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Hospice chaplains: avoiding the modern day inquisition.

Abstract

There is now a substantial body of literature on spirituality and spiritual care in healthcare. Despite the fact that many hospice chaplains are finding that they have to explain, if not justify, spiritual care, they have authored very little of that literature. As a retired hospice chaplain I hope that my research may help redress the balance. This paper summarizes the history of spirituality and spiritual care in English healthcare, considers the significance of Cicely Saunders' spirituality for her vision of hospice and presents some of the findings from the research, a work in progress. Using a guided interview I sought to discover how hospice chaplains understand spirituality in their practice of spiritual care and in their descriptions of their own spirituality. Analysis of the twenty-five interviews revealed difficulties in finding a language which both expresses spirituality and the soft descriptions of what happens in spiritual care and satisfies the inquisition of outcome-oriented management.

Keywords: hospice, hospice chaplains, spirituality, spiritual care, Cicely Saunders, language, outcome-oriented management, Inquisition.

Introduction

Although the term 'hospice' has been used since mediaeval times for a place of hospitality for travellers, pilgrims and the sick and dying, the first of the modern hospices was founded in England in 1967 by Cicely Saunders[1]. At that time spirituality was still generally associated with religion and regarded as the domain of the Christian chaplain. Since that time interest in spirituality and spiritual care in the healthcare context has increased exponentially.

In 2010 the Department of Health commissioned a review of the literature around Spiritual Care at the End of Life in the United Kingdom. Holloway, Adamson, McSherry and Swinton reviewed literature from 2000 to 2010. Two hundred and forty eight items were found comprising empirical studies, policy documents, commentaries or case studies, over 80%

[1] Throughout this paper, which is based on a conference presentation, I use either both names or

of which were from disciplines other than chaplaincy. Only 14% of the literature was by chaplains (Holloway et al 2010:2) and the majority of these were hospital rather than hospice chaplains. Furthermore there is no agreed definition for the concepts of spirituality and spiritual care but much material on assessing and documenting spiritual need. Since 2010 contributions to the field have further increased but, even including books, material from hospice chaplains is still lacking. However, at the same time papers, protocols and research on spiritual care in Scotland have increased and started to dominate not only the UK scene but the wider international scene as well[2]. Whilst such material is helpful I was, as a retired hospice chaplain, concerned at the lack of literature reporting how hospice chaplains in England understand and describe their work. My research question therefore concerns the understanding of spirituality and spiritual care amongst hospice chaplains in England.

This paper presents some of the material collected in the research. As background I describe the role of spirituality and spiritual care in the history of healthcare, and the development of Cicely Saunders' vision as a counter-cultural product of her own spirituality. I then describe the method of the research, the sample and selection of interviewees and the analysis of the interview data. Material from the interviews is then presented to show chaplains' understanding of spirituality in their practice of spiritual care and in descriptions of their own spirituality. Similarities between Cicely's spirituality and the interview data are observed. However, when Cicely was developing her vision in the late 1950s and early 1960s outcome-oriented management and evidence-based practice were not the major issues they are today and my conclusion summarizes the position of contemporary hospice chaplains.

Spirituality and spiritual care in the history of healthcare in England

Over the centuries the relationship between spirituality and healthcare has changed. In Medieval times the hospital ward looked like a church for the only healthcare available was provided by religious orders. Treatment was based mainly on herbs and today's medical profession would probably regard it as complementary therapy. The thirteenth century hospital, whether founded by the church or an individual, shared the characteristics of

[2] The Scottish National Health Service, which operates independently of the NHS in England, started to address issues of spiritual care over ten years ago, producing 'Guidelines on Chaplaincy and Spiritual Care in the NHS in Scotland' in 2002.

monastic life, in the structure of the building, in being managed by a priest (Hospital/Health Care Chaplaincy 2006 website) and the division of the day according to the monastic offices and services including mass[3]. Patients were not referred to as patients because they were regarded as temporary members of a new spiritual community (Swift 2009:13). In these hospitals religious care was spiritual care and the healing of the spirit had priority over the healing of the body (10).

The Dissolution of the Monasteries saw these hospitals replaced by 'houses for the poor' – for example St Bartholomew's and St Thomas's in London, which were the responsibility of the Civil authority which appointed beadles to trawl the streets to find the sick-poor, the crippled, the blind, the infirm (Swift 2009: 18). The hospital was still a religious space - its management was the responsibility of the chaplain who was now called the 'hospitaller' - but the spiritual community was replaced by a place of instruction in the Bible and moral improvement (24). This ethos of concern for public order continued, culminating in the nineteenth century establishment of workhouses with infirmaries, In order to ensure conformity to a God-given social order the chaplain's role focussed on the practice of religion rather than on spiritual care. However, there were those for whom hospitals could do nothing and in 1905 the Religious Sisters of Charity opened St Josephs Hospice, Hackney[4], as a place for the dying (Hospice website) with no suggestion of control or conformity, a place that would later be significant for Cicely.

The establishment of the National Health Service (NHS) in 1948 included the provision of chaplains whose role according to the British Medical Association In 1955 was to assist in moulding patients' attitudes (Swift, 2009: 43) to comply with the treatment being given by the doctor. Such paternalism, albeit in feminine form, was present in nurses' training in the fifties when matron and sister had real authority. Nurses 'had to obey matron in their private life as well, taking instructions on how late they could stay out, how smartly dressed they were and the suitability of any young man they wished to marry – although getting married meant leaving the job' (O'Dowd 2008[5]). Hierarchy was strong: the deference paid by a consultant to Matron in the 1967 film *Carry on Doctor* was not entirely unrealistic.

[3] See: http://www.nhs-chaplaincy-spiritualcare.org.uk/WhoWeAre/infohistoryhcc.htm [accessed 14/7/2012]
[4] See: http://www.stjh.org.uk/ [accessed 12/6/2012]
[5] See: http://www.nursingtimes.net/nhs-nursing-in-the-1950s/461928.article 10th Jan 2008 [accessed 21/08/2012]

Cicely Saunders' spirituality and her vision of hospice

Despite training as a nurse, almoner and doctor in the hierarchical world just described Cicely's vision was of a community where spiritual care was not about control but about self-worth: 'You matter because you are you, and you matter to the last moment of your life' (du Boulay 2007: 193). Cicely had been impressed by the care and hospitality of the nuns at St Joseph's where she worked, for three years from 1958, as a medical researcher observing, evaluating pain control and listening.

As a teenager Cicely was an atheist but at university, she had searched for God. By 1945, aged 27, her emotionally deprived childhood and her role in enabling her parents to separate after twenty eight years of marriage had weighed her down with guilt. She desperately needed forgiveness and reconciliation (du Boulay 2007: 31) and was longing for real conversion. The theological wrangling of her university years no longer fulfilled her need but sound evangelical Biblical teaching gave her assurance and security.

In 1959 Cicely was reading Daily Light, a selection of irrationally linked bible readings affectionately nicknamed 'Kangaroo exegesis' by evangelicals (du Boulay 2007: 60). On the day when the reading, from Psalm 37, was about trusting God, she knew that the time was right for her to act on her long-held dream. She went on retreat to confirm that this was God's will (61). She produced two documents on the hospice vision in which her style of writing was openly religious, but her vision was as much medical as spiritual (63). Cicely realized that the medical needed to be foremost in fundraising but in order to do the job properly she would need people who were spiritually equipped to help the patients (69). These people would be 'Christians of devotion and maturity' and there would be regular corporate worship and prayer amongst the staff (69). However, on a personal level Cicely found that whilst she did not want to lose what her evangelical conversion had given her she herself was searching for something wider (70). She was becoming less exclusive, more ecumenical (71) and the hospice vision changed from an evangelical community to a wider Anglican community to an interdenominational community. The question was: how to bring people of different churchmanship and different denominations to pray and work together? Ecumenical communities were as yet unheard of and for Cicely community was a means to the end of giving security to both patients and staff.

Nevertheless, in 1967 St Christopher's was founded rooted in Christianity (Bradshaw 1996:411). The chapel was centrally situated, prayers were said on the wards and four theological students acted as male orderlies and porters. However Cicely also stipulated

that religion was not to be forced on anyone (du Boulay 2007:63) but the gospel message of love should be communicated through actions and atmosphere. She remained an Anglican but in the 1970s when she was in her sixties became convinced that all faiths led to the same God. 'She did not seek to impose her own faith, rather to set people free to find their own' (123).

In 1988 at the age of seventy Cicely wrote 'Spiritual Pain', a paper in which she argued that the spiritual covers more than the higher moral qualities. 'Memories of defections and burdens of guilt may not be seen at all in religious terms and hardly be reachable by the services, sacraments and symbols that can be so releasing to the "religious group"' (Saunders 1988). She explores the search for meaning and what it is to face meaninglessness, pointing out that to tell one's story requires a listener and the most important characteristic of that listener is their understanding of their own search for meaning.

The research

Whilst working as a hospice chaplain I was an executive member of the Association of Hospice and Palliative Care Chaplains (AHPCC). I obtained permission from the executive to conduct an online survey amongst the one hundred and sixty two members to establish the profile of the Association and a population from which a sample might be drawn. 67% of members responded and of these 84% were willing to be interviewed.

The survey results showed that respondents were slightly more likely to be male than female (55% to 45%), predominantly aged over fifty with only two under forty. All but three were Christian and of those just over half were Church of England. Other denominations represented were Methodist, Baptist and Roman Catholic. The three non-Christians were Moslem, Jewish and Buddhist. Ten respondents (9%) were volunteers. Just under half (44%) were full-time employees with males more likely to be full-time than part-time and females were more likely to be part-time than full-time. These results, and a concern to ensure a good geographical spread across England[6], guided my selection of interviewees. The size of the sample had been estimated at twenty but this figure was extremely arbitrary. To continue interviewing until theoretical saturation was reached was neither practical in terms of time nor feasible in terms of financial resources. In the event thanks to

[6] Interviews were limited to chaplains working in hospices in England because of the absence of spiritual care directives from the NHS. The NHS functions autonomously in Scotland, Wales and Northern Ireland and in these countries such directives are in place and have impacted on hospice practice.

a couple of incidences of snowballing twenty five interviews were completed before my set date of November.

Interviewees were selected such that the group profile was similar to the AHPCC survey profile in terms of gender, age, full-time or part-time work, employed or voluntary, faith group, Christian denomination and ordained or lay. Twenty two were Christian, with Jewish, Buddhist and Moslem disproportionately represented by one of each. Guided or semi-structured interviews were carried out between February and October 2013 in locations spread across England. Each interviewee signed a Consent Form and permission to record was obtained at the beginning of each interview. To ensure that I obtained relevant information I wrote a script for the interviews, estimating that each would take one and a half hours. As time went by I was more relaxed about covering every point as I could see themes emerging and there was always the possibility of following up by email or phone. Some chaplains rambled – their own description - and I let them, keeping an eye on my script to ascertain what might not have been covered. I personally typed the interview transcripts preserving confidentiality by using pseudonyms, and analysed the data linguistically and thematically[7]. At this point in my analysis four themes have emerged

Hospice Chaplains' understanding of spirituality and spiritual care

According to Walter (2002:134) Cicely Saunders' connection of spirituality with the search for meaning is not found other than in English-speaking countries. He argues that in Catholic countries the understanding of spirituality is traditional and orthodox: of the human being in relation to God, and that secular healthcare in the English-speaking Protestant world is developing a different language of spirituality in order to distance itself from religion (134).

The research certainly indicates the use of a different language but it is not clear that distance from religion is the motive. What comes through clearly is the desire to find a language that enables the patient, who in the round of appointments, treatments, investigations has lost sight of who he is, to tell his story and in so doing to re-engage with his own spirituality. Chaplains felt that the language of the many definitions of spirituality, including terms such as 'transcendent meaning and aspiration to life'[8] is appropriate to the academic world and possibly to hospice management but it does not express the actual

[7] I am still analyzing the data

[8] Association of Hospice & Palliative Care Chaplains Guidelines 2012

experience of the patient. Understanding spirituality as what animates a person, their passions, what feeds them when they are down, what resources them, their relationships, chaplains say spirituality is 'what floats their boat', 'what makes them who they are', 'what makes you tick', 'your engine', 'what makes me me and you you'.

However, describing the practice of spiritual care, the encounter between chaplain and patient, was generally easier than defining spirituality, although two chaplains were wary of using either term as they had experienced confusion with spiritualism, in one case by a patient and the other by a senior manager. Chaplain Martin made it clear that he was not there to preach or teach, but 'to hold this with you'. He remarked that the local hospital has a team of Chaplains which includes a Jewish chaplain, but the hospice has one chaplain who happens to be Jewish. When asked by a non-Jewish patient how that works he uses his German background 'I am the Seelsorger, the one who cares for the soul'. Another chaplain observed that faith-specific chaplains meant that the vast majority of hospice patients were effectively denied specialist spiritual care. Doubtless those patients would still receive loving attention from other staff but those staff are not expected to deal with existential or religious issues and they themselves also need, deserve, spiritual care.

Beth said spiritual care means really listening, with all the senses, in order to hear the patient's spirituality and 'meet him where he's at and love him'. Love him regardless of whether he has a belief system or what that belief system might be, love him using his language and respecting his culture. William saw his role as enabling and mediating and described how one member of staff had drawn a picture of him with very big ears and a very tightly shut mouth. Alan said 'a lot of what I do is just pastoral support that crosses faith boundaries'. Larry said 'A lot of conversations are affirming people for their value and sense of worth, for who they are, not for what they can do'.

Doreen and Yasmin both spoke of spiritual care as relationship building, chatting about the weather, hobbies, family, moving on to life achievements, hopes and fears, planning the funeral and considering what happens when you die. Doreen also made the point that all staff and volunteers are involved in spiritual care to a greater or lesser degree. The nurse bathing the patient may hear far more than the chaplain about the spiritual issues troubling them - but nurse and chaplain are part of the same team, working together for the benefit of the patient. Xelda described spiritual care as like eating a globe artichoke, enabling the patient to work his way to the centre, to the bit that actually supports and holds.

Many stories were told but only two used Biblical material. Greta used the dying patient's favourite Psalm with the daughters who did not share their mother's faith. They had

however seen the film ‘Shadowlands’. Greta linked the film’s portrayal of loss with their experience and with the comfort offered by the psalm.
To help patients look at regrets and sorrow for past actions John uses the story of the Prodigal Son in his own words, freely describing dad waiting at the garden gate longing to welcome him home.
Larry used a story told by a Buddhist monk of a man half-way down a cliff with a lion at the top and a lion at the bottom and a mouse gnawing at the creeper he is holding on to. He spies a wild strawberry, picks it, smells it, puts it in his mouth and savours it. The lions and the mouse are still present but he cherished the strawberry. We must all cherish the strawberries whatever they may be.
However there are times when the patient’s strawberry is alien to the chaplain: John reported that as he knew nothing about football he briefed a volunteer to provide spiritual accompaniment for a football fanatic. John was very aware of the use of language, recounting how at his informal licensing he pointed out to the Bishop the inappropriateness of promising to do the liturgies ‘as specified’ when the patient is drawing their last breath. The promise was adapted and the bishop trusted him to do and say what would be appropriate, which gave John a freedom to explore and be creative with language with patients but he admitted that he still was not creative enough when recording encounters in the notes.

Language for recording in patient notes

Part of the difficulty is knowing what to record and the variety of understanding amongst those who will read the notes. Writing ‘a special moment watching the cygnets on the lake’ might seem a dubious example of spiritual care to some but others would read the previous nursing entry ‘had a rough night, couldn’t sleep’ and realize that the chaplain’s entry signified balance restored. The challenge is to find words that will faithfully report an exchange in a way that is understood by and acceptable to management.
A note indicating a conversation about death and dying, or relationships, or regrets and forgiveness is relatively straightforward but a conversation about sport? One patient stated that his religion was the local rugby team, another came alive talking about the television programme ‘Strictly come dancing’. Some hospices have stickers saying ‘significant conversation’ to put in the notes but this is not appropriate if the patient is in a coma. Keith said that in the hours sitting by the bedside of someone in a coma he is ‘conscious of

something happening in that space but I cannot prove it to the person who pays my wages.' Fred observed that the patient whose hand he held in silence, and who was able to be welcomed by his maker peacefully, cannot come back to write in the notes 'I was really happy that you were there'. Fred also asked how he could turn relatives' thank-you letters into acceptable evidence.

Recording pictures, analogies and metaphors sometimes helps the evidence record – Tracy puts 'used this picture to talk through the patient's concerns', and often staff will be interested enough to ask her to tell them more. She also observed that nursing staff hesitate to explore spirituality with patients because they lack confidence in their own spirituality.

Chaplains' speaking about their own spirituality

Interview data suggests that whilst chaplains may have confidence in their own spirituality finding the language to speak about it, even vernacular language, did not come easily and the spontaneous connection with sustaining their work was rarely made. Descriptions of their spirituality and whether it was adequate to sustain the role were varied in content and in the ease of response. Several chaplains mentioned mystery and 'broader than church'. Alan spoke easily of his own spirituality which was 'broader than church' and how it sustained his work: sitting in silence 'I am fed at a level beyond words'. Tracy observed that she had gone 'wider' in her spiritual search and traditionalists might regard her spirituality as off the wall, heretical, not rooted in anything concrete. She acknowledged the way her work had affected her spirituality, saying that her faith looked quite different from ten years ago. She asked whether other chaplains have the same experience. Beth summed up her sense of God as the life-energy in the universe, the creator of all, 'working in me and through me' as 'God is the ground of my being'. In comparison Charles struggled, saying it was a horrible question as spirituality is vast, mysterious and not capable of being reduced to a few words. The heart of his spirituality is engaging with his own soul by himself and in community with others but he felt this was a work in progress and there were times when his spirituality was not sufficient to sustain him in his work. Ian recognized that he had not paid enough attention to his own spiritual care and had come close to a breakdown.

Some chaplains described their spirituality in terms of what they believed in relation to Jesus and two (Doreen & Larry) said: 'as I get older I find that the things that I find it

necessary to believe as a Christian get fewer and fewer but the things that I do believe I believe more strongly'. Larry also made the point that he was happy to speak of his spirituality using his own language but would not use what he called 'religious' language. Two chaplains, Tracy and Greta described their spiritual development, spontaneously making the connection between their spirituality and being sustained in the work. Greta was passionate about spiritual self-care saying 'if a chaplain loses sight of his own spirituality how dare he sit by the bedside of others to encourage them to discover their own spirituality'. She was one of several chaplains who mentioned the importance of putting their own spirituality on one side, leaving it at the hospice door, in order to meet the patient where he is. Ian illustrated this with the lady who after a long chat thanked him for helping her to become a pagan. He commented that, based on his understanding of who she was and where she was in her life, it was a good choice.

Laying aside one's own beliefs seemed to invite a comparison with Christ laying aside his divinity but then the Moslem chaplain said 'I need to be the person they need me to be'. The focus is on the patient and both a Christian and the Moslem chaplain described spiritual care as 'when the divine in me meets the divine in you'.

Norman described his spirituality in terms of his practice of prayer and meditation saying it was essential for his work. Martin spoke of his spirituality as a relationship with God through music, art, nature, shabat observance but he also likened it to a butterfly landing here and there, being open to whatever is going to meet his need at that point in time. Some mentioned prayer, the office, sometimes honoured more in the breach than in the saying, some mentioned a rule of life. John admitted he was not disciplined in prayer or bible reading so appreciated having to prepare to lead worship and preach in local churches.

A few (Larry, Keith, Fred, Xelda) recognized that their spirituality had been affected by the transformation of a personal tragedy or difficult experience into a creative force which sustains them.

Cicely's spirituality and the spirituality of hospice chaplains today

Just as Cicely's spirituality broadened beyond that promoted by the institutional church so too the spirituality of the hospice chaplains interviewed. However, it must be said that whilst many chaplains, including the Moslem, currently bemoan the lack of support from their parent bodies none reported antagonism to that broader spirituality. There may be

ambivalence but, unlike the thirteenth century, the church is not the source of the Inquisition. Rather the potential for antagonism lies within Hospices themselves with the inquisition of Senior Management whose concern with the financial viability of the organization constantly questions the value of spiritual care. As well as her hospice job Queenie works as chaplain to a supermarket where her listening role is acknowledged to keep down the cost of absenteeism. She suggested this was one way of making the case for spiritual care which might appeal to a management skeptical of the relevance and value of soft anecdotes.

Cicely's original vision was for the hospice as a community providing security for patients and staff (du Boulay 2007: 73), a vision of what today might be termed a particular workplace spirituality. My research indicates that the extent to which today's hospices are communities varies: some chaplains feel 'embedded', fully acknowledged as part of the team, whilst others struggle as new management with little or no understanding, and even suspicion, of what has been called 'the heart of hospice' cause the ethos to change. Several chaplains described living through this change at the time of interview. Steve described staff no longer feeling valued and the loss of good will such that staff involvement in fund-raising is declining. Tracy felt that the community ethos was still present in the In-patient Unit but not elsewhere in the hospice.

Cicely's vision was of a hospitable place where people would feel safe to tell their story and explore life's meaning. That story would be heard by a person who understood his own story, a person who was comfortable with his own spirituality. Analysis suggests that use of vernacular, rather than religious, language is essential for chaplains to describe their own spirituality as well as when enabling patients and staff alike to understand their spirituality. However, even using vernacular language some chaplains still struggled to grasp and express their own spirituality.

Conclusion: Hospice chaplains and management

In today's financial climate the necessary hard-headed approach to the future of hospices means that there has to be a reason for every service offered (Help the Hospices 2013). To a management concerned with financial stability the anecdotal nature of spiritual care and its use of vernacular language does not appear to justify its existence. Just as the thirteenth century Church reacted to the use of non-liturgical, vernacular, language by establishing the Inquisition, to suppress what was regarded as heresy, today's hospice management consistently questions that which does not conform to financially-oriented

medical-liturgical language in demonstrating evidence of added value. However, such an approach appears to deny that for which Cicely was renowned: bringing humanity back into medicine (du Boulay 2007:193). This seems to suggest that hospice chaplains have a counter-cultural role of demonstrating that humanity matters, not just the physical body but the whole person, and that spiritual care nurtures humanity. However, in order to be acceptable to management such a role needs to convert the anecdotal and the soft vernacular words of spiritual care into the hard language of outcome-oriented management.

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