How Australia Cares For Its Dying Population: History, Health Services and Hopes

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The history of care for Australia’s dying population is interesting for its pattern of reversals—a pattern reflecting the world-wide trend over the last 200 years to move from family and community care to institutional care and then back again to a qualified style of family and community care. Inside this back and forth cycle of preferences for care sites is an equally paradoxical cycle of viewing aging as dying to viewing incurable diseases as qualifying for the title of ‘dying’ and then back again recently to including aging as, apart from anything else, a life stage to legitimately include in ‘end-of-life’ care.

Such cultural and policy reversals in the Australian national imagination reflect wider forces in epidemiology, sociology, demography and health care politics and policy-making. In this essay, my aim will be to describe these reversals in images of dying and its care and sketch some of the social changes that drive these reversals. At the end of the essay I will reflect on similarities and differences in contemporary care of the dying in Japan.

Before commencing this discussion I should like to say that my approach in this essay will be to take a very basic descriptive approach to the material. I have done this for two important reasons related to the readership of this journal. First, most readers will be from humanities and social sciences backgrounds that have little experience or familiarity with the shape of health services in general and how these services actually work. To maximise accessibility for this readership I have tried to assume minimal prior knowledge about health service matters in general and Australian health services in particular.

Secondly, those familiar with health services may not necessarily be familiar with the more recent development of hospice and palliative care health services. Of those who do know what these services provide in Japan I have found that Japanese hospice and palliative care services are based on significantly different history, care models and service assumptions. In this context, it has been incumbent upon me to develop my arguments and views in a manner that will allow the actual detail to reveal those differences. In this way, I hope to provide both nation-specific information about Australian services for the dying, many of which Japanese social and policy observers are commonly unfamiliar, but also some observations and arguments about future challenges for all of us involved in developing such services.

Care of the Dying: Some Historical Background

For most of Australia’s early history, family and community were the key carers for people who experienced a lingering dying. The contrasting experiences of sudden death and the related experiences of care of the bereaved must be viewed separately as a history and sociology in Australian terms. But in matters to do with caring for someone who experiences a short but
severe period of illness and disablement ending in death the usual pattern of conduct in indigenous and non-indigenous contexts is relatively the same. Aboriginal people have tended to care for their own unless the dying person had become a danger or liability to the health and welfare of the group. In this specific instance, in a particular hunter-gatherer lifestyle, a dying person may be left behind. Even if dying people were left behind it was obviously and clearly the decision of the group/tribe and possibly also with the consent or understanding of the dying person.

In early European settlement, sudden death was very common, mainly through accidents, and this made the dying experience quite short. Short dying experiences were attributable to the fact that infectious diseases were the major causes of death. Cancer, motor neuron disease or cardiac failure were often the diseases of older people—at least those over 40 years of age. It was only after World War I when most people in Australia could expect a life expectancy beyond 40 or 50. After this period (1920s) the Australian population experienced a ‘mixed’ burden of disease that included infectious diseases and chronic diseases of ‘modernity’ such as cancer.

So in the nineteenth century most of the dying occurred in homes and occurred quite quickly—over some days or weeks from the initial onset of the (usually) infectious disease. But another factor also played a role in the circumstances of family and community care of the dying. In the early nineteenth century contexts of hospitals, the death rate inside hospitals was higher than the community prevalence. Under pressure from governments to reduce the death rate in public hospitals, clinicians quickly identified those they ‘could do no more for’ and quickly discharged those people into the care of their families. Such deaths, without the support of adequate medical and pharmaceutical interventions were often cruel and painful deaths (Jalland 2002).

In defence of the clinicians at the time, there was also little that nineteenth century medicine could offer by way of treatments because the interventions for symptoms such as protracted pain, breathlessness and nausea were in their infancy. After the Second World War medicine had improved its stock of interventions and investigations. The general population, and therefore the medical experience with cancers and heart disease, rose sharply as people lived longer lives. The front line attack on cancer in particular was lead by chemotherapy treatments, radiology and surgery. The clinical approach at the time was to be aggressive in the treatment of such diseases, believing this approach to be important to the aim of extending the person’s life. The worth of the idea that ‘fighting’ to prolong the length of a person’s life was believed to be self-evident.

But after the Second World War, Australia experienced significant economic growth and prosperity, as was the case in all the major industrialised nations. The adults of that time just after the war had fewer children, fed them well, and sent them to school for an unprecedented long period. The 1950s through to the 1970s was a period of mass university education of a cohort now famously identified and described as the “Baby-Boomers”. This gentrification of the population in industrialised countries produced a more discerning, critical, well-read and more
demanding population of people who redefined themselves away from the former role of ‘passive patient’ to one of ‘health consumer’. Both academically and in the popular media the medical gaze came under increasing scrutiny and criticism and this was especially obvious in fields such as disability (de-institutionalisation movements), psychiatry (anti-psychiatry movements), hospital care (community health movements), and cancer care (public health and palliative care movements) to name only a few.

In cancer care, sections of the professions and the general public began to question the efficacy of cancer treatment; the balance of funding between primary prevention (preventing disease) and tertiary intervention (curing and managing the disease) programs in cancer; the wisdom of extending life expectancy over considerations of quality-of-life; and the appropriateness of death and dying in institutional settings such as hospitals and nursing homes. Voluntary Euthanasia movements also questioned the right of the medical profession or even families to decide the meaning of ‘quality-of-life’, the ‘right’ time to cease treatments and the ‘right’ time to die.

Out of these recent developments in social criticism and change created by the equally recent national experience of a long life-expectancy, gentrification from rising social mobility, and the global spread of alternative policy ideas for care of the dying, palliative care has become one of the most rapidly rising health care services in Australia.

The Rise of Palliative Care Services

Palliative care is a health service. The primary clinical aim of these services is to control disagreeable symptoms in people who have diseases for which there is no cure and for whom any further treatment would provide little to no benefit. Most palliative care services have specialist medical practitioners trained in ‘palliative medicine’. In Australia, a special medical college of practitioners of ‘palliative medicine’ exists under the umbrella of the Australian and New Zealand College of Medicine. Such practitioners are trained in the special medical interventions relevant to symptom control—pain, nausea, breathlessness, nutrition issues, etc.

The World Health Organization (WHO) describes palliative care as ‘interdisciplinary care’ and this means that ideally all palliative care services should have, or have access to allied health services such as social workers, physiotherapists, pastoral care workers, music therapists and community nurses. There is also a common tendency for such services, more than other health services, to employ complementary medical practitioners such as aroma therapist, massage therapists and Reiki practitioners for examples. The interdisciplinary culture of palliative care coupled with a desire to place the support and comfort needs of the dying person at centre stage encourages such historically unusual professional relations (Kellehear 2003).

Although palliative care traces its history to the care offered to pilgrims in the European Middle Ages, such history is also claimed by observers of the development of nursing, hospitals, and pastoral care. Such care was usually offered by religious orders and this continued, at least for the poor and dispossessed in Europe and Britain, until the early 20th century. However, the commencement of the modern palliative care movement is attributed to Dame
Cicely Saunders and her founding of St Christopher's Hospice in England during the 1960s. These ideas spread to the USA in the 1970s and then to Australia in the 1980s (Rumbold 1998). Saunders’ idea of palliative care was to provide ‘whole person’ care in a ‘home-like’ environment where family and community could participate in that care without the unnecessary structures so commonly associated with hospitals and their rigid routines. The needs of the dying person were central to such care. Rather ironically, this philosophy of care commenced its practical demonstration in a ‘hospice’—an institution run by clinical staff.

Nevertheless, the philosophy was one that argued that hospitals were not the places for care of the dying; that there was a time to cease all ‘unnecessary’ treatments; that the aim of care should neither hasten nor postpone death; and that all efforts towards care must include social, psychological and spiritual supports as well as medical and nursing ones. These ideas permitted and encouraged the idea that such care could be delivered at a number of sites including the home.

As a result, palliative care occurs in a number of forms: hospitals that have a palliative care facility, in hospices, in community-based palliative care services, and in general practices and remote area nursing services supported by specialist palliative care ‘consultants’. The actual ‘model’ of care varies enormously from region to region and from country to country but the pattern of service design is similar to the above list.

Because of the interdisciplinary nature of palliative care services the peak professional bodies representing palliative care interests are not solely medical or nursing ones. In Australia, the peak body representing national palliative care interests at the policy level is Palliative Care Australia, based in Canberra. All states also have state palliative care bodies that represent palliative care policy and funding interests at that level. They are usually simply known as “Palliative Care Victoria” or “Palliative Care Queensland” etc. Other peak professional bodies such as ANZCPM (Australian and New Zealand College of Palliative Medicine) represent the interests of the medical profession in palliative care and these interests might include curriculum development, in-service training, staffing needs of the field, and policy matters to do with practice.

Palliative care services have nation-wide coverage in Australia. In a city such as Sydney or Melbourne it will be common to find a blend of different types of services in each city. These will include freestanding hospice services that have admissions for bed-ridden people who are in their final weeks or days of life. But such hospices will also commonly offer day-care facilities for people to receive treatment for a day and to return home or work again. Admissions are not necessarily ‘final’ and people with life-threatening illnesses come and go as the progression of their disease and the treatment of their symptoms allow. Such facilities are also offered by some hospitals and some ‘wards’ are set aside for just these kinds of palliative care facilities. This type of service also commonly provides ‘respite care’—to give families a break from 24/7 care of chronically ill and dying relatives—providing short admission stays.

Aside from these obviously institutional services, palliative care is also offered as a community-based service. In these services, doctors and/or nurses will visit the home for
assessment and regular treatments and other services. ‘Other’ services might include volunteers who come to help with daily tasks such as shopping, reading or simple companionship. In some rural and remote areas in Australia a ‘district’ or domiciliary nursing service (RDNS) will provide palliative care under the guidance and supervision of a larger ‘regional’ palliative care service that has specialist nurses and doctors. In these cases, patient management will be a joint health service.

Finally, although most palliative care services are for older adults with cancer, there are specialist hospices and community-based services for children with life-threatening illness (Hynson et al 2003). For hospices that specialise in this work, rooms are often provided for parents to stay with their children.

Palliative care services in Australia are largely secular services funded by governments. There are a sizeable minority of Christian services—especially from the Catholic and Uniting Churches in Australia. There is at least one Buddhist service in the state of Queensland (Karuna Hospice). And there are a small but increasing number of private for-profit services. But the bulk of funding for palliative care services—as for most health services in Australia—is largely from state governments.

Although it is common for federal governments to develop national health policies they do not fund direct services. States fund direct services through ‘operating grants’ received from the federal government. To ensure co-operation and compliance with national guidelines, federal governments will often provide these grants ‘conditionally’—they receive such monies on the condition that those funds are dispersed for services and functions identified by the national policy.

Until quite recently—in fact 2002—most of the grants to palliative care services have gone to clinical palliative care services and very little has made its way to allied health concerns such as social work, public health or pastoral care services. In particular, the funding concentration has been employed to support institutional and professional care initiatives and programs. Community development and community care of the dying, those living with loss and those living with the burden of care have received little policy attention and funding. This has recently changed with the introduction of ‘Caring Community’ capacity building grants from the federal government.

These grants are designed to supply extra funding for services that are able to show community initiatives and partnerships with the community to help that community care for their own populations of dying, bereaved and carers. Such initiatives must also demonstrate potential for sustainability—that these programs are useful and that they can continue without funding, or with very little funding in the future. These are among the first public health initiatives in palliative care in Australia and show a return of interest from institutional/professional care to one embedded, once again after a hundred years or so, in the life cycles of the community itself.
Who are the Dying?

One of the most interesting policy questions in Australia is who is to be regarded as dying, at least for the purposes of developing criteria for admission as a client to receive palliative care services. The short answer since the 1980s has simply been that dying people are people with advanced cancer with a short life expectancy in terms of days or weeks. Where did this idea come from?

As mentioned earlier, the early 20th century was witness to a sharp rise in life expectancy. Better public health measures—better housing, nutrition, work practices, and clean water—boosted life expectancy for most people in the industrialised world including European Australia. By the mid to late 20th century cancer had become a very difficult disease to treat and a very difficult illness to watch. Cancer generated widespread fear and loathing in the general population generated by ever increasing images of people losing their hair to chemo or radiological treatments. Severe weight loss and the difficulties in treating a sometimes intractable pain struck fear into the hearts of many. And then after these scenes, death seemed to follow quickly.

Heart disease, although killing more people every year than cancer, did not have the same public relation problem. People who died in the Middle Ages tended to die suddenly of ‘a heart attack’; or alternatively they appeared somewhat breathless and weakened—they appeared ill—but looked reasonably ‘normal’. Repeated hospital admissions did not believe the fact that many of these people were just as dangerously ill as anyone with advanced cancer. Cancer then became the thing feared; and the disease that bestowed the title of ‘dying’ on a person who had it.

In the early 19th century people over the age of 65 were uncommon. When they died, it was widely assumed that they died of ‘old age’—a kind of vague, amorphous petering out at the end of life. The body simply wore out in some mysterious way. And anyway, old people die because that is when ‘dying’ ‘naturally’ occurred. To die before old age—from cancer or a ‘heart attack’ was ‘unnatural’ and ‘premature’. But people’s actual experience of late deaths were uncommon. Later, in the mid to late 20th century people over 65 became quite common and indeed people began to live well into their 70s and 80s. This new generation of the elderly was characterised by new types of thinking about aging and death.

Apart from the mass numbers of ‘old people’ now appearing, many of them have ‘baby-boomer’ children caring for them. The educated view of such children toward their aging parents was not characterised by thoughts about ‘death and dying’ but of ‘quality health or nursing care’. Parents were aging and become more fragile, breaking limbs from falls at home, or not recovering quickly from a stroke or some other chronic illness. The vulnerability, fragility and care burden required by such people were a serious confrontation to the work-a-day family and career responsibilities of small modern nuclear families. The nursing home quickly gained ascendancy, as a place where round-the-clock care could be obtained without wearing out the limited emotional, social and financial resources of younger families. But the preference and
general use of nursing homes for the elderly was one couched in terms of health care NOT end-of-life care. The elderly were not seen as ‘dying people’ but people to be ‘minded’—in need of nursing care for chronic illness and vulnerability.

In this context, the last 20 years of the development of palliative care services in Australia has occurred in a sealed and separate way from the development of aged care services. In general, aged care has developed its own specialities in geronic nursing, social gerontology and geriatric medicine and it has been these clinical specialities that have served the cancer, circulatory and general organ failure needs of the elderly.

In the last few years we have seen a shift of thinking about such separation of health services and governments in particular have renewed their interest in the possibilities of cross-service developments from palliative care. There is recognition now that old people in nursing homes have a need for quality palliative care just as younger or more independent people outside the aged care system. There is growing recognition that people living with cardiovascular diseases such as heart failure have symptoms just as seriously in need of control as people with advanced cancer. There is a growing realisation that beyond the ridges of the experience of advanced cancer that AIDS, motor neuron diseases, heart diseases and the needs of the elderly are important and legitimate targets of end-of-life care and that these may require a ‘mix’ of services—palliative, geriatric, chronic, community health and conventional acute services. The discussion and debate about the shape of such services and the models that might deliver them continue in current policy and practice circles in Australia today.

**Japanese Palliative Care Services**

In Japan, the first government-approved hospice was established in 1990 and by 2001 there were 86 such hospices throughout Japan (Ida et al 2002). There are now over 100 hospices in Japan. The Japanese palliative care services seem to place a heavy emphasis on the establishment of freestanding hospices—机构s devoted to the in-patient care of dying people. Home care services are frequently also available from these hospices and other palliative care services are offered through Home Care Agencies. Nevertheless, compared to Australia, palliative care services in Japan seem to place a much greater emphasis on institutional care.

My impression is also that most of the palliative care services in Japan seemed to be run by Christian organisations or have important financial and cultural support from Christian organisations (Becker personal communication). Buddhist organisations, for example, have yet to have a major presence in these kinds of services. Hospices in Japan are much more clearly seen as medical and nursing services than their counterparts in Australia and this too seems to reflect the importance and power of the medical profession in the provision of Japanese health services as a whole.

But the preponderance of bed-based hospices over home-based community services also has much to do with the preferences of Japanese people about where they wish to die. In Australia, most people wish to die at home with friends and family by their side. In Japan, a sizeable minority wish to die in hospitals (Japan Times 2003). But like their Australian
counterparts more and more Japanese are beginning to see the pointlessness of unnecessary treatments at the end of life, preferring instead not to have their lives prolonged 'unnecessarily'. Some 74% of Japanese respondents surveyed about this question preferred palliative treatments (Japan Times 2003).

Such social attitudes parallel similar ones in Australia, Britain and the USA and are largely responsible for fuelling the development of palliative care services in all those countries. The so-called 'cultural ambivalence' that Japanese display about matters to do with dying is also undergoing significant changes (Kellehear & Tanaka 2004). Death education—learning from health professionals about matters to do with life expectancy, the process of dying and the experience of grief and loss, is also becoming increasingly popular in Japan (Kawagoe and Kawagoe 2000).

In a recent report by physicians from Fukuoka (Seo et al 2000) the majority of patients now want to know their diagnosis (even if it turns out to be cancer) and the majority of medical staff believe such knowledge generally has a positive effect on patients in the long term.

In general guidelines published by the National Cancer Center of Japan it is recommended that patients be told before their families wherever this is possible. We cannot underestimate the importance of this shift in Japanese social and professional attitudes because in Japan as for most places in the industrial world, cancer and death are closely identified with each other.

**Future Challenges**

There are several important challenges that all services for dying people must face in the coming decade of development. Palliative care services are in their infancy all over the world. In Japan, where services are a mere decade or so old, it is sometimes forgotten that service development in the rest of the world is only several decades older (see Rumbold 1998). We remain firmly in the initial stages of debating care models, staffing and funding priorities, service delivery approaches, and even defining and refining basic philosophies and practice concepts, especially in areas to do with social and spiritual care (Rumbold 2002).

There remains much to be problem-solved in the area of cross-cultural and culture-specific practices (Lickiss 2003; Maddocks and Rayner 2003), in remote area service delivery especially in countries characterised by vast distances such as Canada and Australia, and the nature and extent of intersectoral collaboration and rationalisation of resources, say, between community health and palliative care, or bereavement care and palliative care.

Debates are not yet settled in various nations about the role of specialist medical personnel in palliative care services, what leadership role they might play if any, how they might be employed as consultants and to whom, and even the nature and extent of their involvement in palliative care services, especially in remote area health provision. These matters are frequent subjects of heated academic debate, policy discussion, political lobbying, and research. The future of how we will care for the dying into the 21st century is now, this day, being forged from attempts to create consensus over these issues.

Two of the key questions that underlie the above complexities are (1) To what extent
should future services be 'clinically-oriented' and 'institutionalised'? and (2) How are we to open up or narrow our understanding of the target group—'the patients' we are supposed to serve? What are people with 'terminal illness', 'life-threatening illness'? Who are 'dying' people? How are we to limit services to the bereaved when grief might be life-long?

The question of the extent to which palliative care services should be composed of clinical and institution-based services is one underlying similar global debates between funding and staffing priorities in acute care services (surgery, development of pharmaceutical therapies, radiology etc) and sites (hospitals, hospices, nursing homes etc) and public health ones (community development programs, self-help programs, school and workplace education etc). Most Western industrialised countries have a substantial public health program alongside an acute care one. Hospitals and intensive care nurses, for example, are crucial in managing episodes of acute and serious illness, and accident. Health educators, public health inspectors or community health doctors are crucial in the prevention of sexually transmissible diseases, heart disease, the spread of food poisoning or workplace accidents for examples. In palliative care such a balance of staffing and funding priorities has yet to be set. Even the need and understanding of how public health programs would work in palliative care are unclear to many (Kelleheah 1999). The traditional idea of dying has been a bedside image—someone in their last days or hours reclining in a bed surrounded by family, friends and the kindly physician. But the experience of 'dying' for many people today is not so simple nor so compressed.

Many people live with a disease with no cure knowing that death will come to them in the next year, or two or five. Such people do not live as 'dying people' every hour or every day just as we do not think of ourselves as academics, parents or adult children every hour or every day of our lives. Identity is multiple, and swaps between different aspects of a self, depending on the needs of ever-changing social and personal contexts. So it is with being 'dying'.

In this way, the modern experience of dying is long—over many months or years. Any palliative care service claiming to provide care for such people must have a good acute care response—for the final days and weeks or a sudden crisis—but it should also exhibit a good public health approach—to enhance the quality of life of people while they remain at work and in normal round of family and social life (Kelleheah 2003, 2004).

For example, such strategies and services are well understood in the HIV/AIDS field. Public health programs in this field develop harm-minimisation (reducing possible harms) strategies for the ongoing sexual needs of the HIV positive person but also for the protection of those they come into contact and who may not be sero-positive. Programs to enhance and maintain the health of positive men and women are important to strengthening the immune system and enhancing a sense of well-being. Living with an illness with no cure can also be a demoralising experience and so health promotion programs designed to help prevent anxiety, depression, suicide or sexual 'acting out' are important to the health and safety of positive people and their social networks. 'Communities' can also be a major source of stigma, discrimination, social rejection and ignorance and good public health programs are designed to tackle these ongoing social problems for everyone.
These are only some ways that public health programs help in the HIV field but such programs in the more cancer-related area of palliative care are quite new. In Australia, the 2003 Palliative Care Australia Planning Guide (Palliative Care Australia 2003) now encourages all services to develop such programs for patients, families and the wider community.

Such programs attract significant time and staff costs and frequently questions are posed that pit clinical priorities against community ones. The health care budget is itself a balancing act and those who want a new hospice built or more doctors supplied to a service might be asked what they must give up for this extra funding for a health education or workplace program that is socially and intellectually difficult for many of these very clinicians to understand. Often, a collaborative arrangement with a local public health or community health service can complement the dual aims of acute and community services but even here there may be a limit to how far the local community health service itself can stretch its funds for palliative public health programs not factored into its original funding applications. These are difficult questions for everyone.

Finally, the definition of WHO is to receive palliative care is a complex one. As mentioned earlier, palliative care has a very cancer-focussed history. But people with serious, chronic and degenerative diseases resulting in organ failure should also be relevant for such services. People who are dying from heart or kidney failure but who are not eligible for transplants should receive palliative care. The elderly in nursing homes are also eligible but these numbers are vast (Kristjanson et al 2003). And since an important part of palliative care services is also to include follow-up after care for the surviving bereaved family, and since grief may be life-long, how is a service to support such people beyond token, short-term programs?

If one is to take a public health approach to the problem of death, dying, loss and caring how are we to define each of these experiences in a way that connects to biological death or the proximity of death itself? If people who have some years to die—someone living with HIV or motor neuron disease for examples—should be eligible for supportive services why shouldn’t all people in the later stages of the life-cycle be eligible? Should there be a community death education program for everyone to raise awareness of the nature of death, dying, loss and care in the way that sexual health, or the value of nutrition and exercise is now currently managed at schools, workplaces and in the everyday media? In other words, how ‘literal’ should we be about ‘death’ or ‘dying’ or even ‘grief’ so that we can confine (or open up) the limits to our service provision in this field?

The challenge of community development in the context of these kinds of questions is now emerging as critical questions for an emerging field claiming care of the dying and the bereaved as its target population. They are very serious questions and they will take substantial time and debate to answer in the coming years. All countries will face them, including Japan. At their heart lies one final, basic question: Is dying to be understood as merely a medical matter, or is it something more, wider and broader as a human experience? How we design our future palliative care systems will reflect our answer to this final question.
References


Japan Times (The) (2003) 60% Want to Call the Shots When the End is Near. December 4, p 3.


