courtyard and that they had heard that it would soon have flowers and they looked forward to being able to sit there. Several people mentioned the atrium and the coffee shop as part of this: both in the sense of having somewhere to go outside the hospital room, to have a different kind of space; a more 'normal' atmosphere. Good to 'have a cup of coffee sort of thing, just to try and you know get her out of the four walls.'

Contact with Animals Many of the participants missed their contact with their pet dog or cat, or, for some farming families their contact with animals more generally. It helped to have visits from a dog that visits interested patients weekly as part of an intentional pet therapy programme. One patient who was missing her cat said 'Thursday a little dog Ruby … jumps up on the bed and loves getting its ears rubbed. Pet therapy does help some people.'

Activities with Others While most of the patients really valued being able to have their own private room, some mentioned the value of contact with those experiencing similar issues. This could simply be an interaction as they walked around the passages, or having breakfast in the activity room with other patients or taking part in a gym exercise group. The music therapy related to this—participating in a singing group or attending a musical event or another event organised by the hospital and/or the pastoral care team.

One commented: 'And I've been invited to a few things they've had now and you sort of start to look forward to those days, because it's, it's something different to the routine.' And another: its 'fun being in the gym with others, camaraderie of, of the people around us and, and a couple of little jokes went by. All of those little things it helps, helps immensely.'

Accessible Information and Practical Support Part of what helped patients and families was that staff readily shard information with them. Information about activities for the day was written on a small white board visible for patients and anyone visiting with the names of current staff involved. Family meetings were also valued.

One patient commented: 'the staff are all nice… In these places, if you want to know something you don't know, if you ask people are always quite happy to tell you' Others commented on how easy it was to access what they needed such as books, newspapers and how helpful volunteers were in doing practical things that helped.

Discussion

The results contribute to the process of articulating what it is that is enabling or helpful about spiritual care. Patients and families were able to name what made a difference to them, what sustained them during their time in the hospital. The themes that emerged resonate with other literature, but also make explicit what participants saw as contributing to their well-being or sense of being spiritually nurtured.

Clinical Implications

Clearly, the results support the view that all staff and volunteers should be seen as contributing to spiritual care in health care from those trained specifically in spiritual/pastoral care to those providing treatment and support services. This has implications for staff training and a Public Health England report (2016, p. 25) recommends that services 'ensure all staff involved in care and bereavement support are trained in faith sensitivity and effective communication.'

There are also implications related to how to generate the kind of culture in the health care system that sees spirituality as an integral aspect of care. In many health care systems spiritual care is seen from a narrow perspective of being the provision of particular religious care. Increasingly, while there is a push towards recognising the specialised professional nature of the effective provision of spiritual care in a broad sense, there is also recognition of the various levels of care, some of which can be and are provided by other health professionals (Gordon and Mitchell 2004).

Part of what was remarkable about this study was that the atmosphere of caring for the whole person, including their spirit seemed to be part of organisational culture. This was particularly reflected in the experience of patients of being treated as a person, not just an illness, and in the building of relationships. Given that this is a Catholic hospital, it may be that staff and patients had different expectations from those in a secular health care system. However, it will still be important to explore how such cultural shifts can be developed and maintained.

The research also affirms the importance of valuing spiritual diversity, acknowledging how differently people experience nurture and renewal. This hospital was open to many

ways of being spiritual, including ensuring connections to religious practices, individually and collectively, individual conversations about what mattered, the involvement of music and pet therapies, and other environmental factors such as contact with nature, shared activities in the gym and breakfast room. Being easily able to maintain connection with family, space for reminders of what mattered, all were seen as important and enabled. Such experiences of spiritual care have also been identified elsewhere in the literature (Tan et al. 2011). The underlying assumption or value was that people needed to be seen as individuals expressing their spirit in their own way and needing to be supported in that. This is increasingly challenging in a financially conscious world, but there is some developing evidence about its significance (Huisman et al. 2012).

Study Limitations

Finally, there is obviously a need for further research. One obvious limitation is that it was carried out in one hospital in a provincial city in Victoria, Australia. It will be important to compare this with data from elsewhere. It should also be noted that this hospital was in a community of limited cultural difference, so a limiting aspect of the research is seeing how the hospital culture would be inclusive for those with significantly different religious or spiritual practices. Clearly, it would also be useful to understand the experience of this hospital from other perspectives: do volunteers and staff also see the pastoral care team as influencing the general culture?

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Compliance with Ethical Standards

Conflict of interest Fiona Gardner, Heather Tan and Bruce Rumbold declare that they have no conflict of interest.

Ethical Approval Ethics approval was granted by both St John of God and La Trobe University (reference 973 and Gardner-973, respectively). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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