



# The University of Bradford Institutional Repository

<http://bradscholars.brad.ac.uk>

This work is made available online in accordance with publisher policies. Please refer to the repository record for this item and our Policy Document available from the repository home page for further information.

To see the final version of this work please visit the publisher's website. Access to the published online version may require a subscription.

**Link to publisher's version:** <https://global.oup.com/academic/product/psychosocial-issues-in-palliative-care-9780198806677?q=9780198806677&lang=en&cc=gb>

**Citation:** Karapliagou A, Kellehear A and Wegleitner K (2018) The public health end-of-life care movement: History, principles, and styles of practice. In: Lloyd-Williams M (Ed.) Psychosocial issues in palliative care: A community based approach for life limiting illness. Oxford: Oxford University Press.

**Copyright statement:** © 2018 Oxford University Press. Reproduced in accordance with the publisher's self-archiving policy.

**Philip J. Larkin**

Professor of Clinical Nursing (Palliative Care), UCD School of Nursing, Midwifery and Health Systems and Our Lady's Hospice and Care Services, and Associate Dean for Taught Graduate Studies, UCD College of Health Sciences, Dublin, Republic of Ireland

**Wendy Lichenthal**

Assistant Attending Psychologist and Director, Bereavement Clinic, Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY, USA

**Alexandra Mancini**

Pan London Lead Nurse for Neonatal Palliative Care, Chelsea and Westminster Foundation Trust, London and The True Colours Trust, London, UK

**Allison M. Marziliano**

Pre-doctoral Fellow, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, NY, USA

**Susan McClement**

Professor, College of Nursing, Rady Faculty of Health Sciences, University of Manitoba, Winnipeg, Canada

**Linda McEnhill**

Head of Supportive Care, St Joseph's Hospice, London, UK

**Maria Giulia Nanni**

Institute of Psychiatry, Department of Biomedical and Specialty Surgical Sciences, School of Medicine, University of Ferrara, and University Hospital Psychiatry Unit University Hospital and Health Trust, Ferrara, Italy

**Holly G. Prigerson**

Professor of Sociology in Medicine, Joan and Sanford I. Weill Department of Medicine, Weill Cornell Medical College, New York, NY, USA

**Genevieve Thompson**

College of Nursing, Rady Faculty of Health Sciences University of Manitoba Winnipeg, Manitoba, Canada

**Klaus Wegleitner**

Assistant Professor, Institute for Palliative Care and Organizational Ethics, Faculty of Interdisciplinary Research and Continuing Education (IFP Vienna), University of Klagenfurt, Austria

## Chapter 1

## The public health end-of-life care movement: history, principles, and styles of practice

Ailiki Karapliagou, Allan Kellehear, and Klaus Wegleitner

### Introduction to the public health end-of-life movement

This chapter provides an introduction to a growing professional movement in end-of-life care that specifically aims to address the *social* dimensions of care and revises our understandings of community action. Most palliative care activity is based upon direct service provision and face-to-face professional encounters with medical, nursing, and allied health professions. The idea of the 'social' has often been subsumed under the idea of psychosocial care. However, in this style of psychosocial care health services merely work with social care services—it is care understood as care by the professions and not as community care in all its civic dimensions. Other community work has so often been defined and confined to actions by hospice volunteers.

Public health ideas have been adopted by a diverse and international range of palliative care programmes for many years now but both their theoretical origins and practice strategies remain poorly understood, or worse, misunderstood. In the following discussion we provide some background to the public health end-of-life care movement encapsulated by the framework known as *Compassionate Cities*, a description of some of its basic principles, and a brief outline of the main practice approaches and challenges associated with this new approach to social care at end of life. We begin with some historical and conceptual background and then discuss the major forms of social actions that have arisen from palliative care that have reflected these principles in some form or another.

## Modern public health: from disease management to health in all policies

All public health concerns itself with health on a population level. It involves the application of scientific knowledge upon organized efforts to improve the health of citizens. Public health as a discipline in its own right was established during industrialization, when a rapid process of urbanization led to the overcrowding of modern cities. Poverty and the lack of sanitary measures and hygiene led to contamination risks, and the spread of infectious diseases, such as cholera, tuberculosis, and malaria epidemics. Public health aimed to alleviate those risks, improve health, and restore economic productivity.

A set of measures (Poor Laws) were taken to support those who could not work due to ill health, and investigations on the causes of disease took place. At this stage, poverty was linked to ill health for the first time, but it was believed that disease causes poverty, rather than poor health being the outcome of social conditions and living standards (Hamlin, 1994). The value of preserving the health of citizens through the application of scientific knowledge and civic mobilization was justified in terms of the financial benefits of improved health for industries and national economies.

The legislative development and sanitary reform that ensued led to dramatic changes. Since the middle of the nineteenth century, control over contagion was achieved, and mortality rates significantly reduced. One of the main achievements of the first wave of public health development was its ability to integrate different sets of knowledge emerging from life sciences (bacteriology, physiology, and social statistics) into 'a coherent and comprehensive model of health and disease' (Potvin and McQueen, 2007). At the same time, the engagement of civic society in the effort to transform health, led to the incorporation of public health into the bureaucratic regulatory system of nation-states (Porter, 1999). In this way, public health was established out of what some authors (Susser and Susser, 1996; Terris, 1983) call a 'revolution'. Potvin and Chabot (2002) justify this characterization in terms of radical transformations in the system, its knowledge base, and practice.

Once the risks of contagion were contained, infant mortality was reduced, and people lived to old age, the attention of the public health movement shifted towards the cure of chronic conditions. In the twentieth century, public health became synonymous with medicine and their services, and a growing professional culture of physicians, nurses, and other health-care professionals concentrated their efforts upon further extending the population's lifespan. Changing lifestyles due to improved living conditions and nutrition patterns, greater prosperity, and the introduction of food manufacturing, significantly

improved health and wellbeing, but did not alleviate the effects of the simultaneous reproduction of inequality and poverty, as well as the lack of awareness about new health hazards. The health needs of populations changed, and diabetes, obesity, smoking, and the simple facts of ageing now triggered chronic conditions, and presented new threats to life. Terris (1983) refers to the process of professionalization of health as the second revolution in the history of public health, but within this approach death was perceived as failure of the efforts to preserve life (Illich, 1976).

A yet more recent direction in public health—what commentators (Breslow, 1999; Potvin and McQueen, 2007) call the third revolution of public health—provides methods and models that emphasize 'health and wellbeing' and not simply disease or illness. Under a 'new regime of total health' (Armstrong, 1993), the view of health as a 'resource' led developments. Advanced governance systems, established health-care systems, the professionalization of health based on broad multi-disciplinary scientific knowledge, and a population involved in political debates and decisions, changed the way in which health and its care is approached in the twenty-first century. Citizens are becoming increasingly engaged in their own health—as a population and citizen-led responsibility—within health ecologies constructed by the media and business (Kickbusch, 2007a). Current public health issues appeal to an educated consumer society that develops health literacy (Kickbusch, 2009), within an expanding health market. In 'health societies' the development of policies and practices that promote health and wellbeing crosscut all social sectors and are participatory, collaborative, and citizen-led. These developments witness a shift away from 'health policy' by health-care professions alone, and a move towards 'health in all policies' and social environments (Kickbusch, 2007b).

Public health in contemporary societies aims to empower citizens to see health as a central personal aspiration in life. Health is no longer exclusively a matter of good health-care provision, treatment, and control. It is a 'resource for everyday life' (Breslow, 1999) that can be promoted by empowered citizens. Participatory methods driven by large public campaigns and the media have been central in health promotion that signals a shift away from a focus on disease to a focus on health and its maintenance (Adshead and Thorpe, 2009). The reduction of co-morbidities, illness prevention, and active ageing, drive current health promotion efforts. The understanding of health issues as global and environmental (WHO, 1978; 1986) also shaped the direction of the second revolution in public health. It invited the development of sustainable solutions and ecological interventions (WCED, 1987; Brundtland, 1989).

The third revolution of public health turned towards health because disease has boundaries, while health knows no limits—whether disease is present or

absent. However, in practice, public health and health promotion continue to make provisions primarily for a situation where disease is absent, or at best curable. A content analysis of academic and professional published titles carried out by Karapliagou and Kellehear (2016) indicated that public health in Britain prioritizes issues arising from smoking, obesity, and diabetes, while marginal experiences that generate their own co-morbidities such as dying, bereavement, caregiving, being in prison, or homeless are largely neglected. Contemporary public health paradigms could be effectively applied to care for the wellbeing of every citizen, whether they are healthy, or have end-of-life care needs. Health care and medical innovations prolong the lifespan of people with life-limiting conditions, while populations are generally expected to die in old age affected by multiple morbidities. Given these recent demographics, the promotion of health among the frail and vulnerable would be vital to the new 'wellness revolution' in complete 'health societies' interested in creating independent and empowered citizens.

### Public health and health-promoting palliative care

The incorporation of end-of-life and palliative care considerations in public health potentially transforms its practice and impact (Kellehear, 2004). The latter becomes a necessity given the centrality and range of end-of-life care experiences in our societies. End-of-life care now starts much earlier in a serious illness because technological innovations and medical improvements prolong its trajectory through earlier diagnosis and prognosis. This is a common observation among the elderly who are disproportionately affected by multiple morbidities and life-limiting conditions. In the UK, 75% of people aged 75 years or more have more than one long-term condition, rising to 82% among those aged 85 years or more (Barnett et al., 2012). Inadequate support systems and care networks lead to unplanned hospital admissions that exhaust the resources of urgent care. Health, social, and technological innovations aim to address the challenges of an ageing population expected to double from 11.7% in 2013 to 21.1% by 2050 (United Nations Department of Economic and Social Affairs, 2013). Public health programmes aim to mobilize communities to develop sustainable frameworks of care that accommodate increasing needs. In this context, the inclusion of end-of-life care considerations in the public health agenda could propose solutions on sustainability, and drive a larger transformation of attitudes towards health and wellbeing that supports the needs of an ageing society.

The incorporation of end-of-life care in the public health agenda has equal value for those who are well and healthy. Citizens in contemporary societies

are becoming increasingly aware of mortality risks, and are socialized into feeling empowered to promote their own health and wellbeing. Large media campaigns raise awareness about the risks of communicable disease, HIV contraction and treatment, and the threats that smoking and obesity pose to life. Simultaneously, there is growing understanding that social inequalities and exclusion present significant morbidity and mortality risks (Sengupta, 2009). Collectively, we now know that lack of social relationships is the most important contributing factor to mortality (Holt-Lunstad and Smith, 2012). The incorporation of end-of-life care in the previously discussed considerations would destabilize the view of 'a perfect ecology of health'. It would counteract its death averse attitude, attend to experiences that challenge one's health status, promote broader awareness about health and wellbeing, and restore resilience. End of life care is about living, and living with one of the most unavoidable but universal experiences—mortality.

A public health framework called *Health-Promoting Palliative Care* (Kellehear, 1999) serves the purpose of acknowledging the significance of end-of-life care in our societies. It draws attention to the broader social issues implicated in health and illness, and attempts to reorient the traditional approach of the palliative care movement from the 'psychosocial' to the explicitly social determinants of health and wellbeing at the end of life. A health-promoting palliative care departs from past formulations of the 'psychosocial' by restoring (and to some extent rehabilitating) substantive concepts of the 'social' shifting the emphasis away from social psychology to matters properly community, civic, and ecological. It is a public health lifespan-focused framework for social transformation that includes end-of-life care.

Past psychosocial and psycho-educational programmes that have driven palliative care support, tended to have focused upon personal reactions to crisis such as anxiety, depression, fear, disorientation, anger, or financial difficulties, the burden of care, and the management of illness (Hudson et al., 2008; Grov et al., 2006; Harrison et al., 2009). Their evaluation often minimizes the impact, lessens the links to and upon social support and social networks (Hudson et al., 2008), and in some instances social support is perceived as burdensome (Wittenberg-Lyles et al., 2014). Rather than providing any guidance about the development of social strategies to address the inadequacies of support, efforts commonly focus instead on the personal ability to 'cope'. To that end, psycho-social and psycho-educational programmes in palliative care are largely driven by service delivery and disease management models and incentives. Limited within institutional or direct health service provision settings, psycho-social approaches often under utilize or reflect upon the challenges of social, cultural, or economic interactions that make-up end-of-life care experiences.

Phenomenological studies on dying and caring at the end of life commonly report 'existential' concerns when there is lack of social integration within the neighbourhood, as well as communication difficulties with family, relatives, friends, colleagues, and professionals in caring roles (Sjolander and Ahlstrom, 2012). These influences weaken peoples' resilience, encourage one to question their sense of identity and belonging, and withdraw from their social environment (Dahlborg Lyckhage and Lindahl, 2013). As a consequence of social isolation, their health, wellbeing, and independence can be further compromised. And yet, psycho-educational services are unlikely to replace the role that meaningful relationships and social networks play in promoting health and wellbeing even at the end of life itself. There is, and has been, a long-term need for actions that address the health-promoting social environments of people living, caring, and grieving at the end of life. The public health end-of-life care movement represents an attempt to address just these challenges.

### Public health end-of-life care

The development and implementation of a coherent public health end-of-life care framework has a number of benefits for public health. Firstly, public health end-of-life care identifies a range of experiences of death, dying, grief, loss, and caring with implications for palliative and end-of-life care, and makes an effort to include related considerations in preventive and health-promoting interventions. For example, public health end-of-life care intervenes in all policies and strategically aims to influence practices that enable the social inclusion of marginal experiences caused by social inequalities and lack of cohesion (poverty, social isolation, loss of homeland, and a safe cultural location, for example). Such conditions are known to compromise health and wellbeing, and may cause co-morbidities and premature mortality (early deaths, sudden deaths, or suicides, for example). Public health end-of-life care also prescribes a number of planned interventions in social settings, makes an early intervention, and offers valuable care in the form of social support at the outset of life-limiting illness. In this way, a number of illnesses (mainly associated with age and ageing), such as dementia, heart disease, and stroke are included in care. Finally, public health end-of-life care promotes greater awareness about mortality, death, dying, loss, grief, and caring, and a broader understanding of experiences that may cause the above. It cultivates a culture of compassionate care, responsibility towards oneself and others, and willingness to prevent but also accommodate the above experiences in everyday life.

Public health end-of-life care makes a large contribution to public health by integrating an orientation towards death, dying, loss, grief, and caring in

its approaches and directions. As a result, a public health approach to end-of-life care is able to address population care needs along the entire life course. It recognizes dying as valuable part of life and promotes well-being in the end of life (see Figure 1.1).

For example, health literacy, which is used as a main prevention and health-promotion measure is complemented by death literacy. In doing so the perspective of healthy living includes 'healthy dying'. The traditional focus upon healthy active ageing is complemented by considerations of elderly care and its overlap with end-of-life care. Finally, the current focus upon palliative and health promoting palliative care is expanded by a decisive turn towards the end of life and its care in social and institutional settings as a civic care approach that makes an early investment, and engages whole societies in related matters.

The driving principle and coordinating force behind all the activities, practices, and policies of public health end-of-life care is *Compassion*. Community attitudes are reoriented towards end-of-life care by cultivating an ethic of compassion and sharing in suffering and in pain. Etymologically, 'compassionate' means to possess an attitude that allows one to accompany another in their suffering (Funk, 1963), to experience empathy, and share the journey. During the last decade, Compassionate Communities emerged around the world in an attempt to implement the basic principles of public health end-of-life care. They were inspired by Compassionate Cities—a model presented in *Compassionate Cities: Public Health and End-of-Life Care* (Kellehear, 2005).

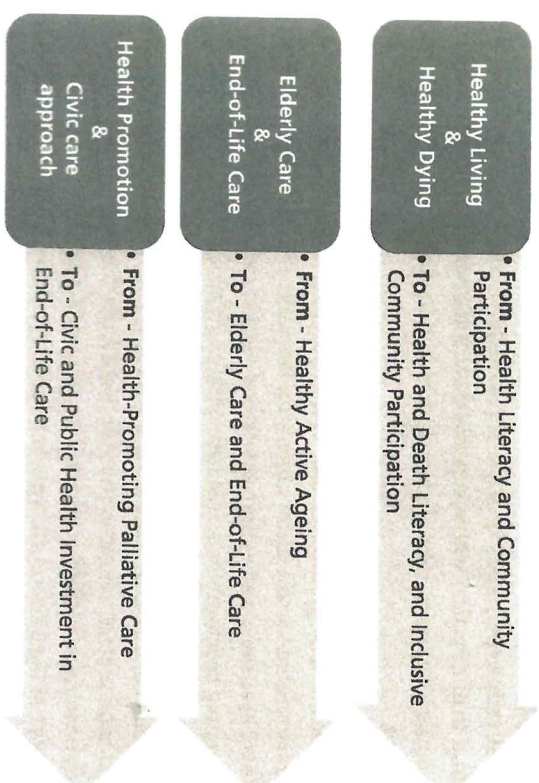


Figure 1.1 Extensions and shifts, through public health end-of-life care

## Compassionate Communities

Sectors within the hospice movement and community organizations that work with people with end-of-life care needs are concerned about patients' and carers' lack of trust in their own abilities to care, and tendency to ask professionals for help in the first instance (Sallnow et al., 2016; Abel and Townsend, 2016; Horton et al., 2016). By the end of the twentieth century, it became apparent that palliative care was challenged by an increasingly professionalized culture that disempowered people with end-of-life care needs, and marginalised their lived experiences. The role of the local community lacked conceptual understanding, and people who are more likely to withdraw due to suffering (Cassel, 2009) became excluded from care and social life.

The professionalization of palliative care poses additional challenges in urbanized and ageing societies; the services of which will struggle to meet increasing demand (Sallnow et al., 2016). By the middle of the century all regions of the world will be predominantly urban and occupied by an ageing population (UN Habitat, 2010). Palliative care already struggles to be inclusive—people from ethnic minority groups (Coupand et al., 2011), lesbian, gay, and bisexual groups (Harding, 2012), and low socio-economic classes (Kessler et al., 2005) are underrepresented, while cancer patients are overrepresented in specialist palliative care services (The National Council for Palliative Care, 2013).

The publication of *Compassionate Cities* (Kellehear, 2005) provided options and solutions to the previously discussed challenges. The emphasis of the approach on social needs and relationships involved in end-of-life care was something that some communities and organizations working in palliative care were already experimenting with. The Compassionate Cities approach gave them a firm direction within a public health framework that makes health-promoting strategies central, and is community building and partnership oriented.

Compassionate Communities employ the basic principles of Compassionate Cities—as health promotion and community development initiatives, and hold compassion as an ethical imperative (Wegleitner, Heimerl, and Kellehear, 2016). These social values and aspirations often translate into neighbourhood befriending programmes, social networking schemes, and community engagement initiatives. Different from traditional hospice volunteering, these initiatives are commonly directed, controlled, and maintained by the communities themselves, and are not volunteer 'services' sent from hospices. Though they may often be initiated by local palliative care services, Compassionate Communities grow out of local cultures, caring networks, voluntary resources, and the outreach activities of other community trusts and organizations.

### Community volunteering

Community volunteering is the most commonly used method of community development in public health end-of-life care. The pitfall of this approach is that stakeholders who are not familiar with the purpose of Compassionate Communities risk conflating their offer of voluntary services in the community with community development in end-of-life care. For this reason, it is worth highlighting the unique features and objectives of community volunteering in Compassionate Communities.

Volunteering in hospices and palliative care settings takes several forms. In the UK there are 125,000 volunteers (Help the Hospices, 2014), mainly occupied in supportive roles in specialist palliative care settings. Evidence from North American research suggests that the ability of volunteers to befriend and meet the social needs of people at the end of life and their caregivers is limited (Planalp and Trost, 2008; Berry and Planalp, 2009). Strict institutional procedures, health and safety regulations, and ethical guidelines contain their activity and communication avenues. As a result, volunteers may be confused or frustrated about their role, or they may feel unappreciated (Claxton-Oldfield and Claxton-Oldfield, 2008). There may also be tension in their relationships with health-care staff (Claxton-Oldfield et al., 2008).

On the other hand, there is evidence to suggest that volunteers are best suited in social roles. They can facilitate meaning-making processes of life review and re-identification following loss. They also help people experiencing loss, gain a sense of belonging, and support their communication with family, relatives, friends, and professionals (Burbeck et al., 2014). In short, they 'help them live until they die' (Seigny et al., 2009). Community volunteering in Compassionate Communities takes this last quality a step further.

Community volunteers are actively encouraged to develop relationships based on empathy and compassion. Employing their strong social observation skills and needs identification training, they explore with the people they support their needs and wishes. In this way, they provide people who are frail and vulnerable with a renewed sense of identity, and make them feel secure in their social environment. In some instances they give them access to the practical support they need to enhance their independence by enabling better communication with social and health-care services.

Community volunteers are also actively encouraged to extend and apply their compassion in everyday situations that they will encounter in the community. Community volunteering starts formally within a community development programme with specified training and standard procedures. However, it cultivates independence in the volunteer, and the ultimate purpose

is to embrace an attitude of compassion and develop additional compassionate relationships in the community, where needs arise. In this sense, volunteering in Compassionate Communities takes an informal character and prioritizes the natural social relationships between citizens, rather than the goal-oriented nature of the encounter in a volunteer-led programme.

The ability of community volunteering to influence a larger societal change, however is often challenged by strict organizational boundaries and procedures, and a risk averse professional culture within palliative care settings. In addition, community volunteering alone is not enough to lead a public health reorientation towards the end of life and its care. Community and other charitable organizations that lead similar initiatives may have more flexibility, and the ability to diversify and be creative with their community development programmes in order to more effectively reach the citizens they serve. However, they are constantly challenged by lack of sustainability in the methods used to implement community development, firm political support, and a stable funding base.

### Social networking

Social networking involves the process of identifying a *supportive* social network, which is likely to help during the end of life and its care. Where necessary roles and responsibilities are assigned within the network, or rearranged as required to support people with end-of-life care needs. The purpose of the social networking technique in end-of-life care is to reorient attitudes, and shift focus away from professional services and towards naturally occurring supportive networks, as a starting point of acquiring help. The social networking approach has been used as a community development method in its own right, but it has also been employed as a community engagement technique within community volunteering (Abel and Townsend, 2016).

Social networking was developed and applied in palliative care in Australia to support caregivers (Leonard et al., 2015). In the UK, it was adopted by Weston Hospice to support similar purposes (Abel and Townsend, 2016). The model used distinguishes between inner and outer links within a person's network (Abel et al., 2013). Formal family ties may provide direct physical care and/or companionship, as well as a sense of trust and safety. Community ties are no less important and can provide practical support, recognition as a citizen who needs and deserves help, a sense of belonging in the wider community, and a renewed sense of identity, all of which can save the caregiver from breakdown and exhaustion.

To mobilize the social network and formation of inner and outer links, a key principle within the approach is 'to just say yes' to offers of help (Abel

and Townsend, 2016). In the evaluation carried out at Weston Hospice, it was observed that in time, people fell into habitual patterns of providing support, adopted consistent roles, and were organized into supportive teams around the one that needed help. The organization of the network gave credit and value to the life experience of the caregiver.

Social networking is a dynamic method of community development that can be applied in everyday situations to alleviate suffering. However, grief is isolating, and bereavement is the long process of re-identification after death has taken place (Walter, 1999). Therefore, the risk of withdrawal is ever present even within supportive and understanding networks. Characteristically, the caregivers that participated in the Weston networking project withdrew following the death of their loved one. To sustain support we need to saturate all social spaces with compassion towards the end of life and its care, and influence a larger ecological change. Social networks are made and unmade by circumstances and losses, but it is our ethical responsibility within Compassionate Communities to pro-actively support fellow citizens in their need.

### Community engagement

Community engagement is the process of involving community members in end of life care by giving them opportunities to reflect upon death, dying, loss, grief, and caring. The purpose of community engagement in end-of-life care is to empower community members to become involved in matters they are likely to encounter at the end of life. For example, advance care planning, wills and inheritance, existential concerns, family relationships, psycho-social issues, how one would like to live at the end of life, and preparations for death and dying can all be discussed at anytime during the life-course.

Talking about end-of-life care matters reorients community attitudes towards related experiences. Conversations sensitize the community and create environments in which people can articulate their worries in times of need, seek support, find understanding and compassion, or simply acquire information and settle their affairs. For this purpose we need spaces and opportunities for conversations and ethical reflection to take place in the context of interactions between individuals and collective experiences, ideas, and concepts. It involves a method of a practicing ethics (Schuchter and Heller, 2016). Community engagement in end-of-life care entails health and death education, and aims to empower citizens to take control of their health and wellbeing at the end of life. Knowledge and active involvement in end-of-life care matters early on in life (or early on in the dying process) can be conducive to healthy living, and/or a good death with one's wishes fulfilled.

In the UK, the National Council for Palliative Care initiated a campaign that aims to address the social taboo present in conversations about death and dying. Towards this end, it published *The Dying Well Community Charter: Principles of Care and Support* that provides policy directions for engagement in end-of-life care in community settings. The Dying Well Community Charter focuses upon recognition and respect for end-of-life care needs, active communication about possibilities of involvement and support, and action plans for their delivery. To contextualize those policy directions and implement its community engagement programme, The National Council for Palliative Care introduced the Pathfinders and Buddies Scheme. Selected communities applied The Dying Well Community Charter in their local communities, and are in the process of evaluating its impact (for more information and to view The Dying Well Community Charter visit <http://www.ncpc.org.uk/communitycharter>).

The Scottish Partnership for Palliative Care also runs a very active community engagement programme with the *Good Life, Good Death, Good Grief* campaign at its forefront (for more information visit <https://www.goodlifedeathgrief.org.uk>). The Scottish Partnership for Palliative Care has a number one priority to promote health and wellbeing at the end of life in its population, and sponsors numerous arts projects and community engagement initiatives around the country. It has gone as far as to propose a rational for a national public health approach to palliative care through the Scottish Public Health Network (ScolPHN) briefing papers (Paterson and Hazelwood, 2015; Gilhes, 2016).

### Compassionate community in Sandwell

The Compassionate Community of Sandwell (Patell, 2016) is part of a larger community development programme that aims to address inequalities that impact upon people's health and wellbeing at any life stage. The Borough of Sandwell has a population of less than 30,000 inhabitants, and is one of the most deprived in the UK. As a site of industrial revolution, the region has a historical record of poor health and above average death rates compared to national standards. Murray Hall Community Trust is a public health and community development body set up in 1994 to improve the health of the region's population. One of the Trust's key aspirations is to raise citizens' self-determination and cultivate their agency in matters that affect them. Their aim is to use social capital in order to create opportunities for care and support, and increase access to information and services. A community development project called Bridges was formed out of the need to bridge the gap that separates the community from health-care services. People with end-of-life care needs felt disoriented and turned to the Trust's information desk for help. The Bridges programme identified and aimed to address the following: information needs; emotional support; practical support; and spiritual needs. Murray Hall Community Trust is a public health and community development body set up in 1994 to improve the health of the region's population. One of the Trust's key aspirations is to raise citizens' self-determination and cultivate their agency in matters that affect them. Their aim is to use social capital in order to create opportunities for care and support, and increase access to information and services. A community development project called Bridges was formed out of the need to bridge the gap that separates the community from health-care services. People with end-of-life care needs felt disoriented and turned to the Trust's information desk for help. The Bridges programme identified and aimed to address the following: information needs; emotional support; practical support; and spiritual needs.

that emphasizes listening to one's story to extract their meanings, worries, and matters. It is on the basis of what cannot be rationally articulated that needs are identified. A team of coordinators then work with health and social services to deliver the care that people mostly need. A team of community volunteers provide emotional support and practical services such as driving people to and from hospital appointments. As a community development organization, Murray Hall Community Trust engages in numerous and varied other activities in which the ethic of compassion is primary. Health and death literacy takes place within support groups, or in the context of art projects and other participatory and networking activities. What is distinctive about Murray Hall Community Trust is that it recognizes that death can take place at any life stage, and creates possibilities for inter-generational learning and exchange of support. The Trust throughout its life has undergone radical transformations. Although Murray Hall has influenced health care services and public health directions in the region, the recognition and inclusion of end-of-life care in public health would provide firm support for their local projects, and formal representation in health policy directions.

### Compassionate Cities

Compassionate Communities have been successful in transforming the cultural fabric of local communities, and reorienting attitudes towards end-of-life care in certain neighbourhoods (Wegleiter, Heimerl, and Kellehear 2016; Kellehear, 2016). Their community development approach and methods borrow from established public health interventions; but their implementation designs are skillfully crafted to utilize social capital, and in this way, meet local needs. As Sallnow and Paul (2015) observe the degree of community engagement that community development programmes in end-of-life care mobilize varies considerably, depending upon the locus of control, and goals set. Some programmes aim to inform citizens, simply consult them on matters that affect them, co-produce solutions, collaborate in the delivery of outcomes, or empower them to take control, make decisions, and influence their health and wellbeing. Compassionate Communities utilize all of these principles to achieve their ultimate goal, which is the empowerment of local communities. They may have to go through multiple cycles of community engagement and focus upon different outcomes, before local communities become independent and empowered.

Despite their empowering potential and impact upon the health and wellbeing of people with end-of-life care needs in local settings, Compassionate Communities cannot support a large-scale societal transformation. At best, they will reach those affiliated with the coordinating organization. If empowerment leads to community networking, it will engage people who are volunteering or use social services, and participate in neighbourhood activities, and for this reason, actively seek out information and participation activities.



given society. They may be suitable for homogenous towns and villages, but for diverse urban centres we need alternative public health paradigms.

To achieve large-scale societal impact we need a national public health campaign that will utilize the media to influence popular knowledge and perceptions, settle consensus on the priority of the end of life and its care, and initiate parallel actions in all social sectors and public institutions. These activities will lead to the reorientation of policy, practice, and social/physical environments. We also need collaborative actions between science, research, business, and social enterprise in order to develop and implement systematic innovations that will transform citizens' relationship to the end of life and its care.

The most profound way in which public health transforms attitudes and promotes health and wellbeing in advanced societies employs the operational mechanism of nation-states, and particularly the concept of citizenship that moderates social life. By introducing the values of health and wellbeing in the arena of civic responsibilities, and cultivating the ethic of care in embedded and sustained social relationships, public health succeeds in reorienting attitudes and preserving social systems. In this way, health becomes part of the governance apparatus, and wellbeing offers itself as a valuable resource that guarantees effectiveness and sustainability. Public health priorities are translated into actions that promote health and wellbeing in all sectors and institutions of a given society. These actions involve the development of policies and practices that deliver measurable outcomes on particular health issues. The coordination of activities in social settings is oriented towards overall wellbeing. Compassionate Cities employ the same mechanisms to introduce and incorporate the end of life and its care in the public health domain.

Compassionate Cities (Kellehear, 2005) borrow inspiration from Healthy Cities (WHO, 1986; Hancock, 1997). Healthy City is a form of urban public health design that develops policies to impact upon health and wellbeing. Healthy Cities target the social determinants of health such as income, housing, food security, employment, and quality of life. This form of social innovation addresses social inequalities to support health, create healthy environments, sanitation, and ensure access to health care. It relies upon the commitment and engagement of the local community through participatory action, and the involvement of multiple stakeholders in policy-making with a clear vision, empowerment, and a sense of ownership. The definition of Healthy City prescribes the use of natural and social resources in collaborative and participatory development that serves and maximizes society's full potential. Demonstrable benefits for health and wellbeing prescribe the accumulation of 'community

capital' as a precondition and a challenge in developing healthy and sustainable communities in the twenty-first century (Hancock, 2001).

Compassionate Cities attempt to redress the imbalance and emphasis of Healthy Cities upon health, and include illness and social disadvantage in its considerations. The approach proposes an alternative framework of social action that is better able to accommodate social inequalities, marginal experiences, and the social determinants that cause morbidity and mortality.

A Compassionate City has several mechanisms in place that empower citizens to engage with the full range of end-of-life care experiences, and develop resilience and coping as a means to health and wellbeing. A basic ingredient in this process is the acknowledgement that people can die due to hardship, grief, and sorrow. For this purpose, Compassionate Cities engage in a wider social transformation achieved in the context of public articulation of diverse cultural narratives of loss and traditions of grief, and their integration in our understanding of social factors that undermine health, and determine death, dying, loss, grief, and caring. The culture of compassion is cultivated through informed empathy towards suffering. Policies translate into established cultural practices that prescribe a widespread commitment towards the aged, and those who experience marginality and social disadvantage. Compassionate Cities are inclusive societies that offer their inhabitants a range of opportunities to representation in care—beyond care offered by professional services. Policies are owned by citizens, and a range of services including palliative care services are easily accessible and designed for an empowered population in control of their end-of-life care.

### The Compassionate City Charter

Social change and the reorientation of the physical and cultural environment are necessary in the development of public health policies that serve end-of-life care purposes. A Charter for Action drives policy and practice development, and environmental reorientation processes. It involves a set number of actions that Compassionate Cities need to facilitate in order to achieve their objectives:

1. Schools have annually reviewed policies or guidance documents for dying, death, loss, and care.
2. Workplaces have annually reviewed policies or guidance documents for dying, death, loss, and care.
3. Trade unions have annually reviewed policies or guidance documents for dying, death, loss, and care.

4. Places of religious worship have at least one dedicated group for end-of-life care support.
5. Hospices and nursing homes have a community development programme involving local area citizens in end-of-life care activities and networks.
6. Cultural institutions (such as museums and arts centres) hold annual exhibitions on the experiences of ageing, dying, death, loss, or care.
7. An annual peacetime memorial parade represents experiences of loss, such as any life-limiting condition, child loss, suicide survivors, loss of animal companion, loss of emergency workers, and accident loss.
8. An incentives scheme celebrates and highlights the most creative compassionate organization, event, and people in the community.
9. A public media campaign showcases local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns'.
10. An annual art competition helps raise awareness about death, dying, loss, caring, and other marginal experiences.
11. Institutions, organizations, and communities that support socially disadvantaged populations (homeless, imprisoned, refugees, immigrants, and ethnic minorities, women's groups, mental health groups, and economically deprived communities) have plans in place for end-of-life care, including loss and bereavement.
12. The understanding of difference and diversity drives policy, practice, and cultural development in end-of-life care. Work in partnership with community organizations and social institutions must steer policy and practice development in directions that are representative, inclusive, and alleviate social inequalities present in end-of-life care, loss, and bereavement.

Local councils as civic authorities commonly hold the responsibility for supervising and overlooking the implementation of the public health end-of-life care intervention in the city. They ensure that all social sectors and public institutions are involved in the delivery of actions and intervene to provide support, guidance, additional resources, and exchange of expertise between actions. The design and delivery of actions is the product of participatory co-creation and engagement of citizens who own the policies, practices, and embody the desirable ecological reorientation in the city. Compassionate Cities can be developed incrementally and according to local needs. Consultations on their design and evaluation involves a collaborative and iterative process between development and practice among multiple stakeholders from all walks of life, social sectors, professions, and communities under the auspices of the civic authority.

## The Compassionate City Challenge

A number of cities in Britain and Europe have expressed interest in becoming Compassionate Cities. Limerick in Ireland, Seville in Spain, Londonderry and Sheffield in England are among recent examples. The challenge for cities that aspire to become Compassionate Cities is multi-dimensional—the process involves social change, during which our beliefs and perceptions of death, dying, loss and grief evolve, our attitudes towards care transform radically, and our relationship to governance changes.

The transition to a co-produced and participatory model of care in community settings cannot materialize unless we confront our fears, and let go of our belief in our inability to care—that makes us invest all our hopes and trust in professional care. A critique of community development in end-of-life care by Mahabhar et al. (2010) summarizes this challenge by simply asserting that caregivers in end-of-life care want to be looked after by professionals, and are fearful of empowerment. The critique also claims that it is actually hazardous to force carers into roles that carry responsibility and deprive them of health-care services. A Compassionate City does not deprive its citizens of professional health and social care. On the contrary, services adapt to the individualized needs of an elderly, involved, and empowered clientele that has a clear vision of its rights and responsibilities, and owns the decisions that affect their experiences of end-of-life care. Compassionate Cities foster continuity of care before, during, and after healthcare services. Professional health services and public health (end-of-life) care are complementary approaches because they have always been policy and practice partners. Compassionate Cities serve to cultivate a different relationship to power and governance—they represent an evolved way of thinking about health and death that requires system-wide, collaborative, and participatory solutions.

To implement Compassionate City models we need to deliver innovation action designs based upon the co-creation of policies and practices that coordinate end-of-life care in urban centres. An integral element of this new public health revolution will be the incorporation of end-of-life care considerations in *all policies*, rather than solely the development of policies in the end-of-life care field (for example, in policies for homeless populations, caregivers, and other groups which are at risk of morbidity and mortality, as well as in policies that regulate everyday life in schools, workplaces, and other social settings).

This brings us to our final challenge—the reconsideration of what we think of as public service provision. Ultimately, Compassionate Cities will challenge our perceptions of professional services through the introduction of a co-produced and participatory model of care delivered by citizens themselves in collaboration with professionals and other stakeholders. Policies will be flexible and

embedded within everyday processes of negotiation of complex experiences that intersect multiple areas of life. The adoption of an incremental and reflexive approach to development that builds upon partnerships and focuses upon positive outcomes for health and wellbeing in end-of-life care will safeguard the success of the transition.

## Conclusion

Palliative care has always been about 'whole person' care. This approach has identified the major components of the 'whole person' as encompassing the physical, psychological, spiritual, and social dimensions of being. As professionals, our care mission has been to address these with a service that has targeted all forms of distress at the end of life. We have usually confined our attempts to address social distress with professional services. We have worked with hospice volunteers to help with issues of quality of care, continuity of care, and balancing professional care with community participation. Public health end of life care takes this much further. Public health practices represent a change from recent ways of working with communities. In public health approaches we see a stronger and more radical emphasis on community partnerships and participation moving from neighbourhoods to the wider care institutions that govern and shape not only palliative care but everyone. This is recognition that if palliative care is to succeed in its ambition to care for the 'whole person' it must do so *earlier, inside and outside* of formal care, and *create alliances* with social institutions that participate in the creation and maintenance of the whole person—as citizen and not solely as patients—at the centre of our care. Therefore, public health end-of-life care aspires to strengthen the community and build new relations and partnerships. Professionals and care organizations can make a major contribution to this by expanding their self-conception as important hubs and actors in local care networks, and by recognizing that strengthening compassionate cities and communities could be a core mission of their behaviour, as professionals and fellow citizens. The history of public health demands that we recognize that end-of-life care—like current health care itself—is everyone's responsibility.

## References

- Abel J, and Townsend D. (2016). Developing community support networks at the end of life in Weston-super-Mare, UK. In K. Wegleimer, K. Heimert, A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.
- Abel J., Wake, T., Carey L.B., Rosenberg J., Noonan K., Horsfall D., Leonard R., Rumbold, B., and Morris, D. (2013) Circles of care: Should community development redefine the practice of palliative care? *BMJ Supportive and Palliative Care*, 0: 1–6.
- Bronfman G.H. (1989). Global change and our common future. *Environment*, 16(2): 16–13.
- Adelard E, and Thorpe A. (2009). Modern public health. In E. Wilson and M. Mahbala (eds) *Key Concepts in Public Health*. London: SAGE: Key Concepts, pp. 11–14.
- Armstrong D. (1993). From clinical gaze to a regime of total. *Health Education Journal*, 22(3): 114–119.
- Barnett K., Mercer S.W., Norbury M., Watt G., Wyke S., and Guthrie B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*, 380(9836): 37–43.
- Berry P, and Plannalp S. (2009). Ethical issues for hospice volunteers. *American Journal of Hospice and Palliative Medicine*, 23(6): 458–62.
- Brook J. (1999). From disease prevention to health promotion. *JAMA*, 281(11): 1030–3.
- Burbeck R., Candy B., Low J, and Rees R. (2014). Understanding the role of the volunteer in specialist palliative care: A systematic review and thematic synthesis of qualitative studies. *BMC Palliative Care*, 13: 3.
- Cassell, E.J. (2009). Suffering. In T.D. Walsh, A.T. Caraceni, R. Fainsinger, K.M. Foley, P. Lane, C. Gib, M. Lloyd-William, J.N. Olarte, and L. Radbruch (eds) *Palliative Medicine*. Philadelphia: Elsevier, pp. 46–50.
- Claxton Oldfield S, and Claxton-Oldfield, J. (2008). Some common problems faced by hospice volunteers. *American Journal of Hospice and Palliative Medicine*, 15(2): 121–6.
- Claxton Oldfield S, Hastings E, and Claxton-Oldfield, J. (2008). Nurses' perceptions of hospice palliative care volunteers. *American Journal of Hospice and Palliative Care*, 25(3): 169–78.
- Coupland V., Madden P., Jack R.H., Moller H. and Davies E.A. (2011). Does place of death from cancer vary between ethnic groups in South East England? *Palliative Medicine*, 25(4): 314–22.
- Dahlborg Lyckhage E. and Lindahl B. (2013). Living in liminality—Being simultaneously visible and invisible: Caregivers' narratives of palliative care. *Journal of Social Work in End of Life and Palliative Care*, 9(4): 272–88.
- Dunk, I.K. (1963). *Punk and Wagnalls New Standard Dictionary of the English Language*. New York: Funk and Wagnalls.
- Galles, M. (2016). *Palliative and End of Life Care in Scotland: The Rational for a Public Health Approach*. Scottish Public Health Network (ScotPHN).
- Grow E.K., Posa S.D., Sorebo S.D, and Dahl A.A. (2006). Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden. *Social Sciences and Medicine*, 63(9): 2429–39.
- Hannlin C. (1994). State medicine in Great Britain, in Porter, D. (ed.) *The History of Public Health and the Modern State*. Amsterdam: Rodopi.
- Hancock T. (1997). Healthy cities and communities: Past, present, and future. *National Civic Review*, 86(1): 11–21.
- Hancock T. (2001) People, partnerships and human progress: building community capital. *Health Promotion International*, 16(3): 275–80.
- Harding R., Fitzphannon E., and Chidgey-Clark J. (2012). Needs, experiences and preferences of sexual minorities for end of life care and palliative care: A systematic review. *Palliative Medicine*, 15(5): 602–11.

- Harrison J.D., Young J.M., Price M.A., Bulow P.N., and Solomon, M.J. (2009) What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer*, 17(8): 1117–28.
- Help the Hospices (2014). *New exhibition showcases rich legacy of hospice volunteering*. Press Release, February. Accessed at <http://www.hospice.com/ArticleView/rahd/10697/ArticleId/9258/View.aspx>
- Holt-Lunstad J. and Smith T.B. (2012) Social relationships and mortality. *Social and Personality Psychology Compass*, 6(1): 41–53.
- Horton S., Zammì, R. and Nio Ong B. (2016). Community partnerships: A public health approach to ageing, death, dying and loss. In K. Weiglertner, K. Heimert, A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.
- Hudson P., Quinn K., Kristjansson L., Thomas T., and Braithwaite M. (2008). Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care. *Palliative Medicine*, 22(3): 270–80.
- Illich I. (1976). *Medical Nemesis: The Expatriation of Health*. New York: Pantheon Books.
- Kiruphlagou A. and Kellehear A. (2016). The forgotten people in British public health: A national neglect of the dying, bereaved and caregivers. *BMJ Supportive and Palliative Care*, 6(2): 153–9.
- Kellehear A. (1999). *Health Promoting Palliative Care*. Melbourne: Open University Press.
- Kellehear A. (2011). Third wave public health? Compassion, community, and end-of-life care. *International Journal of Applied Psychoanalytic Studies*, 1(4): 313–23.
- Kellehear A. (2009). *Compassionate Cities: Public Health and End-of-Life Care*. New York: Routledge.
- Kellehear A. (2016). The Compassionate City Charter: Inviting the cultural and social sectors into end of life care. In K. Weiglertner, K. Heimert, A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge, pp. 76–87.
- Kessler D., Peters T.J., Lee L., and Parr S. (2005). Social class and access to specialist palliative care services. *Palliative Medicine*, 19(2): 105–10.
- Kickbusch I. (2007a). Innovation in health policy: Responding to the health society. *Gaceta Sanitaria*, 21(4): 338–42.
- Kickbusch I. (2007b). Adelaide revisited: From healthy public policy to Health in All Policies. *Health Promotion International*, 23(1). Doi:10.1093/heapro/dan006.
- Kickbusch I. (2009). Health literacy: Engaging in a political debate. *International Journal of Public Health*, 54: 131–2.
- Leonard R., Horsfall D., and Noonan K. (2015). Identifying changes in the support networks of end-of-life carers using social network analysis. *BMJ Supportive and Palliative Care*, 5(2): 153–9.
- Patel M. (2016). Compassionate Communities in Sandwell, West Midlands, England. In K. Weiglertner, K. Heimert and A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.
- Patterson R. and Hazelwood M. (2015). *Palliative and End of Life Care in Scotland: The Rational for a Public Health Approach*. Briefing Paper 5: Good Life, Good Death, Good Grief. Scottish Public Health Network (ScottPHN).
- Plausky S. and Host M.R. (2008). Communication issues at the end of life: Reports from hospice volunteers. *Health Communication*, 23(3): 222–33.
- Porter D. (1999). *Health Civilization and the State*. London: Routledge.
- Porter D. and Halbot P. (2002). Splendour and misery of epidemiology for evaluation of health promotion. *Revista Brasileira de Epidemiologia*, 5(1): 91–103.
- Porter D. and McQueen D.V. (2007). Modernity, public health, and health promotion. In D.V. McQueen and I. Kickbusch (eds) *Health and Modernity: The Role of Theory in Health Promotion*. New York: Springer, pp. 12–20.
- Richardson I., Humm A., and Richardson H. (2016). Community development and hospices. In K. Weiglertner, K. Heimert and A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.
- Sullivan J., and Paul, S. (2015) Understanding community engagement in end-of-life care: Developing conceptual clarity. *Critical Public Health*, 25(2): 231–8.
- Swobeger P., and Heller A. (2016). Ethics from the bottom up. In K. Weiglertner, K. Heimert and A. Kellehear (eds) *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.
- Wagner A., Dunton S., Cohen S.R., and Frappier A. (2009). Helping them live until the end: Volunteer practices in palliative home care. *Nonprofit and Voluntary Sector Quarterly*, 39(4): 734–52.
- Wongkha S. (2009). Determinants of health. In E. Wilson and M. Mahabala (eds) *Key Concepts in Public Health*. London: SAGE Key Concepts.
- Woolander E., and Ahlstrom G. (2012). The meaning and validation of social support networks for close family of persons with advanced cancer. *BMC Nursing*, 11: 17.
- Woolphar, K., Funk, L., Jakobsson, E., Ohlén, J. (2010) A critical analysis of health promotion and 'empowerment' in the context of palliative family care-giving. *Nursing Inquiry*, 17(3): 221–230.
- Worner M., and Susser E. (1996). Choosing a future for epidemiology: Eras and paradigms. *American Journal of Public Health*, 86(5): 674–7.
- Worner M. (1983). The complex tasks of the second epidemiologic revolution: The Robert G. Cookshank Lecture. *Journal of Public Health Policy*, 4(1): 8–24.
- The National Council for Palliative Care (2013). *National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2011–2012*. The National Council for Palliative Care: London.
- United Nations Department of Economic and Social Affairs (2013). *World Population Ageing*. New York: United Nations.
- United Nations Habitat (2010). *State of the World Cities 2010/2011: Bridging the Urban Divide*. United Nations Human Settlement Programme: Kenya.
- Waller E. (1999). *On Bereavement: The Culture of Grief*. Maidenhead: Oxford University Press.
- Weiglertner K., Heimert K., and Kellehear A. (2016). *Compassionate Communities: Case Studies from Britain and Europe*. London: Routledge.
- WHO (World Commission on Environment and Development). (1987). *Our Common Future*. Oxford, UK: Oxford University Press.

World Health Organization (WHO) (1986). Ottawa charter for health promotion.

In: *Health Promotion* 1/4: i–v.

World Health Organization (WHO), UNICEF (1978). Primary Health Care: Report of the International Conference on Primary Health Care. Alma-Ata USSR. 6–12 Sept. 1978. WHO. Genf.

Wittenberg-Lyles E., Washington K., Demiris G., Oliver D.P. and Shaunfield S. (2014).

Understanding social support burden among family caregivers. *Health Communication*, 29(9): 901–10.

Chapter

Comm  
issues  
pallia

Alexand

### Background to n

In the United Kingdom neonatal intensive care born with congenital c delivery, however just care (Bliss, 2017). The irrespective of gestatic had conditions diagno receive palliative care e many weeks, even mo active treatment along

One cannot underes end of life of an infant years after the infant h. Association of Perinat neonate, or infant with in care, from the point death, and beyond. It care following multid principles of palliative the quality of care infar therefore the integrati experience for the infar

Recent studies by Fr than the original estim being within the UK, a oids. This phenomena l