

Spirituality and discourse: A postmodern approach to hospice research

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Abstract

In modern western society, because of the dominance of secular modernist ideas of rationalism and positivistic science, notions of spirituality have been at best marginalised, at worst excluded from our discourse on health care. Research into spirituality has been limited by modernist epistemological assumptions concerning 'objective' proof and measurement. This discussion seeks to help reverse such a direction by offering an example of research on an Australian hospice service (Karuna Hospice Service) which is inclusive of the notion of spirituality. This research indicates that a spiritual discourse was not only important in the genesis of this organisation, but is also a significant factor in energising and guiding the ongoing democratic, holistic, compassionate praxis of this hospice service.

Introduction

In this era of economic rationalism, where health policy is conceptualised in such quantifiable terms as resource consumption (Olver, Long & Halbert 1995), outcomes (Rissel, Ward & Sainsbury 1996), efficiency (Duckett 1996, p 8) and cost control (Nelson 1994), the non-measurable aspect of health care can be marginalised, forgotten or, at worst, deleted from considerations of service delivery. This policy concern with pragmatic issues of proof and measurement is reinforced and exaggerated by the positivist, scientific approach to research which informs our discussion of health care in Australia.

In an attempt to address this epistemological hiatus, this paper will focus on one such silenced, or 'ignored dimension' (Soeken & Carson 1986, p 52) to health care: that of spirituality. This paper will use recent research findings on an

Australian community hospice organisation, Karuna Hospice Service, to indicate that the notion of spirituality, although rarely described in the literature on health care, is, at least for this organisation, a most important determinant, energising and guiding ideology and practice. The paper will show that Karuna Hospice Service's discourse on spirituality is an important dynamic, underpinning the organisation's genesis, its democratic organisational structure, and its holistic service delivery. Indeed, the research carried out on this organisation indicates that the primacy and value given to spiritual 'talk' is *the* central dynamic energising the work of this service. As one participant in the research stated:

We are something different and I hope that that something different [spirituality] stays. Because that is what energises people and sort of gives us the satisfaction.

Although the focus of this article will be on sharing the findings on Karuna Hospice Service's spiritual discourse, it is important first to situate the discussion in an understanding of the postmodern approach taken to the research on this organisation.

Rationale for research

The aim of the research was to move away from the usual, but restricted, scientific understandings of health care to a different way of doing research, based on a postmodern approach. It was hoped that such an alternative research direction would include ideas marginalised by more conservative, modernist research methodologies in our body of research on health services.

Predominantly, such modernist research is predicated on positivist, scientific notions of neutrality, objectivity and truth. All too often such epistemological assumptions in health care translate into reductionist physiological understandings (the biomedical model). The metaphor for this reality is body as machine, not individual as spiritual entity. Even where such knowledge includes a psychosocial dimension, it is still accessed by science because, historically, behavioural and social scientists adopted their model of research from the physical sciences (Fahlberg & Fahlberg 1991, p 276).

If notions such as holism and spirituality, which are now mentioned in the literature on health care, are to be included in the research which informs considerations of policy and service delivery, then the challenge becomes one of exploring new directions in research. As Diaz (1993, p 326) explains:

If Spiritual health is truly a viable dimension of optimal health, as so many profess, then we should do more than simply give verbal assent to the notion.

As can be seen by the following discussion, postmodern ideas of discourse provide one such effective approach to research, in which notions of spirituality can be captured and research findings on the subject at least able to be discussed, without the need for proof, verification or quantification.

Methodology

Different discourses...about the world are assessed not in terms of their truth, i.e., accuracy of representation, but rather as different ways of talking about the world (Mumby 1988, p 130).

A postmodern approach to research, rather than adhering to the idea of objective truth, is situated in Mumby's (1998, p 130) notion of discourse as presented above. Such an *episteme* rejects the notion that the researcher can, by using a strict methodology, somehow be situated outside of reality looking in, observing, recording and analysing in a vacuum of neutrality, untainted by life experience, personal values, culture or history (Capra 1990, p 416). Instead, the production of truth is linked with notions of discourse and power. From such an epistemological viewpoint, scientific method is viewed as one, albeit a dominant, discourse of truth production in our society. As Foucault explains, 'each society has its regime of truth, its "general politics" of truth; that is, the types of discourse which it accepts and makes function as true' (cited in Rabinow 1984, p 73). In modern western societies, positivist, scientific ways of knowing are in direct relationship with truth production and, hence, the creation and inscription of what is deemed to be reality. Understandably, any notion of a spiritual reality is not easily captured by such a rational, secular, scientific epistemology.

As an alternative to the problems of embracing a strict methodology, this research turned instead to notions of discourse, by exploring the social construction of reality of one hospice organisation through an examination of its talk (or discourse). This paper uses Mumby and Stohl's notion of discourse (1991, p 313), which is stated as:

a process of signification, [which] functions to structure systems of presence and absence within organisations, such that certain conceptions of reality are organized into everyday practices, while other possible conceptions are organised out.

Discourse, or talk, is thus seen as the medium through which an organisation's reality is created and described. Examining the talk associated with Karuna Hospice Service is consequently seen as providing insights into that service's construction of reality.

This discourse was captured through 15 open-ended, non-structured interviews. Exact replications of these interviews were made through audio-recordings and then transcribed verbatim to produce the basic language/texts for analysis.

The innumerable accounts I had heard from health and allied health professionals, as well as clients and families associated with Karuna Hospice Service, of the unique and special, caring, compassionate and holistic work of this service fuelled and sustained the curiosity for this research. Consequently, these interviews focused on the topic of understanding this widely held notion of Karuna Hospice Service's 'uniqueness'. The research task was not to prove or measure such compassionate service; although very positive client satisfaction surveys (Walker 1996) and moving accounts by families (Darragh 1994; Montgomery 1995) do exist. Rather, the project was to explore through talk how those associated with this service understood this expressed difference or uniqueness, which was noted in the positive comments about this service. The research intent was descriptive and interpretive rather than comparative: neither quantitative nor qualitative comparisons are made to other or similar hospice services.

The aim of such text creation was not a modernist concern for collecting objective data to prove or affirm a research agenda, but rather a postmodern interest in exploring difference and discourse. The concern was to protect the possibility of interpretive complexity and heterogeneity of discursive expression. Consequently, a wide range of individuals were chosen for these interviews, from both within and outside this service. These interviews lasted from one to one and a half hours. When transcribed, they produced an immense amount of text: varying from 6000 to 10 000 words per interview. McCracken (1988, p 17) describes the rationale for such data collection, where considerable information is collected from a few persons, rather than a small amount of information from a large population, as 'less is more'.

The data were then examined using a thematic analysis of significant statements. The exact words of participants were used, not abstract concepts (as in content analysis), so as to preserve the notions expressed in the discursive practices of the organisation.

The notions used by writers on deconstruction (Norris 1982; Dear 1988; Lemert 1992; Smart 1993; Elam 1994) formed the basis of the process chosen to analyse the discourse from the language/texts gathered. Central to such a postmodern approach to power/knowledge is the idea that reality is defined as much by what is not spoken as by concepts that are. Consequently, the analytical focus in interpreting these data was on examining the privileging or silencing of notions

within Karuna Hospice Service's discourse as recorded in the language/texts gathered for this research.

Research findings: The importance of spirituality

It is important to note that the focus of this research was on exploring how this service described its 'uniqueness', not on examining the notion of spirituality *per se*. The starting point for the research was an awareness of Karuna Hospice Service's positive reputation for its compassionate service. The spiritual talk, which was privileged throughout the language/texts as the central notion energising the work of this hospice, arose tangential to the discussions on 'uniqueness'. The important point is that during the interviews the researcher in no way directed the conversation to spirituality. This aspect of the hospice's construction of reality, which was privileged extensively throughout the language/texts, was an unsolicited but integral part of the talk of those associated with this service. This spiritual talk was found to be *the* connecting thread that linked all of the discussions, whether it be about Karuna Hospice Service's work with clients or organisational issues. Although it was acknowledged that the spiritual dimension was difficult to define, all those interviewed perceived this aspect of the hospice as contributing significantly to a sense of its difference.

The significance placed on the notion of spirituality within the talk of the hospice was clearly articulated by one participant who stated:

*I think to give it [spirituality] a place...to give it some sort of recognition.
What I am saying is I think that is what Karuna has done.*

The following presentation of research findings will concentrate specifically on the data directly relevant to understanding the central importance given to this spiritual discourse in the talk of Karuna Hospice Service. This discussion will begin by looking at the significance of the hospice's spiritual discourse during the organisation's genesis.

A spiritual beginning

Spirituality is recorded as a generic element in hospice formation. Early hospice leaders were characterised by their 'spirituality'; their singleness of focus; their power to engender enthusiasm in followers; and their ability to stimulate change through their single-minded spiritual devotion to what they were doing (James & Field 1992, p 1366). For example, the British leader of the modern hospice movement (DuBois 1980), Dame Cicely Saunders, whose pioneering work

established St Christopher's Hospice in London in 1967, acknowledges the importance of her Christian spirituality as the inspiration and guidance behind her work (Du Boulay 1984). Similarly, Sheila Cassidy, another significant British hospice innovator, leader, practitioner and educator, whose London hospice presently serves as a model for followers throughout the world, clearly articulates in her writings the significance of her single-minded devotion to Christianity (Cassidy 1991). In her book, *Sharing the Darkness: The Spirituality of Caring*, Cassidy (1991) communicates the essence of this spiritual framework for her work with the dying. Such leaders were characteristic of hospice development, as reports indicate that Christianity, in particular, gave the impetus for hospice formation (James & Field 1992, p 1366).

Similarly, participants in this research recorded that the 'original dreaming' or idea for starting this service came from their charismatic, spiritual leader, Venerable Pende, as can be seen by the following language/text:

So we got to know [Pende] quite well and he started to share this instruction he had got from [his teacher] and his dream...so we got involved with [him] and his dream.

This leader's ability to implement that dream through a consciously conceived, single-minded plan of actively enlisting the support, skills and energy of many resourceful individuals was legendary to those who were members of, or associated with, the organisation. The core dynamic of this process was expressed in such comments as:

He cleverly seconded a lot of people from a lot of different avenues of life and with a lot of different skills and connections and contacts and pulled them altogether...he got really hooked into people's dreams.

Karuna could not have happened without him...I am sure...with his ability to attract people with expertise and people with drive...I mean he was very much a driving force.

This charismatic leader acknowledges his debt to spiritual guidance. However, unlike most of the other hospice leaders, who are recorded as having Christian backgrounds, this leader follows a Buddhist metaphysic. A life-long commitment to Buddhism began in 1979 for this spiritual leader, then known as Ken Hawter, when he undertook his first month-long meditation course in a remote monastery near Kathmandu. Profoundly influenced and motivated by the 'extraordinary personal example of humility, compassion and wisdom' (Simpson 1991, p 8) displayed in the tutelage he received from two Tibetan lamas, he went on to further study in the Mahayana tradition. In 1987 he was ordained in Dharamsala by the Dalai Lama as a Buddhist monk. It was the guidance and

instructions that Venerable Pende received from his own spiritual mentor, the Lama Zopa, in 1989 that directed him to undertake the project of starting a hospice. Karuna Hospice Service thus originated as a Buddhist inspiration and is still spiritually (though not financially) under the auspices of The Foundation for the Preservation of the Mahayana Tradition. Understandably, Pende contributes the success of the hospice to Buddhist spiritual inspiration and guidance. The power of prayer, the blessings of highly realised beings, and the compassion of all the Buddhas and Buddha saints were factors articulated by this leader to be key ingredients in the success of the hospice.

Charismatic leadership is seen to be inherently unstable, resting to a large degree on the ability of the leader to generate and sustain support. This support, in turn, depends on the follower's belief and interest in the leader and their mission (James & Field 1992, p 1366). The transcripts of this research strongly privilege the notion of this particular charismatic leader's early and ongoing support from his followers. Pende was referred to as 'the spiritual overseer of it all', with participants expressing the awareness that those involved in setting up the hospice 'all realised that it was his dream...his direction' that instigated and sustained the organisation's formation. Described as a 'sort of charismatic person' who has 'been the linchpin right through', Pende was referred to as 'a key player in the way Karuna has developed'.

The genesis of Karuna Hospice Service, similar to hospices elsewhere, can be seen to have a strong spiritual underpinning generated by the contribution of a charismatic leadership, situated within the motivating and supportive metaphysical discourse of Mahayana Buddhism. This spiritual leadership was not only the initial catalyst to action, but also succeeded in activating and sustaining the ongoing support of followers needed for the establishment of this hospice project.

Such followers described themselves as spiritually-based people with an alternative value system, and 'a little non-mainstream'. Participants spoke of the early members 'commitment to a certain kind of values' and 'ways of relating to each other' based on ideas 'about compassion, and love and caring, being an integral part of the whole service'. The shared concern was that the service would be 'based around love and compassion rather than the medical model'.

The spirituality of such visionaries was expressed in terms of the common goals to 'serve', 'help', or to 'care', as seen by the following transcripts:

And that common goal is to help people, however you define helping.

Each one had a selfless motivation...and are willing to serve others, and had a willingness to make great sacrifices, personal sacrifices to serve others. I think historically that has always been a great ingredient for success.

...a spiritual interest in helping others in a very practical way.

Research indicates that many involved in hospice service refer to their work as a calling, with religious beliefs, predominantly Christian, underlying their philosophy of care. Others, though not professing a religious orientation, are documented as bringing a spirituality or an articulated philosophy of practice which gives meaning to life, death and suffering (Vachon 1986, p 77).

Similarly, this research would affirm the central importance of a spiritual dynamic behind the motivation of the visionaries involved in establishing Karuna Hospice Service. However, it must be stressed that this is a generic spirituality which welcomes and affirms individuals from a wide range of philosophical beliefs. Although Karuna Hospice Service is a Buddhist-based organisation, participants in this research noted that 'it was the spiritual aspect rather than the particular Buddhist aspect' which was considered of importance in the daily life of the organisation. There was no exclusive concern with one theology or philosophy, but rather 'people of all different religious backgrounds' were made welcome. The factor these individuals from different religio-philosophical backgrounds shared in common was expressed as 'a spiritual yearning for some sort of satisfaction' based on 'a selfless motivation and a willingness to serve others'. Such a tolerance of different spiritual perspectives was phrased as 'the universality of religion' and described by one participant as:

...they might talk about being positive or being healthy or giving another label but what they are actually talking about is their spiritual selves: what the Christians call the Holy Spirit, and what the Buddhists call the pure essence. It is that aspect of themselves that can really change things and I think that is what makes Karuna unique.

Participants found such a generic spirituality difficult to describe, but saw it as proof of a religious tolerance in action.

A spiritual subjectivity

Not only was spirituality recorded as an energising and guiding force in the genesis of this organisation, but it was documented as an important factor influencing the everyday expression of Karuna Hospice Service's hospice ideology. To explain such findings it is necessary to digress for a moment to explore the notion of subjectivity.

According to Davies (1994, p 23), discourses create the possibilities for certain subject positions through which the individual interacts with others. Part of the effect of discursive practices is shaping or actualising certain ways of being, of speaking about the world and, hence, is constitutive of the persons who adopt them (Davies 1994, p 44). The individual, as author of statements, cannot be viewed as an entity outside of, and independent to, discourse, but is rather a function, or effect, of the discourse itself (Fairclough 1992, p 43). There is a direct and creative link between discourse and the subjectivity of the individual.

This research indicated that Karuna Hospice Service's discourse shapes a spiritual subjectivity which attracts and supports individuals who are comfortable with a gentle, caring, tolerant and dedicated way of seeing the world. Such a subjectivity includes notions of compassion, gentleness, and a willingness to serve and strive for excellence. Indeed, an analysis of the language/texts gathered for this research indicated that there are eight key attitudinal ingredients which inform this spiritual subjectivity. These are:

- a desire to serve
- a tolerance of multiplicity in thought and action
- a seeking of self-actualisation through interconnectedness and altruism
- a compassion expressed as love and caring kindness
- a commitment to selfless or pure motivation
- an ongoing concern to seek the integration of spiritual practices into everyday life
- a holistic orientation to the care of the individual
- seeing life as a spiritual journey.

Such a subjectivity or way of 'speaking the world' (Davies 1994, p 44) is compatible with, and supportive of, hospice ideology and practice. Understandably, members of this organisation attributed their sense of 'uniqueness' to this spiritual dynamic and valued such spiritual talk and way of being. This is demonstrated by the following comments:

I think that there are some exceptionally wonderful people operating in Karuna and they will do their best to maintain that special stuff.

There are some people in there who are spiritual to the core and as long as they are there they will keep it.

If we hang on to those kinds of people we will survive and we will keep our spiritual way of doing it.

So privileged is this discourse within Karuna Hospice Service that members speak of themselves in descriptions reflective of valued spiritual characteristics. For example, one participant stated, 'proudly I could say that I was very caring for individuals and other human beings and respecting people's rights to do it their way'. Members of the organisation suggested that they were not concerned that those associated with the hospice should be the 'perfect person or saint' but rather that they are 'genuinely compassionate' people 'who can express their warmth, their love, their compassion and their willingness to serve others'.

As Karuna Hospice Service is an organisation that values the spiritual aspect of life, it was stated that individuals attracted to this service 'actually live what they believe'.

The hospice's spiritual talk embraces a holistic notion of client and in so doing moves away from the reductionist, biomedical view of the dying to a psycho-social-spiritual perspective that respects the individual's meaning-making as an important aspect of their dying experience. Such a spiritual client subjectivity was expressed by participants as:

I suppose for me it is some sense...some real sense that there is some other aspect to people than just their emotional and intellectual selves.

Acknowledging that it [spirituality] is a part of their whole person.

...if we leave that out [spirituality] we leave out the most essential part of life.

Such a subjectivity privileges, supports and reinforces the possibility of spiritually inscribed ways of seeing and acting. Such ways of seeing and acting are directly compatible with the democratic, holistic and compassionate hospice ideology which informs this organisation's daily practice. At the interface between hospice worker and client, the spiritual discursive practices and the subjectivity such practices sanction were acknowledged as powerful mechanisms influencing hospice praxis. Consequently, the centrality of Karuna Hospice Service's spiritual discourse is seen as an important aspect of this organisation's work with the dying.

Conclusion

So I think what Karuna has done is to put it on the agenda, to give it [spirituality] some acknowledgment and say this is an important factor.

The conclusion reached by research carried out on Karuna Hospice Service is that this organisation's spiritual discourse can and does make a difference,

particularly in patient care. Such a discourse is constitutive: it creates and maintains a discursive space and subjectivity for both health worker and patient that inscribes an enriched notion of choice and the possibility of democratic, holistic, compassionate, non-judgmental care.

By recording these findings, this paper seeks to communicate the importance of the notion of spirituality to a community-based, Australian hospice organisation. This transcendent reality has been made discussable through a postmodern approach to research. Such a discussion, it is hoped, has gone some way to meeting Diaz's (1993, p 326) call for:

...a broader base of acceptance for the concept of spirituality in the health field as well as...accelerated study and research in this relatively unexplored new field.

Note

Karuna Hospice Service is a Buddhist, non-profit, community-based hospice organisation which provides comprehensive home care services for people with a life-threatening illness and their loved ones. This service provides full hospice-at-home service, with expert nursing, counselling and respite care. Nursing care is provided on a 24-hour, 7 days a week basis and specialist palliative care medical consultation is made available if required. Individual and family counselling is provided, as well as bereavement counselling and support, and pastoral care. The hospice team cares for adults and children who have a life expectancy of less than six months, who have a carer available and a general practitioner willing to be involved in home-based care. This service was established by a group of visionaries in the community under the charismatic leadership of a Buddhist monk. It is now five years old and presently receives some of its funding from the Regional Health Authority. The postal address of this service is Karuna Hospice Service, PO Box 2020, Windsor, Queensland 4030. Ph: (07) 3857 8555.

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