

A CALL TO ACTION: AN IWG CHARTER FOR A PUBLIC HEALTH APPROACH TO DYING, DEATH, AND LOSS

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ABSTRACT

The current systems of care for dying persons, the people caring for them, and the bereaved operate in ways that frequently lack sufficient sensitivity to their needs. We describe a new model for dying, death, and loss that adopts a public health approach. Specifically, we describe a deliberative process that resulted in a charter for a public health approach to dying, death, and loss. Modeled after the World Health Organization's 1986 Ottawa Charter, our charter includes a call to action. It has the potential to bring about significant change on local, societal, and global levels as exemplified by four projects from three countries. Public health and end-of-life services and organizations need to form partnerships with the community to develop a public health approach to

dying, death, and loss. Learning from each other, they will affirm and enhance community beliefs and practices that make death part of life.

INTRODUCTION

The current systems of care of dying persons, the people caring for them, and the bereaved operate in ways that frequently lack sufficient sensitivity to their needs. The limitations in the operations emerge from specific foci, what has been termed the “medicalization”¹ or “professionalization”² of dying, death and loss that is adopted by many of those caring for the dying and their loved ones. The current professional foci often result in a unidimensional focus that can be isolating for all involved. *The National End of Life Care Strategy for England* published in July 2008 recognized the need to raise, at a National level, the profile of End of Life Care and to change attitudes to death and dying in society (Department of Health, 2008). It recognized that as a society we do not talk openly about death and dying and few individuals have discussed their own preferences for care at the end-of-life. The purpose of this article is to describe one attempt to integrate a wider social context by introducing a public health approach into this hitherto unidimensional focus on dying, death, and loss. A public health approach has a broader orientation that encompasses both population and individual approaches. This effort to widen the existing focus includes the development of a charter as presented in this article that addresses these issues and has the potential to bring about significant change on local, societal, and global levels.

BACKGROUND

Insufficient sensitivity to the particular needs of people affected by death is a common failure of healthcare systems that position health professionals as the exclusive experts in charge of end-of-life care (Vafiadis, 2001; Freidson, 1971; Howarth, 2007; Starr, 1982). Another consequence is a societal expectation that professional care is needed by everyone to cope with death and bereavement. In fact, much of the expertise lies in the world of the dying person and their bereaved community (Kellehear, 2004). The growth in this area of the numbers of professionals and the focus on their “disciplines” and duties has shifted the discussion from “people” to “patients” and “clients.” The shortcomings in delivery

¹In this context, *medicalization* is seen as a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders (Conrad, 2007).

²*Professionalization* refers to the view that most social and personal problems can be solved or treated only by people with the technical knowledge derived from special education reflecting professional attitudes and control and who have been licensed to practice their “trade” (Hughes, 1958).

approaches are in part due to a widespread aversion to acknowledging the universality of death, with the subsequent pattern that the community does not get actively involved in the processes (Kellehear, 2005; Sinclair, 2007; Small, Froggatt, & Downs, 2007).

End-of-life is a broad concept that encompasses dying, death, and loss (including grief). End-of-life care involves all the support (by families and communities, as well as professionals) needed and provided for people affected by death. Examples of these services may include, but are not confined to, the following: disaster management; care of the elderly; chronic illness care; accident and emergency care hospice and palliative care; funeral and mortuary care; and bereavement care.

In relation to dying, death, and loss, public health has frequently assumed the old medical view of death as failure rather than recognizing and accepting it as a fact of life (Henley & Donovan, 1999). Beliefs and practices associated with “death as part of life” world view and the associated celebratory rituals are still widely evident in large populations. However, service providers involved in end-of-life care, typically medical professionals, shift the focus away from the preferences and resources of the dying. They commonly overlooked the need to strengthen and build on the social potential of the communities of the people they seek to support (Kellehear, 2008). The current situation within society is illustrated in Figure 1, which shows a minimal interaction between public health and services for dying, death, and loss. The strengths and distinctive expertise of the two fields (public health and end-of-life care) need to come together for community building that would lead to more responsive attention to dying, death, and loss.

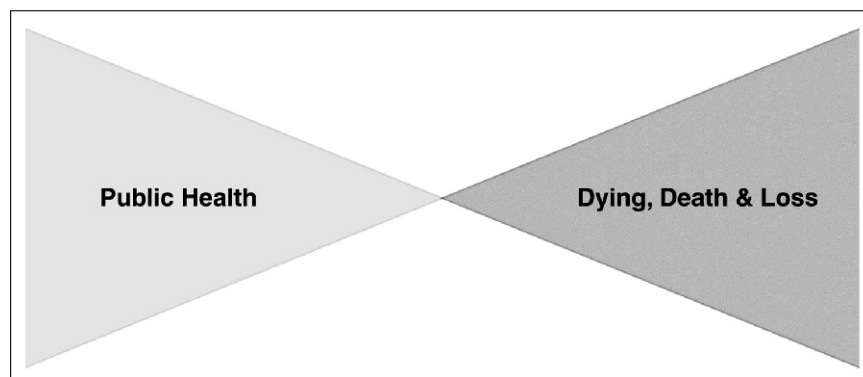


Figure 1. The public health challenge: minimal integration. IWG Charter Workgroup 2004, 2005, 2007, 2008. All Rights Reserved.

Globally, an important focus of public health is on an approach that pursues the goals of the population's disease prevention, health promotion, early intervention and harm minimization. Applying this approach can lead to building sustainable community health capacity through community development, education, participatory healthcare approaches, and legislative and policy changes (Baum, 2002). A public health approach promotes social justice and the capacities of whole communities to respond in supportive and respectful ways towards each other's health experiences. A public health approach would recognize that death is an inevitable part of life and that dying, death, and loss should be a shared concern and responsibility of all individuals and communities, including professionals.

Furthermore, a culture with a public health orientation is characterized by a recognition that: dying, death, and loss are inevitable and universal; experiences of dying, death, and loss are diverse and can have both positive and negative aspects; environments need to be created and promoted where communication about dying, death, and loss is supported and safe; some communities have capabilities and traditions in dying, death, and loss that others do not or have lost; dying, death and loss are complex and can present special difficulties that require professional help (Kellehear, 2005). However, a public health approach promotes the recognition that most people's needs and experiences can be positively supported by their individual lifestyles and communities (Baum, 2002). These societal responses are both alternative and complementary to current professional end-of-life care services.

The essential elements of a public health approach towards end-of-life care that would bring together professional caregivers with the communities they seek to support include: a culture of open discourse; sensitivity and adaptability to social and cultural differences; a whole-context approach including physical, spiritual (including all religions), psychological, and social environments; equal access for all; a focus on the needs of whole communities; and sustainability. In summary, a public health approach focuses on educating all stakeholders on the promotion of community capacity and the global diversity in needs arising from the universal experiences of death and loss.

Within the new public health movement (Baum, 2002), the Ottawa Charter (WHO, 1986) has been a seminal document in shaping practice. Building on a key message of the Declaration on Primary Health Care at Alma-Ata (namely, the importance of community; WHO, 1978), the Ottawa Charter identified five action areas and three action principles. The action areas are: build healthy public policy; create supportive environments; strengthen community actions; develop personal skills; and reorient health services. The action principles are: advocate, enable, and mediate (see Table 1 for details). The Ottawa Charter acknowledges the importance of the community and social environments. Thus, we used this charter as our stimulus for an orientation for action to achieve the vision proposed in this article.

Table 1. The Ottawa Charter: Actions and Principles
Adapted from World Health Organization (1986)

Actions	Examples
Build health public policy	Put health on the agenda of policy makers in all sectors and at all levels, combining diverse yet complementary approaches including legislation, fiscal measures, and organizational change.
Create supportive environments	Require a socio-ecological approach to health that recognizes the links between people and their physical and psychosocial environments
Strengthen community actions	Focus on empowerment and work through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them
Develop personal skills	Support personal and social development through providing information, education and skill development, thereby increasing options for people to have control over their own health
Reorient health services	Direct attention to an expanded mandate for health services that are sensitive and respectful of cultural needs, and open the health sector to acknowledge broader social, physical, political, and economic environmental components
Action Principles	
Advocate	Direct attention to the underpinning influence of political, economic, social, cultural, environmental, behavioral, and biological factors and the need to accommodate these in implementation
Enable	Focus on achieving equity and providing the conditions for people to achieve their fullest potential to be able to take control of things that determine their health
Mediate	Demand coordinated action by all concerned, including government, non-government, community, and voluntary organizations taking account of differing social, cultural, and economic systems

Process

The idea of developing a vision for a public health approach to dying, death and loss grew from a workgroup discussion at the 2004 meeting of the International Work Group on Death, Dying, and Bereavement (IWG, <http://www.iwgddb.org/>) in Tucson, Arizona. It was stimulated by professional and lay views that raised the issue of the medicalization of grief loss (Groopman, 2004). The group saw merit in this critique of current practice, and took it further to focus not only on grief (loss) but also on dying and death.

At IWG meetings, members form smaller workgroups to focus on particular issues. The group who discussed and formulated this article included professionals from multiple disciplines (nurses, psychologists, palliative care physicians, social workers, public health professionals, sociologists, educators, thanatologists, and philosophers) who worked in five countries serving in a variety of roles (researchers, educators, and frontline practitioners).

We began by seeking ways to integrate the wider social context into the treatment of dying, death, and loss. Drawing on the experience of our members with backgrounds in public health and who are applying this approach in their current work (Kellehear, 2005; Rowling, 2005; Silverman, 2004), we developed the idea of generating a charter as a call to action for integrating public health and end-of-life care.

We drew on the example of the Ottawa Charter (WHO, 1986), extensive dialogue and debate, and a consensus development approach to bring together the group's disparate views and language. Through a Delphi method, we clarified and collated the salient elements into a draft document that included examples of targets and strategies for a public health approach. We circulated the charter draft via e-mail to the 150 members of the IWG prior to seeking worldwide feedback from other end-of-life experts. We sought this feedback by posting the charter draft on several websites in Australia, Great Britain, and the United States and in comment sections of key journals in the dying, death, and bereavement field (Clark, Dawes, DeSpelder, Ellershaw, Gordon, Howath, et al., 2004-2005; Clark, Dawes, DeSpelder, Ellershaw, Gordon, Howath, et al., 2005; Clark, Dawes, DeSpelder, Ellershaw, Gordon, Howath, 2005a; Clark, Dawes, DeSpelder, Ellershaw, Gordon, Howath, et al., 2005b). Workgroup members integrated feedback from these postings into the current charter (Appendix 1) at the IWG meetings in 2005 and 2007.

RESULTS

The workgroup matched targets and strategies identified through the Delphi and consensus methodology with implementation examples and linked with the health promotion action areas and action principles from the Ottawa

Charter (WHO, 1986). The results are shown in Table 2. The vision of the International Work Group Charter is to bring a public health approach to dying, death, and loss work and to integrate end-of-life issues into public health as illustrated in Figure 2.

Following the second round of consultation and feedback, the workgroup undertook further work to develop a representative model (Figure 3). This figure shows the proposed relationships among the key elements represented by the arrows of the Charter (the International Work Group Charter for Public Health Approach to Dying, Death and Loss) through the action principles of advocate, enable, and mediate. For a specific project, a dynamic combination of principles (as denoted by the arrows) may be employed at any one time. This combined approach facilitates information (knowledge, attitudes, and values) and skill transfer among the key elements and creates an enhanced joint goal of developing a comprehensive seamless response toward dying, death, and loss. The proposed approach involves an expanded integration of community development into the care of individuals and their families, as shown in Table 3 by four examples of this approach being implemented in several countries.

DISCUSSION

This International Work Group Charter for Public Health Approach to Dying, Death and Loss acknowledges that, in a number of countries, the current approaches to dying, death, and loss have shortcomings and commonly result in scepticism and criticism of services and initiatives in both the public health and end-of-life care realms. This Charter responds to these shortcomings by calling for an integrated understanding of dying, death, and loss. The purpose of the Charter is to acknowledge the publicly expressed call for a re-focus (Groopman, 2004) by highlighting the need for permeability between direct service provision (i.e., palliative care services) and this growing community need for a public health approach to dying, death, and loss.

The innovation in the model (Figure 3) is the central role of the community as a bridge to defining services and creating accountability. To achieve this partnership model, supportive environments need to be created that facilitate development of community leaders and professionals who will hear the currently unheard voices and who will advocate policy to enable the interaction and mediation among organizations, agencies, and communities. This innovative approach promotes the recognition that death is an inevitable part of life and that dying, death and loss should be a shared concern and responsibility of all individuals and communities, including professionals and the services they provide. This public health approach promotes resilience and competence, even though it acknowledges the inability to prevent dying and the subsequent grief of survivors.

Table 2. Implementation of a Public Health Approach to Dying, Death, and Loss

Examples of Targets and Strategies	Health Promotion Actions	Implementation Examples	Action Principles: A = Advocate E = Enable M = Mediate
1. Advocate for the “normal” and recognize that the normal can be painful	Create supportive environments Develop personal skills	Build resilient communities through education and awareness raising about the process of grief and loss as a life event for professionals and the community	E
2. Ensure a collaborative approach to identifying needs, establishing definitions, and defining outcomes	Build policy Reorient health services	With consumer and broad professional support, develop an end-of-life strategy at a national level	E, A
3. Promote “action” and “practice” research priorities	Build policy Create supportive environments	Lobby research organizations to have as a priority end-of-life collaborative research such as community-based participatory studies	A, M, E
4. Ensure access and choice from the community’s perspectives	Create supportive environments Facilitate community action	Ensure that the community takes a leading role in the development of services for dying, death, loss, and bereavement	E
5. Create imaginative involvement and partnerships with community bodies	Create supportive environments Facilitate community action	Share individual agencies’ and community resources during times of national disasters	E, M
6. Actively promote community development	Facilitate community action	With consumer collaboration, develop community-based bereavement services	E, M
7. Mandate the participation of people using services	Build policy	Make consumer representation a prerequisite in policy development	A
8. Promote political lobbying by consumers, services, and lead organizations within the community	Build policy	Promote lobbying by HIV-positive people in collaboration with hospices for development of specific HIV policies	A

9.	Target legislative changes	Build policy	Promote availability of opioid services for pain management in all countries	A, E
10.	Promote intersectorial collaboration	Build policy Reorient health services	Broker interagency agreement for collaboration for care delivery	M
11.	Develop media partnerships	Develop personal skills Create supportive environments	Help national hospice organizations develop guidelines and training for their members regarding engagement with the media	E, M
12.	Adopt a social marketing approach	Facilitate community action Develop personal skills	Encourage TV and radio coverage promoting the choice to die at home	E
13.	Provide public health resources for dying, death, loss, and bereavement	Reorient health services	Propose fiscal policies to reorient healthcare services for dying, death, loss, and bereavement	E
14.	Develop a media communication role for lead organizations	Build policy Create supportive environments	Ensure that organizations have media communication embedded in their business plans	E
15.	Promote education and supervision (interdisciplinary, cognitive and affective, critical, and reflective)	Develop personal skills Reorient health services Create supportive environments	Incorporate education about dying, death, loss, and bereavement in the school curriculum, with professional development for teachers Develop teachers in support roles who create seamless links with relevant community services	A, E
16.	Promote communication among diverse organizations about common needs in relation to dying, death, loss, and grief, especially in respect of their common, diverse, or absent languages	Develop personal skills Reorient health services	Promote fiscal support and training for personnel in prisons to reorient prison healthcare to provide dying, death, loss, and grief services to include culturally diverse groups	M, E
17.	Combat professional paternalism	Develop personal skills Reorient health services	Effect attitudinal change, education, and learning strategies to promote autonomy and the active role of consumers in service development	M, E

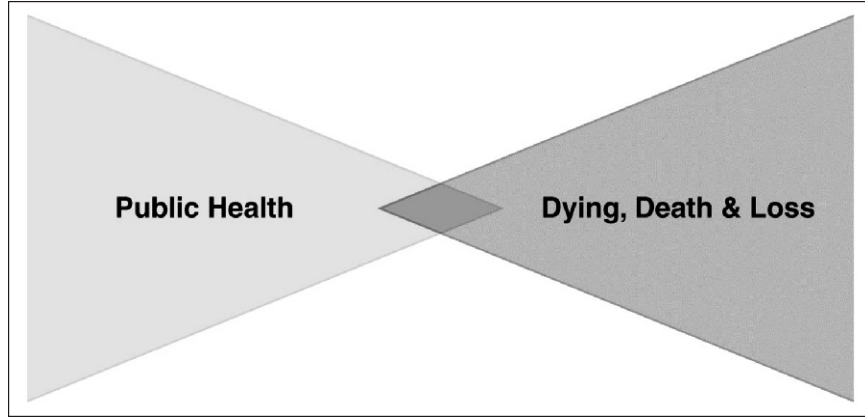


Figure 2. The public health challenge: proposed integration. IWG Charter Workgroup 2004, 2005, 2007, 2008. All Rights Reserved.

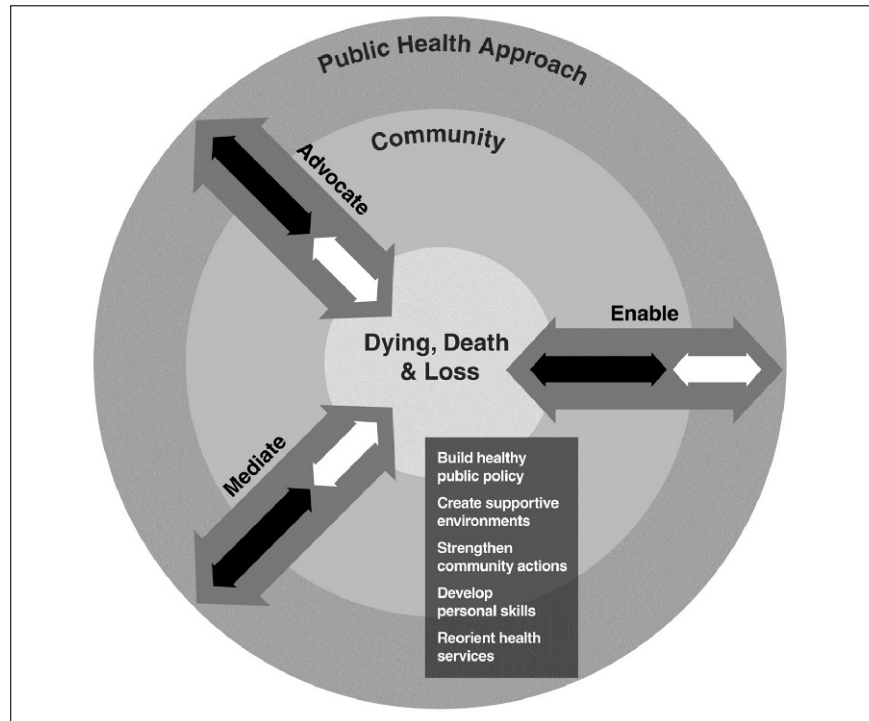


Figure 3. The public health goal. IWG Charter Workgroup 2004, 2005, 2007, 2008. All Rights Reserved.

Table 3. Public Health Approach to Dying, Death, and Loss in Practice:
Examples Describe How the Public Health Approach Can Be Applied

Example 1: Implementation of the basic principles of a public health approach

A Public Health Approach in a British Hospice by David Oliviere, Director of Education and Training, St. Christopher's Hospice, London

This example illustrates how the participation of service users and carers can begin to change the planning mechanisms around service delivery and harness their voices and power (Monroe & Oliviere, 2003; Small, Froggatt, & Downs, 2005), as suggested in Target 7 (Table 2). It works on the basis that service users and carers have life experiences, ideas, and professional backgrounds of value. Research on user involvement has hitherto demonstrated that the main benefits are that users and carers are better informed and more empowered (Payne et al., 2005). The impact on staff—clinicians and educationalists—has been a shift in professional mindsets, allowing for fuller development of the user-professional partnership rather than just the therapeutic relationship (Oliviere, 2006). Organizational change has been necessary to allow for user involvement processes, releasing staff and resources, as well as adjusting clinical governance processes to accommodate input by service users.

A large hospice and palliative care service has been developing feedback into its service development and education provision over several years. A number of components and methods make up this “user involvement” or “user participation” approach to providing care and education:

- **Traditional Feedback** through a range of user, carer, and visitor questionnaires on the quality of the palliative care service. Occasional audits (e.g., on food) have elicited more detailed views.
- **Information Group** with professionals and users working together on drafts of information leaflets. No information/documentation is now released without the input of users/carers.
- **User Forum** meetings with between 15 and 40 users and carers, facilitated by non-clinicians. These meetings are opportunities for the organization to consult, as well as for the users and carers to generate their own agenda.
- **User Forum** meetings for professional users (i.e., hospital palliative care teams who refer users to the hospice; primary care team; care homes). These recognize the part that other professionals and agencies play in the partnership of care. They also are a device for discussing some of the concerns of the users/carers (e.g., constant fear of “hospice” at early stage of introduction prior to visiting the establishment).
- **Clinical Governance** meetings with heads of clinical departments receiving the feedback and suggestions from the user forums. With the nominated Trustee from the Council of Management (who attends the User Forum) present, the whole process is given important status. Response from the organization is sent in written form to the service users/carers who attended the User Forum.

Table 3. (Cont'd.)

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- **Individual Interviews** with users in the Hospice Unit to elicit views on services.
 - **Users' Education Advisory Group** made up of eight users and bereaved carers who attend, sample, advise, and monitor courses, to ensure that "the user is always present in education." The group inputs to the planning of the annual education program. Suggestions have included: more courses for primary care teams; care assistants' education; and men's needs.
 - **Users Teaching** medical students, multi-professional groups and chairing. One of the many successful initiatives has been the "Goldfish Bowl," where users discuss their illness experiences with a member of staff sitting in an inner circle. Questions are then generated by the medical students sitting in an outer circle.
 - **Listening Days** for bereaved users and one-off consultation meetings on a range of subjects related to their experience of service delivery.
 - **Public Education** program of events from single days to a lecture series on aspects of caring for someone with advancing illness and bereavement is offered to any member of the public, including current users and carers in the service. It offers an open space to be informed but also to ask about some of the myths and anxieties in using hospice and end-of-life services. It is, interestingly, attended by a number of professionals as well as the public, and users/carers are involved in the presentations.
 - **School Projects** have been initiated by the day center and bereaved children's service, with the aim of introducing hospice to primary school children in a creative and non-threatening way to promote healthier attitudes to death and dying in themselves, their teachers, their parents, and carers. This offers a different approach to public education. Over four sessions, the children meet patients and staff, listen to their experiences and, with the Arts Team, produce artwork. Teachers and parents are involved with the children's presentations of their experiences and final celebration. The projects have been so well received that they are being rolled out in other primary and secondary schools.

Example 2: Partial Implementation of the public health approach

A Public Health Approach to Community Palliative Care in India by Suresh Kumar, Institute of Palliative Medicine, Medical College, Calcut, Kerala, India

The present services for the care of the dying cater to only a minority, often providing support to a small number of patients (Olweny, 1994). What is available to these few patients is also often a patchy service provided by professionals. The real challenge for palliative care (PC) workers today is to develop a culturally and socioeconomically appropriate and acceptable system for long-term care (LTC) and PC that is accessible to most of those who need it. A social experiment from Kerala (India) has been trying to address this issue through organized interventions by laypeople in the community.

The Neighborhood Network in Palliative Care (NNPC) is an attempt to develop a sustainable community-owned service capable of offering comprehensive LTC and PC to most of the needy. In this program, volunteers from the

Table 3. (Cont'd.)

local community are trained to identify problems of the chronically and terminally ill people in their area and to intervene effectively, with active support from a network of trained professionals. Essentially, NNPC aims to empower local communities to look after the chronically ill and dying in the community. The program is inspired by the concept of primary health care described by the World Health Organization in the Declaration of Alma-Ata:

“Primary healthcare is essential healthcare based on appropriate and acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost the country and the community can afford, to maintain the spirit of self-reliance” (World Health Organization, 1986).

Over the last few years, this initiative has replaced the earlier hierarchical doctor-led structure in PC in northern Kerala with a network of community volunteer-led, autonomous initiatives (Shabeer & Kumar, 2005).

NNPC is an attempt at a community development program in PC. This approach, in essence, sees participation as an end, where the community or group sets up a process to facilitate its own development. Under the program, people who can spare at least two hours per week to care for the sick in their area are enrolled in a structured training program (16 hours of interactive theory sessions plus four clinical days under supervision). On successful completion of this “entry point” training (which includes an evaluation at the end), the volunteers are encouraged to form groups of 10-15 and to identify the problems of the chronically ill people in their area and to organize appropriate interventions. These NNPC groups are supported by trained doctors and nurses in the region.

NNPC groups usually work closely with the existing PC facilities in their area or build such facilities on their own. Volunteers from these groups make regular home visits to follow up on the patients seen by the PC team. They identify patients in need of care, address a variety of vital non-medical issues (including financial problems), organize programs to create awareness in the community, and raise funds for PC activities, including salaries for professionals. Community volunteers act also as the link between the patient in the community and the healthcare provider in the institution.

The enormous amount of participation of people from the poor and middle class of the society has been one main characteristic of the NNPC program (Pringle, 2005). What is being observed in the PC scene in Kerala can probably be described as a “palliative care version” of community development. The NNPC experiment has also shown that it is possible to bring individuals and groups with different social, religious, and political perspectives together on a broad spectrum of social justice issues to work for marginalized people in the community (Sallnow, 2005).

Table 3. (Cont'd.)

Example 3: Comprehensive implementation of the public health approach
A Public Health Approach to Grief in School Communities by Louise Rowling,
 University of Sydney, Australia

In this article, Target 15 (Table 2) is to promote education and supervision. The following example focuses on an interdisciplinary approach to this target. The health promotion action areas that are used concentrate on developing personal skills within a supporting context to address the grief of school community members, students, teachers and other school personnel, parents, and community members. It also involves a reorientation in practice of school personnel and bereavement service providers. Advocacy and enabling principles underpin this approach.

The current individualized approach to intervening with grieving young people in schools focuses on providing counselling services to individual students or groups of students and in some cases outside referral to doctors who may prescribe medication as part of a treatment regime. In this way, young people are seen as having a problem (being bereaved), and action focuses on fixing the problem. A public health approach would focus on the school community and how organizational conditions can be created and enhanced that assist students as well as school personnel in student support roles (Rowling, 2005). This supportive environment can provide a normalizing and affirming environment (Kendall, 1989). The “normality” of school routines establishes these conditions. The normality is not just “business as usual” in time of crisis but uses organizational structures of schools of personal interactions, time schedules, and pastoral care networks as frameworks for effective support.

Working strategically to achieve a public health approach to bereavement in school communities will require a reorientation of service delivery for bereavement service providers working with schools, from acting solely as grief experts to also being facilitators and supporters of the actions of school personnel. These bereavement service providers will also need education to develop skills to work in different ways with parents, teachers and other school personnel. Additionally, school community members such as school leaders, teachers, school psychologists, and parents will need information and strategies to recognize grief as a normal part of life experience and an experience that can be managed within schools (with support from bereavement services) for positive outcomes for all. In this organizational approach, service providers need to take a wider view of their efforts and work strategically with schools to build their policies and practices to support grieving school community members (Rowling, 2003) and to provide guidance to those school community members who are interacting with young people.

While debates exist as to whose role it is to support students, young people themselves often seek out adults with whom they already have an ongoing relationship as people from whom to seek help. That is, their active participation through the naturally occurring supportive relationships in school communities is a key strategy and can be strengthened.

Table 3. (Cont'd.)

Example 4. Comprehensive implementation of the public health approach
A Public Health Approach to Community Palliative Care in Australia by John Rosenberg, Research and Practice Development Centre, University of Queensland, Australia

This practice example is drawn from a recent study of the integration of a health-promoting palliative care approach in a community-based palliative care service in the Australian city of Brisbane. Referred to in this document as “the hospice,” this service undertook a process of transition from conventional approaches to palliative care provision, to a health-promoting approach.

The hospice was driven by a concern for the return of death and dying to community ownership, moving beyond conventional models of care dominated by biomedical approaches (Clark & Seymour, 1999). Social models such as health-promoting palliative care were seen to be congruent with their organizational goals, and health promotion was seen as a fitting approach to the provision of palliative care. The transition to a health-promoting approach was spelled out in the hospice vision statement, which was “. . . to promote the creation of healthy community attitudes in relation to death and dying” (Rosenberg, 2007). Fundamental to the success of this transition was the ability of stakeholders to perceive the “fit” between these two seemingly disparate fields. Their perception of the conceptual congruence of the components of health promotion with the established philosophy, values, and practices of palliative care facilitated the implementation of health promotion principles and practices in the hospice. One staff member observed, “It’s going to be taken up more readily and incorporated more readily because there’s an alignment there . . . it’s not out of place with what is already in the philosophical thinking or with the work practice. . . .”

Hospice personnel saw synergy between early attempts of the hospice movement to promote personalized, contextual care of dying people and the hospice’s embracing of health-promoting palliative care. Consequently, the reorientation of the hospice to a health-promoting approach represented an adjustment to understanding, rather than a substantive conceptual transition.

This acceptance of the “fit” of health promotion to palliative care enabled the hospice to “*Ensure a collaborative approach to identifying needs, establishing definitions, and defining outcomes*” (Target 2). However, like other services, the hospice struggled to maintain a critical mass of organizational personnel skilled and knowledgeable in health promotion (Whitelaw, Martin, Kerr, & Wimbush, 2006). This required the development of strategies to reintroduce health-promoting palliative care perspectives to a greater number of staff and volunteers, such as providing information at commencement of service for newcomers, and regular-in-service sessions for existing personnel. With an organization-wide perspective evident in the organizational documents, such as policies and procedures, and expressed through community development programs such as a death education program, these strategies were implemented into the hospice’s educational activities, in an attempt to address the target area above. Further, the hospice sought and obtained the inclusion of community members on their governing board.

Table 3. (Cont'd.)

With an organization-wide focus on health-promoting palliative care, the hospice considered the development of public policy regarding the end of life within its remit, arguing that death and dying are concerns for whole communities and society, and is consequently a concern of governments in their policy-making role (Kellehear, 1999, 2005; Kellehear, Bateman, Rumbold, 2003; Rao et al., 2005; Rao, Anderson, & Smith, 2002) This embracing of Target 8, “*Political lobbying by consumers, service and lead organizations,*” was founded upon the hospice’s view that responsibility for developing, implementing and evaluating this contribution rests in partnerships between communities and organizations concerned with end-of-life issues. In practical terms, the hospice participated in the policy advocacy activities of the regional peak body, liaising with regional government to develop health-promoting approaches to end-of-life care. Further, in its holding of death education programs, hospice open days, and street art markets, the hospice created and utilized these opportunities to raise public awareness of issues of the end-of-life and equip community members to lobby government representatives for consideration of these issues in public policy development.

CONCLUSION

The combined approach proposed in this article, illustrated in Figure 3 and exemplified in Table 2, facilitates information (knowledge, attitudes, and values) and skill transfer between the key elements and creates and enhanced joint goal of developing a comprehensive seamless response toward the human experiences of death and loss. The proposed approach involves an expanded integration of community development into the care of individuals and their families

The Charter outlines the essential elements, action principles, action areas, and strategies for a comprehensive public health approach within end-of-life care and inclusion of appropriate end-of-life issues in public health initiatives. It contains a call for action, namely that globally, in partnership with the community, public health and end-of-life services and organizations need to join together to develop a public health approach to dying, death, and loss. Learning from each other, they will affirm and enhance community beliefs and practices that make death part of life.

Appendix 1 follows on next page

APPENDIX 1

³IWG CHARTER FOR PUBLIC HEALTH APPROACH TO DYING, DEATH AND LOSS

The current systems of care of the dying person, the people caring for them and the bereaved have shortcomings. They are organised in ways that fail to recognise wider social contexts and position health care professionals as the experts. These shortcomings are in part due to lack of acknowledgement of the universality of death as a fact of life, with the resultant loss of community in the processes. This charter proposes a new approach that involves: adapting new public health actions areas to enhance involvement of community, and applying new public health advocating, enabling and advocacy principles to dying, death and loss.

Essential Elements

A culture of open discourse

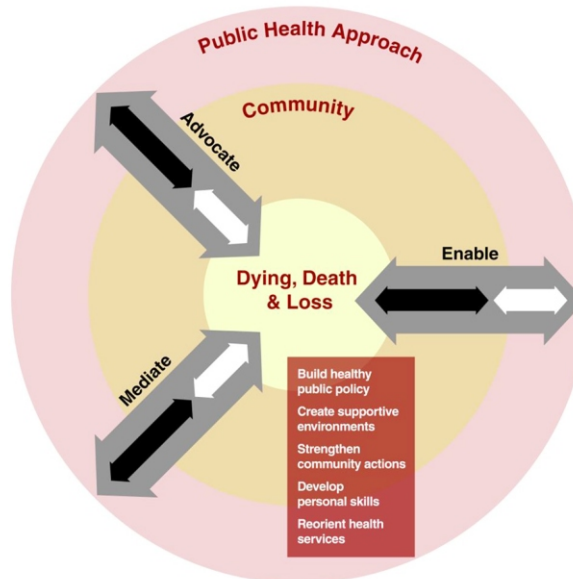
Sensitivity and adaptability to social and cultural differences across the life span

A whole-context approach including physical, spiritual, emotional, intellectual and psycho-social environments

Social justice by promoting equal access for all

A population health approach that focuses on the needs of whole communities

Sustainability



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A Call to Action

On a global level, in partnership with the community, public health and end-of-life services and organisations need to join together to develop a coordinated public health approach to dying, death and loss. Learning from each other, they will affirm and enhance community beliefs and practices that conceive of death as part of life.

³An early draft of this Charter was published (Clark, Dawes, DeSpelder, et al., 2005; Clark et al., 2005; Clark, Dawes, et al., 2005a, 2005b) and posted on websites in Great Britain and in the United States. International feedback was received and considered at the 2005 Hong Kong IWG meeting, and revisions were made by the workgroups in Hong Kong and at the 2007 Sao Paulo meeting.

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