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**COMMENTARY**

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# End-of-life care for older people: the way forward

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## Abstract

Even though many older people will live longer in good health, many will also be confronted with frailty, multi-morbidity, cognitive decline, disability and serious illnesses in the last years of their life. The end-of-life trajectories of frail older people have a major impact on the care that needs to be provided. Older people develop different physical, psychological, and/or social needs in varying intensity during the last years of life. Moreover, determining a clear terminal phase of life is difficult in this population. In this commentary, we aim to highlight the importance of an integrated palliative, geriatric and rehabilitative care approach for older people, emphasizing the importance of setting-specific and cross-setting interventions. We stress the importance of person-centred care planning with the older patient and the role of their families, communities and society as a whole. We identify and formulate some of the research gaps that can be addressed in the near future.

**Keywords:** end-of-life care, person-centred care planning, integrated care, setting-specific interventions, older people

### Key Points

- A model integrating principles of palliative, geriatric, and rehabilitative medicine and care is needed
- Person-centered care planning centralising the voice of older persons and their next of kin is important
- Setting-specific and cross-setting interventions to improve quality of end-of-life care should be further developed
- Family, close friends, neighbours, the larger community, social and voluntary networks will play an important role

## Background

The challenges that come with the aging of the population are well known. Even though many people will live longer in good health, many will also be confronted with frailty, multi-morbidity, cognitive decline, disability, and serious illnesses in the last years of their life [1]. Older people develop different physical, psychological, and/or social needs in varying intensity throughout this illness trajectory and determining a clear terminal phase of life is difficult in this population [1–3]. These end-of-life trajectories and cause-specific mortality have a major impact on the care that needs to be provided in these last years of life of older people. Since 2020 and the start of the COVID-19 pandemic, ensuring high-quality end-of-life care for all older people in the world, has only gained importance and hopefully also momentum. The pandemic has sharpened the vulnerable position of older people, in our society, in nursing homes, the community and hospitals. In this commentary, we aim to highlight the importance of an integrated palliative, geriatric and rehabilitative care approach for older people, emphasize the importance of setting-specific and cross-setting interventions, stress the role of families, communities and society as a whole, and identify future research gaps.

## A model-integrating principles of palliative, geriatric and rehabilitative medicine and care is needed

The substantial overlap in the goals of palliative and geriatric medicine and care when it concerns older people has

been repeatedly described in previous work [4–6]. Less well recognized or described are their commonalities with a rehabilitative care approach, which strives to achieve many of the same goals as geriatric or palliative care [7]. Although each discipline has its own merits and accents—e.g. specificities of palliative care include a focus on symptoms and concerns, while in geriatrics, there is more attention to maintaining function, and in rehabilitative care on supporting intrinsic capacities—important convergent principles include a focus on goal-oriented care based on comprehensive needs assessment and peoples' priorities and preferences, on optimizing quality of life and well-being ('adding life to days instead of days to life') and on supporting the family caregivers. Hence, instead of describing how they differ, we believe there is a need to describe what an integrative palliative, geriatric, rehabilitative care approach entails, which is centred around the older person and his/her close relatives, irrespective of where or by whom that care is provided. A Delphi consensus study aimed at identifying the core principles and domains of care of such an approach is currently being undertaken as part of the Aging and Palliative Care Reference Group of the European Association of Palliative Care (EAPC).

Of course, in practice, service delivery models for such an integrated care approach can vary substantially between countries, as the different possibilities and pitfalls of the existing health and long-term care systems and services for older people need to be considered. In any context however, it will be important for the different disciplines and specialities in health and social care to determine optimal ways of collaboration, referral and communication, to be able to provide high-quality care for older people and their families and understand when referral to specialist care is needed.

## The importance of care planning with older people and their families

A widely recognized and fundamental aspect of care for older people is the importance of person-centred care planning [1, 8–10]. This can be challenging, however, as prediction of actual survival can be very difficult, and clinical uncertainty and complexity are inherent features of many older person's end-of-life trajectories [1–3, 8]. Recent guidelines on end-of-life care in frailty therefore highlight the importance of recognizing, identifying and discussing uncertainty, and to plan for multiple scenarios ('parallel planning') [8]. Goals of care conversations and advance care planning (ACP) with older people and their family are seen as central to such an approach, as are recognizing indicators of deterioration (e.g. multiple unplanned hospital admissions) or clinical tipping points (i.e. when a patient's condition deteriorates) to trigger such care planning discussions [8].

Notably, over the past decades, there have been a multitude of concepts and definitions aiming to delineate these planning and communication processes. While most concepts were defined rather narrow in the beginning (e.g. ACP focused on documentation of preferences in the early days), many have evolved to be much broader concepts (e.g. ACP as a communication process about 'what matters to you') [11, 12]. This has led to quite some overlapping concepts and debates about usefulness and implementation in practice. Regardless of these conceptual debates, it will be important to focus on how optimal implementation of person-centred care planning can occur in clinical practice, so that it benefits the well-being of older people and their families.

Inherent to such an approach will be to centralize the voice of older people in the care planning process. While there are differences between older people, research shows that most want to be involved in a shared decision-making process, together with family members [13]. Studies on ACP for example have shown that satisfaction with the care at the end of life among older patients is strongly associated with the way that they are informed and involved in medical decision-making [11, 14]. This stands in sharp contrast with research showing their lack of involvement in advance care planning or end-of-life decision-making [15–17]. Involving older people in the decision-making process should be a core ethical value for all health care workers and society, even if cognitive capacities are declining [14, 18]. The only way to have any idea about the preferences and wishes of an older person is to ask him or her directly. Therefore, it is important to support peoples' decision-making capacities as much as possible throughout this process, and more effort should be directed towards the engagement of physicians and patients/families in high-quality discussions concerning medical and care decisions, throughout the entire care trajectory. Even in the absence of advance directives, timely open discussions on personal values, life goals, needs and preferences are extremely important to direct later end-of-life decision-making in the group of patients who would no longer be able to be involved in the decision.

## The need for setting-specific and cross-setting interventions to improve quality of end-of-life care for older people

Many older people live at home, alone or with family, in the last years of life. A significant proportion of older people reside in long-term care facilities (nursing or care homes) at the end of life—although figures vary considerably between countries [19, 20]. Many older persons are admitted to a hospital during the last years and months of life or die in a hospital setting [21, 22]. In all settings, epidemiological studies over the past decades have shown there is substantial room for improvement in caring for older people, within each one of these settings but also across settings as continuity and coordination of care across settings has proven to be a challenge in many health care systems in the world [1, 17, 22–24].

Over the past decades, some important intervention studies have been performed to improve end-of-life care and comfort at the end of life for older people in different care settings. In a cluster RCT, the Care Programme for the Last

Days of Life (CAREFuL) showed improved nurse-assessed comfort in the dying phase after its implementation in acute geriatric hospital wards in Flanders [25]. The programme is currently being implemented on a large scale in the Flemish-speaking part of Belgium. As older people are hospitalized in all different types of hospital wards (oncology, cardiology, pneumonology, ED, ICU, etc.), it will be important to develop and evaluate interventions that can identify the specific needs of older people regardless of the ward and support them and their family members in a way that is aligned with an integrated palliative, geriatric and rehabilitative care approach at the end of life.

Specifically for nursing homes, some important innovations have been developed [26, 27]. The PACE Steps to Success Programme, a train-the-trainer programme to improve general palliative care in nursing homes based on the UK Route to Success, was evaluated in a 7-country trial [28, 29]. While dying comfort was not impacted as main trial outcome, positive changes in quality of care were observed as well as improvement in staff competences in palliative care as findings from the process evaluation showed. The trial showed it is possible to change practice in nursing homes but some important barriers and challenges inherent to the nursing home sector hindered optimal implementation. Difficulties in implementing quality improvement initiatives in nursing homes have been found in a multitude of studies in this sector [30]. One of the major reasons for this is the historical undervaluation of the nursing home sector and the accompanying lack of necessary resources, staff and support. While it is important to recognize that there are many nursing homes that are delivering high-quality and compassionate care to their residents, many are also struggling and the COVID-19 pandemic has clearly exposed these issues. An urgent and sustainable policy response is needed.

A recent review on palliative care for older people at home highlighted the lack of evidence and the need for improvements in care for older people with complex care needs, among others in information flow between professionals, knowledge on palliative care for case managers and social workers, and the importance of support for family carers [31]. One of the biggest challenges for the future of the older persons with complex care needs in the last years of their life will be to ensure optimal coordination and continuity between care settings, including out-of-hours care. We might prevent some transfers to other settings for older people, but all hospitalizations or nursing home admissions are probably not avoidable.

## Role of family, communities and societies

Family, close friends, neighbours, the larger community, social and voluntary networks, will inevitably play an important role in supporting older people throughout the last years of their life. As much research has shown, the increasing number of people with complex care needs, for a longer duration in the trajectory, and the limited workforce and capacities of formal health care services to meet these needs, lead to consider the potential of the informal care network of an older person, the role of social care and its integration with health care, and the role of communities and volunteers [3]. Inspirational new models of care and community support services are currently being developed in many countries in the world (e.g. compassionate community approaches [3], volunteer navigation interventions helping older people to navigate the system and increase access [32], peer support groups), and future research should focus on evaluating what works well, in what context, for whom. Specifically for informal family carers, it will be important to recognize their needs as care providers as well as care recipients and support the family system as much as possible. Finally, as more people experience loneliness, lacking close connections with others, aggravated by the current COVID-19 pandemic, innovations in socialization of care are urgent and pressing. Palliative and geriatric care are in a good position to lead on these developments, together with all stakeholders involved and particularly older people and their caregivers themselves. This would corroborate well with the exciting new initiatives of The Lancet Commission on the Value of Death advocating for a radical change across death systems and valuing the role of all those surrounding people who are dying.

## Future priorities

We are a long way from realizing an integrated palliative, geriatric, rehabilitative care approach for older people and their family in any setting where people reside. Future research should focus on:

- Defining the core principles and domains of a care approach for older people in the last years of life based on the integration of the principles of palliative, geriatric and rehabilitative care
- Developing guidelines and interventions to support all professionals who are involved with caring for older people and their families, to deliver person-centred and family-focused care, which is holistic and goal-oriented in nature and focused on quality of life and well-being of the person.
- Evaluating how health and social care services can collaborate to deliver optimal care for older people and their families in different care settings; and how continuity of care can be improved or how older persons and their family can be supported to navigate the system.
- Understanding how to support, empower and value older people and their family to ensure optimal involvement in care and decision-making throughout the end-of-life care trajectory
- Accelerate social and community innovations to ensure older people can live and die well, physically as well as socially and emotionally.

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