



Palliative Care in Chronic Illness and Multimorbidity

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Abstract

Extended chronic phases of life-limiting illness and increasing multimorbidity present growing challenges that require a new approach to healthcare. A population-based approach is needed to harmonize policies, systems and services relating to chronic and palliative care. Partnerships are needed between different healthcare disciplines and specialties, and between health services and communities. Technology is likely to play an increasingly important role in transfer of information (including advance care plans) and enabling coordination of care. During periods of stability, patients and families should be actively involved in keeping well and helped to “hope for the best while preparing for the worst” to support sustained coping. A rapid response is needed to clinical events that helps people return to stability and takes preventive action against future events wherever possible. Transitions between chronic and terminal phases of illness and different settings (community, residential and hospital) need focal support to prevent people “falling through the gaps.” The optimal timing of referral to specialist palliative care services is the subject of ongoing debate and research. Consumer advocacy may play an important role in raising awareness and advocating for appropriate resourcing and changes to policy and legislation.

1 Introduction

Aging of the population and medical advances are leading to ongoing changes to the community who have palliative care needs. Illnesses that once were a major cause of sudden death have

become progressive and chronic in nature, resulting in many people living with extended and unpredictable cycles of wellness and disability. With increased longevity, people are also accumulating more than one chronic illness, together with associated symptoms and treatment side effects and progressive disability. This changing epidemiology demands innovative models of care. This chapter will use the World Health Organization (WHO) Framework for Innovative Care for Chronic Conditions to consider the implications of these changes for a needs-based approach to care from the perspectives of the patient/family, health organization, wider community, and policy.

2 World Health Organization (WHO) Framework for Innovative Care for Chronic Conditions

The WHO Framework for Innovative Care for Chronic Conditions (ICCC) is the most widely accepted framework for chronic care (World Health Organization (WHO) 2002). This framework identifies that people with chronic illness and their families require support not only from formal healthcare services but also their communities and the wider policy environment (see Fig. 1). Healthcare enablers are focused on promoting continuity and coordination, organizing and equipping healthcare teams and communities, using information systems to support coordination and communication, and supporting patients and families to self-manage health within the context of everyday life. This framework provides a useful lens for considering the supports required

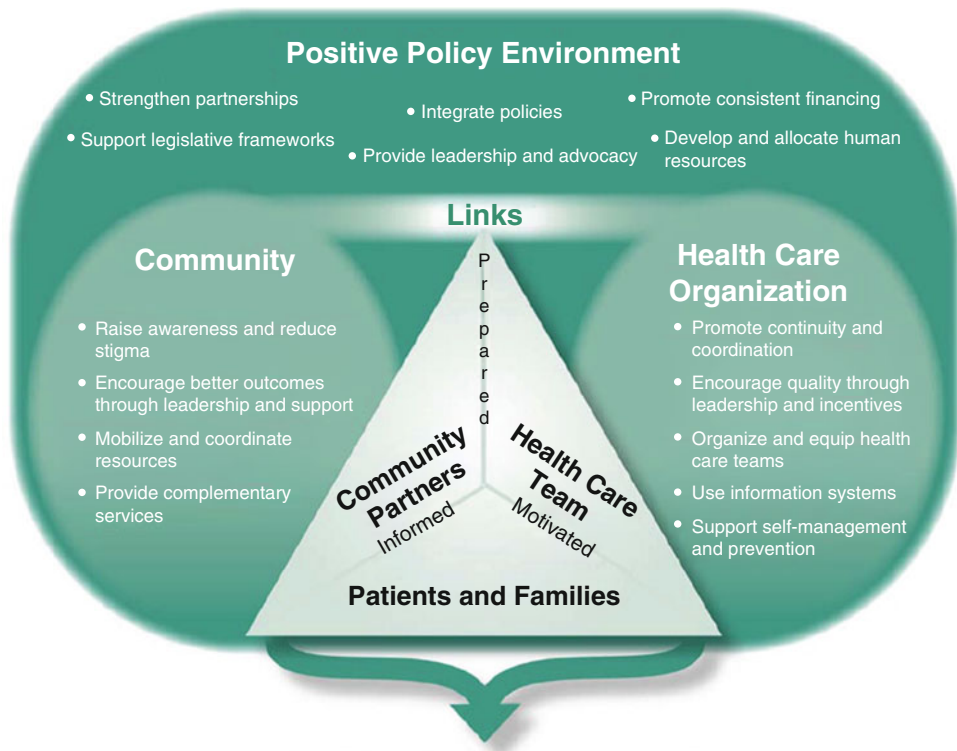


Fig. 1 World Health Organization’s Framework for Innovative Care for Chronic Conditions (World Health Organization (WHO) 2002)

by patients and families during the chronic phase of a life-limiting illness.

3 Defining Chronic Illness and Multimorbidity

3.1 Chronic Life-Limiting Illness

Treatment advances are enabling people with life-limiting illness to live for many years longer than previous generations (Canadian Hospice Palliative Care Association 2013). Life-limiting illnesses that are now frequently described as chronic include respiratory, heart, cerebrovascular, and kidney disease, HIV/AIDS, dementia and other neurodegenerative disorders (e.g., Parkinson’s disease), and many types of cancer. Worldwide, the most common chronic life-limiting illness is chronic obstructive pulmonary disease (COPD), affecting 26.6 million people in 2004 (World Health Organization 2004). An

analysis from the UK found cancer to be the most costly for healthcare services but dementia to have the greatest social care costs (Luengo-Fernandez et al. 2012).

For some of these diseases, such as dementia, medical advances have led to incremental rather than exponential benefits. But for cancer in particular, developments over the past decade in targeted therapies have been profound. This has led to more recent and explicit consideration of what is meant by “chronic” for cancer than for other life-limiting illnesses. While references to cancer as a chronic illness go back more than half a century, definitions have changed over time to reflect developments both in treatment and healthcare (Harley et al. 2015; McCorkle et al. 2011; Phillips and Currow 2010). The most recent definition by Harley et al. (2015) refers to a “chronic phase” that is finite, unpredictable, and associated with a burden of symptoms, treatment side effects, and medical appointments (see Box 1).

Box 1 Working definition of the chronic phase of cancer provided by Harley et al. (2015), p. 344)

- A diagnosis of active, advanced, or metastatic cancer that cannot be cured.
- Active anticancer treatments are available that can lead to symptom control, slow disease progression, or prolong life.
- The patient is not considered to be at the end stage of cancer.
- The chronic cancer phase ends when the cancer no longer responds to treatment and there are no treatment options available that are expected to slow disease progression or prolong life. Patients will leave the chronic phase when they are expected to have only months to live.

The expansion of genomics, proteomics and metabolomics will continue to impact on improved cancer diagnosis, prognostication and treatment decisions (Roychowdhury and Chinnaiyan 2016). In the future, advances are likely to result in better matching between therapeutic agents and the molecular characteristics of the individual patient. Currently, however, the new generation of advanced cancer treatments are available for only some tumor types and have variable efficacy between individuals. For many, treatment response leads to recovery commensurate with prior functional status. However, for others, adverse effects such as febrile neutropenia can sometimes confer a similar trajectory to that traditionally associated with heart and lung failure (see Fig. 2).

Advances in treatments for heart and lung failure have also extended life and increased the variability in trajectories, decreasing the likelihood of acute events but often at the expense of significant disability. The field of mechanical circulatory support for heart disease has seen particular growth, with important developments in pacemakers, implantable cardioverter defibrillators (ICDs), and ventricular assist devices (VADs). Most recently, VADs have transitioned from being “bridge to transplantation” devices to destination therapy for critically ill patients with heart failure, allowing individuals

to live at home (Abraham and Smith 2013). While organ transplant success rates have improved and eligibility criteria have expanded, those with multimorbidity are less likely to benefit, and an inadequate supply of organs means that many people die on the waiting list. Emergent developments in dialysis include wearable artificial kidneys that may lead to much less interruption of everyday functioning during dialysis.

The healthcare needs conferred by benefits and burdens associated with expanding chronic phases of life-limiting illnesses will be discussed in the next section, which is concerned with the “healthcare organization” component of the WHO’s ICCF Framework.

3.2 Multimorbidity

In the absence of a clear definition, the term “multimorbidity” is typically operationalized as the coexistence of two or more long-term health conditions (National Institute for Health and Care Excellence 2016). The related term “comorbidity” assumes that a particular condition is the main focus and refers to each “additional co-existing ailment” (Feinstein 1970, p. 455). Distinctions between constructs such as “health condition” or “ailment” and developmental disorders (e.g., learning disability), symptoms (e.g., chronic pain), functional status (e.g., cognitive impairment), geriatric syndromes (e.g., frailty, falls), sensory impairment, and alcohol/substance misuse vary between conceptualizations; sometimes, it may also be difficult to distinguish these based on aetiology. Multimorbidity in the context of chronic life-limiting illness may either refer to more than one life-limiting disease (e.g., lung cancer and COPD) or else to diseases that have potential to become life-limiting (e.g., chronic renal disease) or non-life-limiting diseases (e.g., skin conditions) presenting comorbidly with a life-limiting illness. Chronic illnesses that are not normally life-limiting but may increase symptom burden and the complexity of care needs include diabetes, musculoskeletal disease, and mental health disorders.

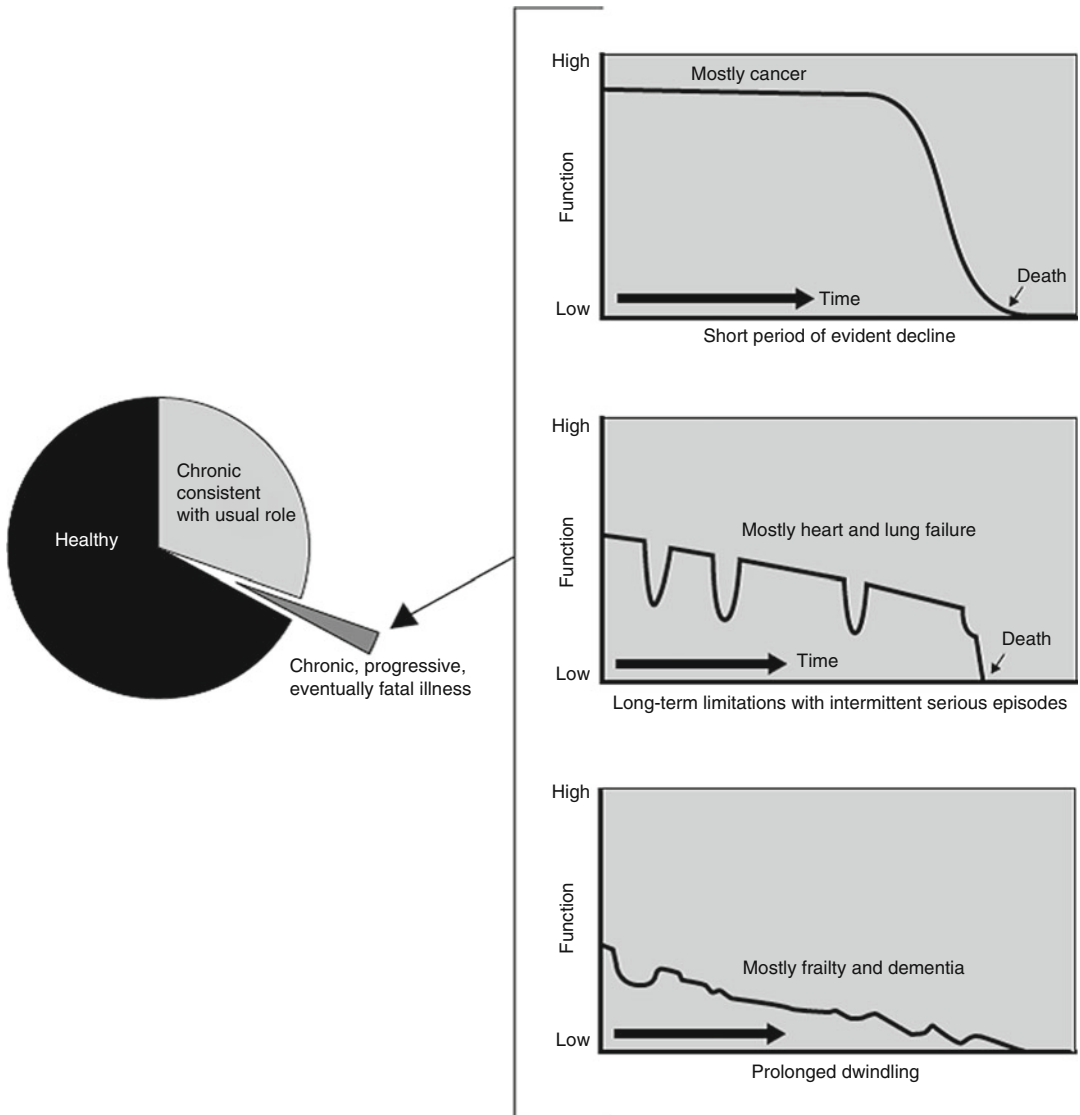


Fig. 2 Chronic illness in the elderly typically follows three trajectories (Lynn and Adamson 2003). Note that adverse effects associated with new treatments for some

advanced cancer types mean the trajectory can sometimes resemble “long-term limitations with intermittent serious episodes”

Estimates of the prevalence of multimorbidity in clinical populations have varied from 20% to 98% depending on the population and definition of morbidity, but are generally more than 50% – higher than the prevalence of any single chronic disease (Marengoni et al. 2011). Multimorbidity has consistently been associated with higher age, female sex, and lower socioeconomic status. Multimorbidity is also increasing in prevalence, with the US National Health Interview Survey

data collected over two time periods demonstrating a 37% increase in multimorbidity in adults aged 65 years of age and older between 1999–2000 and 2009–2010 based on self-reports of two or more of nine listed conditions (hypertension, heart disease, diabetes, cancer, stroke, chronic bronchitis, emphysema, current asthma, and kidney disease) (Freid et al. 2012). Increases over time were especially notable in hypertension, diabetes, and cancer. Multimorbidities involving

life-limiting illness identified as common in either this study or others have included hypertension combined with heart disease or cancer, and angina with asthma and COPD.

Measurement of multi- or comorbidity has tended to focus on relative burden (de Groot et al. 2003). Many such measures weight comorbidities according to their association with mortality. However, the burden for any given condition is highly variable, especially where the additional impact of each new morbidity is synergistic with others, resulting in greater overall burden than expected based on simple accumulation (Verbrugge et al. 1989). Understanding the mechanisms by which these synergies occur is a priority for future research because of its potential for informing which interventions may offer the most cost-effective opportunities for improvement in outcomes.

4 Elements of the WHO's Framework for Innovative Care for Chronic Conditions as Applied to Chronic Life-Limiting Illness and Multimorbidity

4.1 Healthcare Organization

4.1.1 Self-Management

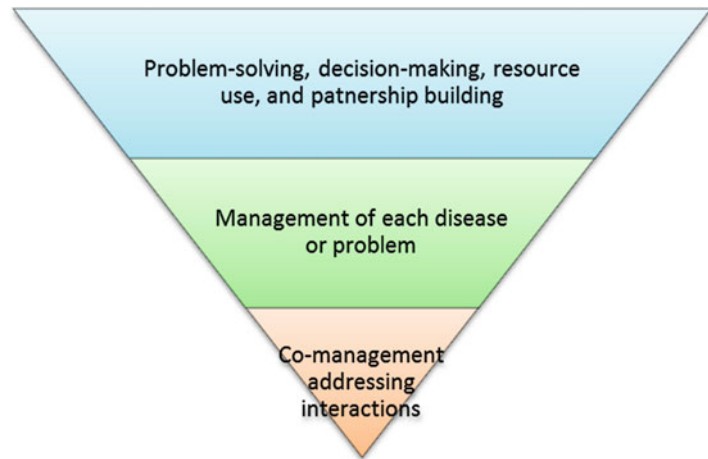
The problems experienced by patients and families in each of the domains of palliative care – physical, psychological, social, and spiritual (World Health Organization 2002) – will vary according to a large range of factors, including the life-limiting illness in question, comorbidities, living situation, occupational roles, financial status and social support (Murray et al. 2005). However, for most people most of the time, support will be delivered within a self-management paradigm. Self-management is best promoted within a partnership or collaborative model, in which patients are considered experts on the experience of illness and its relationship to their daily life, while health professionals assume a coaching role aimed at building confidence in one's ability to manage (“self-efficacy”) as well as necessary skills themselves (McCorkle et al. 2011).

As well as practical aptitude in disease and symptom management, self-management skills include more generic abilities in: problem-solving; decision-making; finding and using information, services, and other resources; and building further partnerships with health professionals as needed (Lorig and Holman 2003). In addition to benefits to quality of life from improved symptom and disease management, development of self-efficacy has itself been associated with a range of positive psychosocial outcomes, perhaps because of an increased sense of control (Marks et al. 2005).

Self-Management in the Context of Multiple Comorbidities

Limited evidence is available for self-management interventions designed specifically for people with multiple comorbidities. However, a layered approach may be required where a foundation of generic skills is developed alongside skills in managing each disease and its interactions with others (see Fig. 3). An initial focus on each separate disease should be aimed at helping patients better understand the processes and consequences of each before considering the reasons and ways that management needs to be modified to accommodate interactions between symptoms and side effects from other illnesses. Developing an understanding of this kind is needed to identify safety considerations and clarify which aspects of the self-management plan are most important. Rather than expecting patients to “comply with doctor's orders,” the partnership model of care supports patients in developing their own management goals and making informed choices among management options according to their priorities and preferences. Regardless of whether doctors are collaborative or paternalistic, patients will often seek participation and control by modulating the medication dose to find an appropriate balance between symptoms and side effects (Lockett et al. 2013) or by using complementary and alternative medicines in addition to, or in place of, those prescribed (Bishop et al. 2007). Encouraging open, honest communication about these decisions will not only improve management safety and quality but also foster patients'

Fig. 3 Suggested foci for self-management support in people with multimorbidity, starting with generic skills identified by Lorig and Holman (2003)



feelings of participation, control, and shared responsibility in “co-producing” their own healthcare and health (Batalden et al. 2016). A partnership approach is especially essential in the context of multimorbidity because the feasibility of treatment for any given condition often becomes questionable due to competing priorities and burden from managing others (Petrillo and Ritchie 2016). Guideline recommendations also note that treatments approved for individual health conditions should be used with caution because the evidence on which approval is based has often been collected in samples specifically excluding those with multimorbidities (National Institute for Health and Care Excellence 2016).

Self-Management in the Context of Palliative Care

Self-management pertains not only to the medical aspects of illness and symptoms but also to managing changes in everyday functioning and the psychosocial consequences of chronic illness (Corbin and Strauss 1988). Unpredictability of prognosis and daily fluctuations in symptoms have led people living with chronic life-limiting illness to liken the experience to being on a “roller coaster” (Brannstrom et al. 2006). Even in the terminal phase, patients and families may continue to hope for a cure (Clayton et al. 2008); in the chronic phase, there are likely to be several

transitions in hope as new treatments succeed or fail and symptoms worsen or abate. The “long-haul” nature of the chronic phase also means that maintaining a degree of normalcy is likely to be a priority for many people (Ohman et al. 2003). Where there are periods of stability, daily concerns may shift away from health altogether either because life events take precedence or people actively seek respite from the “medicalization” of their lives (Mendes 2015). However, even during periods where people are well enough to carry on everyday roles such as working and parenting, there may be insidious impacts from illness. For example, healthcare costs can sometimes mean that patients have to extend their working hours at a time when they might otherwise be reducing them to enjoy other aspects of life while they remain well (Zafar et al. 2013). This challenge is likely to become increasingly common even in countries with universal healthcare because of the delay in approval for new treatments and their high associated costs. The psychological impact on dependent children may also be especially complex during the chronic phase because of periodic reversals in the role of parents as the giver versus recipient of care and associated expectations placed on children (Kennedy and Lloyd-Williams 2009). While evidence is lacking, it may also be that “false hope” during periods of wellness and consequent disruption of anticipatory grief can have

a negative impact on bereavement outcomes after a parent dies.

4.1.2 Advance Care Planning

Psychosocial impacts of the above kinds require a balanced approach to support that empowers patients and families to self-manage their response to the challenges of chronic illness by helping them “hope for the best while preparing for the worst” (Feuz 2012). Evidence suggests that patients and families tend to welcome honest and accurate information communicated with empathy and understanding. Formally structuring this through a process of advance care planning (ACP) will enable information to be contextualized within an individualized discussion regarding patient and family values and preferences for the future. Clinicians are often reluctant to discuss ACP with people before the terminal phase for fear of undermining hope and demotivating self-management (Lockett et al. 2014b). However, when appropriately facilitated, ACP is viewed by patients as empowering rather than damaging to hope (Davison and Simpson 2006). Delaying ACP may also mean that patients lack time to thoroughly consider and discuss their wishes and risk a loss of decision-making capacity, especially for people with organ failure or respiratory disease who may face a sudden clinical crisis or increasing cognitive impairment (Shen et al. 2016).

Key considerations for ACP during the chronic phase concern the unpredictability of the disease course and likelihood that preferences for life-sustaining treatment may change dramatically in response to clinical events. These considerations warrant a “slow start” and iterative approach to ACP that:

- Helps patients consider the relative possibilities of a range of future scenarios that may each become more or less likely over time
- Enables “death awareness” to develop gradually, allowing time for adjustment (Sanders et al. 2008)
- Ensures that ensuing directives are both well considered and current

Approaches should be aimed at anticipating, identifying, and providing focal support during

transitions from the chronic to terminal phases of life-limiting illness, which may otherwise lack the same attention as diagnosis. A good example of this kind of transition concerns the decision to withdraw medicines aimed at treating underlying disease. Advance discussion regarding the net benefits of continuing or discontinuing such medications as goals of care change may help frame this decision as a positive choice rather than “giving up” and decrease the likelihood that patients continue medications inappropriately (Reeve et al. 2017).

Patients with organ failure commencing life-sustaining treatment require special consideration for ACP. The dynamic ratio of benefit to adverse effects for treatments like dialysis needs careful discussion, especially in the context of increasing age and multimorbidity (Dasgupta and Rayner 2009). Patients awaiting transplant and their families will also require specific information and support to deal with uncertainties regarding organ availability and transplant outcomes (Larson and Curtis 2006). Finally, ACP for people with heart failure may need to include consideration of resuscitation status and device therapy at the end of life. Recent studies found that the majority (85%) of ICD recipients believed that “switching off” the device equated to immediate death (Stromberg et al. 2014), and few realized that almost a third (31%) of dying patients with ICDs receive shock therapy in the last 24 hours of life (Kinch Westerdahl et al. 2014). Shock therapy at the end of life is likely to cause discomfort to patients and distress to family, highlighting the importance of developing a deactivation plan.

While self-management and patient empowerment through choice are key principles in the care of people with chronic life-limiting illness, it is important to recognize that:

- Some patients will want more of an active role than others
- There is a risk of overburdening patients and families
- Caution is needed to avoid any sense of blame being attached to perceived failures in self-management or “bad” choices (Thorne et al. 2016)

4.1.3 Services and Coordination

Care Coordination

Care coordination is the most significant challenge in delivering healthcare to people with chronic life-limiting illness and multimorbidity. Unlike people at the end of life, those in the chronic phase are likely to require treatment from one or more specialties focused on their underlying condition – for example, oncology, cardiology, or respiratory medicine. At the same time, care for people with multimorbidity requires a shift from single disease practices to a patient-centered framework that recognizes the broad range of services that are likely to be needed, the burden faced by the patient and family both from the illness itself and its management, and the duration of time people will be living with the illness (National Institute for Health and Care Excellence 2016; Petrillo and Ritchie 2016). The complexity of care needs and difficulty in successfully integrating care associated with multimorbidity is evidenced by the higher rates of unplanned and emergency care seen in this population (Lehnert et al. 2011; Marengoni et al. 2011).

Case management is the service element with perhaps the most evidence for coordinating care and improving outcomes: in chronic illness (Ouwens et al. 2005); during the chronic phase of life-limiting illness (Aiken et al. 2006); for people with multimorbidity (Smith et al. 2012); and at the end of life (Lockett et al. 2014a). Case management has been found cost-effective for older people living in the community over 1 year due to avoided hospitalizations and GP visits (Black 2007). However, cost-effectiveness for people with chronic life-limiting illness has yet to be evaluated and is likely to be a “moving target” as the chronic phase becomes further extended through medical advancements in the future. Given the likelihood of exacerbations and decline in people with life-limiting illness, case management needs to pay special attention to timely prevention, response to acute events, and support for transitions to and from hospital as needed, in addition to helping patients maintain health and functioning during periods of stability.

A special challenge is faced by healthcare services trying to provide integrated care to people

with chronic life-limiting illness and multimorbidity living in nursing homes. Models tested by research have typically involved in-reach from a specialized healthcare team either to deliver direct care or to train and support clinical champions within the nursing home (Goodman et al. 2016). To effect more sustainable change, models of care are needed that value and motivate nursing home personnel, support joint priority setting, and foster ongoing relational working. Successful models will likely need to make use of systems and processes for encouraging regular communication and shared decision-making, such as case conferencing (Phillips et al. 2013). Systems also need to be in place for formally monitoring changes in residents’ needs and communicating information between nursing homes and acute care during transitions.

Managing the Transition from Chronic to Palliative Care

Changes in the trajectories of life-limiting illnesses mean that the optimal timing of transition from a chronic to palliative approach to care may be becoming increasingly difficult to identify and will vary between individuals (Burge et al. 2012). For many people, the optimal transition may be gradual and draw on elements of both approaches concurrently for much of the trajectory (see Fig. 4).

Involvement of Specialist Palliative Care Services

While palliative care has traditionally focused on the last 6 to 12 months of life, its ethos has much to offer those with complex care needs at any stage of the disease trajectory (Agar et al. 2015). Palliative care has an established philosophy that aims to help people focus on “living with” rather than “dying from” advanced illness. It focuses on the whole person rather than disease and is needs-based rather than discipline-based in its approach to delivering care. Indeed, if we assume that palliative care should be assigned according to needs rather than prognosis, it may be that a palliative approach is relevant from diagnosis onward for patients with life-limiting illness of any kind (Beernaert et al. 2016).

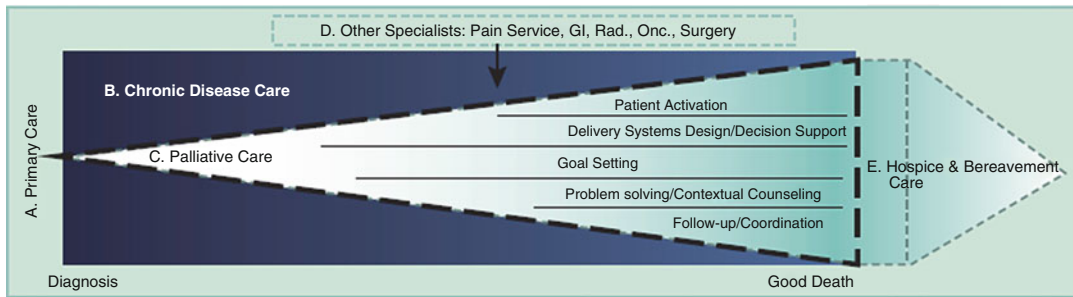


Fig. 4 Model of concurrent chronic disease palliative care for people with cancer (Canadian Hospice Palliative Care Association 2013, p. 5)

At the same time, it is important to distinguish between palliative care as an approach to care versus specialist palliative care services (SPC). Worldwide, resourcing of SPC is insufficient to enable its provision to everyone with life-limiting illness from the time of diagnosis; nor is this necessarily desirable (Glare and Virik 2001). In Australia, the New South Wales Department of Health (2007) has identified three populations of people with life-limiting illness with differing levels of need regarding input from SPC, namely, (A) those whose needs can be met almost entirely within primary care, (B) those who are predominantly managed within primary care but who experience exacerbations that require support or intervention from SPC, and (C) those with complex needs who require direct and intensive intervention from SPC. It seems likely that people in the chronic phase of life-limiting illness will generally be included in the first or second of these categories and will also be spending most of their time in the community rather than in the hospital. For these people, the responsibility for care coordination will likely sit with primary care. Indeed, it could be said that primary care health professionals are themselves the “specialists” in managing chronic illness.

The question of appropriate timing for SPC referral is the subject of much ongoing debate. Interest in “early” referral was sparked by the 2010 publication of a landmark trial which found this contributed not only to quality of life but also survival for people with advanced lung cancer (Temel et al. 2010). However, the mechanism by which early referral might have

contributed to this outcome remains unclear (Irwin et al. 2013), and little research is available on referral even earlier in the disease trajectory or for other disease groups. Published guidance has tended to make use of the question “would you be surprised if this patient died in the next 6 or 12 months?” taking into account disease progression and general indicators such as functional decline, weight loss, and unplanned admissions (Boyd and Murray 2010). However, the UK Gold Standards Framework has acknowledged increasing difficulties with predicting prognosis and now advocates “instinctive, anticipatory and insurance-type thinking” which lowers the threshold at which end-of-life care planning and referral to SPC should be undertaken (National Gold Standards framework 2011). Based on this reasoning, there may be many patients with chronic illness and multimorbidity not traditionally considered life-limiting who might meet criteria for – and benefit from – referral to SPC, including people with diabetes and nonhealing foot disease (Calam et al. 2012).

A special role for SPC in the care of people with multimorbidity is supported by research suggesting that cost savings may increase with the number of comorbidities (May et al. 2016). However, further discussion is needed both within SPC and across specialties to better define the parameters of optimal SPC service provision and, if necessary, inform advocacy for funding to increase capacity. Promotion of earlier referral to SPC would also need to change perceptions among people with chronic illness and health professionals that palliative care is reserved for

people who are imminently dying (Mason et al. 2016). US research suggests that both patients and health professionals may favor the term supportive rather than palliative care even during the terminal phase (Maciasz et al. 2013). While a change in terminology of this kind is controversial in the context of end-of-life care, the fact that supportive care is currently used in oncology to refer to management of problems associated with active treatment suggests it may be a good fit for the chronic phase of life-limiting illness.

4.1.4 Information Systems

The WHO's ICCC Framework identifies information systems as being critical in organizing care for people with chronic illness. In the context of life-limiting illness, these need to include systems for sharing up-to-date information about ACP at the point of care. Transitions between care settings (e.g., aged care and hospital) are especially notorious for hampering communication about ACP as well as current care plans, test results, and medication management (Coleman 2003). Little evidence is available to support particular information system approaches, although several countries have implemented national patient healthcare information systems that enable patients to upload and share ACP information along with other medical records if they so wish. Uptake of these systems to date has been limited, and little research has been conducted on the impact on processes and outcomes of care. A recent systematic review of personal health records found evidence of benefit for chronic conditions such as HIV, asthma, and diabetes but none for cancer or multiple sclerosis (Price et al. 2015). Benefit seemed to be related to personal health records' potential for monitoring and informing self-management.

4.2 Community Perspective

The WHO ICCC Framework recognizes the need to build community capacity to support people with chronic illness in addition to formal health services. Recently, a global movement called Compassionate Communities has emerged with

the aim of developing community "death literacy" and capacity to support people who are dying and their families. The movement is based on a premise that, compared with previous generations, modern communities tend to have less awareness about death and dying and weaker local networks to provide support in times of need. Research has consistently found the public to have a limited understanding of advanced illness and palliative care (Cox et al. 2013).

Initiatives aimed at improving death literacy include those promoted by the Compassionate Cities program which include "death cafe" and "death over dinner" events where people talk about their experiences of bereavement or caring for someone who is dying or death and dying more generally, visual and performing art projects, initiatives within workplaces and schools to raise awareness, and memorial events. Initiatives of this kind may be run by local government, healthcare organizations, or citizen groups. One of the largest and longest running public health and advocacy campaigns of this kind has been the Project on Death in America (PDIA) run by the nonprofit foundation, the Open Society Institute (Aulino and Foley 2001), which from 1994 to 2001 funded 94 projects to a sum of US\$34 million.

Initiatives developing community capacity to support people who are dying and their families have been primarily aimed at enabling people to die at home through establishment and support of social networks that meet practical needs (e.g., preparing food, shopping), sharing knowledge about services, and, in some areas, healthcare professionals to provide training to help carers deliver care (Sallnow et al. 2016). The optimal interface between formal healthcare and community initiatives of this kind is the subject of ongoing debate. A central tenet of the Compassionate Communities movement is that care for people with life-limiting illness is "everybody's business." For some, a goal of demedicalizing death and dying is a natural corollary. Healthcare services may be viewed as "essential but not central" to care for people who are dying, with some arguing that their role is primarily to equip communities with the skills to care for themselves, providing as little

direct intervention as possible (Abel 2017). This view differs from the partnership model to self-management introduced above in that service provision is seen as community-centered rather than patient- or even family-centered.

It is unclear whether public awareness has kept pace with changes in disease trajectories, but it seems likely that this will be similar to death literacy in needing focal education and support to increase community capacity. Nongovernment organizations (NGOs) (e.g., Macmillan Cancer Support [UK], Lung Foundation Australia) may play an important role in raising awareness and advocating for resources to meet the needs of this population. Many NGOs already provide support well-suited to the needs of people during the chronic phase of life-limiting illness, including telephone helplines, wellness programs, and peer support networks. These interventions have potential to respond more quickly than healthcare systems to changing illness trajectories. They also present immediate opportunities for community engagement and leadership.

4.3 Policy Perspective

Community initiatives form just one part of a public health approach long since advocated for both palliative and chronic care (Institute of Medicine 2012; Sepulveda et al. 2002). A population-level approach that integrates policies in these two domains is needed to ensure coherence, efficiency, and progress toward addressing disparities in access to services and outcomes (Murray et al. 2009). A population-based approach will also distill the special requirements of the burgeoning population of people with chronic life-limiting illness and how these differ from palliative and chronic care populations more generally. Surveillance measures are also needed to measure progress, including a composite of patient-reported measures (e.g., life satisfaction and well-being), healthcare system (e.g., access), and population-level measures (e.g., clinical, access, and funding policies) (Institute of Medicine 2012). Cost-effectiveness analyses are needed that compare different public health models and take into account

societal costs and benefits at a population level (Dzingina and Higginson 2015).

The ICC Framework emphasizes the need to support chronic care through policies aimed at appropriate financing and partnership building. Many of the world's health systems remain geared toward a single-disease model rather than integrated care (Bayliss et al. 2007). Funding models are needed that acknowledge multidisciplinary contributions and clinician time spent on preventive healthcare, psychosocial support, and self-management. In practice, this may mean moving remuneration away from a fee-for-service basis to the patient or population level (Oliver-Baxter et al. 2013). This approach is being adopted by a new Australian initiative called "Health Care Homes," which aims to integrate care for people with chronic and complex care needs across community and acute settings. Bundled payments, made to general practices and Aboriginal Medical Services, can be managed between services as needed and are responsive to changes in patients' needs over time, making this model especially suited to people with chronic life-limiting disease whose needs are likely to fluctuate.

Legislative frameworks presenting a barrier to outcomes for people with chronic life-limiting illness include those relating to approval and funding of new treatments. The need for these frameworks to be more responsive to emerging evidence has become an increasing focus in the popular press. Consumer advocacy is likely to be key in driving changes to policy and legislation to better align these with the needs of people with chronic life-limiting illness, as it has been in recognizing other patient populations, such as cancer survivors.

5 Conclusion and Summary

This review of the changing nature of life-limiting illness and associated healthcare needs with reference to the WHO's Framework for Innovative Care for Chronic Conditions shows the need for advocating a population-based approach aimed at harmonizing policies, systems, and services relating to chronic and palliative care. Elements of the

ICCC model requiring special support include healthcare coordination and community awareness and capacity building. More evidence and debate is needed to inform the question of optimal timing for referral to specialist palliative care services. NGOs and consumer advocacy will be expected to play an important role in advocating for appropriate resourcing and changes to policy and legislation.

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