Psychosocial Issues in Palliative Care

A COMMUNITY BASED APPROACH FOR LIFE LIMITING ILLNESS

THIRD EDITION

EDITED BY MARI LLOYD-WILLIAMS

WITH A FOREWORD BY Stein Kaasa

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Edited by

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To my parents, sister, husband, children and friends for all their love, care, support and guidance and for forgiving me for probably spending far too much time on my work.

Foreword

The discipline of palliative care primarily focuses on the patient who has the disease—whether it be cancer or other chronic diseases. It is crucial to take psychosocial issues into consideration in order to deliver optimal palliative care. The patient-centered approach ought to be combined with a disease-centered approach in order to deliver optimal care. This combined approach is expected from the patients, the family, and from society.

Most textbooks in medicine focus mainly on the disease approach. This approach is well-covered, including new knowledge about pathology, epidemiology, diagnosis, and treatment of the disease. However, knowledge and competence in psychosocial issues are needed in order to combine the disease- and patient-centered approaches; this combination is seen in 'early integration of palliative care'.

The WHO already changed some of the content of their definition of palliative care, in 2002. It clearly states some fundamental issues related to organization, content, and competence in palliative care:

◆ For patients and families 'facing the problems associated with life threatening illness';

◆ From an organizational perspective, 'palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life';

◆ Palliative care should be performed 'through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment'

◆ Palliative care constitutes a broad approach to the patient's 'assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

Four main issues are debated today with their background in the WHO definition. These issues are also relevant for the needs of psychosocial care:

◆ Integration of palliative care early in the disease trajectory;

◆ Correct use of diagnostic tools, and methods to identify patients in need of treatment;

◆ Family involvement—a life-threatening disease will also have impact on the family;

◆ Patients with life-threatening diseases often suffer from several symptoms and signs in parallel; physical, psychosocial, and spiritual in nature.

In terms of content, psychosocial issues in palliative care are one of the main pillars of modern palliative care.

This book covers the main areas of psychological and social care. Many of the chapters give excellent updates, and more than that; the book discusses fundamental approaches to patient care and health care. A community-based approach is necessary in order to reach a basic goal in palliative care: to give the patients the possibility of staying at home as much and long as possible, and of dying at home if desired. The latter goals will probably need to be facilitated by involving end-of-life care in community care as well as a part of national public health policies. This book is therefore highly relevant for clinicians in general, and even more for palliative care specialists.

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Preface

I feel privileged to be writing a preface to the third edition of *Psychosocial Issues in Palliative Care: A community based approach*, and to be editing an edition that truly reflects the huge changes that have taken place in palliative care since the first edition was being prepared for production in 2002.

In 2002, palliative care was still a fairly new speciality and unheard of by many people including clinicians. At that time the definition of palliative care was as it is now, but the reality was that palliative care was confined in the vast majority of cases to those dying of cancer.

In the last fifteen years we have seen a much-needed shift in understanding, and an acceptance that palliative care can offer so much to patients living with all life-limiting conditions and provide much-needed support for their families. This new edition contains chapters exploring subjects from neonatal palliative care to supporting usually older patients living with dementia and frailty.

The global increase in longevity brings with it increasing demands on health and social care and the realisation that what many people need within our communities is a compassionate neighbour who is there to support, help, and guide. By empowering volunteers to work alongside health and social care professionals within communities, palliative care in its broadest sense can be extended to more people, with a possible reduction in demand for professionally-provided health and social care as a consequence. The pioneering work of Suresh Kumar in Kerala shows clearly how community volunteers can deliver total palliative care within their community.

However, much still needs to be done. The majority of those training in health and social care will have some exposure to palliative care, yet we still have situations where palliative care is not considered, or considered too late to make a difference, and where families are distressed and humiliated by the care, or lack of care, given to family members in the last days and weeks of life. Yes, this lack of care is often due to palliation of physical symptoms, but frequently also due to the lack of consideration and attempt to palliate the myriad of psychosocial aspects that make for good palliative care not only at the end of life but to all those living with life-limiting illness. It is with all of these situations in mind that the third edition of *Psychosocial Issues in Palliative Care: A community based approach* has been written, and the aim is that the book is accessible to patients, families, and volunteers as well as health and social care professionals.

Within this book there are a number of colour plates which are the work of people who attend the Waen Outreach Day Care, near St. Asaph in North Wales. In 2011, a group of volunteers linked with a very small welsh chapel decided to try to help and support those in their rural community who due to illness or older age had become isolated. Support is offered to all in need. From the first day in June 2011 when precisely two people attended (and were cared for by four volunteers!), it has grown to offer two days a week of day care to an average of fifteen people each day, all supported by volunteers with no paid staff, and has also extended to a practical befriending service supporting those living with life-limiting illness but who are too unwell to leave their homes.

In 2012–2013, the group were able to have an accomplished artist, Rhian Catrin Price, to attend the group weekly and to support people with dementia, cancer, and many other life-limiting conditions, along with some family members to use art as a way of expressing thoughts and feelings, and to have fun and laughter as they painted and developed their ideas. The project culminated in an exhibition in 2012, and Waen Outreach is delighted that Rhian still inspires and encourages the day care groups, in addition to those at home as part of the befriending service, to gain so much from art in all its forms. I am humbled to be able to include this art work and particularly grateful to Mrs Hafwen Roberts who has very kindly allowed her wonderful art work to be used as the cover for this third edition.

I am very grateful to so many people for their support and guidance for this third edition: my research team at the Academic Palliative and Supportive Care Studies group has helped shape its format; the service users who are engaged in our research programme gave perspectives and insights on what aspects would be invaluable for patients and family carers; all the contributors who so kindly agreed to write a book chapter in addition to hugely busy timetables and for delivery of the chapters on time; and all my clinical colleagues and academic colleagues at the Hospice and the University of Liverpool who are so ready to give wise counsel and advice on many aspects of this book.

Despite a busy academic workload, I consider myself first and foremost a clinician and it is in my weekly clinics that I learn so much about what did and what would make a difference to the patients' care. To all my patients who over the years have taught me so much and compelled me to strive for excellence in academic and clinical psychosocial care, I give my heartfelt thanks.

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Contents

Plates

The colour plate section includes work of the people who attended the Waen Outreach Day Care, near St. Asaph in North Wales. In 2012–2013 the group were able to have an accomplished artist Rhian Catrin Price attend the group weekly, helping to support people with dementia, cancer, and many other life-limiting conditions, along with some family members to use art as a way of expressing thoughts and feelings, and to have fun and laughter as they painted and developed their ideas, which culminated in an exhibition in 2012.

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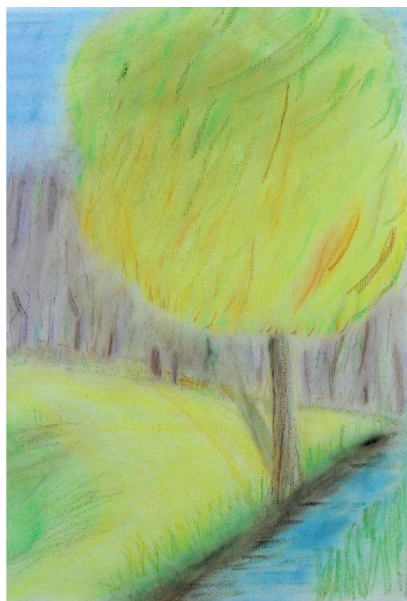

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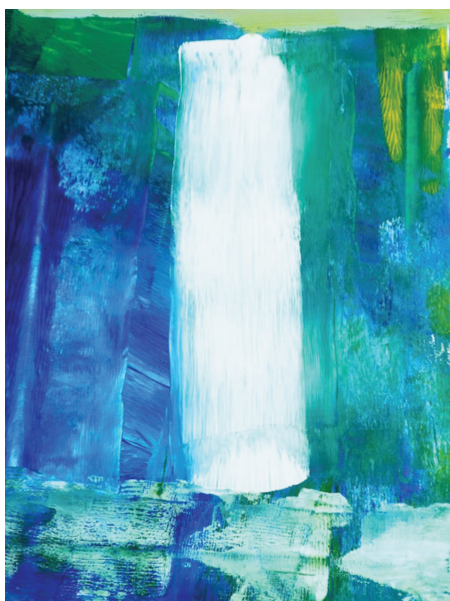
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The public health end-of-life care movement: history, principles, and styles of practice

Aliki 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 contagion 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). Characteristically, 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-focussed 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 focussed 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, psychosocial 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 Lindahi, 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 marginalied 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 ethic minority groups (Coupland 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.