67

Palliative Care, Frailty, and Older People

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Contents

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Abstract

This chapter provides an overview of the symptoms of frailty, the tools used to recognize and assess older people living with frailty such as the frailty phenotype and frailty index, and some of their common palliative care needs. Further, it details some of the perceived challenges of frailty to current palliative care practice, namely, recognizing dying, multiple morbidities and symptom burden, and the focus or goals of care. Palliative care for older people with frailty requires a broader disability rather than a single disease focus. Coordination and interdependencies with other care providers become as important as the discrete patient/professional clinical encounter. The centrality of the older person with frailty and their "family" living and dying over time means the social environment becomes paramount local resources; support and the interplay between services and community are vital. While evidence on the best ways to provide palliative care to this population is still developing, the chapter offers some examples of current services and suggests key elements derived from the literature and practice. The authors suggest there is a moral and clinical imperative for palliative care services to engage with older people with frailty and their caregivers, both lay and professional. This imperative brings opportunities and challenges, including revaluing living and dying rather than an overemphasis on care in the last days of life and remodeling palliative care services to focus more on need than diagnosis and the reorientation of palliative care, so that it can be integrated with older people's services.

1 Introduction

1.1 Frailty and Palliative Care

Frailty is a complex medical syndrome, combining the effects of natural aging with the outcomes of multiple long-term conditions and loss of fitness and reserve. Frailty has been termed "the most problematic expression of population ageing" (Clegg et al. 2013) and, as such, is an increasingly important consideration for palliative care. Globally, the number of people living and dying in old age is growing; by 2050 21.5% of the world's population will be aged over 60. People living into late old age are the fastest growing sector of the population (particularly in more economically developed regions),with the number of people aged over 80 growing at twice the rate of people over 60 years (McNicoll 2002). Most people who need palliative care are older adults. Increasingly, the need will be for palliative care associated with older people dying with multiple, long-term conditions and frailty (World Health Organization 2015).

Yet older people with frailty are sometimes called the "disadvantaged dying." They constitute a section of society with poorer end-of-life care experiences and less access to palliative care than other groups (Gott and Ingleton 2011). Reasons for this include siloed services related to singular diseases, perceptions that palliative care referrals relate to medical condition rather than need arising from the interplay of multiple conditions, and under-recognition of palliative care needs in older people, including from older people themselves (Hall et al. 2011). Precisely because people have lived with their symptoms for so long, older people and those around them might overlook needs, normalizing them as part of growing old (Teunissen et al. 2006). Palliative care with the emphasis on quality of life and person-centered approaches is a vital intervention for older people with frailty; indeed Morrison et al. (2003) PX111 (Morrison et al. 2003) note "*frailty is the quintessential model for palliative care in older adults as optimal medical treatment for the frail patient typically includes preventive, life-prolonging, rehabilitative, and palliative measures in varying proportion and intensity based on the individual patient's needs*."

Older people living and dying with frailty for palliative care raise both challenges and opportunities. This chapter provides an overview of the symptom complex of frailty, the tools required to recognize and assess older people living with frailty, and the potential need for palliative care. Further, it details some of the perceived challenges of frailty to current palliative care practice, namely, recognizing dying, multiple morbidities and symptom burden, and the focus or goals of care. We argue there is a moral and clinical imperative for palliative care services to engage with older people with frailty and their caregivers, both lay and professional. Such an imperative will help to bring the realization of the WHO 2014 palliative care resolution (WHO 2014) – to be an essential healthcare service for people with chronic and life-limiting illness. Palliative care needs to move its focus from a discrete service with an overemphasis on care in the last few days of life to a service integrated with the treatment of long-term conditions and with older peoples' services.

1.2 What Is Frailty?

In practice, the term frailty is used as both a general descriptor and to signify a discrete medical syndrome. Individuals whose health status indicates they may be susceptible to decline may be described as "becoming frail." Those people who meet specific diagnostic criteria are identified as having the medical syndrome of frailty. This chapter focuses on the latter. Hence, while cognitive decline is a component of frailty (considered later in the chapter), the distinctive palliative care needs of people with severe cognitive impairment or dementia are discussed elsewhere within this publication.

Frailty is a distinctive health state related to the aging process in which multiple body systems gradually lose their inbuilt reserves, leaving a person vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a change in medication or an infection (Clegg et al. 2013). Figure 1 illustrates the reduced recovery potential of older people with frailty following a seemingly minor illness. The red line demonstrates the longer recovery time with incomplete return to levels of functional ability for a person with frailty compared to an older person without frailty.

While not all older people become frail, frailty becomes more prevalent with age. Choi et al.'s (2015) study using national population-based surveys in the UK, Europe, United States, Taiwan, and Korea found frailty prevalence was between 4.9% and 27.3% in the total population. Figures

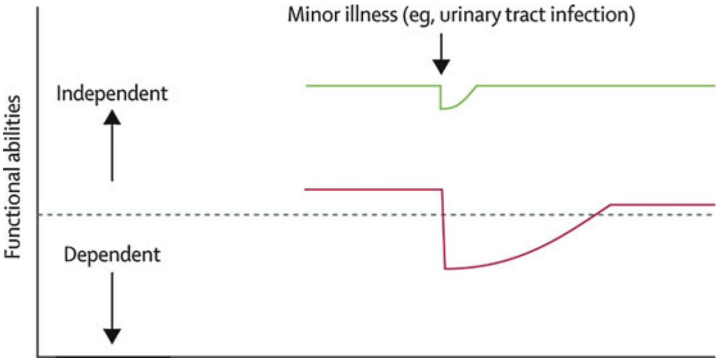


Fig. 1 Vulnerability of frail elderly people to a sudden change in health status after a minor illness (Clegg et al. 2013)

from the UK suggest frailty affects around 10% of those over 65 increasing to around 65% of those 90 and above (Clegg et al. 2013). Frailty is a dynamic state and is known to change over time, mostly worsening rather than improving (the red line in Fig. 1 does not come back to the previous level). Frailty in old age is often characterized by a progressive decline in physical, mental (Rockwood et al. 2005), and social functions (van Campen 2011), increased vulnerability to sudden deterioration (Covinsky et al. 2003), and reduced recovery potential (Turner and Clegg 2014). Typical signs and symptoms of frailty include sarcopenia, anorexia, exhaustion, and low mood. Evidence of the pathophysiology of frailty is growing, and chronic systemic inflammation leading to neurological and immunological dysfunction is a major contributor, as is cardiovascular degeneration and genetic predisposition (Fulop et al. 2010). Frailty biomarkers are being studied. Velissaris et al.'s (2017) systematic review explores the relationship between older people with frailty and systemic inflammation. C-reactive protein is an easily measurable biomarker, but not consistently associated with frailty. However, robust evidence demonstrates the association between morbidity and mortality with frailty, which increases as an older person becomes progressively more frail. Compared to fit older people, those with frailty are at greater risk of disability, nursing home admission, hospitalization, and death (Fried et al. 2001). Those with even mild frailty have almost twice the mortality risk of a fit older person; for those severely frail, the risk is almost five times higher (Clegg et al. 2016).

1.3 Identifying Frailty

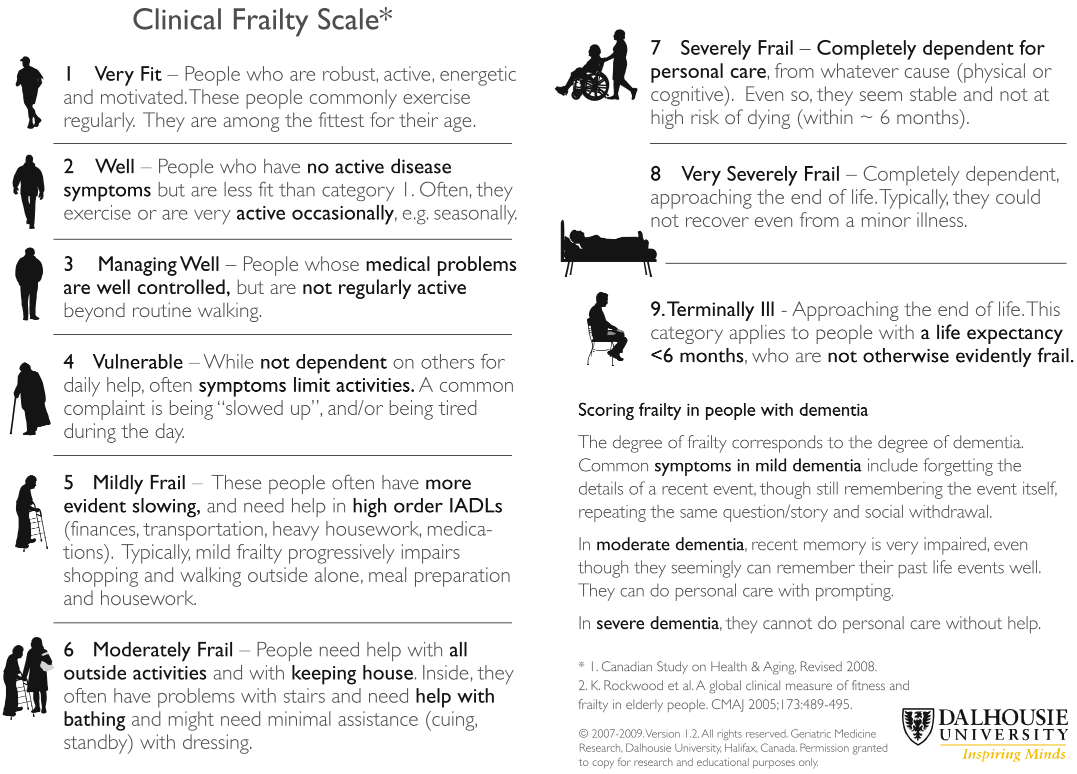
It is important to identify frailty because it is predictive of adverse outcomes. While there is currently no robust evidence of the reversibility of frailty, research does demonstrate that the side effects of frailty, e.g., weakness and fatigue, can be lessened with intervention, particularly in the early stages. Frailty identification means we can deliver the most appropriate therapeutic interventions, including palliative care to those with severe frailty. The evidence on recognition, effects, and treatment for the symptom complex of frailty has grown exponentially over the last 10 years; however, it is still a concept in evolution. The two most common ways of operationally defining frailty are (1) the frailty phenotype (Fried et al. 2001) and (2) the frailty index (Rockwood et al. 2005) (see Table 1). It is useful to see the phenotype and frailty index as complementary rather than opposing approaches to identifying frailty (Cesari et al. 2013). The frailty phenotype assesses five dimensions that are hypothesized to reflect systems whose impaired regulation underlies the syndrome. These five dimensions are unintentional weight

Table 1 Comparing the frailty phenotype and frailty accumulation of deficit index approaches to identify frailty

Identifying frailty – table comparing the frailty phenotype and frailty accumulation of deficit index approaches	
Frailty phenotype	Frailty index
Frailty as a pre-disability syndrome Signs, symptoms relating to sarcopenia	Frailty as an accumulation of deficits using a combination of factors including symptoms, diseases, activities of daily living, and results of holistic clinical assessments
Categorical variable – five dimensions with set criteria: pre-frail meets one or two criteria, frailty requires satisfaction of three or more	Continuous variable which describes a risk profile moving from pre- to severely frail depending upon the accumulation of deficits
Five predefined dimensions with criteria: involuntary weight loss, exhaustion, slow gait speed, poor handgrip strength, and sedentary behavior	Predefined set of deficits identified over physical, psychological (including memory and cognitive problems), and social domains
Identification possible outside of a full clinical assessment	Identification part of a comprehensive clinical assessment or through an Electronic Frailty Index (EFI) (Clegg et al., 2016) calculated through routinely collected patient data in primary care

loss, exhaustion, muscle weakness, slowness while walking, and low levels of activity. Those who meet at least one or two of the criteria for these dimensions are defined as pre-frail, and those meeting three or more of the criteria are defined as frail. The frailty index is based on the concept that frailty is a consequence of interacting physical, psychological, and social factors. As deficits accumulate, people become increasingly vulnerable to adverse outcomes, moving from mild to moderate and then to severely frail. The number of deficits that are needed to indicate the presence and grade of frailty has changed with further research from the original 70 items of the earliest version of the frailty index (Rockwood et al. 2005). The Electronic Frailty Index eFI (Clegg et al. 2016) identifies 36 deficits across physical, psychological, and social domains to calculate a frailty risk value (an eFI) from data collected routinely from community-dwelling older people. The eFI is calculated by the number of deficits the patient has, divided by the number of deficits considered. Such indices can be used to identify the possible presence and grade of frailty, confirmed by a clinical assessment thus tailoring clinical services.

Clinically, there are many ways to recognize frailty. The NICE Multi-morbidity Guidelines (https://www.nice.org.uk/guidance/ng56) argue for two main approaches: (1) assessment through simple instruments based on the two main ways of identifying frailty discussed above, e.g., timed get up and go test (taking more than 10 s to get up from a chair walk 3 m and sit down again) is based on the frailty phenotype approach, or (2) through routinely collected data such as the Electronic Frailty Index which draws on the accumulation of deficits frailty index (Clegg et al. 2016). The choice of instrument is informed by purpose of identification, clinical setting, and availability. Simple tools are often a useful clinical starting point. The Clinical Frailty Scale, see Fig. 2 (The Clinical Frailty Scale), is a pictorial scale based on activities of daily living (ADLs) which



Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally Ill - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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Fig. 2 The Clinical Frailty Scale. (http://camapcanada.ca/Frailtyscale.pdf) categorizes frailty on a scale of 0–9 into mild, moderate, and severe frailty (see Fig. 2). It is a pragmatically useful tool to identify people in with frailty and appropriate therapeutic interventions, including palliative care.

2 Frailty and Multi-morbidity

While frailty might be the sole long-term condition with which an older person presents, it is often the case that it is the interplay between a combination of long-term conditions, called multi-morbidities, which are life threatening. The UK NICE guidelines (https://www.nice.org.uk/guidance/ng56) define multiple morbidity as a combination of two or more physical and mental health conditions such as diabetes or dementia, ongoing conditions such as learning disability, symptom complexes such as frailty, sensory impairment, and substance misuse. Fortin et al.'s (2012) systematic review of prevalence of multimorbidity in European and North American countries suggests there is marked variation between the prevalence of multiple morbidities due to methodological and definitional differences. However, the prevalence of multi-morbidities was associated with increased age in both general population and community-only studies. Barnett et al.'s (2012) much cited cross-sectional study across 314 community practices in Scotland suggests by age 65, 75% of the population are multimorbid, and for those 85 and over, 55% will be living with at least three long-term conditions, the number of conditions rising with age. As well as frailty, common morbidities identified by NICE from physical and mental health conditions include dementias, respiratory disease, urinary incontinence, and depression. Evidence is growing about the interplay between the frailty syndrome and cognitive decline, e.g., frailty is a risk factor for dementia (Searle and Rockwood 2015), there is a shared mechanism of pathophysiology (Sampson 2012), and cognitive decline is one of the deficits included in the frailty index accumulation of deficit approach to frailty. Pragmatically, clinicians will see many older people with frailty who have a component of cognitive decline. However, severe cognitive impairment, such as Alzheimer's disease, is a distinct condition.

The complexity of symptom burden and need over time for older adults with frailty cannot be fully captured by a biological disease model alone. This underlines the need for holistic assessment, incorporating medical, spiritual, social, and psychological care needs. Palliative care is such an approach, working with the whole person and addressing need rather than solely focusing on pathology.

3 Frailty: Moving Beyond a Biomedical Approach

Moving frailty beyond a biomedical deficit, conceptualization requires an acknowledgment of the resilience and resources of older people with frailty within the communities in which they are living and dying (Nicholson et al. 2012). An alternative conceptualization of frailty is also one where an older person is in a state of imbalance, experiencing simultaneously accumulated biopsychosocial losses while working to sustain and create new ways of connecting to their surroundings. Achieving balance between loss and continuity is crucial for the well-being of older people with frailty and is supported, or undermined, by the quality of their interactions with health and social care and the wider contexts of their lives (Nicholson et al. 2013). This approach moves beyond the dichotomies of independent/dependent or coping/requiring care to a person-centered approach, recognizing capabilities as well as potential needs, even when severely frail. It seeks to recapture McCue's (1995) insight of life naturally moving toward closure in old age. In this formulation, severe frailty is engaged with holistically and not, without careful thought, resisted biologically. However, while the case for palliative care involvement with frailty is clear, what is not so evident is robust data to describe or quantify specific palliative care needs. The following section of this chapter details some of the main issues identified to date in meeting the palliative care needs of older people with frailty.

4 Palliative Care for Older People with Frailty

4.1 Identification of Palliative Care Needs

Recognizing where a person might be in their dying trajectory is an increasingly important marker of potential care need and referral to palliative care. It also aids communication across teams and supports person-centered decision-making at end of life. Lunney et al. (2003) (ref) explores functional decline in four disease-based trajectories: sudden death, malignancy, organ failure, and frailty. The functional trajectory of frailty describes a progressive decline or prolonged dwindling over several months or years, punctuated by episodes of acute illness. This unpredictable trajectory makes it difficult to diagnose when people are nearing the end of life, and their increasing vulnerability to sudden health changes means dying might be characterized as unexpected. This is confirmed by Gill et al.'s (2010) retrospective study of disability trajectories of community-dwelling older people in the last year of life. They note considerable heterogeneity in the sample of frail older people; 25% of older people with frailty had progressive, severe disability in the last year of life, compared with 70% of people with advanced dementia. The authors conclude that the findings indicate the need for services to assist at end of life is at least as great in frailty as for those with a defined terminal condition. However recognizing this need is difficult. Pailoux et al. (2013) note that the sum of several illnesses or syndromes encompassing frailty is often looked at as separate diseases (rather than an accumulation of deficits), and thus, "practitioners have difficulty integrating the inevitably fatal nature of the situation" (p. 3). Nicholson et al. (2018) illustrate this in their work comparing patient needs and concerns of older people within an innovative new palliative care service with those of the conventional specialist palliative population (typically those with malignancy). Surprisingly similar needs were identified at first contact however Older people entered palliative care with a much lower performance status and remained in a longer period of stable deterioration than those with malignancies. Consequently, the dying phase can be very short or indeed unrecognized by clinicians. Murray et al. (2017) explore trajectories of decline with a more holistic perspective. The authors posit three main functional end-of-life trajectories: rapid, often associated with malignancy; intermittent, often associated with organ failure or multiple morbidities; and gradual, often associated with frailty or cognitive decline. For each pattern, the authors describe the likely pattern of physical, psychological, social, and spiritual decline and set out the implications for palliative care. They argue such an approach may help clinicians to identify, plan, and involve palliative care earlier.

What is clear is that in order to receive palliative care, older people with frailty need to be identified as having palliative care needs. There are a number of prognostication tools to help identify people in need of palliative care. However, evidence of reliability and validity for older people with frailty is sparse. Maas et al.'s (2013) systematic review of European and North American studies identified tools commonly used for identification of community palliative care. These include the RADPAC, Radboud Indicators for Palliative Care Need (Thoonsen et al. 2011) (which contains disease-specific assessment criteria for cancer, COPD, and heart failure); the SPICT Tool (the Supportive and Palliative Indicators Tool, a combination of general indicators, and disease-specific assessment criteria) (Highet et al. 2014), and the Gold Standards Framework Prognostic Guidance (Gold Standard Framework (GSF)) (based on three triggers that suggest that patients are nearing the end of life: the surprise question and general and specific clinical indicators for decline in organ failure, dementia, and frailty trajectories). The surprise question, "*Would I be surprised if this patient died in the next 12 months?*" has been shown to be of poor to moderate performance in specificity and sensitivity in identifying people in the last year of life (Downar et al. 2017). This is particularly the case in older people with frailty where lack of underlying pathology, and unpredictable illness trajectories, means some doctors are less likely to use the surprise question with this patient population (Elliott and Nicholson 2017).

The SPICT Tool (Highet et al. 2014) has been validated in hospitalized geriatric patients (De Bock et al. 2017), demonstrating a significant association with 1 year mortality. The Dementia/Frailty specific section of SPICT uses functional decline, activities of daily living, and frequent falling as clinical indicators of deterioration. As such, it links well to frailty syndrome. Multiple hospitalizations (Kelley et al. 2017) and recurrent infections (Leibovici 2013) have been evidenced a marker of poor prognosis in older people with frailty. While such clusters of triggers may be helpful in identifying need for older people with frailty, they are service dependent. Studies (Campbell et al. 2004; Ávila-Funes et al. 2008) suggest it is often a complex interplay of variables that coalesce to contribute to poor prognosis. These variables might include, for example, the effect of hospital admission, multiple morbidity, as well as frailty, age, gender, cognitive function, and sociodemographic factors on baseline before admission to hospital.

4.2 Specific Palliative Care Needs of Older People with Frailty

The principles of symptom assessment remain constant, focusing on relief of discomfort and enhancing quality of life. The gold standard in geriatric care for the assessment and management of frailty in older adults is a process of care known as the comprehensive geriatric assessment (CGA) (Ellis et al. 2011). CGA has been defined as a "multidimensional and usually interdisciplinary diagnostic process designed to determine a frail older person's medical conditions, mental health, functional capacity and social circumstances" (Ellis et al. 2011). CGA has much in common with palliative care holistic assessment. The application of both geriatric and end-of-life expertise is often beneficial because of the complexity of coexisting social, psychological, and medical needs in older people with frailty.

4.3 Defining Symptoms

4.3.1 Sarcopenia, Falling, and Fatigue

Sarcopenia is the loss of skeletal muscle mass and function with old age. Frailty shares common biomedical determinants with rapid muscle aging, i.e., inflammation, malnutrition, changes in neuromuscular function, and structure, and both are closely linked with falling and exhaustion. Muscle fatigue is a common symptom associated with older people with frailty at the end of life. It can be measured through low grip strength, walking speed, or balance. The management of sarcopenia includes leucine-enriched protein and vitamin D supplements (Morley 2016). Evidence over decades suggest that exercise involving strength and balance, even those who are very frail, is the key intervention component (Cadore et al. 2013). In older people with frailty, functionality, rather than diagnosis of disease, is one of the best indicators of health status. De Labra et al. (2015) systematic review of RCTs of exercise interventions in older people with frailty noted improvement in mobility balance, strength, body composition, and falls. However, the optimal exercise program is not yet clear. A Pan-European intervention program, the VIVIfrail project, has devised a range of resources including a practical exercise guide, including those with severe frailty and at risk of falling (http://www.vivifrail.com/resources). A Cochrane systematic review of the effect of functional rehabilitation programs in older people living in long-term care showed improvements in physical function (Gold Standard Framework (GSF)) such as strength, flexibility, and balance, as well as the potential to improve mood (Crocker et al. 2013). Pulmonary rehabilitation in particular may be helpful for older people living with frailty, as it targets key frailty symptoms such as fatigue, weakness, and dyspnea and encourages physical activity (Maddocks et al. 2016).

4.3.2 Polypharmacy

An important aspect of assessment of older people with frailty is medicine optimization: there is a strong association between polypharmacy (four or more medications) and falling in old age (Ziere et al. 2006). Palliative care clinicians need to be aware both of the medications they may prescribe and the need to optimize medications to decrease the risk of inadvertently increasing the burden of symptoms for older people with frailty including falling. Sedative hypnotics, antidepressants, cardiovascular drugs, and cardiovascular medication are of particular concern. Validated tools, e.g., the START/STOP tool (O'mahony et al. 2015), can be of use. Additionally, an important and an often underutilized expert is the pharmacist, both in the hospital and community.

4.3.3 Weight Loss

Given the interconnection between weight loss, sarcopenia, and frailty, anorexia is a powerful, independent predictor of poor quality of life, morbidity, and mortality in older persons (Morley 2003). One of the most important goals in the management of older, frail people is to optimize their nutritional status. Nutritional interventions may include smaller, more frequent meals, high caloric foods, altering consistency and referrals to speech and/or occupational therapists, and dietitians. Evidence supporting the use of nutritional supplements for older people with weight loss is mixed, in part because the underlying frailty pathology, rather than an inadequate intake, may cause the loss of weight. However, the importance of accessible nutritious food, assistance, and teeth and oral hygiene is interventions that can be overlooked. Morley (2003) notes the importance of enhancing the environment for older people and the importance of breakfast as a meal – circadian shifts in old age mean people eat more in the morning.

4.3.4 Depression

Depression is a major cause of weight loss in older people and there is a strong association between frailty and depression (Brown et al. 2014). Older adults with depressive symptoms have poorer functioning compared to those with chronic medical conditions such as lung disease, hypertension, or diabetes. Depression also increases the perception of poor health, the utilization of medical services, and healthcare costs. It is important to treat depression, as it is associated with increased mortality and risk of physical illness. Older people who attempt suicides are more likely to die than younger people, while in those who survive, prognosis is worse for older adults (Rodda et al. 2011). While not all older people with frailty who attempt suicide are depressed, treating depression is often overlooked in assessments. The British Geriatric Society (BGS) suggests medication should not be offered as a first-line treatment. Psychosocial interventions such as increasing social contact and physical exercise are first line. See http://www.bgs.org.uk/depression/cga-toolkit-category/how-cga/cga-assessment/cga-assessment-mental/cga-management-of-depression for further details. It is beyond this chapter to discuss physician-assisted suicide across differing cultures and contexts. However, it is important sensitively to addresses the fears of some older people with frailty.

5 Quality of Life and Goals of Care

Older people with frailty are frequently evidenced as having a significantly lower quality of life, compared with non-frail counterparts (Kojima et al. 2016). However, quality of life and health status are often narrowly measured, which has led to an increasing call for better measures including social, community, and psychological domains (Malley et al. 2012). Puts et al. (2007) used qualitative methods to explore the meaning of quality of life for older frail and non-frail people. Five common themes emerged, physical health, psychological well-being, social contacts, activities, and home/communities. Quality of life was derived through comparison to others, and adapted, dependent on the degree of frailty. When health was poor, there was a shift from health to social contacts as the most important factor, although poor health was not completely accepted and social goals, e.g., helping other people, checking on neighbors and friends, feelings of safety, and living conditions, became important. This adaptive shift has much in common with Knight and Emmanuel's (2007) reintegration of loss theory in palliative care. Building from literature on loss and adjustment, they describe a conceptual framework of key adjustment processes that allow for a shift in self-concept that supports quality of life while becoming more dependent, as one approaches death.

This approach is congruent with the focus of rehabilitative palliative care (Leslie et al. 2014), an essential approach to enable goals and preferences of older people to influence quality of care. Rehabilitation aims to improve quality of life by enabling people to be as active and productive as possible with minimum dependence on others, regardless of life expectancy. In the context of palliative rehabilitation, Jennings (2013) highlights the alternative term "habilitation" to dispel any unrealistic expectations of returning to premorbid levels of function which the "re" of rehabilitation may imply. However, rehabilitation is broader than symptom management alone, focusing on enabling people with long-term conditions or a terminal diagnosis to live well, and as independently as possible, until they die. Those with long-term conditions, such as frailty, are empowered to set goals to achieve their personal priorities with the support of those important to them and with adaptations to surroundings as necessary. The centrality of such approaches for older people with frailty cannot be underestimated, the importance of independence, dignity, and continuity of personhood providing a vital counterpoint to being frail (Lloyd et al. 2014).

6 Advance Care Planning

Promoting the empowerment of older people and their surrogate decision-makers in healthcare decisions through advance care planning can also aid quality of life. Advance care planning (ACP) is an ongoing conversation between professionals and someone nearing the end of life, often with family involvement (Thomas 2011). This dialogue provides an opportunity to discuss and document what matters most about future care, including preferred care, place of care and death, unwanted treatments, and proxy decision-makers. When successful, ACP decreases inappropriate emergency admissions and invasive procedures and improves quality of life by ensuring care represents the dying person's wishes (Sudore et al. 2017). However, while ACP is reasonably embedded for diseases such as cancer and within palliative services, it is seldom used with older people with frailty, due to its complex systems and personal and family challenges (Brinkman-Stoppelenburg et al. 2014). As previously discussed, prognostication is challenging in frailty, with its repeated episodes of deterioration and subsequent recovery. It is therefore unclear when best to start ACP discussions. Further, evidence suggests older peoples' engagement with ACP is mixed, as they have a different set of preoccupations and concerns to those traditionally associated with planning future care. Older people with frailty often make decisions within their social network, a shared ecology of decision-making, which is processual and develops and changes over time (Musa et al. 2015). Decisions about preferred place of treatment and care may focus more on not wanting to be a burden to others, as well as on where the older person with frailty feels most safe and secure. This may include a preference for dying in hospital (Barclay and Arthur 2008). Further, when older people with frailty are managing well, they, and their significant others, do not always wish to discuss future planning, and there are often misunderstandings around what ACP might mean (Sharp et al. 2013).

Consequently, while ACP is particularly relevant for this population, often their priorities have not been discussed prior to a significant deterioration. This leads to crisis decision-making, for which the person may not have capacity, and often means older people with frailty are under- or overtreated and experience unnecessary hospital admissions or inappropriate, invasive procedures. Critics of ACP often relate to the process; too often ACP is defined as a stand-alone activity, with its focus frequently being only on future care decisions. However, ACP, when carried out well, should be an ongoing process, not a one-off event, a realistic and supportive conversation between professionals, the older person, and their significant others. It should focus on the persons' goals for their care, both now and in the future, and, in that way, promotes the fundamental aim of palliative care, "*to live until you die*." Engaging in ACP does not guarantee that the dying person's wishes are realistic or possible and acknowledges that priorities may change. However, only by enabling people to make informed decisions, to articulate and record these, can we hope to deliver person-centered end-of-life care (Sudore et al. 2017). Working with older people and their significant others in partnership enables professionals to provide person-centered end-of-life care. Further, enhancing the idea of ACP as a process rather than a single event enables the focus to be on living well now, as well as planning for future terminal care needs.

7 Revaluing Living with Dying in Frailty

Frailty's dwindling trajectory fits poorly with the popular idea of a "good death in old age," in which awareness of dying, choice, communication, and control are central (Seymour et al. 2005). The idea of dying in old age with frailty as an "event" is therefore perhaps less useful than thinking of dying as a process (Martin et al. 2018). With this framing, the idea of "living as well as possible until you die" seems relevant. It is helpful to think of the concept of supportive care. This model maximizes quality of life in life-limiting illness by giving equal importance to the palliative, end-of-life approach and appropriate medical treatments, to meet patients' overall needs from diagnosis to bereavement (NICE 2004). Sometimes an open awareness of dying requires time for patients and the people, including professionals, caring for them. Supportive care can provide a bridging language and practice between curative and end-of-life discourses (Nicholson et al. 2017). Reframing language around uncertainty allows for a different praxis. Parallel planning, an approach from pediatric palliative care (Wolff and Browne 2011), acknowledges there may be numerous possibilities; some become more obvious over time, while other outcomes become less likely. Crucially, these discussions are with the family, and acknowledging honestly that this is an uncertain journey builds partnership between the clinical team, child, and family. While older people with frailty are in no way children, the degree of dependency on others for fundamentals of care and centrality of family and friends in coordinating care resonates.

A revaluation of living and dying with frailty requires a reconfiguration of partnerships and expert knowledge in palliative care. Evidence reveals that friends and family of older people with frailty are often unrecognized, unsupported, and overlooked as they care for people at the end of life (Lloyd et al. 2016). They are often coordinating a number of services, carrying out physical and emotional care over many weeks or months, and living with the uncertainty of a person dying in a protracted and often erratic way (Grande GaK 2011). While carers are often "the conductor of the orchestra" (Lowson et al. 2013), evidence (Thomas 2011; Sudore et al. 2017) highlights that their knowledge and resources are overlooked by health services. Living and dying partnerships align to health-promoting approaches to end-of-life care (Sallnow et al. 2016) in which citizens are actively engaged in their own care, drawing on partnerships between services and communities, and building on their existing strengths and skills, rather than replacing them with professional care. The focus of outcomes of care then shifts to enhancing capacity, resilience, and empowerment at an individual, social network, and wider community level, alongside more traditional palliative care outcomes.

8 Service Models to Meet the Palliative Care Needs of Older People with Frailty

Older people with frailty challenge our assumptions about who palliative care is for and where it should be delivered. Specialist of palliative care could be censured for delivering a discrete service, largely unconnected to, rather than integrated into, wider systems of health and social care. Jerant et al. (2004) criticize this model of palliative care for an emphasis on symptomatic and disease-focused treatment, resulting in a reactive and crisis-driven approach. Older people with frailty require a focus on both living and dying well within prolonged and uncertain disease trajectories. This reorientation of palliative care models, integrating across geriatric and palliative care, supports the wider World Health Assembly (WHA) (Organization WH 2015) position for palliative care to be considered internationally as an essential health service for all people living with chronic and life-limiting conditions. Increasingly there are shared goals in geriatric and end-of-life care, to improve quality of life and to enable people to die "well" based on benefit rather than prognosis. However, what is underdeveloped is evidence on the "best" systems and models of service delivery, which and how to tailor care to meet the complex health needs associated with frailty. Sawatsky et al. (2016) argue that extending a palliative care approach to others with life-limiting and chronic conditions, such as older people with frailty, requires clear delineation of the underlying concepts of a palliative care approach. Their systematic review identified three core concepts: (1) upstream orientation toward the needs of people who have life-limiting conditions and their families, (2) adaptation of palliative care knowledge and expertise, and (3) operationalization of a palliative approach through integration into systems and models of care that do not specialize in palliative care.

The recent WHO Evans et al. (2018) scoping review of systematic reviews on service models to maximize quality of life for older people at end of life builds on Sawatzky's approach. The scoping review identified end-of-life service models as being on a continuum. At one end of the spectrum is integrated geriatric care, conceptualized as person-centered care, mainly given at an earlier trajectory of functional decline, focusing on quality of life with emphasis on strengthening and maintaining function. At the other end of the spectrum is integrated palliative care, conceptualized as person-centered care commonly accessed at a later trajectory of functional decline and dying, focusing on quality of life with emphasis on reducing symptom distress and concerns. This service continuum and the interface between integrated geriatric and palliative care balance functionality, quality of life, and quality of dying for older people with frailty and multiple morbidity. Key components across the service models reviewed were (1) multiple service providers, (2) person-centered care targeting quality of life, and (3) education of service users and providers (conceptualized in Fig. 3). However, the heterogeneity of the data within the review did not allow for detailed analysis of key components or processes to support sustainability/transferability of service models. Common outcome measures identified were quality of life, function, and impact of symptoms. However, there was insufficient data consistently to analyze outcomes and patient benefit in relation to particular service models. Health economic data was reported in less than half the reviews and results were inconclusive. Data for the review was derived mainly from high-income countries. The report argues that service delivery models must build on specific population needs, characteristics, and resources, e.g., using volunteers to deliver an end-of-life service in low- and

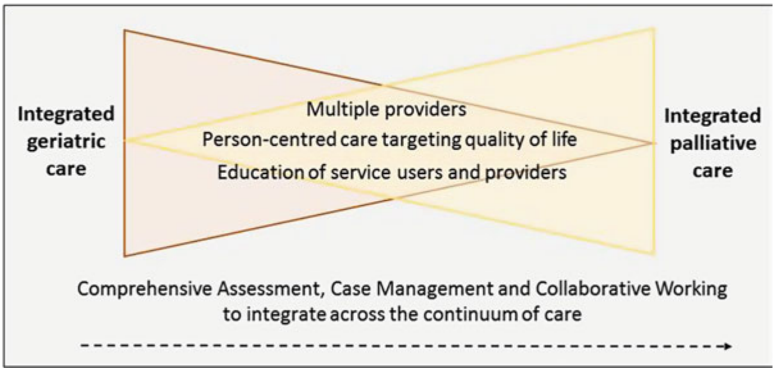

Fig. 3 Overarching integrated service delivery models and processes to maximize quality of life for older people in the last years of life (Evans et al. 2018, Adapted from Hawley 2014)

middle-income populations and consideration of the amount of primary/community palliative care available.

We consider here three examples of models of end-of-life care for older people with frailty and progressive conditions. These models seek to improve quality of life and quality of dying across the continuum of integrated palliative care and integrated geriatric care. These are as follows: first, short-term integrated palliative and supportive care, SIPScare (Bone et al. 2016); second, ongoing shared care coordination within primary care with community doctors (Bromley Care Coordination (BCC)) service via St Christopher's Hospice (Nicholson et al. 2018); and, third, skilling up the acute older adult workforce via the Assessment; Management; Best practice; Engagement and Recovery (AMBER) care bundle (Carey et al. 2014).

SIPScare (Sawatzky et al. 2016) aims to provide specialist palliative care using an approach of a consult service to assess and improve management and treatment of physical, emotional social, and other concerns and act as a catalyst to access health and social care services. Service provision is based on potential for benefit at points of actual or anticipated deterioration, with a presentation of two or more symptoms or concerns for the patient and/or their carer(s). The service is delivered "short-term" with the palliative care team providing one to three visits to assess and review concerns with expectation that the patient is discharged within 3 months. The service is integrated with the existing community services, notably GP and community nursing and other specialist nursing services (e.g., respiratory nurse). Patients/carers and practitioners re-refer at future points when care needs indicate likely benefit from palliative care services. This may be at points of anticipated or actual decline (e.g., an unplanned hospital admission), unstable symptoms, and/or concerns and care in the dying phase. The central tenets are to provide palliative care early in an individual's illness/condition based on potential for benefit and integrated professional working with the palliative care team working with the existing main provider of care. The addition of supportive care increases the emphasis on enabling individuals to live life well. Findings from the phase II trials indicate the acceptability of SIPScare for patients, families, and staff and potential for patient benefit in improving the key symptoms identified as the respective main outcome and evidence of cost saving.

Bromley Care Coordination (Nicholson et al. 2018) was commissioned by a community care-commissioning group in December 2013 to enable patients with progressive and advanced illness or frailty, thought to be in the last year of life, to receive timely and coordinated end-of-life care. The majority of patients are older and would not have met the referral criteria for "specialist palliative care" services. The service aims to address the inequalities of access to services for dying patients to prevent unnecessary hospital admissions, to help people die with dignity in their place of choice, and to provide support for their families and carers. BCC is a nursing-led service, with the community doctor taking medical responsibility for the patient. The team consists of clinical nurse specialists, community staff nurses, and administrators. Other hospice services are available as necessary to meet patient needs. Those using the service can access advice and help around the clock, 365 days a year. The service averages 280 people on the caseload at any 1 time, of which 85% have a non-cancer diagnosis and 63% are over 85 years of age. To date, outcomes include reduction of deaths in hospital (76% of patients have died at home, compared with the average in the borough of 23%) and reduction in inappropriate hospital admissions. It also increased patient and family satisfaction and anticipatory care planning. Resource implications to the proposed model include an increase in key working some patients, rather than the original plan to assess and refer onto other services. This is in part due to the lack of services for some patient groups, e.g., people with dementia and long-term neurological disorders who have high levels of dependency and uncertainty around deterioration. In part, the nonexistent or fragile social networks of people living on their own make the ongoing connection or "watchful waiting" aspect of hospice care of extra importance.

The AMBER care bundle was developed and piloted in the UK for patients in hospital whose clinical situation was uncertain in terms of recovery or continued decline, increasing risk to end of life. The model of care was in response to inconsistencies in the quality of care for patients presenting with decline and clinical uncertainty as to recovery and risk to end of life. Typically, these were older patients with frailty and multi-morbidities presenting with signs and symptoms not defined by a chronic illness. The AMBER care bundle follows an algorithmic approach to encourage clinical teams to develop and document a clear medical plan, considering anticipated outcomes and resuscitation and escalation status and revisiting the plan daily. The AMBER care bundle encourages staff, patients, and families to continue with treatment in the hope of a recovery while talking openly about preferences and priorities for end-of-life care and increasing nearness to end of life. It aims to increase and improve communication, support shared decision-making, reduce patient and family anxiety and distress, and increase attainment of preferences for end-of-life care and reduced unplanned hospital admission. Evaluation of a single site demonstrated increased communication between clinical staff and patients on prognosis and reduced length of hospital stay. However, the quality of the communication was not assessed, and relatives of patients supported by AMBER reported more unresolved concerns about providing care at home. A cluster feasibility trial is underway.

Key features of palliative care provision for older people with frailty exemplified in these models are summarized as follows:

1. Partnership with the older person and their family to enable hopeful and realistic conversations about living and dying with frailty. There is a delicate balance between perseverance/continuity and adaption to loss/dying in old age.
2. The importance of goals of care which maintain function and center on the quality of everyday life of the older person in their community as well as future planning for the last few days of life.
3. Early introduction and revisiting of advance care planning during an unpredictable and possible prolonged dying trajectory.
4. Integration and interdependencies with other care providers is an essential component as assessment and care focus on living and dying with frailty.
5. Early identification and involvement of palliative care which requires close collaboration and discussion.
6. A dynamic model which involves palliative, older person and their family, voluntary, health, and social care providers. With shifting service provision aligned to a person's needs and goals of care.
7. Proactive care – Health service care tends to manage points of decompensation on the frailty trajectory as "event-based care" by treating and managing the cause of the decline, e.g., an infection (see Fig. 1). Equal attentiveness is required to the older person's gradual deterioration with each event increasing their risk to unplanned hospital attendance, and requirement for long-term care and end of life. Regular planned assessment and use of identification tools, e.g., Electronic Frailty Index (Clegg et al. 2016)

This chapter has argued that person-centered palliative care demands a meaningful engagement with the older person with frailty within the social networks in which they are both living and dying. An understanding and valuing of capacity and strategies of continuity, alongside older people's potential and actual vulnerability, is crucial as older people with frailty reach the end of their life. However, living and dying with frailty does not always fit well within current palliative care policy and practice. This chapter argues for a flexible practice that works with uncertainty, transitions, and need, rather than a defined prognosis. The invitation to palliative care with the rise and need of older people living and dying with frailty can be framed within the potential to flourish within dying. Illes (2016) suggests that dying is the most grown up thing we will ever do, moving the focus away from productivity, external validation of worth, and the future to a more conscious habitation of the present. Such flourishing requires an integration of palliative and older people's care crucially working with older people and the communities in which most older people will live and die.

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