

## EDITORIAL

Despite the growth of the modern hospice movement over almost forty years, death is still one of the great taboo subjects of our civilisation. Natural death, in many ways, remains hidden away, feared and avoided at all costs and yet death is a part of life which none of us can avoid. Death touches individuals, it touches families, it touches communities, it touches societies and it touches nations but still somehow we manage to sequester it as something that is obscured and rarely discussed. Alongside decreasing rates of infant and maternal mortality and improved longevity in western populations, and in the face of intensifying existential anxiety (Conrad 1994; Giddens 1991), death has become an uncomfortable topic. Individuals and communities have lost the ‘competency’ in death and dying that accompanied the relatively high death rates of 19th Century Europe and colonial New Zealand, and the cultural capital associated with death and dying has been relegated to specialists in medicine and religion and the profession of funeral directors.

The growth of palliative care as a medical speciality is mirrored by the establishment, over the same period of time, of the field of death and dying within the discipline of anthropology. One key area of interest in anthropology has remained the social meanings pertaining, and cultural responses, to death. In the context of western cultures and societies, this includes ritual, bereavement and grief (see for example, Aries (1974), Green, (2008), Hockey, Katz, and Small (2001), Kellaheer, Prendegast and Hockey (2005), Lawton (1998, 2000), Palgi (1984), Metcalf (1991), Schafer (2007), Walter (1994, 1999)). Kaufman and Morgan (2005) suggest that more recent anthropological investigations of the ends of life attend to the cultural production of death and the oft vexed relationship between the dead and the living. This includes investigation into the ways in which medicine organises the process of dying (Kaufman 2005). Cassell (2005; Cassell, Buchman, Streat, & Stewart 2003), for example, examined the impact that administrative models have on decision-making around end-of-life care in intensive care units (including one in a New Zealand hospital). Her research also highlighted the reluctance within many hospital based medical specialties to recognise when it is appropriate to move from curative to palliative care. Life extending technology attenuates the ambiguity of the

boundary between life and death (Kaufman 1998; Lock 1996, 2000; Muller & Koenig 1988), and 'troubles' the definition of death (Lock 2001). This is both a socio-political and a bio-political issue, as is the issue of organ donation which is dependent both on the definition of death and the ability to clinically sustain life within the boundary between the living and the dead (Sharp 2000).

The manner of dying within hospital and hospice settings is the subject of another group of medical and applied anthropologists; in particular how to facilitate a 'good' death for patients. Johnson, Cook, Giacomini and Wilms (2000) explored end-of-life narratives in intensive care settings and the way such narratives construct the 'good' death, while recent research by Good et al. (2004) examined the discourses of North American internal medicine specialists. In Australia, McNamara, Waddell and Colvin (1995) used ethnographic methods to examine the ways in which staff facilitate a 'good' death in the hospice setting. McNamara (2004) has also identified how 'the good death of the original hospice movement has been abandoned in favour of a philosophy of a "good enough" death' – a notion that appeals to many.

New Zealand offers a rich field of enquiry to researchers interested in palliative care. Although the discipline of palliative care is still developing in New Zealand the growth of palliative care services has predominantly been driven by public interest. This has resulted in a diversity of organisational arrangements, with hospices ranging from local community based services run entirely by volunteers to specialist palliative care units offering a broad range of clinical expertise as well as education, research and quality improvement programmes. There are currently 35 hospice and palliative care services in New Zealand, the first three hospices being established in 1979. Each service in New Zealand has a different configuration but generally services comprise a range of elements e.g. in-patient care, home-based care, bereavement care, volunteer co-ordination, expert consultation, education and research. Despite the evidence that palliative care is effective in improving the quality of life for people who are dying, it is still poorly understood by many health professionals in New Zealand. Undergraduate education in end-of-life care in particular is still seen as variable and inadequate by many (Janssen, Walker & MacLeod 2008, Lloyd-Williams & MacLeod 2004). Despite huge support from the public many people still see the focus of hospice care as dying rather than living (MacLeod 2001).

This special issue of *Sites* is a 'sampling box' of contemporary enquiry into issues around palliative and end-of-life care in New Zealand. It illustrates that medical anthropology is at once academic, applied, outcome oriented, and

multi-, or more accurately perhaps, trans-disciplinary. Lambert and McKeivitt (2002) have previously argued that anthropology offers health researchers relevant conceptual frameworks, substantive knowledge, and methodological insights that can assist lay persons/patients and health professionals understand each other's perspectives and actions. Another contribution anthropology makes to health research is the anthropological attention to the details of daily lives (Lambert & McKeivitt 2002). This issue demonstrates a range of methodologies employed to support research into end-of-life issues, borrowed from a variety of disciplines including anthropology. It also demonstrates the usefulness of anthropological theoretical frameworks in understanding the experiences of patients, which in turn might enable health professionals to better care for them. Medical anthropology is useful to healthcare professionals and health researchers, but the insights of health professionals are also useful to anthropologists. One lesson from health professionals is that medicine is not a monolithic institution; rather there are discernible variations between specialties. Palliative care, for example, is a specialty with a set of cultural values that distinguish it from hospital-based specialties. It spans primary, secondary and tertiary healthcare as well as several health professional jurisdictions and boundaries. One particularly useful insight from health professionals is the reminder to medical anthropologists that, despite local capitalist and neoliberal political economies and institutional drivers, those providing end-of-life care attend to the dying (and their families/ whanau) with empathy and compassion, even in the face of growing constraints on both human and fiscal resources. They remind us of the importance of being human in the often frightening and emotional context of illness, suffering and death (Janssen & MacLeod 2010).

This volume represents an open ended and ongoing conversation between the disciplines of medical anthropology, health professional education, palliative care and nursing. As Singer (2007, p. 8) notes, medical anthropology is committed to making a difference, and this is evident in all contributions to this special issue. Health professionals and carers are reminded of the need to be patient centred and remain cognisant of the lived experiences and lifeworlds of their clients and patients. Contributors also ask how health professionals and carers can better care for those approaching the end of their life, and how policy makers and palliative care service providers can better support those who are receiving end-of-life care, as well as those who are providing it.

In the first contribution McKechnie, Jaye and MacLeod offer a contemporary treatment of the anthropological concept of liminality in the context of palliative care in the community. People who are diagnosed with a life threaten-

ing condition face enormous emotional and psychological challenges as they (re)negotiate daily life, roles, relationships, and identities, often in the face of increasing physical frailty. The liminalities associated with illness experiences, including interactions with health professionals and clinics, have received limited attention by health researchers across several disciplines. Here, the liminalities described by those receiving end-of-life care at home are explicated and theorised. The take-home message for health professionals working in the arena of community palliative care is that a meaning-centred approach might enable more appropriate framing and delivery of health services.

Aged care residential facilities provide the setting for Latta and Ross' contribution. The need for improved palliative care in rest homes and aged care facilities provided the impetus for the study which they report here. Care assistants provide the day-to-day care for most residents but there are limited educational opportunities for gaining and improving skills in palliative care. This research suggests that while courses can be positively received by carers, the likelihood of such learning being transferred to practice in the workplace depends on institutional factors such as workload and management support. Latta and Ross argue for policies that mandate institutional support for carer education in end-of-life care.

Walton presents an evocative contribution based upon her reflections on nursing practice in the hospice setting. She discusses a case study which highlights issues in care; focussing on the relationships that palliative health professionals and carers need to foster with those they care for. Those who are dying must make peace with their lives. Health professionals and carers can facilitate this process, and Walton offers a framework for such engagement. End-of-life service providers such as hospices, hospitals and rest homes can ensure that their policies and practices enable carers and health professionals to be receptive to cues from patients and clients who want to talk about their anxieties.

The use of photographic compositions to represent elements of the lived experiences of those receiving and providing palliative care is the subject of Richardson and MacLeod's contribution. They present an innovative methodology. Here, themes emerging from research participants' narratives are represented through photographic compositions along with a guide to interpretation. The authors discuss the reflexive processes involved in the composition of such images from research data, and the ways in which meaning is constructed between participant, photographer and audience.

Horrell and Stephens examine end-of-life care in the context of rurality. Access to health services in rural populations cannot be assumed, and palliative care services in many rural areas of New Zealand are patchy. Although the ideal of the 'close-knit' communities continues to be espoused, many rural regions have experienced radical social upheaval and dislocations in family and whanau networks and relationships. In this paper, the authors explore the challenges of dying well through the lenses of those who provide end-of-life care in rural settings. They identify competing social discourses and shifts in generational expectations and experiences around dying. This paper challenges health service providers and policy makers to ensure that those dying in rural areas receive quality care.

Kumaran and Bray outline issues in neonatal palliative care. In their contribution, they review the current status of palliative neonatal service provision in New Zealand, arguing the need for a coherent and comprehensive neonatal palliative care strategy. Such a strategy should address education and training for health professional and carers, cultural issues, and delivery models for service provision. They also review physician attitudes towards palliative care and issues for parents whose infant has a life threatening condition, identifying a need for further research in this area.

By collecting these manuscripts together in one issue we hope to make visible some aspects of death and dying that are usually hidden from view and encourage others to seek ways of bringing their studies and observations to a wider audience.

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