Section 2

What does a public health perspective bring to understandings of ageing and end of life?

Introduction

Merryn Gott and Christine Ingleton

The relatively recent framing of palliative care as a public health issue seems to offer significant opportunities to address the urgent need to improve older people's experiences at the end of life. Indeed, the scant regard given to defining 'health' in the context of palliative care is identified as an oversight in the opening chapter of this section. Bruce Rumbold argues that a 'health promoting palliative care' approach 'can both improve existing services for aged dying people and identify wider social reforms needed to develop age-friendly communities'. He argues that there is a need for health services to hand back ownership of dying to communities so that they become responsive to, rather than directive of, end of life experiences. Whilst public health approaches to palliative care have been developed internationally, Rumbold outlines specific developments in Australia where, by 2003, Palliative Care Australia asked that all palliative care services involve themselves in at least one of the following: community development, community education, prevention strategies aimed at reducing social morbidity, and social policy practice and advice.

The need to seek consumer perspectives and mobilize community participation is recognized and it is this theme that Neil Small and Anita Sargeant take up and expand in Chapter 8. They identify the potentials of increased user and community participation at the end of life, as well as the risks, namely that it becomes 'something paternalistic, imposed to colonize a further area of our lives'. The nuances of community and user involvement are drawn out. Barriers to any level of 'involvement' are identified for certain groups, in particular, the 'older old' where practical, generational, and attitudinal factors all seek to mitigate against inclusive involvement. The authors conclude by identifying a need to view user and community participation as processes which must be 'nurtured and grown not switched on and off'.

Chapters 7 and 8 both mention advance care planning (ACP) as a mechanism to further engage individuals in thinking about, and making plans for, their own dying. In Chapter 9, Koen Meeuseen and colleagues from Belgium and the Netherlands outline why they believe ACP is such

an important component of palliative care provision globally. They trace the development of the complex legislation concerning ACP from the United States to Europe, and outline some of the key models proposed to implement ACP into practice. The complexities of implementation are also highlighted; to date, the prevalence of ACP remains low internationally. However, the authors argue that overcoming barriers to effective ACP is critical to ensuring greater congruence between the expressed wishes of patients and their families, and the provision of palliative and end of life care.

The diversity of these wishes, and end of life experiences in general, is explored by Jonathan Koffman in Chapter 10 in a critical review of issue affecting experiences of palliative and end of life care amongst older people from minority ethnic groups. The semantic difficulties of categorizing individual identity by 'ethnic' and 'cultural' factors are discussed, as are the complex and multiple ways such 'difference' can impact upon physical and psychological well-being amongst older people at the end of life. A need for culturally appropriate care across increasingly diverse societies internationally is identified, but it is acknowledged that no easy solutions exist. In concluding, Koffman proposes a 'double lens: one that applies a framework of equity to understand and serve population needs of specific communities; and another that never loses sight of the individuals and families before us—those with clinical, psychosocial, and spiritual needs and concerns that may not conform to preconceived or stereotyped patterns'.

If public health approaches to palliative care are to be fully responsive to individual and community needs, the effect of bereavement on health and well-being must be considered. In Chapter 11, Amanda Roberts and Sinead McGilloway discuss community-based initiatives in the area of bereavement care. The tendency to overlook bereavement as an issue affecting the health and well-being of older people is identified and the case made for the importance of addressing the diverse bereavement-related needs of older people. Roberts and McGilloway outline salient issues to be considered when developing or enhancing bereavement support services for older people at a community level, drawing on examples of specific services established internationally. In this discussion, the potential to reframe an ageing population as a resource, rather than a 'demographic time-bomb', is evident. Voluntary bereavement support is typically provided for older people, by older people, a development that brings us full circle to our opening chapter and the argument that communities need to be empowered to support each other.

Chapter 7

Health promoting palliative care and dying in old age

Bruce Rumbold

Introduction

This chapter contends that a public health approach, as exemplified by health promoting palliative care (HPPC), can both improve existing services for aged dying people and identify wider social reforms needed to develop age-friendly communities. Developing such an argument, however, involves a conversation between health care disciplines that have until recently had little to say to each other.

The fact is that the late modern disciplines of health promotion, palliative care, and gerontology, which emerged during the 1970s, took shape with virtually no interaction between them for the remainder of the 20th century. They have only recently moved into conversation and some tentative forms of cooperation. Many conceptual differences and practice difficulties continue to separate those trained in one or other of the disciplines—for very few, if any, are trained in all three. A proposal of new possibilities for collaboration that does not take into account the decades-long estrangement of these disciplines is likely to meet the fate of new wine placed in old wineskins.

It is not particularly surprising that health promotion and palliative care have not been dialogue partners. After all, health promotion has focused upon strategies to avoid morbidity and postpone mortality: death and dying are subjects absent from the health promotion literature, except as outcomes of behaviours that contribute to increased morbidity and early mortality. It is rather more surprising that palliative care and aged care have not engaged with each other from the start, given that death brings an end to all careers as an aged person. Yet health promotion's reluctance to engage with palliative care is matched by gerontology. This can be verified quite simply. Take any text on gerontology, particularly texts in the 'successful ageing' genre, and look for 'death' and 'dying' in the index. Often neither term will be found. When 'death' is indexed, it nearly always refers to epidemiological findings (causes of death) rather than an event approached through the universal human experience of dying. Dying as the process and experience that ends people's identity as aged citizens is notably absent from these texts.

Health promotion in aged care has typically focused upon maintaining physical function and overall well-being for as long as possible (1–3). Mental health similarly has been addressed in terms of preventing or reducing the impact of physiological changes to cerebral function, with less focus upon strategies for adjusting to age-related changes (4). There is a remarkable absence in this literature of considerations as to whether the relative proximity of death might affect older people's mental state or decision-making, and a corresponding lack of consideration of how well-being might be understood in the face of diminishing capacity and increasing infirmity. Successful ageing, with its focus on continuing active participation, clearly is important. But a narrow focus upon success in terms of resisting incapacity sets up the situation where inevitably most people's ageing is no longer successful. (To their credit, this omission of 'dealing with death' is noted by Wykle et al. in their epilogue (2)).

Palliative care joins the mainstream

It seems that a necessary condition for developing a conversation between the disciplines was for palliative care to join gerontology and health promotion as part of mainstream health services. During the 1970s and for much of the 1980s palliative care, more often at that stage called hospice care, operated at the fringes of the health system, with funding from local communities and philanthropic organizations supplemented by varied amounts of income from government sources (5, 6). During the 1990s, however, most Western health services moved to incorporate palliative care as one of the services delivered by their public health systems.

One consequence of this mainstreaming of palliative care was that it became clearer that palliative care was not, and was not necessarily equipped to become, the only provider of end of life care. While palliative care philosophy paid attention to the changed forms of dying in modern societies, palliative care practice was largely a response to 'out of time' deaths from cancer (7). As a method of care it was at its best when illness had interrupted expectations of continuing normal work and family life, when the dying person was supported by family and friends, when good communication was at a premium in helping all involved adjust to this radically-changed situation, and when the dying trajectory was relatively predictable so that service provision could be paced with the dying person's decline. As George and Sykes (8) point out, few of these criteria apply to most deaths in old age. Here dying can eventuate from multiple causes and is often not detected until shortly before death, communication can be difficult, and practical social support is limited in comparison with the palliative care 'ideal'. Others have suggested that, unlike people experiencing the disruption of dying 'out of time', old people are somehow accepting of death and thus do not require the supportive care that is integral to palliative care—a suggestion that is singularly lacking in evidential support. In any case, the transfer of palliative care knowledge and skills from cancer care to aged care is not straightforward, and has only been addressed systematically in the last few years.

Another consequence of mainstreaming hospice and palliative care services was to create a new specialism. Specialist palliative care focused on what had become the core business of hospice, cancer care, and generated the associated trappings of specialist associations and career paths for its practitioners. This led to a new set of issues. Questions about the relationship of hospice care with the health system in general now became questions about the relationship of the new speciality with other specialist disciplines within the system (9, 10). Placing palliative care into a health services or population health context also made it obvious that, while it was addressing a particular form of modern dying, the 'out-of-time' death, the majority form of dying in Western societies was death in old age. This in turn raised questions about specialist palliative care's contribution to society's end of life care. From a health systems perspective, policymakers and managers began, and it might be said continue, to ask about the relationship between specialized palliative care delivery and other services offering end of life care (aged care, emergency care, intensive care, primary care), and to explore the possible wider application of palliative care insights and strategies. These discussions were largely confined within health services, although at least some recognized the way health service provision is embedded in, and relies upon, communities that provide informal care and promote a variety of forms of self-care (11–13).

Palliative care and aged care

Individual practitioners and researchers had in the 1990s considered the relationship between aged care and palliative care, but only in the last decade has that relationship been systematically developed. The application of palliative care philosophy and strategies to aged care contexts has followed somewhat different routes in different countries. Australia published Guidelines for a

Palliative Approach in Residential Aged Care in 2004, following a 2-year consultation process (14) (as discussed by Deborah Parker in Chapter 19). Corresponding guidelines for aged care in the community are nearing completion. Increasingly the term 'palliative approach' developed in the project (15) is now being applied generally to care in which primary care providers draw upon their own supplementary training and experience in palliative care and/or consult with a regional specialist palliative care service in order to provide end of life care informed by palliative principles.

Canada and the UK have chosen not to focus overtly on aged care but rather to pursue a general transfer of palliative care principles and practice into the primary care system, using a palliative care and end of life approach. In the UK, general practices have been enlisted in the Gold Standards Framework (GSF) (16), which provides 'strategies, tasks and enabling tools to deliver the best possible care for people nearing the end of their lives'. The programme, which was developed in primary care contexts, is now being implemented in Care Homes. Canada too has focused upon developing palliative care and end of life care within primary care, with some recent specific applications to end of life care for seniors (17). Again, advance care planning is a major part of strategy, directed not only to aged or ill people, but all adults, although admittedly here policy is running ahead of evidence: there has been little rigorous evaluation of these tools to date.

Despite their differences, all these approaches have been largely constrained by the boundaries of the health systems: that is, aged care and end of life care continue to be seen essentially as matters for medical management.

The UK National Health Service (NHS) End of Life Strategy, published in July 2008, has built upon the GSF, and led to a number of important initiatives intended to raise health care practitioner and community awareness of the opportunity and need to be involved in end of life planning (12). Similarly in Canada, implementation of advance care planning has drawn attention to the need for raising awareness and providing information to the community in general, not only to health care practitioners (11). Furthermore, policymakers are becoming increasingly aware that community engagement is needed not only to increase awareness of what health services provide and the decisions they require but also to shape the delivery and character of those services.

This sort of consumer involvement raises boundary issues for clinical models of care that have maintained a clear distinction between professional and lay perspectives and contributions. It is here that a health promoting approach can contribute as it provides a framework that incorporates the insights and concerns of both professional services and communities. Health promotion began by raising, in the face of medical dominance, a question about who owns health. In the same way, health promoting palliative care asks who owns dying? Health promotion answered its question with the assertion that health is created in communities, so that in a sense all policy that shapes community life is health policy. In the same way, health promoting palliative care asserts that dying is a matter for community management, and that health services should respond to, rather than direct, the experience of dying.

What is health promoting palliative care?

Health promoting palliative care stems from a social model of health, and brings into consideration, among other things, the social context of beliefs and practices surrounding death, the tradition of the good death, the role of community, and limits to health services contributions.

The term 'health promoting palliative care' for at least some readers may create cognitive dissonance. As already noted, health promotion for the most part seems interested in death only as something to be avoided or postponed by health promoting practices. The discipline of palliative care, while having the goal of a good death, seldom talks about this as a health outcome.

One of the first systematic attempts to link the health promotion and palliative care literatures was Allan Kellehear's *Health Promoting Palliative Care* (18). Kellehear took a new public health approach, encapsulated in the Ottawa Charter, and considered palliative care through this lens. His intention was to provide a critique of the health service-based understandings of palliative care that had grown out of the community-based hospice movements of the 1970s and 1980s. This critique in turn suggested strategies whereby characteristics of the hospice model of care that were being marginalized in the new mainstreamed palliative care (6) might be reclaimed and incorporated in the revised practice models. Kellehear contended that mainstreaming had skewed palliative care practice, and that as a result aspects that had been integral to the hospice philosophy were now underdeveloped, including:

◆ Social science and public health perspectives

◆ Social and spiritual aspects of care

◆ Early stage care

◆ Active treatment of disease

◆ Care for those with life-threatening illness (not just terminal illness) (18).

He saw the dominance of clinical priorities in treating life-threatening illness as encouraging people to be passive recipients of technical care rather than active agents in their own lives. Restoring a holistic perspective, as exemplified in hospice care, required palliative care to be reframed within a participatory model of health. For this Kellehear used the Ottawa Charter (19), the key policy framework of the new public health movement that began with the Declaration of Alma Ata (20). The Charter states that building healthy societies requires governments, agencies, and citizens in general to:

1. Enable, mediate, advocate in pursuit of healthy public policies and practices

2. Create supportive environments

3. Strengthen community action

4. Develop personal skills

5. Reorient health services.

Here health is connected with all aspects of life and is the concern of all citizens. Health promotion should involve a wide range of community and professional groups, while health services should be responsive to the societies they serve. A capacity to be an agent of one's own health, to have access to health education and information, and to work with, rather than submit to, health professionals, are outcomes of policy that recognizes the social character of health.

Bringing together the hospice philosophy of care and the Ottawa Charter, Kellehear developed the HPPC model to redress the effects of mainstreaming. The model reasserted ideals, identified resources that should be provided (such as health education that includes death education), and shared strategies for living with life-threatening illness and for confronting the social conditions that limited or opposed this resourcing and sharing. The goal was to encourage palliative care services to see that their unique insights into the experience of dying today should be offered to their communities so that the attitudes, knowledge, and understandings with which people experience illness in themselves or those close to them might begin to change. People might then encounter life-threatening illness and dying with resources already in place rather than have to assemble or develop them from scratch in the midst of that experience. The key strategies of HPPC aim to provide:

◆ Health education which includes death education

◆ Social support

◆ Interpersonal reorientation

◆ Policies that do not separate dying from living (21).

In so doing the model addresses areas neglected by contemporary palliative care models. HPPC:

◆ Complements clinical approaches

◆ Encourages community alliance

◆ Challenges current health policy

◆ Restores social and pastoral interventions

◆ Allows diversity amongst clients

◆ Expands understanding of health

◆ Reclaims an holistic perspective (18).

Reception of the model was mixed. Some practitioners were enthusiastic, seeing the model as tackling problems of which they were aware, but which they felt relatively powerless to address. Others were dismissive, suggesting that their services were already doing health promotion, by which they usually meant marketing their service. Yet others saw the ideas as a good thing, but considered that any such initiatives should be funded from outside the (clinically-focused) palliative care budget: HPPC in their opinion was not 'core business'.

HPPC is not the only public health approach to palliative care, and the recently-formed International Network for Public Health in Palliative Care (http://www.pubhealthpallcare.in/) has promoted sharing amongst these public health programmes and approaches. Here the focus will be upon HPPC in Australia; other countries can draw their own parallels (22).

In Australia, as word spread, local champions emerged to implement HPPC approaches in their own services and regions. The interest generated by the HPPC model, and by projects based upon it, resulted in growing acceptance at the national level of the legitimacy of public health approaches in palliative care, and the need for services to see this as an aspect of practice. By 2003 the national peak body, Palliative Care Australia, in their Service Provision Planning Guide asked that all services involve themselves in at least one of:

◆ Community development

◆ Community education

◆ Prevention strategies aimed at reducing social morbidity

◆ Social policy, practices, and advice (23).

Early health promoting strategies initiated by the La Trobe University Palliative Care Unit, founded by Kellehear, included conducting health promotion groups with people living with life-limiting illness, and providing education for palliative care providers in health promoting approaches (21). Further projects were developed in partnership with palliative care services and community groups (24–27). Responses of practitioners and services to the education programme and project outcomes have provided a basis for implementation and policy development.

The initial focus of HPPC was upon reforming the practice of mainstream palliative care practice services along lines indicated in a set of practice guidelines (28). In this sense the model was subject to the limitations of the hospice and palliative care models of care it wished to reorient. That is, its focus was upon health service responses to modern dying, and to particular aspects of that dying; namely 'out-of-time' deaths from cancer. In addition to providing a rationale and strategies by which social and spiritual interventions might be maintained or restored, it also pointed to new horizons in end of life care. Initial work with services made it increasingly

clear that any process of reform needed also to involve the communities in which the services operated. This expanded model, published as Compassionate Cities (29) brought palliative care concerns into dialogue with the healthy settings movement (30), in particular the Healthy Cities programme. The Compassionate Cities model provides a broader framework within which end of life issues in general can be addressed, not merely those that fall within the more specialized interests of palliative care. Attention turns to developing communities in which citizens living with dying and loss can continue to participate in meaningful ways.

Health promoting palliative care and aged care

A health promoting approach to the end of life in old age would thus pay attention to the settings in which old people die, their expressed needs in the later years of life, the ways communities in general and health services in particular should seek to meet those needs, and the strategies that should be put in place to prevent distress and minimize harm to those who are dying, their family and friends, and others who care for them. Strategy must take account of all aspects, as public health interventions are systemic, multidimensional, and multidisciplinary. They do not provide lists of possibilities from which a few aspects may be selected as targets for action: individual and structural aspects must be addressed together (19, 31).

Lloyd (32) has in fact outlined such an approach, identifying the key elements as promoting non-institutionalized services, encouraging openness about illness and dying, enabling older people to exercise choice and control over caring interventions, minimizing older people's fear of death, and maintaining family and other social networks. Kellehear's HPPC model applied to dying in old age demonstrates not only a process by which Lloyd's goals might be addressed, but also identifies conceptual and procedural changes that are necessary if these desired outcomes are to be achieved.

Considering the four key strategies of HPPC focuses both possibilities and problems involved in implementing a health promoting response in aged care contexts.

Provide health education that includes death education

It is clear that health promotion in aged care, as expressed both in practitioner texts and government policies, has resolutely separated any discussion of death or dying from health education. This has been noted earlier in the case of aged care texts, but it is equally true of health promotion-influenced 'successful ageing' policies. The WHO *Active Ageing: A Policy Framework* report (33), for example, contains no discussion of death and dying as part of the ageing process (although the discussion paper (34) preceding the report did assert that people are entitled to death with dignity, albeit without commentary on what this goal might imply for aged care policy). The Australian Parliament in a report *Future Ageing* (35) shows some limited awareness of work being undertaken on applying palliative care to death in residential aged care, but otherwise juxtaposes palliative care with physician-assisted suicide as if these two medically-managed processes are the only end of life options available to be considered.

Given the universality of death, and the health care system's determination to develop best-practice interventions throughout the life course, it should be possible to inform citizens about healthy ways to die. The challenge then is to understand health as inclusive of human mortality.

Provide social support

Social support is usually assumed to be diminished or absent for older people, although evidence for this is less clear. Cornwell et al. (36) find for older non-institutionalized adults in the USA that, while network size might decrease with age, the frequency of socializing and social

participation increases. They suggest that some late-life transitions, such as retirement and bereavement, may in fact prompt greater connectedness.

A study of loneliness by Victor et al. (37) in the UK complements these findings. For some, loneliness has been a way of life they bring into old age; for others, old age initiates loneliness. Most vulnerable are the 'oldest-old', those living alone and the non-married. Widowhood massively increases vulnerability to loneliness; although loneliness can also decrease as time goes on.

The most important forms of social support appear to be relationships that provide continuity with the past, and this includes relationship with place (38). Occupying particular familiar spaces or places can support a sense of competence, and also help mediate other unavoidable changes. Hockey et al. (39) demonstrate how loss can be engaged through renegotiating familiar spaces, and how, paradoxically, support to do so is provided through continuing bonds with the person whose physical absence is the primary source of loss. The social support provided by continuing bonds has been identified (40–42) but the importance of such support seems not widely recognized. For many old people, relationships with others who have died remain lively sources of encouragement, hope and resilience. Such relationships are further enhanced by contact with people who also have known these others who have died.

Relocation to unfamiliar places and new relational networks will thus affect not only remaining social relationships with the living but also to an extent relationships with important others who have died. The possibility here is to recognize the changing nature of social relationships that incorporate not only the living but also the dead, and the ways in which all these relationships are mediated by place. The challenge is to develop patterns of social organization, and spatial expressions of those patterns, that protect and maintain social support (43).

Encourage interpersonal reorientation

For health promoting palliative care, interpersonal reorientation involves negotiating a changed identity—that of being a dying person—within current social relationships. Whatever a person's age, this task is not assisted by society's difficulties in seeing dying as a part of living.

The evidence concerning ageing people's capacity to incorporate an identity as a person soon to die is mixed, in part due to the fact that a significant amount of the (relatively sparse) data concerning aged people's experience, concerns, and needs is derived from research questions devised by others rather than old people's own accounts. As an example, consider studies of death anxiety (44) in aged people, undertaken with little attention to how these researcher-selected characteristics might relate to the whole of an old person's experience.

In studies that started with the actual reported experience of older people, a different picture began to emerge (45–47). These studies, along with others eliciting elderly people's reflections on ageing and death by Erikson et al. (48), Howarth (42), and Vaillant (49), demonstrate a dynamic tension between the limits imposed by dying and death and—in most cases—a continuing affirmation of life. This is further corroborated by Field's study of older respondents' views concerning death (recorded in the Mass Observation Archive of the University of Sussex) (50), showing that to be accepting of death does not mean giving up on living. There is a tension or a balance between maintaining control and losing control (51). Individuals' perception of the balancing point for them is a function of both their personal history and the resources currently available to them. The caregiver's task, argues Hasselkus (52), is to deal realistically with both aspects of experience, and to support an appropriate equilibrium.

Older people thus balance a spectrum of concerns, from staying healthy and being as active as possible, through to maintaining dignity and dying well—concerns which are not necessarily experienced as inconsistent by those who hold them. However, the health system privileges some of these (staying healthy and active) whilst regarding others (reflecting on decline and dying) as

detracting from the pursuit of those 'positive' goals. Aged people are thus provided with social roles that privilege some aspects of their concerns and limit or ignore others, allowing their actions to be misinterpreted or misunderstood. Clarke and Warren (53) pick this up very neatly, demonstrating the complexity of experience and (implicitly) cautioning against simplistic inter-pretations of behaviour alone (for example, a decision to limit activity, which could be seen as 'giving up', may in fact be empowering rather than disempowering). They also show how much of the focus for older people is upon everyday life—ordinary needs, deeds and relationships. This focus needs to be taken seriously when developing strategies for care, particularly at the end of life.

Develop policies that do not separate living from dying

Aged care policies in most Western democracies focus strongly upon maintaining the independ-ence of ageing people, expressed through strategies that reinforce individual responsibility. Increasingly individuals are seen by government, and see themselves, as responsible, through superannuation, for their post-employment life. They are responsible, by following the dictates of health promotion programmes, to age in healthy, successful, active ways (54).

The effect of selecting one dimension of experience, 'successful ageing', and making this the sole focus of public policy is to polarize ageing people's experience. Some elements are publicly acceptable, while others are not. Diminishment, decline, decay are private matters, to be resisted and, when resistance is not longer possible, to be endured with medical support and a consequent loss of independence.

Whether policy makers understand independence in the way older people understand it is debatable (55). The most common conceptualization seems to equate independence with not relying on other people. For older people independence encompasses not only self-reliance but also self-esteem and self-determination. In this understanding, high levels of physical dependence can coexist with high levels of felt independence. Autonomy is probably a better term to use than independence: and indeed Marmot and colleagues (56, 57) have shown the significance of personal autonomy for health status throughout the life course, not merely in old age.

Plath (58) argues that interpretations of independence affect the way policy is translated into strategy. Particularly at the end of life, where reliance on others is usually unavoidable, these interpretations can impinge upon dying people's autonomy as frailty and decline are managed largely in clinical contexts, where patients lose control of the everyday issues that have to this point expressed their independence. Daily schedule, activities, social contacts, and information are now regulated by others. Independence is impossible, and preserving autonomy—control over one or two aspects of life important to the person—becomes a struggle. In contrast with this, the focus of end of life care, as Wilkes expressed it, should be 'not to prolong life but independ-ence [autonomy], for as long and as comfortably as possible' (59).

Aged care policy until quite recently has failed to address the horizon at which the life course is completed. When it has ventured to discuss death and dying, it has usually treated them as medi-cal, rather than social, events. Discussion quickly moves from discussing the problems of life-prolonging treatments to considering life-shortening treatments, as if the antidote to medically-constructed problems of over-treatment might be compensated for by offering an alternative treatment of physician-assisted suicide. In such discussions, death and dying remain medicalized.

Health promotion contributes to palliative care in old age

Applying the four key HPPC strategies to old age has highlighted several important themes. One is the need to understand better old people's experience. It is clear that much health care practice,

strategy, and policy contains assumptions about older people's experience and attitudes that are not supported by evidence, or even fly in the face of evidence that is available. At present, however, the evidence available is partial and uneven. We need some focused and concentrated research upon which to build better process.

A second theme is the importance of settings, including both the social networks that shape the experience and attitudes of older people and the health care institutions that become increasingly influential in most people's lives as they age and die. Society's choice to manage old age in terms of perceived health deficits leads to an increasing segregation of older people from the general community as they are placed in retirement communities, sheltered housing, residential aged care facilities, and nursing homes, largely on the rationale that this clustering increases social support and allows the most effective delivery of scarce medical resources.

A third theme is the way that organizing aged care around health service delivery imposes a framework in which dying tends to be seen as the antithesis of living. The medicalization of old age—which is a social strategy administered, rather than determined, by health systems—appears as a major barrier to achieving healthy dying in old age.

Health promotion based on the new public health offers strategies that can move society from the current situation where expert management of death is invested in clinical approaches toward a situation where communities can develop different approaches. Ageing can then be recovered as a social event, with people's citizenship rather than their patient status shaping the discussion. Palliative care might then develop from a health services response to end of life care towards being a community concern and responsibility. Examples of such strategies can be found in work on strengthening palliative care in Victoria through health promotion (60) and in initiatives outlined in the NHS End of Life first annual report (61). Awareness is raised through poster campaigns, café conversations, theatre productions, and school-based projects. Training in 'how to care, what to say' is offered to primary care health practitioners, volunteers, family caregivers, and people such as hairdressers and taxi drivers who are the accidental listeners to end of life conversations. Information is offered at festivals and street markets about patient rights, advance care planning, and palliative care services. These, and many other grass-roots strategies like them, are aimed at raising community awareness of issues in the current governance of death and dying, and encouraging citizens both to exercise the options already available to them and to ensure that their needs and preferences are included in end of life policy development. In a sense these activities are part of a wider movement toward increased community participation in health service design and delivery, ranging from the health social movements (62) that have reformed, for example, breast cancer services through to the patient-centred and person-centred models of care (63). All seek in one way or another to restore autonomy to those who receive health services.

Policies promoting autonomy

The need for autonomy has been recognized in different ways in aged care and palliative care. Both have recognized the structural constraints upon individual responsibility and decision-making. Both have developed policies to address these constraints. Two in particular are worthy of further comment.

Incorporating a consumer voice: advance care planning

Advance care planning (ACP) as a means for individuals to express end of life care preferences has been available for decades in some jurisdictions, although the scope and status of these plans has varied. In practice, even when preferences have been documented (see Chapter 9, this volume), they have often been ignored, overridden by standard clinical practices, or expressed family wishes.

They have not had binding force, and implementation has relied upon the presence at the bedside or in the clinical meeting of an advocate determined to argue the dying person's case. And as an individual's preference, an ACP has focused more upon resisting the possible decisions of others than in creatively constructing conditions for a 'good death'. ACP risks remaining a conversation held on professional territory, driven by professionals' desire to clarify their own options and actions.

End of life decisions need to be made in age-friendly communities, but are too frequently initiated in contexts characterized by ageism and avoidance. End of life decisions need to be seen as completing life's narrative, not shaped excessively by loneliness, marginalization/ageism, guilt or despair. Again, this suggests that focusing end of life discussions around clinical treatment preferences, as much ACP tends to do, misses an opportunity to engage with aged people's actual end of life preferences and issues. As Clarke and Warren (53) remind us, everyday living is the focus of concern, and end of life decisions involve everyday relationships, activities, and inter-ests, identifying those things that need to be retained, those that can be negotiated, those that can be relinquished.

Only in the last few years has ACP become an interest of governments. Now ACP strategies have been produced (12, 17) or foreshadowed (64) by health services. A recent Australian report even presents ACP as a consumer tool for shaping end of life services (65). Perhaps the best inte-grated response is that of the UK, where the NHS End of Life Care Strategy expresses the intention that all citizens be given the opportunity to register an End of Life plan, and that all health care practitioners be trained to participate in end of life conversations (12). The first annual report (61) outlines a range of infrastructure developments and resources that have been prepared to support implementation of the Strategy. Interestingly, this preparatory work has led to the realization that community involvement is an essential context for effective development of the Strategy. From the initiatives and programmes now emerging, of particular interest from a health promoting point of view are the North East Patients' Charter for a Good Death (66) and *A Guide to involving patients, carers and the public in palliative care and end of life services* (67).

Settings: age-friendly communities

The importance of place is recognized in various ways in policies such as Ageing in Place (68) and Lifetime Neighbourhoods in the UK (69). The function of place has not been investigated as fully as it might be, but one study shows a plausible link between place, occupation, and sense of iden-tity (70). Perhaps the most graphic demonstration is the research reporting differing responses of aged people engaged in the same activity—sitting in a chair in different contexts. In their own home, sitting in their own chair, people report remembering and imagining, recalling past events and making new journeys in their minds. In a residential facility, sitting in an institution's chair, people typically report: 'I just sit here all day'. It would of course be naïve to assume that main-taining aged people in familiar settings would ensure successful ageing: but it is equally naïve to assume that people can experience radical changes to their setting without major disruption to their activities, occupation, and sense of self.

An age-friendly community is one in which aged people continue to contribute, in which autonomy is respected so that change is negotiated and supported. Liu et al. (71) in a review of international literature identify as core themes an integrated physical and social environment, and a model of participatory, collaborative governance. Thus individual decisions can be made in a context that respects continuity between the past, the present, and the future.

In the WHO Global Age-friendly Cities report (72), however, there is—again—no reference to death or dying as part of aged experience. The same is true of corresponding national reports: lifetime

environments in the UK (69), elder-friendly communities in North America (73). Similarly, the Humanitas projects, held up as practical examples of age-friendly planning, make no mention of death or dying in their key documentation (74). End of life decisions remain relegated to the clinically-organized environments in which much end of life care is offered, and these environments do not offer 'an integrated environment' and 'participatory governance'. Until dying is an issue included in the age-friendly discourse, death and dying will remain clinical concerns, accompanied by the surrender of much of what has sustained ageing people for the majority of their lives (75).

Conclusion

The core argument of this chapter is that insights of both health promotion and palliative care are essential for developing appropriate and sustainable end of life care, particularly in old age. But in order to do so, health promotion needs to find a concept of health that incorporates the idea of a good death. Palliative care needs to move beyond its limited horizons as a health care discipline that promotes a particular idea of a good death for people with degenerative illness, mainly cancer. Both need to re-evaluate their relationship with aged care in order to address the fact that most people today die after a long life, many living with chronic illness and disability during their later years.

As we have seen, conversations between aged care, health promotion, and palliative care encounter communication problems. Some of these are conceptual: their understandings of health, and in particular a possible relationship between health and death, differ. But the fundamental barrier is that collaborative discussions of dying in old age in Western societies are fundamentally compromised by the relentless separation of living and dying that permeates policy, health care systems, health and welfare practice, community planning, and much of popular discourse. Even the initiatives bringing health promoting principles to bear upon ageing through successful ageing and age-friendly communities programmes focus on extending wellness rather than engaging constructively with the end of life. These forms of health promotion remain captive to a professionalized health services perspective. They aim to defer the problem for which apparently no solution is seen—the problem of diminishment, disability, dying, and death in human life.

A new public health approach takes us beyond a health services perspective to consider not merely amended or added professionalized strategies near the end of life, but the settings in which life draws to a close, the resources with which people come to the end of life and—closely linked with both of these—the communities that shape these settings and resources. To put it another way, it invites us to reflect upon what health means over the life course: to develop an idea of a good life that can encapsulate the idea of a good death. Life and death may be binary opposites—but living and dying are not, and should be linked seamlessly in our policies and practice.

Health promotion strategies can incorporate consumer perspectives and mobilize community participation, and such strategies are readily available. The issue is not just one of reforming our health services to become more responsive to consumer perspectives, as important as this may be. Health Promoting Palliative Care, as we have seen applies these health promotion and community development strategies to end of life experiences and needs in order to reform health services and engage community participation. These initiatives will not on their own overcome the separation of living and dying in our understanding of health and the practice of care. This separation is not a health services invention to be overcome by the reintroduction of popular opinion; rather, in this respect health services reflect the societies in which they are embedded. A philosophical or

cultural shift in social understanding is involved in reforming the attitudes and policies that separate dying from living.

The possibilities for such a shift can be seen in the origins of today's palliative care movement. It was renewed philosophical, psychological, and social interest in human mortality that prepared the soil that grew the practical strategy of hospice. In subsequent decades, however, the openness to existential questions with which hospice and palliative care began was muted through health service alliances seen as necessary to ensure survival of the movement. Palliative care became incorporated in a clinical framework, focused around cancer treatment, and relegated to the margins of health care practice. The wider existential and reflective framework was downplayed or forgotten.

It may be that increasing longevity in Western society has allowed the postponing of existential questions that were more immediate in previous generations. It is unlikely that this can persist as increasing numbers of people born in the post-Second World War baby boom enter old age. The debates that will ensue—that are already beginning to take place in, for example, the revival of spirituality in a post-religious world—are debates that have at their heart questions of value and meaning. They will drive us to re-evaluate the resources of the past, and develop fresh resources for the future.

Traditionally, both religion and philosophy have concerned themselves with finding meaning in the face of human mortality. Health and death have been connected through transcendent frameworks of value and belief. Some people today still understand health and death through these frameworks, whether formally through religious belief or informally through personal conviction that draws upon cultural memory. Those approaching death may still be exhorted with propositions that range from detailed images of a (religiously-accessed) afterlife to a challenge to be courageous in choosing to live constructively in the face of extinction, or at least the radically unknown. But these propositions tend to be fragments of past belief systems, not an integral part of a contemporary understanding of what it is to be human. We need a fresh normative vision of a good life throughout the life course, including the end of life.

Such a vision can only be effective in reforming end of life care if it emerges within broad social consensus. But a disciplined, critical, multidisciplinary conversation between aged care, health promotion and palliative care can contribute to the wider social and cultural conversation that will take us forward.

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