Public Health Approaches to Palliative Care:
Developments in Australia

Allan Kellehear, PhD*

At La Trobe University in Melbourne, Australia, we have a palliative care unit that resides in a School of Public Health rather than what is usual - a medical or nursing school. Furthermore, this unit is the first government-funded palliative care unit in Australia whose sole purpose is to promote public health initiatives in clinical services.

In this paper I will summarize some of the work that occurs in this unit. I will first sketch some theoretical background on the relationship between public health and palliative care before pausing to describe basic definitions and rationales for this kind of practice in end-of-life care. I will then proceed to illustrate the advantages that use of public health language has over competing languages of care or policy such as medical or social sciences languages.

The last half of the paper will be devoted to outlining the broad policies that should be encouraged in any health services desirous of incorporating public health into its more clinical offerings as well as the usual targets for such policies and practices. I will end with a description of three simple examples of health promotion for end-of-life care and a small list of related readings for readers with a serious interest in these approaches to end-of-life care.

Some Background

Public health has only just become an important part of national initiatives in palliative care, evidenced by the fact that the national palliative care association has only recently published national guidelines for the delivery of public health practices for palliative care providers (Palliative Care Australia 2003). They now require that palliative care services round Australia offer public health programs in one form or another. Six or seven years ago, the idea of teaming public health initiatives with palliative care services was unknown, less considered. Many people viewed the idea as almost contradictory phrases - public health and palliative care. The job of the work of my unit is for the staff (6 people) to spend all our time, visiting palliative care services and training clinicians in public health approaches. This function is performed by real visits, short in-service training initiatives, award offerings from our university in terms of degree and diploma courses, and of course, our national and international research and writing obligations.

We are the only unit currently in Australia performing this work, although there are two other states that are starting to employ public health officers inside actual palliative care services or peak professional bodies. Probably the reasons why public health has been introduced and has been pushed very strongly in Australia is the realization that palliative care was originally defined as care for people with life frightening illnesses - from the point of diagnosis until they die. Unfortunately the last twenty years of the development on funding of palliative care by government has defined patients that are eligible for this service as people in their last weeks or days of life. Palliative care has become terminal care so in this narrowing of the meaning of palliative care much of the global practice

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* Allan Kellehear is the 2003-04 Visiting Professor of Australian Studies at the University of Tokyo. His usual appointment is Foundation Professor of Palliative Care at La Trobe University in Melbourne, Australia. [email: a.kellehear@latrobe.edu.au]

of palliative care has failed the original vision (Dudgeon et al 1995).

Now palliative care has now been identified with clinical care in the last days of life and it has become very medicalized (See special 2003 issue of Medical Journal of Australia in this bibliography). So public health initiatives - and language and ideas - have been introduced to help reverse the clinical identity of palliative care and to reclaim the original vision of palliative care as long term care of people with life threatening illness (Kellehear 1999b).

Some Definitions and Rationales

In a technical sense, the general meaning of the term 'public health' means the whole health care system. So under that meaning, the hospitals are a part of any public health system, but that's not really the way in which the term is used in specialized circles. In specifically public health circles there are really only two specific meanings; there's the old meaning and the new meaning. In the old meaning, public health referred to infection control measures: things like surveillance, reportage and containment of sources of disease, food, water problems, sewerage problems, pests, sexual conduct and all the medical, social and legal interventions to prevent, contain and overcome those problems. Although the old meaning still has some currency, particularly in dealing with indigenous or 3rd world health, but also in dealing with HIV or hepatitis C, for examples, most of the new meaning of public health refers to public health as 'health promotion'. The health promotion meaning of public health has been introduced basically to refer to the fact that a lot of modern life style problems like heart disease and cancer are actually preventable and amenable to public health measures. But rather than the old emphasis of *preventing disease* the aim of the so-called 'new' public health is to *promote health* as a holistic way to prevention of most ills and dis-ease (Ottawa Charter 1986).

Why have we used public health as a language in palliative care? There are number of reasons. I think that the first major reason is that social sciences language is poorly understood by biomedicine; and of course reciprocally speaking, biomedical language is poorly understood by social sciences. Social science concepts are also inadequate for the development of models of care. They are not designed or intended to develop models of care; and again, on the other hand, biomedical concepts have been inadequate for understanding matters of meaning and culture. Medical language was not designed to understand those kinds of issues; it was designed for detection and care.

What happens to ideas such as 'social' and 'spiritual' if there is no social science language and no public health language? Well, in palliative care, one of the first things that happen is the 'social' is mistaken for 'support' or is reduced or narrowed to refer to professional support and/or family support (Rumbold 2002). Secondly, community is left out of care plans. This is not to say that there is no health services relationship to community, but the problem is that palliative care services frequently think that they are taking care of 'community' if services are simply offered to the community or in a community location. Palliative care services seldom see community as a partner – someone they do things WITH rather than something they do ON others.

Next, the settings or context basis of the social becomes interpreted in 'behavioral' or 'attitudinal' terms. This can be a very difficult idea to get across to clinically minded health services people. What is a 'settings' or 'context' approach? (Stokols 1992) Let me employ an example to explain.

Before I came to my chair in palliative care, I had another position in drug and alcohol studies. I lead my state's largest drug and alcohol research team, and we were asked by a small neighboring industrial city to conceive of suggestions to control alcohol-related violence, particularly on the weekend. In this working class city, every Friday and Saturday night, many men would visit the clubs and the hotels. In these places they would drink to excess, and then come out, smash

shop fronts, get into fights, stab each other, and in general do a lot of property damage. Many of them and their victims would then appear in local hospitals. In general then, the middle of the city was a minor catastrophe every Friday and Saturday night.

So my research team decided to change the settings, change the context of drinking so as to change the behavior. We made an arrangement with the police, and with all of the clubs and hotels in the area over a six-month period. During that time we also asked the police that when they found anyone drunk on the ground, that they would agree to drive them home and not jail them. Hotels and clubs were instructed to bolt all the tables and chairs to their floors. Clubs and hotels were to provide food at the bar. There were to be no more free drinks or discount drink periods. We also asked that every time club or hotel owners played two fast, loud pieces of music, that they would be obliged to play one soft piece of music.

In that experimental six months, the drunken and disorderly, assault and damage-to-public-property charges dropped significantly. There were significantly less admissions at the emergency sections of the local hospitals. This is a settings, context approach to working in public health. It is very important that the idea of 'social' is not simply seen in psychological terms as attitudes or behavior. It is important to understand people do things because buildings are organized the way they are; or because organizations in schools, workplaces, transport or recreational spaces help shape of behavior.

So when palliative care doesn't have a proper language to understand this kind of thing, the 'spiritual' becomes conflated or confused with religion. People in palliative care who are scared of religion, then tend toward unnecessary secularization. The term 'spiritual' and 'quality-of-life' becomes a phrase over-identified with freedom from physical and psychological distress instead of the improvements or the maintenance of a known social life lived in community.

The Importance of Public Health as a 'Bridging Language' of Care

As you can see, medical language is not really designed to deal with quality of life issues and social language is not really designed for care issues. I'll give you a few examples. In biomedicine, they use experimental, clinical, and technological language. In experimental science, for example, medical people may talk about the Krebs cycle, randomized controlled trials, desmosomes, or anoxic reactions. If you are of social science person, chances are you probably will not readily understand half of these words. Of course their clinical language, for example, palpation, auscultation, or their clinical conditions such as edema, bradicardia, arrest, or fibrillation, are also very unfamiliar terms for social scientists.

Technological language makes all these other terms and phrases even worse. There are things like EEG (electroencephalographs), ECG (electrocardiographs), stethoscopes, sphygmomometers, stents and shunts, and the jargon go on endlessly. But if there were clinicians reading this they would read these terms effortlessly. But in the matter of social science language positions quickly reverse and social sciences language becomes equally mystifying to them.

Social science people, and social researchers in general, tend to use epistemological, methodological and theoretical language. The epistemological terms will often refer to dualism, epiphenomenalism, phenomenology, and positivism, for examples. We also employ methodological language like chi-square, semiotics, deconstruction, tri-angulation. And there is much theoretical language, too: social interactionist, critical social science, structural functionalism, patriarchy, and so on. A lot of social science people are very comfortable with this language, but of course, many doctors and quite a few nurses have no idea what you are talking about when you use that language.

The language of public health, on the other hand, is a post-biomedicine and social science language. Public health has three traditional sources of language:

colloquial, health preservation language and the language of social and experimental methodology. Some examples of colloquial language can be found on the posters and signs that you read in a lot of places in Australia anywhere, such as "smoking kills"; "if you drink, don't drive"; "cover up under the sun", all very simple language indeed. And that's because the common everyday person in the street must understand it. That's the design rationale after all.

As a result, public health language is a positive language. Public health people don't generally talk about disease, but rather speak about health preservation, like prevention, harm-reduction, sustainability, or community. Despite having a simple, accessible and positive language, it also has a language tradition that can be understood by both medicine and social sciences. That's the methodology language, things like chi-square, deconstruction, randomized controlled trial, qualitative, semiotics. These things can be understood by both medicine and social science because these words and ideas are borrowed from both traditions. These are the things that public health has in common with them.

How public health works in palliative care: Agency Policies

When training palliative care providers in public health ideas we basically highlight four fundamental public health policies which all palliative care services and grief services should adopt. First, we advocate a Parallel World Policy. This is the idea that what we insist on for our clients or our patients, we must also insist on for each other. We also encourage a Policy of Knowledge Transfer. This is the idea that principles of health promotion can be translated and applied to all clinical areas including end-of-life care. Thirdly we encourage a Teamwork Policy. This is the idea that every person can play an important role no matter what their usual professional background or community role. Finally, we advocate adherence a Keep-it-Basic policy. In this policy we advocate that we should not try to

make our ideals overly complicated. We should always try to adhere to the basics of the public health practice message.

Let me now elaborate. *The Parallel World Policy*: staff should be supported in their own grief work. This should be performed as professional supervision by more senior people in their own profession; or conducted as a weekly or monthly debriefing session in small groups. Work environments should be 'health-promoting', offering many informal opportunities for support and sharing to be integral to the workplace. Opportunities for learning about death, dying, loss and care should be on going. There should be encouragement of in-service training opportunities, especially in death education, spirituality and social models of care. Staff should be supported in their higher degree aspirations. And a journal club should be encouraged. An agency library or library inside the health service should cater for staff learning needs as well as patient ones. In each one of these staff needs are just as important as patient needs. The problem of death, dying, loss, and care is not simply the sole province of a palliative care program. Palliative care agencies and services should seek partnerships with other health or welfare services for mutual learning and support. Palliative and hospice care services may seek alliances with emergency services, bereavement care services or aged care facilities.

The second policy refers to *Knowledge Transfer*. We employ public health messages and practices, already in Australia, for road safety, for child safety, drug and alcohol issues, cancer prevention, crime prevention, renal and cardiovascular health care, so the question is: why not end-of-life care as well? Social stigma and rejection from life- threatening illness such as cancer and HIV can be combated. Social inadequacy around bereaved people can be educated for and prepared for. Inadequate social supports at work or at school for people living with life-threatening illness, loss or the private burden of care can be strengthened. These are only just a few targets of public health activ-

ity.

The principles and concepts of public health are well documented. Their programs widely evaluated and praised. Their language is multidisciplinary and inclusive of clinical sciences, basic sciences and social sciences, and combines this with an active respect and desire for knowledge about culture, heritage and spirituality. It is the true postmodern bridge to overcome nation-state-like attitudes towards working together. It is a central plank of World Health Organization offerings to the world. Finally, people who are not dead are alive (!), and therefore have a right to expect quality-of-life, well-being, human compassion and support right up to the end of life.

The third policy is a *Teamwork Policy*. First of all, a doctor should be a doctor and not feel pressure to be a counselor. A counselor should be a counselor and not feel pressure to be a writer. But if someone is interested and has ability in writing they should be encouraged to write for the health promotion purposes of the service. Anyone, irrespective of professional background who has an interest and an ability to perform in media opportunities - on radio, TV or Internet - should be encouraged and supported to do so. There needs to be an explicit recognition that health promotion activities are an important part of the service, an important part of the routine work of the service and the personal time and budget implications need to be rolled into any future funding submission or allocation. And finally, what cannot be done by staff can be done by 'friends' and 'partners' of the service. Encourage the use of volunteers, board members, local service clubs, local schools, local chamber of commerce, allied and related services.

The fourth policy is simply to emphasize to practitioners the importance of sticking to 'the basics'. We ask them to keep their message, their ideals and the jobs simple. We ask them to follow ten very simple ideas. 'Prevention', in other words, try to stop the trouble from happening. 'Harm-Reduction', in other words, if you can't prevent it, try to minimize the

harmful effects. 'Partnership', in other words, work 'with', not on people; we do not work alone, we collaborate equally with others. 'Settings approach always', in other words, we change others and ourselves by changing the social or physical environment. 'Educate', in other words, we encourage life-long learning about death, dying, loss and care. 'Social marketing', in other words, we employ commercial advertising techniques, practices and sites to get our messages across; we sell social support and public compassion.

'Build community capacity', in other words, we work with local government, workplaces, schools, clubs, museums, art houses and media; we work the streets and shopping malls. We ask people to help us help them to understand and work better with issues of death and loss. 'Be culturally and socially appropriate', in other words, we problem-solve from 'bottom-up' not 'top-down'; we facilitate creative thinking, create creative messages and practices consistent with each subculture in our society. 'Sustainability', in other words, we cannot expect success if the program needs our ongoing presence and input to survive. There must be 'ownership' by other people of the things we do, or they will fail. 'Evaluation', in other words, we need evidence that we are doing good things.

How public health works in palliative care: Focus

So what should be the relevant targets of health promotion in palliative care? What are the kinds of things that public health actually does in palliative care? Palliative care is interdisciplinary care; it is whole person care according to the World Health Organization; it's social care, psychological care, spiritual care and physical care. So the targets of health promotion in palliative care are those four areas. For the social aspects of the person's life, there are sexuality issues, work, friendships, recreation, legacy, hobbies, discrimination and stigma, and the desire and struggle by most people to stay 'normal', as fully and as long as

possible. All these are important areas for health promotion (Kellehear 1999a).

Among many psychological aspects of living that can be targeted by health promotion are experiences such anxiety, depression, loss and grief, despair and anger. In the spiritual dimension of a person's life, there are issues such as the meaning of survival and suffering, matters of religious belief, and possible desires or fears about reunion or reconciliation with people who are alive or possibly in the next world. The medical treatments in oncology, hematology, or palliative care are treatments targeted to the disease process and symptoms. The question we have to ask in health promotion and the question we need to solve in palliative care is, what are we doing to promote health and positive well-being when someone is dying?

Sometimes it is very difficult idea to understand idea 'being healthy and dying'. But only a few years ago, we had the idea that if you are disabled, somehow you aren't healthy. In Britain some years ago (Bunton et al 1995) they employed an advertising campaign, (rather ironically a 'health promotion' campaign) to make people more careful on the roads. This road safety campaign used a wheelchair as a major symbol. Consequently, many people in wheelchairs in Britain got very angry and upset at the suggestion that simply because they were in a wheelchair that they were less human than anybody else. Disability does not mean less health or life. And so it is with the so-called experience of dying. Note this well: actual dying takes about thirty to forty-five seconds - the rest is life. And in life one can and should expect health and well-being as often as one can. Palliative care can help with this goal.

Among the other facts that you need to remember when thinking about health promotion for dying people, is first that the longer part of dying occurs outside health care institutions. Most of the care, most of the time, is non-professional care. You spend most of your time with your friends and your family. In between visiting a doctor, being in bed, having bad days, dying

people spend an overwhelmingly large amount of their 'care experiences' with the people they normally live and play with (Kellehear 1998).

The other fact that we all need to recognize very carefully is that the actual experience of dying as a 'lived-in' experience is actually in people's heads and relationships, not their bodies. If you don't know your dying, you're not. Dying is quintessentially a psychological and social experience triggered by an awareness of a physical reality. Thirdly, palliative care is also about loss and grief. We must remember our responsibilities for prevention and harm-reduction in that area too. Loss and grief is a relationship and social context matter (Groopman 2004).

So the question I ask a palliative care service is what relationship and social context response can we make. Never mind about your grief counseling services. That's fine if you have one. But I want to know how you are changing the social environment to help people with their grief and loss. Public health is a concern with the influence of our culture and peer relationships on our sense of health, dis-ease and well-being. In palliative care, we also talk about "psychosocial". Psychosocial is fuzzy; it's vague; it's abstract and it's no use. We must be clear now about what we do and we can be clear with the language of the public health. How are we involved in changing a person's everyday setting to make grief and loss more bearable?

Practice Suggestions

We distributed small practice suggestion's brochures to clinical services in Australia (see Kellehear 2003; also Kellehear, Bateman & Rumbold 2003, for full list), and I will summarize some of the principles behind that brochure now. These suggestions are suggestions for how one might act inside a service if you desire to conduct health promotion. The first suggestion is death education for all-everyone. You must learn about death, dying and loss as a staff member and as a volunteer. Death education must go

on at school and clubs and workplaces too; it must not only be something we offer solely to patients and families. And just because palliative care people work in death and dying all their time does not make them experts in this area.

The second suggestion is community development. Health services need to talk to the local councils, to ask their volunteers to work with them, to ask the service clubs to work with them, or simply employ a community development worker. Talking or working with public health colleagues, or the trade unions and the business associations – this too is important. All those people can help create the settings approach to living with a life-threatening illness day to day, and living with the loss day to day. An important part of community development is to create partnerships, working with people, not coming to them as 'experts' necessarily, but to go into schools, to create relationships with the local newspaper, TV and radio, the sporting associations and clubs, the welfare centers of any community, and also the churches and temples of a society.

Often, when palliative care services first realize their health promotion responsibilities, they go into shock. They often feel the task is enormous. There really isn't need to do that because public health has a long tradition, there are a lot of allies, a lot of professional friends, who can help palliative care services develop health promotion approaches. I'm not sure what the public health or community health associations are in Japan, but in Australia we have health promotion associations who can help; there are community health services; there is a national and state AIDS council; there are women's health services; social workers are very well trained in community development; and education departments and public health associations in state and national bodies are also available. All of these groups are quite familiar with basic public health ideas and practices and can support palliative care services if those palliative care services (1) ask for their help; (2) show those public health services the

potential targets of health promotion in palliative care; (3) and encourage collaboration and partnerships. Finally our unit publishes a newsletter three times a year and each issue features palliative care services swapping ideas about how to practice health promotion. Each region does it differently and so a newsletter where other interested agencies can read what others are doing is helpful in supporting everyone ("Social Networks" Newsletter – see bibliography).

Conclusion: Three Practical Examples

In the final analysis, it is vitally important to remember three things with respect to public health and palliative care: harm-minimization, early intervention, and prevention. We CAN do these things in end-of-life care. People often ask me what actual things do you do to prevent, to harm-minimize; what is the detail; what do I actually do in these things; and so I often pull up a list and I say this is only twenty-seven but you can have four hundred and twenty-seven if you like, and I give several examples from this. I will not go through my whole list but I will mention a few before closing.

The first one is a poster campaign. Let me provide an example. When I go into any international airport but specially if I go into an airport in Australia, I go into a toilet, I close the door, and on the back of that door is an advertisement poster for condom use. In Australia, about two hundred and fifty people die every year of AIDS. About thirty thousand people die every year of cancer. Over a hundred and forty thousand Australians die of any cause. If you multiply that last figure by five or ten, you get the number of people who are affected every year by grief or bereavement.

Now recognize this. Most Australians know how to use a condom. But most Australians have no idea what to say to somebody who has lost their child to an incurable illness or accident. I would like to go into an international airport, go into the toilet, close the door, and on the back of that door, read a poster that says, "Another person's grief? Don't talk - just listen". So a

poster campaign similar to the example I have just offered, in any area of death, dying and care, has much valuable potential in Australian society, and I think internationally as well.

Another example is the annual short story competition. A lot of people are ignorant about what dying is like and what caring for somebody who is sick is like, or indeed, what grief is like, because we don't talk about these things to each other very much. So we have asked our palliative care services in each of their own areas around Australia to encourage their local newspaper to conduct an annual short story competition with a small prize offered by the palliative care service. This is one important way in which community can learn from each other about their experiences of dying and loss. The winner of the prize and the second and third runner-ups, have their stories published in the newspaper every year and people can read them there.

My final example is the idea of an animal companion remembrance day. There is, in Australia, a tendency to trivialize human-pet relations. There is a tendency to see the relationship to dogs and cats as only important to children. Unrecognized in this myth is the fact that a significant and very large and growing number of Australians actually keep dogs and cats as important members of the family and that they are important to adults as well as children. Increasingly people are living alone, they are not getting married, and they are not sharing their house with lovers. An increasing number of all the people are also living alone because they are widowed, and the majority of those people have animals. When their animal dies because of accident or disease, the grief that accompanies the loss of their animal, is often as great as the grief people experience at their loss of their own children, friends or lovers. And the international research on grief has indisputably demonstrated that grief is worse if it goes unrecognized ('Disenfranchised') than recognized. So animal companion Remembrance Day is a health promotion idea to bring this damage of death and loss into the open and to provide good public health support for

a significant minority of people in any society. People can march through the main street of town with photos of their animal companions; or there can be a small memorial service by the local temple or church; or a shrine can be built on the edge of town for people to regularly visit or hold annual festival to talk and celebrate their animals passing.

Each of these three above examples of health promotion activities assist in strengthening personal and community resilience to living with dying, grief and the burden of care. Each assists people to deepen their understanding of frequently hidden experiences. Each activity helps educate us all. Each activity assists in reducing harms and hurts that may result from early harms and hurts. Each activity promotes health, openness, and broad-based social support. And finally, each is a community activity, perhaps suggested or even initially led by health services, but conducted, supported and sustained by ordinary men and women in ongoing partnerships with professionals. Each is a good example of 'health-promoting palliative care' – a living public health approach to the holistic practice of palliative care.

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