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To cite this article: Catherine Rose Hughes, Kate van Heugten & Sally Keeling (2015) Cultural Meaning-making in the Journey from Diagnosis to End of Life, Australian Social Work, 68:2, 169-183, DOI: [10.1080/0312407X.2014.939668](https://doi.org/10.1080/0312407X.2014.939668)

To link to this article: <http://dx.doi.org/10.1080/0312407X.2014.939668>



Published online: 14 Aug 2014.



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Cultural Meaning-making in the Journey from Diagnosis to End of Life

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Abstract

This article is based on an ethnographic study undertaken to explore whether eight people diagnosed with terminal cancer and their families drew on aspects of their cultural identities to make sense of their journey towards death, and if so, how. Ethnographic methods were supplemented by semistructured interviews. Most participants received medical treatments until close to death and invested much effort, time, and hope in these. Consequently, they made little sense of their palliative referrals. Instead, they accommodated the biomedical cultures of treatment-oriented services, thus delaying their own and their family's preparation for death. Only three participants appeared well prepared one month prior to death. An ecological perspective helped to explain the systemic factors involved in this prioritisation. The authors make recommendations for greater involvement of social workers in palliative care, and for more attention to supporting dying people and their families to make culturally meaningful decisions in the journey toward death.

Keywords: Decision Making; Health Social Work; Palliative Care; Qualitative Research

There is a considerable body of international literature about death and dying, including in relation to coping (Folkman & Moskowitz, 2004); experiences of family care-givers (Kissane & Bloch, 2002; Phillips, Bernard, Phillipson, & Ogg, 2000; Wright, 2000); and professional perspectives on working with individuals and families receiving palliative care services (Carter, McKinlay, Scott, Wise, & MacLeod, 2002; Mitchell & Owens, 2003; Sinclair, 2011). Over recent years, along with changes in service delivery, more researchers have begun to consider the delivery and experience of palliative care in community settings (Baines, 2010). Concerns have been raised about how people who are dying can be better involved in decision making about end-of-life care. While most researchers have recognised that experiences of dying and death occur in cultural contexts, the definition of culture has tended to be narrowly confined to denote ethnicity. Chan, Macdonald, and Cohen (2009) critiqued this reductionist interpretation of culture and emphasised the

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Accepted 9 May 2014

need to explore how dying acquires meaning from the broader social and structural contexts that shape people's lives. The focus of their discussion was on dying in hospital settings, and how the meaning of dying takes shape in interactions between the cultures of individuals and families, and the cultures of care that exist within various professional groups.

From an ecological perspective, the term culture refers to the broad contexts and meanings of people's everyday lives at intersecting micro, meso, exo, and macro levels. Family life, social interactions in particular places, and commonly held world views, shape the meanings of people's experiences, and constitute culture and people's cultural identity (Hutchison, 2003). The term culture does not merely refer to the world views and practices of particular ethnic or social groups, for example, Māori or Pacific peoples. There has been longstanding critique in anthropology and cultural studies of the idea that culture is a reified thing that belongs to particular groups. Instead it is understood as an unbounded, shifting, and more fluid set of practices and meanings that can alter from context to context (Otto & Nils, 2010). It is also useful to consider the contrast of medical culture, medical settings, and church or religious settings to provide a comparative analysis of the meanings of culture associated with death and dying. A key argument in this article is that medical culture often excludes consideration of important aspects of people's cultural identity.

Against this background of a gap in the research literature about how culture mediates experiences of dying, this New Zealand study was conceived as a doctoral thesis project by the first author (the researcher), a student in social work, under the supervision of the second and third authors (Hughes, 2009). The aim of the study was to explore how people who had been diagnosed with a terminal illness perceived and made meaning of palliative care, taking culture into account. It was expected that findings might have implications for policy development and social work practice. In the Australian context, Pockett, Walker, and Dave (2010), have previously advocated for more fully involving social workers in end-of-life care, to better enable dying people to articulate their subjective experiences and wishes.

Alasuutari (1995) described culture as being a kind of "collective subjectivity, that is, a way of life or outlook adopted by a community or social class" (p. 25). More recently, definitions of culture have emphasised its fluid nature, whereby people's values, beliefs, and behaviours along with changing contexts shape the "... process through which ordinary activities and conditions take on an emotional tone and moral meaning for participants" (Chan et al., 2009, p. 117). This more dynamic interactional conceptualisation fits with the orientation and design of our study.

The New Zealand Ministry of Health's *New Zealand Palliative Care Strategy* defined palliative care as "... the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatment has come to an end" (Ministry of Health, 2001, p. 2). In referring to total care, the Ministry emphasised that palliative care included emotional and spiritual care alongside physical care and pain relief. A stated goal was to ensure that, "All people who are dying and their family (whānau) who could benefit from palliative

care, have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way” (p. vii). This expectation, that cultural and personal meanings are incorporated into assessment and care planning, is shared by palliative care professionals and organisations internationally (Palliative Care Australia, 2005). Despite this aim and although a majority of people prefer to die at home, in Euro-Western and Anglophone countries such as New Zealand, most die in hospitals or residential care facilities (Broad et al., 2013). As the New Zealand Ministry’s (2001) publication noted, “Hospitals have a strong curative, intervention-based culture, and ... it appears likely that the palliative approach may be lacking in the hospital environment” (p. 43). Furthermore, due to a lack of palliative care beds in public hospices and hospitals, a significant number of people die inappropriately placed in residential homes for the elderly. In 2010, a review by the Palliative Care Council of New Zealand raised a concern that it was likely that minority ethnic groups, including Māori and Pacific peoples, as well as rural populations, children, young persons, and older persons in residential care, continued to have poor access to palliative services. Lack of awareness of the availability of palliative care was causing late or no referral for many, and most of those referred were people with cancer (Naylor, 2010). The reviewer called for a national stocktake, and the incorporation of palliative care into health policy and strategies for chronic diseases.

Methods

Because we were interested in the impact of culture on the palliative care experiences of people who were dying and their families, we determined that an ethnographic research method would be most appropriate, augmented by semistructured interviews. Ethnography involves participation in the daily lives of research participants, often over an extended period. The researcher may simply observe, or join in activities in a natural manner, learning a new culture by being part of it (Maso, 2001; O’Reilly, 2005). Over time, this natural manner evolves into mutual information sharing and coreflection, and there is no need to attempt to maintain distant emotional neutrality (Coffey, 2002).

Ethics approvals were obtained from three bodies: The provincial Canterbury District Health Board’s Canterbury Ethics Committee; the regional palliative service’s Nurse Maude Ethics Committee; and the University of Canterbury’s Human Ethics Committee. The major ethical concern related to the vulnerability of the proposed participants who might be experiencing severe pain and distress, and whose lifetime was limited. An ethnographic methodology openly positions the researcher’s “self” as a source of information and reflection. Information and skills held by the researcher as a trained and qualified social worker supported her to be discerning about managing ethical concerns about participant distress if and when they occurred. The researcher was particularly conscious that for some people, ethnography might be too intrusive a method, at any stage, or as they drew nearer to death. To avoid people feeling pressured to participate, initial information about the research and

explanations of informed consent were given by community palliative care nurses. After contact was established with the researcher, consent was signed in a meeting between the potential participants and the researcher. The intention had been to recruit 10 people with terminal illnesses. To be eligible for funded palliative care services in New Zealand, people must have a prognosis of less than six months left to live. However, people who received a terminal diagnosis and were referred to palliative care were already much closer to death. Few were therefore able to be recommended for the study. Ultimately, six participants were successfully referred via the palliative care team, and a further two participants approached the researcher via mutual acquaintances from whom they had heard about the research. Both were already in receipt of palliative services, and the referrals were accepted.

The researcher informed participants that they could withdraw from the study at any time. They were assured that withdrawal would not affect their access to, or the quality of, their care. The eight participants, four men and four women, remained engaged in the study until their deaths. In addition, there were 83 consenting family members. In all, the researcher spent 20 months in the field, recording over 300 entries in her field notes. Many family members maintained sporadic contact with the researcher for approximately six months to a year after their bereavement.

Whenever the researcher accompanied participants, for example to medical appointments or treatments, she sought relevant permission from service providers. The researcher prioritised participants' comfort and wellbeing ahead of the study at all times. During fieldwork, observations and disclosures were made that, had they been revealed, might have been embarrassing for dying participants, family members, or service providers. Those were kept confidential. In recognition that cultural differences might make the researcher unaware of what would be embarrassing (Sieber, 1992), she provided drafts of research findings to participants for their comments and amendments. Participants and family members were offered access to transcripts of semistructured interviews. They were also given access to field notes that pertained to them upon request. Family members were also given reflective letters once the participant passed away. This served as a form of feedback when confidential data from the participant could not be given to family members.

The researcher was careful to negotiate and renegotiate the amount of time spent with each participant. She also took care to delineate her role as being that of a researcher and not a social worker. Although unresponsive neutrality is neither helpful nor possible in ethnography, our academic and professional backgrounds cautioned against the researcher becoming involved in the role of a caregiver, because this might disrupt the participants' other relationships and compromise the researcher's reflective capacity (O'Reilly, 2005). The ways in which the researcher balanced professionalism and reciprocity differed in each of the relationships, but activities often included driving people to appointments and finding scarce parking places; repeating and translating medical information from field notes; and sitting with the person who was dying to enable family members to attend to other tasks.

The researcher also referred participants and families to social workers when it became evident that they lacked services and resources.

In qualitative research, and specifically in ethnography, the position of the self of the researcher should be articulated (Coffey, 2002). The researcher and supervisors had experienced personal and professional encounters with dying and death, and taught on the subject of grief and loss in social work courses. Ethnographic methods of observation and analysis helped us, not only to tease out and articulate assumptions we held in common with participants, but also to challenge our presumptions about having common cultural understandings when in reality these were individual and diverse (Maso, 2001). For example, although the first and second authors had been diagnosed with breast cancer, neither of us had received a diagnosis that we were dying, and our experiences were therefore critically different from participants' in that regard. Field notes included reflections on the researcher's feelings and these often provided the basis of reflection in our supervision meetings. At times the research was emotionally draining, and it was essential to ensure that the researcher had support and was encouraged to practise self-care.

Semistructured interviews were an additional means of collecting data from participants and some family members. An open-ended interviewing technique was utilised where the precise wording of the questions had not been predetermined. Interviews were conducted over a period of time, depending on availability of participants. The main topics covered in the interviews were culture, awareness of terminal diagnosis, understanding of the health system, and issues of concern or importance to the participant. Within each of these four areas there were a number of subthemes that were explored. Some analytical strategies drawn from a grounded theory approach were used to analyse these. This involved initial open coding, followed by theoretical sampling of the data against information in the literature, and finally more focused coding and selection of core categories (Strauss & Corbin, 1990). Version 7 (2006) of QSR International's NVivo qualitative data analysis software was used to manage and keep track of the wealth of data, themes, and ideas. The ethnographic and grounded analyses combined to lead to the discovery of two major overarching concepts: "time and place" and "preparedness for death", each threaded through participants' journeys.

Results: The Participants' Journeys

Initial discussions and meetings with participants took place in their homes. All of the participants had been married, and seven currently lived with a partner. When partners, family, or friends were present, they often participated in discussions. The initial focus of interactions with the researcher revolved around the telling of stories about the diagnosis with terminal cancer. There were four types of stories. For Jack and Joan (names have been changed throughout to provide anonymity), the diagnosis had been the end result of a long process during which they were mistakenly treated for other illnesses. This was despite Joan having had cancer four years earlier and this

being a recurrence. For Daniel and Billy, preexisting chronic medical conditions had obscured the diagnosis of cancer and they were therefore also diagnosed late in the disease process. By contrast, four participants had received diagnoses of terminal cancer soon after consulting a medical practitioner about being unwell. Elisabeth and Helen had never before been diagnosed with cancer. Alice and Tom were diagnosed with metastases of cancers from which they had hoped to have been cured.

When diagnosis was late, regrets were inevitable. Although participants felt some relief that their concerns about their health had been validated, they expressed regret at the loss of opportunity to be diagnosed while treatment might have been curative. After a protracted prediagnosis phase, loved ones needed to be informed of revised prospects. Daniel said, "I asked the doctor to explain what was wrong with me because I wanted my family to hear it from an expert, not from me, because they would pay more attention". Daniel was being cared for by his extended Māori family, and listening to the doctor telling the diagnosis to his family and answering their questions probably enabled him to better absorb its meaning.

Irrespective of the lead-up to diagnosis, participants recalled finding it hard to take in the news that they had incurable cancer. Not all participants appeared to be fully aware of their diagnosis and the reasons for their referral to the palliative care team. Elisabeth, who had received an immediate diagnosis with her first, metastasised, cancer, often said, "My chest is good, I had an x-ray of my chest from the front, and the back and the sides, and it's clear, there's nothing wrong with my breathing". Out of all the participants, she never verbalised awareness that she was dying. Aged in her 70s, she had left her abusive husband and her home postdiagnosis, moving to another city to live with her daughter. Although Elisabeth's daughter knew, she did not attempt to persuade her mother that her cancer remained present. Helen, similarly diagnosed late, moved from hopelessness to optimism and back saying, "You just can't fight brain tumours. I went home and cried and cried. I knew it was the end; I prepared to die". Next, however, having been offered and accepted treatment she considered herself in remission saying that she had "learned to live with cancer". She returned to work and discharged herself from the palliative care services until later on when her condition deteriorated and she re-enrolled.

The diagnosis had provoked many participants to make immediate changes to their lifestyles. One participant was aged in her thirties; one woman and two men were in their forties, one in his fifties, one in his sixties, and two women were in their seventies. Although most were therefore not yet at retirement age, they had initially either left or reduced their paid employment. In New Zealand, withdrawal from public social life is an expected transitional step for people diagnosed with terminal illness, and this could be classed as part of a "rite of passage" (Kenworthy Teather, 1999). Over time, however, because they were still physically able, and because they became engaged in medical treatments in settings where the dominant narrative was about curing people, the realisation that their illness was deadly appeared to fade. A few, like Helen, temporarily returned to work.

The researcher observed that over a period of months, most participants became heavily occupied with the tasks involved in being a patient who is receiving treatment in a public hospital setting. In the chemotherapy suite, they joined with nurses and patients in a hopeful banter about the “fight” against cancer. They wore outdoor clothing instead of pyjamas, signifying that they were still “in and of the world”. Although their time was realistically predicted to be limited, their timetables revolved around access to services. On days when they were to meet their doctors, they might spend hours waiting for their turn to see them, in addition to the hours spent receiving chemotherapy treatments. Their support people, who took time off work to accompany them, often had to leave to attend to other business.

It appeared that when participants were encouraged by oncologists to pursue treatment, they and their families interpreted that as indicating this treatment might improve their prognosis. They developed hope that their cancer might be stopped or their life might be significantly extended. Most participants reported that their oncologists had told them that “they still have a few things up their sleeves”. Tom, who had been diagnosed with metastasised cancer, had initially declined treatment, but engaged when given this message. Joan and Alice, also with their second cancer diagnosis, undertook treatment because their families wanted them to, but stopped before they completed it. Only Billy, drawing on his spiritual beliefs, persisted in refusing medical treatment, other than pain relief, from the outset.

The researcher had been interested in exploring the participants’ experiences of their referral to the palliative care team and the meaning that they made of this. However, we discovered that while participants remained uncertain or unconvinced that they would soon die, and since they had seen palliative care only in the context of pain relief at the end of life, just half of the participants (Joan, Billy, Alice, and Tom) noticed or remembered much about their referral to the palliative care team. Tom retained a connection with the palliative team, although his efforts and conversations began to revolve around fighting for his life. Joan and Alice took a relatively direct route from shock and chaos to a realisation that curative treatment was not possible. They, along with Billy, spoke directly of death. They did this despite not receiving a clearly verbalised prognosis that they were terminally ill, but in the context of being able to contrast messages they now received from medical practitioners, with those received at their first diagnosis, when they had been potentially curable. They were given fewer recommendations about treatment options, and the prognoses they were given were more conservative or pessimistic relative to their eventual survival time. Although Joan and Alice started chemotherapy, they withdrew before its completion and they therefore spent less time in treatment-oriented contexts. They revised their earlier goals once they realised those were no longer attainable. Billy gave away his belongings, and Alice made up boxes with keepsakes for each of her children. Joan made her peace with an estranged son.

Even while they pursued treatment, most participants reconsidered and reinvested in values, beliefs, and relationships. Daniel said, “This cancer has really changed me. I used to be really hard, now I’m softer. I want to just live every day I have now, not

thinking about when I'll die, but just live each moment". Jack, who described himself as a tough man before his diagnosis, said he wished he had been more open about his feelings with his children as they were growing up. He now told them he loved them every time he saw them. Of the seven participants who were with partners, three decided to marry or move their wedding date forward. One other delayed wedding plans.

Most of the participants had lived relatively stereotypically gendered lives. When the researcher visited, she would often find the women located in the kitchen and dining rooms of their homes. The men, as long as they were able, spent their time inside cars and garages, and they reminisced about pubs and rugby clubs. However, on reflection they expressed regrets about some of the behaviours that had emanated from their adherence to stereotypes. Men, in particular, regretted not expressing feelings. When participants' illnesses began to impair their physical functioning, more skills were actively transferred by being taught by the dying partner to their surviving spouses in these heterosexual couples.

As participants became less well, they spent more time in settings where their worsening health status was known, and they made less effort to hide it. Cultural markers of illness such as commode chairs and beds began to take up more space in their homes. Alice, who had lost her hair as a side effect of chemotherapy, had stopped wearing a wig or headscarf and said that she did not mind if people "looked at [her] funny". She said, "People say to me, 'You don't look like you're sick'. At least this time, they will know won't they?" When confronted about her use of a disabled car park, Helen, who was normally friendly and placid, turned on her accuser and angrily said, "I have breast cancer which has spread to my lungs, my liver, and my bones, and I will be lucky to live another year or two, so I think I have every right to park in the disability car park". Daniel, temporarily admitted to the hospital ward, visited a pub for a drink dressed in his pyjamas.

Eventually, admissions to the hospital's oncology ward became more prevalent than time spent being treated in the chemotherapy suite. The oncology ward was a place where people went if they were to undergo invasive tests, and when they became seriously ill with nausea or infections. There they again spent time waiting. They waited for results, for nausea to wane, for visits by doctors, for decisions on medications, and for discharge home. While in the ward they became patients, without makeup, wearing pyjamas and hospital gowns. There were few conversations between patients. Interactions with staff and family were conducted in hushed tones. "Out of place" behaviour by family members was censured by ward staff, the key cultural consultants in these spaces, as shown in the following observation from the field notes:

[Jack's uncle's] cell phone went off and he answered it. The receptionist told him off in no uncertain words. She told him that he was not allowed his phone on when he was on the ward. He said, "Sorry", and walked back out of the ward to continue his phone conversation.

Even during the last days of the cancer journey, the researcher observed that she rarely heard words such as dying, death, or terminally ill used by professionals. Privately, participants and their families would interrogate the words professionals had used and how they had said them to determine their real meaning in relation to how much longer they were likely to live. Impending death was usually heralded by worsening ill health and increasing difficulties with managing cares or pain at home, often resulting in an acute crisis. Six of the eight participants presented to the accident and emergency department from which five were admitted to hospital. Although most had wanted to die at home, only three people did so. Three died in a private room in the oncology ward. Tom and Billy died as planned, in a hospice setting and surrounded by many family members. Billy, who had spent a year engaged in spiritual preparation for his transition of “leaving the body”, lost consciousness, but awoke just prior to his death and prayed as he had intended. Although predictions around remaining time spans were again optimistic, there was some notice of impending death for members of six of the eight extended families. They travelled, sometimes from other cities, leaving their workplaces, partners, and children, to keep vigil at the bedside. In the hospital and hospice, they would take shifts, some returning home for changes of clothing or sleep, and others refusing to leave and being catered to by others. None of the participants died alone, although Alice, who had not been admitted after presenting at the emergency department that day, died in the night while her husband was asleep. He did not realise this until some hours into the morning.

The private rooms in the (public) hospital had insufficient space to accommodate medium-sized families, from which five to 10 people were present at any one time, causing them to spill into nonprivate spaces such as corridors. Nevertheless, and in spite of physical space constraints making this difficult, at this point in the journey staff members, in particular nurses who had the most contact, began to take cultural instructions from family members. Daniel’s 28 whānau (family) members were accommodated in a staff seminar room. While hospice rooms were larger, and they more easily accommodated medium-sized family groups, the hospice staff struggled to accommodate Tom’s 23 family members.

The researcher met with participants on a weekly basis and, although this had not initially been foreseen, was invited to be present during each of their last days. Examining field notes and transcripts in detail revealed that by one month prior to their deaths, three participants, Joan, Alice, and Billy were prepared for their deaths, having said and done what they believed they needed to. Influencing factors appeared to include their previous experiences with serious illnesses. Unlike any of the other participants, they had also each been given at least one overly pessimistic prognosis of their remaining lifespan. They spoke of their acceptance of their prognosis. Joan said, “We all have to die sometime, and I’m not afraid”. Alice said, “I’m not going to live, there is no cure, so I don’t want to pretend”. Billy said, “I want to be prepared for death, so I need to face the reality that I’m not going to live”. This contrasted with the prevalent fighting talk of four other participants: “I’m a good staunch kiwi bloke, and

I'm not about to give up"; "I'm as tough as an ox and fierce as a grizzly bear"; "You have to tighten your bootstraps and get on with it"; "If I keep eating and getting lots of fresh air, I'll be fine". Elisabeth never ceased asserting that her cancer was gone.

In addition to their prior physical illnesses and differently presented prognoses, all of the three prepared participants described how they had struggled with a significant experience of abandonment in their childhood. Although all participants re-evaluated meaning, this small group appeared to have engaged in a deeper level of introspection in order to achieve resolution. Introspection may have also enabled them to tune in to changes happening in their bodies, and helped them to realise that death was closing in.

Participants' age, gender, and other demographics impacted on what cultural symbols they drew on, and shaped the content of their values and beliefs. We were unable to determine from our ethnographic study whether these factors impacted on how well they were able to prepare for death.

Discussion: Cultural Meaning-making and the Social Work Contribution to End-of-life Care

In considering the results of the study, it appeared that when participants were offered some hope that treatment might be of assistance, they became enculturated in treatment-focused settings to the extent that they and their families were unprepared for their deaths. By contrast, participants who spent less time in treatment settings were prepared, having said goodbyes, written to loved ones, gifted belongings, and arranged their funerals. These participants also had hope, but they more clearly derived this from their personal spiritual and cultural realms, including their relationships with treasured people, environments, and beliefs and values (Sheldon, 1997; Smith, 2000).

Several studies have focused on examining the conversations that patients with terminal cancer have with their physicians. Wright et al. (2008), in a longitudinal study with 332 people who were dying from cancer and their informal caregivers, found that only 60% of participants recalled having had a conversation with their physician about the end of life. Yet people who had been engaged in such conversations received less aggressive treatment and had better quality of life in their final weeks. Their caregivers also reported better postbereavement adjustment. Others have noted that when engaged in treatment, people with incurable cancer might leave important decisions so late that they are no longer able to make these (Harrington & Smith, 2008). In our research, one of the participants became unconscious before he was able to sign his will. While some people with cancer might forget end-of-life conversations due to anxiety, denial, or medication-related confusion, physicians also avoid discussing death. Researchers have found that the vast majority of patients and their families want their doctors to be truthful and compassionate. Although doctors sometimes state that they fear that honest conversations will result in loss of hope, there is no evidence to substantiate that

concern (Harrington & Smith, 2008; Kirk, Kirk, & Kristjanson, 2004; Smith et al., 2010).

Although it is understandable that most studies have tended to focus at an individual level, on physician to patient conversations, and on patient coping, our ethnographic study provided an opportunity to explore more widely, and we identified two interlinked core categories: place and time, and preparedness. Participants' meaning-making was shaped by cultural settings that "othered" the dying, including places of treatment, and the time they spent immersed in these. Places of treatment were, however, also reciprocally impacted by the participants' cultural identities, particularly toward the very end of life when families took over decision making at the bedside. At this time, the setting became a space for dying, rather than for treatment. Medical and nursing staff began to follow the families' directions on how to conduct themselves there. We next drew on social work knowledge of ecological perspectives to link these categories more dynamically, and to theorise about what happened in and between the various systems involved in palliative care.

The ecological systems perspective (Bronfenbrenner, 1986) drew our attention to nested structures of micro, meso, exo, and macro systems wherein living and dying took place. As participants moved from engagement in work and family life to patienthood, they made major adjustments to fit into the new microsystems in which they now became embedded. Communication between these microsystems was impaired, and families were frequently excluded from important exchanges, either by the timing of appointments with physicians, or by being asked to leave the consulting room. At the mesolevel, communication between the hospital, the palliative care team, and family caregivers seemed disrupted or lacking. It was notable that few participants had been referred to a social worker who might have provided networking assistance to overcome that. Their contact was primarily with nurses and doctors. Occupational therapists and physiotherapists also provided relatively little input into their care. The exosystem, including current welfare systems, did not appear to be sufficiently resourced to support participants to maintain individual cultural identity alongside exploring treatment options. For example, palliative care specialists were lacking, and beds were in short supply at the time of our study, with just 16 being available for a large geographical area with a population of 462,783 (Te Ara, n.d.). Such shortages are likely to lead to fewer timely referrals and fewer options for timely respite.

As treatment options ran out participants were once again reconnected with their cultural identity, supported especially by family members who came from afar and were potentially less impacted by prior exchanges with the health system. Nevertheless, the exosystemic context constrained their ability to die in their chosen way. Dying at home was made difficult, not only due to problems identifying an expected time of death, but also due to problems resourcing the managing of pain in the home. When the dying person relocated to a hospital (3) or hospice (2), space constraints forced families to grieve in corridors.

The participants' families clearly expressed a need and wish to be present around the time of death, and, from a macrocultural perspective, this is a common desire globally. Yet other macrocultural imperatives, such as economic expediency, obscure the needs of the dying. The need for adequate facilities was not mentioned in the *New Zealand Palliative Care Strategy* (Ministry of Health, 2001). While the strategy did note the importance of attending to the needs of culturally diverse people, it is not possible to do so if physical space does not allow it.

Our study's findings have important implications. In agreement with Chan et al. (2009), we think it is valuable to raise awareness in interdisciplinary teams, about the pressures on patients to adjust or subsume their cultural identity at a time when they are sick and vulnerable. In addition, palliative care provisions require adequate resourcing. Facilities need to be spatially designed so that they can accommodate families. Increased use of prognostication instruments, and better staffing and protocols for the delivery of pain relief at home may help to prevent some of the considerable trauma experienced by dying people and their families.

Improvements to biomedical care alone are not enough. If end-of-life care is to be appropriately tailored to the cultural needs of dying people and their families, we need to raise the profile of social workers, who are qualified to undertake relevant assessments and make appropriate interventions. Good communication and networking skills, understanding of family and cultural dynamics, and knowledge about grieving are essential aspects of a holistic approach to end-of-life care and these are contributions that social workers are well placed to deliver (Cullen, 2012). Social workers as care-coordinators could assist families by providing education around normal processes of grief, and about what physical changes might be expected, so they can notice these and request timely assistance. Yet, in New Zealand, the need for palliative social work remains woefully under-recognised and underfunded (Hughes, 2009).

In terms of the limitations of the study, it had not been our intention to focus on people dying of cancer but more broadly, on people dying with any incurable illness. The decision to consider for participation only those people referred to a palliative care team prevented this from happening, because few people who are dying from causes other than cancer were being referred to the service. Future research might helpfully explore the experiences of people dying from other causes, including factors preventing their referral to palliative care services. While this research focused on the perspectives of people who were dying, consideration of the experiences and perspectives of health professionals would add important further information about how they understand and negotiate cultural contexts. At eight, the number of core participants was small, but this was appropriate to the ethnographic design. Replication of an ethnographic design might be difficult outside of a doctoral study because this method proved to be extremely time consuming and emotionally demanding for the researcher. The aim of qualitative research is not, however, to ensure that findings can be replicated, but to draw attention to new important angles

on an underexplored topic. The findings of the study support the importance of incorporating a broader view of culture, beyond ethnicity, in research.

Conclusion

For five of the participants in this study, a focus on medical treatment and the unreliability of end-of-life prognoses complicated preparation for death. However, on reflection these issues could be seen to occur in a context of lack of resourcing for a more integrated palliative approach. The use of social workers in care-coordinator roles could help ensure that a “person in environment” model is kept to the fore, and that persons who are dying with little time remaining are not forced to disavow their individual and family culture. The findings of the study support a conclusion that when language of living with dying is used, when overly optimistic prognoses are avoided, and participants and their families receive holistic care, then people who are dying are more likely to achieve a prepared death.

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