

AGEING IN PLACE – DYING IN PLACE: COMPETING DISCOURSES FOR CARE OF THE DYING IN AGED CARE POLICY

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ABSTRACT

Australian Government aged care policy documents emphasise healthy ageing. Even though death in the aged care setting is a common occurrence, minimal policy exists to underpin activities that surround dying in this setting. Issues and practices about caring well for the dying remain a hidden discourse in aged care policy, the literature and therefore in practice.

A discourse analysis of aged care and palliative care policy documents for the period 2000-mid 2001 was undertaken. The analysis highlighted competing discourses about care of the dying in residential aged care. This paper describes the main discourses, explores competing and hidden discourses, and raises questions about the disparities found.

The conclusion is that care received by the dying person in Australia is dependent upon the setting in which this care is delivered. 'Dying in place' should be attached to the Government's policy slogan - 'Ageing in place'.

INTRODUCTION

Death is a common occurrence in residential aged care (RAC) facilities. Despite this, little is known about how dying actually happens or how facilities deal with the issues of death and dying, particularly in Australia (Wilson and Daley 1998; Irvin 2000).

Palliative care practice espouses access to expert care for all people facing the end of life. People in the final stages of life in RAC should expect comfort and care that is aimed at enhancing the quality of their remaining life. However, significant evidence in Australian and overseas literature indicates that care for the dying in this setting causes concern (Hudson 2001; Froggatt 2001; Avis et al 1999; George and Sykes 1997; Komaromy et al 2000; Lloyd 2000; Melding 2002).

Although 31% of those admitted to RACs die within six months, and 43% within 12 months (Australian Institute of Health and Welfare 2000), aged care facilities are not equipped to provide the sort of care that a dying person might need. Given the emphasis on healthy ageing in recent Australian Government Aged Care Policy documents this is hardly surprising. Consequently, issues and practices about caring well for the dying in the RAC environment remain hidden in policy, the literature and probably in practice. A major impetus for this study was exploration about why there is little written about care of the dying in RAC.

A discourse analysis of aged care and palliative care policy documents was undertaken for the period 2000-mid 2001, utilising a broad range of documents - mainstream media, academic literature, press releases and formal Australian Government policy documents.

The study involved a review of recent literature about ageing, death and related issues, in order to place the particular issues in their historical and social context. Additionally, articles on the care of people in RACs were sought from the national newspaper *The Australian* from

1999 to mid 2001, in order to paint a broad picture of influences and developments that have contributed to policy in the public arena. Finally, Australian Government policy documents, press releases and speeches on palliative and aged care from the same time period were examined.

This analysis highlights the competing discourses about care of the dying in RAC found in policy. This paper outlines the methodology utilised to report on the competing discourses.

DISCOURSE ANALYSIS

A starting point in the analysis of discourse is a recognition that language is socially and culturally situated. Language can be indicative of values contained within, or symbolised by, words, and language can alter in content and meaning depending on the setting of words. Discourse has been used in helping to construct social relationships and contributing to systems of knowledge and belief, thus assisting us to understand each other. The link between policy and society is noted in the work of Green (1993), who states that policy reports are a 'major means of reality and knowledge construction in modern society'(p.xiv). He argues that the connection between words and their meaning, within the milieu in which they are spoken or written, contributes to a particular discourse.

As a research tool, discourse analysis is concerned with producing meaning from talk or texts to reveal aspects of cultural understandings, which may have been hidden. If society is symbolised by the words that are used to describe it, then language is an important part of that society's social construction. Fairclough (1992(a), p.5) argues that something becomes a social reality only in its linguistic representation and the use of language. He makes a two-layered distinction in the construction of discourse - it is influenced from the outside by such things as culture, context and political theories, as well as from the inside by the textual meaning that is applied. A social theory discourse becomes clearer and more distinctive through the process of political debate, comment, writing and referencing (Fairclough 1992(b)).

Discourse analysis challenges the dominant knowledge about a particular issue or phenomena, and seeks to disrupt easy assumptions about the meanings and organisation of social life. It seeks to examine how 'public attitudes... are shaped, reproduced and legitimised through the use of language' (Seale 1998, p.253).

METHODOLOGICAL APPROACH

Roe (1994) suggests that 'the starting point of (narrative) policy analysis is the reality of uncertainty in the polarised issues and controversies of today' (p.10). The relevance of this statement is heightened by the contentious political climate of aged care, which is characterised by publicity designed to demonstrate

Australian Government efforts to improve systems of delivery. Despite these efforts, the community's perceptions about care in aged care facilities remain critical.

The study utilised discourse analysis as described by Fairclough (1989; 1992(a)) and Seale (1998; 1999), building on particular interpretations of Foucault (1970; 1977; 1978).

Seale (1999) suggests that while it is good research practice to be faithful to a text's overall meaning, there is no necessity to account for every text on a particular subject; indeed it is legitimate to be selective and, for the purposes of the analysis, to focus on those sections which provide the best source of material for analysis (p.253).

Themes within discourses were identified and used as the main analytic tool. Words and themes were drawn out manually, by continual questioning of the texts to determine variation in a text and among texts, seeking emphasis and detail. Vague, difficult to challenge, language and descriptions like 'the good death' or 'the team' were also sought. Dominant themes emerged.

FINDINGS

Through thematic development, different discourses about this one issue have been developed from different perspectives - the many 'truths' of the issue. The method is reflective, open-ended in the questioning of text, rather than seeking solutions or developing a particular dominant view. Issues often develop through the push and pull of conflicting discourses, communicated to the community in different ways, raising awareness of an issue and forcing political debate. Four competing discourses emerged from the study:

- what is the purpose?
- there's no place like home,
- the burden of dying; and,
- bold self sufficiency.

What is the purpose?

Two conflicting discourses emerge about the purpose of RAC - a focus on living to maximise independence for the majority of residents, while providing comfort and supportive care for those approaching death. The different focus of care between the dying and other residents involves a shift, from the promotion of independence to promoting quality and comfort in the life remaining.

Engle (1998) describes the difference between 'maximum function' - prevention of falls, independence in activities of daily living, treatment of illness - and 'comfort care' - assessment of mental status, function, mood, symptom control, spiritual pain and withdrawal of food and fluids as requested (p.1172). Parker-Oliver (2000) makes a distinction between different constructions of illness - 'the sick role', and the accompanying behaviours and responses required to get better.

In contrast, an emerging 'dying role', for the terminally ill person, frees them of responses demanded of the sick role and allows a focus on tasks concerning the end of life (p.495). This is applicable in aged care, where the dying person may need to be freed from activities of daily living, in recognition of the different requirements for the journey to death. Additionally, Komaromy, Sidell and Katz (2000) suggest that:

'The protection of the residents who live in the home from the sight of a departing corpse appears to contradict a frequently expressed belief... that residents who are very old are more accepting of death. Home staff frequently stated that residents accepted death because they had seen so much death during their long lives. Also they were at an age where they expected to die, and others expected them to do so'. (p.310)

Recent palliative care policy changes for in-patient services (or hospices) have targeted shorter length of stay, for specific reasons like symptom management, respite and care in the final days of life (Aranda et al 1998). If long-term care is not regarded as the purpose of in-patient palliative care, the flow-on effect may be pressure on RAC to admit people with vague or lengthy prognoses. In comparison, the National Council for Hospice and Specialist Palliative Care Services in the United Kingdom (UK) recommended that hospices should offer nursing and respite care for older people rather than being limited to their current restrictive practices (Clark and Seymour 1999). Thus, the effect on the Australian system is like the bubble in the carpet - one part of the health care system policy is clarified, refined and appearing to work well, but an impact is felt elsewhere in the system. In reflecting on these different levels and costs of care, is the person pushed to the least expensive option?

There's no place like home?

The major qualifying factor for admission to aged care is assessment of the need for continuous nursing care, or chronic illness not requiring acute hospital care (Australian Law Reform Commission 1995). Assessment is based on the inability of care to be provided in the community (in the person's own home), implying a high level of dependence, usually because of increasing frailty, dementia or chronic illness. Over recent years, people entering RAC are arriving with increased dependencies due to a range of factors, (but perhaps significantly because of improved community support systems. Sixty two percent have high-level care needs, compared with 38% needing low-level care (Australian Law Reform Commission 1995).

In keeping with long-standing Australian Government policy (Australia, Commonwealth Working Party on Nursing Home Standards (CWPNHS) 1987), aged care facilities are required to present an ambience that emphasises the 'home-like' environment, rather than a clinical one. This means that 'although the provision of high quality nursing care is essential, a nursing home is not a

hospital... A homely, personalised environment in which residents are able to retain their identity, values and individuality adds greatly to their quality of life' (CWPNHS 1987). The contradiction is, that while residents who live in this setting are often dependent and frail, with the majority requiring high level care, aged care policy continues to emphasise this sense of homeliness, implying less requirement for nursing and medical care (CWPNHS 1987).

Thus, there are conflicting discourses in calling an aged care facility a 'home', which, despite the best endeavours to create a 'homelike' environment, belie the intensive caring required by most residents. Is the facility set up as a 'home' with connections within the local community that make it an important part of the community? Or are the facility and its residents sequestered from the life of the community, with a subjective posturing about what occurs inside? What are the opportunities for interaction within the surrounding neighbourhood - visitors, volunteers, fundraising, church interaction, or open days?

Further, Mannix (1998) queries the symbolism of more recent changes in the name of a nursing home to an 'aged care facility'. The title 'nursing home', together with the policy of homeliness, implied a balance of both the need for professional care and the sense of being homely. The newer title removes the implication of the requirement for nursing. Requiring aged care facilities to be homelike implies that people are not sick and downgrades levels of dependency; if this is their 'home', perhaps nursing care is not needed.

In challenging the dominant discourse of 'home', Wilson and Daley (1998) describe the social context of nursing homes compared to the acute health sector. There are different staff ratios, unskilled workers provide care, there are 'limited physician involvement, more deaths from chronic and prolonged illnesses, limited family involvement and often, less opportunity for the resident to communicate their needs and preferences'. All these factors influence the picture of the facility as perhaps not as 'serious' as the acute environment, thus impacting on the way care and, in particular dying is regarded in the aged care environment (p.22).

There may be ambivalence on the part of staff, about the level of involvement of other residents in the dying process (Komaromy 2000). Participation in 'usual' home rituals that surround dying and death - explanation about and involvement in the dying, saying farewells and even being informed of the person's death, do not appear to be routine in the fabric of life in the RAC, or at the very least are regarded as 'nice additions'.

Australian Aged Care Standards (Commonwealth Department of Health and Aged Care 1998) require working toward single room accommodation for all residents over the next few years, but is this always appropriate, especially for the dying? The physical environment may serve to encourage involvement or to

separate the person (Komaromy 2000). For example, areas for privacy for the dying person and their loved ones are needed, as well as flexible areas to accommodate the 24-hour involvement of families as appropriate. However, the dying person ought not be too isolated from the main institutional activity - creating a sense of being 'put away', such as the routine removal of a dying person to a single room. Komaromy (2000) regards these practices as contributing to an environment of denial of dying. With the development of new building standards, such sensitive issues may be appropriately addressed by individual facilities.

Is the RAC facility the preferred place of death for the older person, over and above their home? Despite the availability of some in-home support programmes, do older people really get the same equitable choices as dying people of other ages, about where they wish to spend their final days? Or is it just assumed that because a person is old, they become increasingly dependent and frail, demand more carer time, and therefore need institutional care? Clark and Seymour (1999), examining care and dying in the home, suggest that even though most people state that home is where they would like to receive care, this could be understood as 'a critique of the hospitalised and medicalised death' (p.89). Wishes about the place of dying for an older person then, are complex and cannot be viewed in isolation outside the fabric of the community, which by its support or not of such care, places a value on the lives of residents.

The burden of dying

As stated, caring for a terminally ill person is not an uncommon experience in RACs. Komaromy (2000) has examined the institutional practices that support hidden death - the removal of the dying person to a single room, the pulling of screens around the bed (which are not sound proof) when someone has died, the removal of the body at mealtimes so no one sees it, not informing other residents that the person has died, the removal of the body as quickly as possible. Perhaps it is this commonality that belies articulation of what dying means and how it occurs? Thus dying and death and the role of staff in these events becomes so 'normalised' as to become a hidden discourse.

Caring for dying residents and their families can be stressful for staff - and a lack of recognition of the need for bereavement can become an issue, especially for untrained staff. Komaromy et al (2000) found staff preferred sharing the care among themselves for these reasons. Staff also stated that they did not like working at night because of a fear of death as well as the additional work this involved when staffing levels are at a minimum. Staff support, embedded in the team philosophy of palliative care practice in recognition of the stressful work, is not as evident in the aged care environment.

Komaromy et al (2000) also note, 'residents of nursing homes were more dependent and often had multiple needs associated with extreme old age, so the care required by

many of these residents was intense' (p.193). The final phase of life may involve physical, psychosocial and spiritual needs compared to the needs of other residents. Extra medication, different equipment and the increased work involved in caring for someone in the terminal stages of illness, can be a significant strain on an already stretched staff. This care may easily become considered both burdensome and disproportionately expensive in this setting.

Palliative Care Australia (1999) notes the difficulties in translating principles of palliative care into a nursing home environment. Of particular concern are the principles of care for the terminally ill person and their family. Other issues reported were the staffing skill mix, the educational needs of staff, the burden of staff stress, the facility's budget, the limited availability of expertise in low care settings, and the lack of resident choice of general practitioner.

Additional evidence of the difficulties manifests in the reluctance of some managers to take on this additional care, particularly in relation to costs. For example, there may be a lack of understanding of the need to bring in the consultant palliative care nurse, who may charge a fee for additional nursing advice. Miller et al (1998) and Watt (1997) suggest that money will be the downfall of alliances between palliative care and aged care in the United States, which are regarded only in terms of the possibility for additional income. In Australia, there is similar disquiet about who pays for the provision of palliative care support to a resident, since government does not fund such 'cross sharing' of care through either aged or palliative care budgets.

Additional anecdotal concerns about the limited availability of equipment in the aged care setting also exists. Flexibility with items such as a particular bed and the call-bell system may be needed as the person approaches death. Access to items like softer mattresses, syringe drivers, and low beds may be limited, with the aged care facility regarding the local palliative care service as a source for the lending of equipment - at times, this has caused conflict between services. Local service relationships require strengthening in terms of this access.

Recognition of this ending phase of life shifts the focus of care away from maintenance of independence to a focus on palliation the management of the final stage of life, and its accompanying symptoms, from ageing in place to dying in place. Komaromy et al (2000) note that when a resident withdrew to his or her room, this was often a sign to others that the dying process had begun. Similarly viewed, was the appearance of the pastoral worker/chaplain, if the RAC did not routinely use these services. Key and Schonwetter (1998) also note that residents, their families, and physicians are 'becoming increasingly aware that the terminally ill may be more comfortable and may receive more comprehensive and satisfying care when palliative measures, rather than life-prolonging goals are pursued' (p.491).

Because of the belief that palliative care ought be available to all Australians wherever they live, there needs to be an ongoing commitment to seeking ways that expertise can be made available to those aged care residents who need it. Perhaps palliative care workers (reflecting community attitudes) have a poor impression of care in RACs, so the impetus to work collegially assumes less importance than other areas of responsibility.

Bold Self-Sufficiency

Komaromy, Sidell and Katz (2000), in their 1997 English study, report being most surprised by the lack of familiarity of nursing home staff with palliative care, a consequent lack of knowledge of what palliative care can achieve, or where to access such expertise. The predictable result was less than optimal terminal care in these homes. Counsel and Care for the Elderly (1995), a charitable organisation in the UK providing advice and practical assistance for older people and their carers, described this as 'bold self-sufficiency' - a lack of staff awareness of what can be done for a dying person and a lack of willingness to seek such expertise. Few policies for palliative care practice were found in nursing homes, suggesting that 'the gap between nursing homes and hospices is greater than one would think' (p.13). Parker's Australian study (1999) also revealed resistance to palliative care, in terms of perceptions about the 'myths' of palliative care - the administration of narcotics, feeding and hydration, and transfer to acute care. Melding (2002) noted concerns about the under-diagnosis and under-treatment of pain in RACs in Australia.

It appears that, for the additional care required, inadequate staffing levels adversely affect the availability and quality of the care that staff is able to give a dying resident (Palliative Care Australia 1999). The use of unqualified staff, perhaps unused to caring for the dying, may make the staffing additionally difficult. There are specific educational needs required to cover areas such as assessing and managing pain, promoting comfort using both pharmacological and non-pharmacological interventions, communication skills, spiritual needs, and family and staff grief support.

Dowding and Homer (2000) and Steel et al (1999), both addressed particular needs in relation to the education of unskilled staff. In providing such education the role of the unskilled worker is valued, since it is often that person and not the registered nurse who spends most time with a particular resident; thus dying becomes a human experience more than a medical event. Dowding and Homer (2000) noted that 'the philosophy and principles of palliative care are an appropriate and necessary educational focus for nursing home care staff' (p.163). Keay and Schonwetter (1998) suggest that the enduring myth that older people are resigned to death will persist without education to assist workers to appreciate what palliative care can achieve.

Resistance to additional expertise may also be because of a perceived invasion of the relationships between residents and staff. There is a paternalistic and protective sense to these relationships that staff may note as deeply significant, even replacing family in terms of importance (Wilson and Daley 1998). So the palliative care team may be regarded as 'outsiders' who arrive to provide end of life care, which is seen as interfering with these relationships. How are more equitable relationships between staff in these settings able to be more effectively facilitated for mutual benefit?

The issue of inequitable relationships, is symptomatic of the lack of system connection between aged and palliative care services rising from separateness in policy. A lack of expertise in the aged care sector is compounded by a lack of connection to places where this expertise can be found. Keay and Schonwetter (1998) found that, even in nursing homes that have contact with a palliative care program, the services may not be regularly used, with neither sector having established policies and procedures for ensuring routine referral for patients who need such care. In particular, a lack of access to the expert knowledge of caring for the dying is resulting in discrepancies in how nurses understand and practice such basics as the principles and practice of pain management.

Accreditation changes in Australia in 1998, requiring demonstration of the provision of palliative care are beginning to impact on this separatist picture (Commonwealth Department of Health and Aged Care 1998). The major criticism of the relevant standard however, is its limited description of a philosophical approach, which assumes staff understands the practice of palliative care. Anecdotal reports suggest that meeting this standard has required facilities to seek palliative care educational support.

DISCUSSION

These four competing discourses illustrate the disparities between policy and practice in care of the dying in RAC, suggesting a false disconnection between aged and palliative care policies, which ultimately serves to disadvantage those people who need the expertise of both disciplines. This analysis of policy has, at the very least, exposed this complexity.

There are many common characteristics about the client groups who are either in RACs or in receipt of palliative care, most obviously that both groups are reaching the end of life - they are 'finishing' (Knepfner 1989). However, there are inequitable and inappropriate disparities - in staffing, care models, funding and services available, like grief support - depending on the setting in which the dying person finds themselves. Counsel and Care for the Elderly (1995) highlight the position in the UK, which like Australia appears to require 'more continuous dialogue between hospices on the one hand and nursing homes on the other, but the functions of the

two sorts of agencies are further apart than might be supposed' (p.13).

Dying in RACs contests the discourse that the facility is the person's 'home' (which subtly negates the nursing needs of the dying person) and conflicts with the purpose of maximising the independence of residents. There is evidence that even in this setting, dying and death are hidden, and support systems for staff and residents are discounted. A person who is dying represents a marginalised discourse in this setting.

The discourse about dying has mostly been the domain of the family, experienced outside the influence of medicine; thus the more recent development of care of the dying as a specialist area reflects a discontinuity. Rooted in beginnings that sought to be different and separate from other parts of the health care system, palliative care has developed an exclusiveness that has resulted in a lack of community understanding of what palliative care is, excluding language and services being somewhat hidden within health care. The resultant model of palliative care is often regarded as special care for the few, and many that fall outside selective criteria are disadvantaged in terms of access to such care. People dying in RACs often appear to miss out on benefiting from palliative care knowledge and practice.

Particular service linkages, based on geography for example, need to be promoted, as well as educational support for all levels of staff like that being developed by the Australian Government's Australian Palliative Aged Care Project (Australian Government Department of Health and Aged Care 2003). Exploration of combined models of aged and palliative care expertise is required, models that provide the most appropriate care in the person's 'own home'. Strengthened linkages would alleviate the need to move the person elsewhere when it was felt that more expert care was required. More fluid funding models would enable the person to receive the expertise they need.

This study highlights the need to understand the impact of policy on the practice area. Nurses who work in aged and palliative care need to be confident of their voice and to develop skills in advocating for the needs of the vulnerable people with whom they work - in many situations, their's is the only voice such people have. The development of a watchful eye on movements in government policies in these areas can only serve to strengthen the nursing voice.

Because of the competing discourses, dying in an aged care facility may still remain hidden and unacknowledged by the community. The challenge for nurses is to find avenues for developing collaborative practices that will benefit those people needing both aged care and palliative care expertise.

CONCLUSION

It seems that care received by the dying person in Australia is dependent upon the setting in which this care is delivered. How to support the dying older person, with access to as much expertise and support to which any other dying person in the community is entitled, remains a challenge. 'Dying in place' ought to be attached to the Australian Government's policy slogan - 'ageing in place', to make a complete model of care. 'Dying in place' is surely the preferred model of care - in a person's final home, with a possibility of being surrounded by familiar places and things and providing continuity of staffing. Newer accreditation requirements provide an opportunity for aged care services to become more skilled in the provision of palliative care and to develop appropriate localised relationships to facilitate this ideal.

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