The geriatricians’ role in end-of-life care

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Abstract

Healthcare aims to help older people to live well, but ultimately must also support them to die well. Most people die in old age, but predicting death in both short- and long-term is impossible for many, although not all, older people. Frail older people live with hope and pride in coping, and often anticipate recovery when ill. Key objectives of healthcare for older people are to maintain independence, minimise suffering and preserve dignity, which requires active medical, mental health and rehabilitation management, even when extending life is not the main goal. Thorough medical diagnosis and appropriate treatment and rehabilitation minimises disability, physical and mental distress and problems resulting from acute illness and crises. In these terms, 'health gain' can be achieved from medical intervention, even when life expectancy is short. Assumptions derived from cancer care about lack of reversibility with medical interventions are sometimes unwarranted. This has to be balanced against investigation- and treatment-burden, including that associated with hospital admission and the adverse effects of drugs and therapy interventions, and the need to respect the identity and autonomy of individuals. The resolution of these tensions requires anticipation of care options, multi-professional assessment, judicious and targeted treatment, good communication with patients and stakeholders and rigorous shared decision-making. In this commentary, we compare geriatric and palliative medicine, and describe how the geriatric medical approach can deliver appropriate healthcare towards the end of life. This is well-supported by the broad knowledge, skill-set, flexibility and professional values displayed by geriatricians working in multi-professional teams.

Key points

1. The trajectory towards the end of life for frail older people is variable and often unpredictable

2. Crises are common, problems are often functional and mental distress is as common as physical symptoms

3. Frail older people live with hope and pride in coping and often anticipate recovery when ill

4. 'Dying well' means minimising suffering, retaining independence for as long as possible and maintaining dignity

5. Multi-professional expertise, commitment to communication and rigorous shared decision-making are required

Introduction

Geriatric medicine has a broad approach and a positive outlook. The central tenet is that well-being is enhanced and disability minimised through thorough medical diagnosis, treatment and rehabilitation. However, older people are inevitably in the last phase of their lives and few would deny that 'dying well' is also a valid goal.

The British Geriatrics Society has published 23 online guides to different aspects of end-of-life care in frailty [1]. In this commentary, we explore similarities and differences between geriatric and palliative medicine, and how the geriatric medical approach can deliver appropriate healthcare towards the end of life. We aim to give geriatricians awareness and confidence that their skill set is applicable at the end of life.

Ill-health and dying in older people

Older peoples' health is characterised by:

- Multi-morbidity, often involving musculoskeletal, cardiorespiratory, neurological and mental health diagnoses
- Disability (lack of capacity to perform necessary or desired tasks), in turn causing dependency (the need for human help)
- Frailty, which leads to frequent crises, caused by a combination of medical, mental and social factors.

Prognosis for survival in old age is both variable and uncertain. The median life expectancy of an 80 year-old woman in the United Kingdom is 10 years, and for a 90 year-old woman it is 5 years [2]. For some it will be much shorter, owing to their health status or socioeconomic disadvantage. Frailty assessment can help refine this, but median survival among even the frailest groups is several years [3,4]. Severe frailty alone, or an increasing frailty trajectory, cannot be equated to imminent dying [5,6]. Only half of those identified as approaching the end of life by the 'Surprise Question', the Supportive and Palliative Care Indicators Tool or QMortality risk predictor will have died within a year [7,8]. Even recognising the last days of life can be misjudged [9]. Evidence from care homes suggests different 'trajectories of dying': anticipated, sudden, uncertain and unpredictable, each needing a different approach [10]. This uncertainty and variability must be accepted, communicated and allowed to inform management.

The convergence of geriatric and palliative medicine

Geriatric and palliative medicine have much in common and can be considered as part of a continuum: palliative medicine traditionally focusing on symptoms and suffering, geriatric medicine on loss of function and independence. Both share a commitment to person-centred care, communication and multi-professional working [11]. Both are problem-orientated. For older people, problems are often functional: poor mobility, falls, incontinence, difficult behaviours, poor safety awareness, managing domestic tasks and keeping occupied. Predominant symptoms at the end of life overlap with, but differ from, those seen in cancer: notably fatigue, anorexia, swallowing problems, forgetfulness, psychosis, anxiety, depression, breathlessness and chronic pain [12,13]. None of these has a simple symptomatic or pharmacological treatment that can be sustained beyond the very short-term without risk of harm. Comprehensive Geriatric Assessment, however, provides an approach that can improve outcomes or help reach a decision that a problem cannot be resolved. Many problems deteriorate during acute illness and – unlike in progressive cancer – recover when it is treated.

Palliative medicine is notable for its commitment to psychological and emotional care. This is less well-developed in geriatric medicine, but can be seen in the advocacy of 'person-centred' care, especially in dementia, but also at the end of life. This requires:

- an attitude of respect
- individualisation, addressing specific health problems, taking account of priorities and preferences
- empathy to understand problems
- effort to build relationships that affirm the person's identity and provide comfort, attachment, inclusion and occupation [14].

Avoiding 'treatment burden' is an idea that originally referred to cancer surgery or chemotherapy, but is well-recognised by geriatricians. For older people burden includes hospital admission, uncomfortable or time-consuming investigations, treatment-associated debility or complications, adverse drug effects, pill-burden, the effort required for exercise or rehabilitation and the stigma associated with visible aids and appliances.

Palliative medicine has evolved, extending into 'supportive care' alongside active cancer treatment [15], and addressing the needs of 'survivorship', in which even progressive cancer may now be managed over many years, punctuated by crises, much like a chronic disease [16]. Co-morbidities and treatment-related complications such as neuropathy may be as troublesome as problems caused directly by the cancer. 'Palliative care principles' have been applied in heart, respiratory and renal failure and progressive neurological disease, with some success. Geriatric medicine, on the other hand, has expanded liaison working with mental health and surgical specialties, and responded to the pressing operational need of acute hospitals for efficient management of older people admitted as an emergency, risking being seen as focusing on 'care with curative intent'. In the UK, at least, geriatricians have been substantially withdrawn from responsibility for rehabilitation and long-term care.

Goals of care

We are rarely surprised when a frail older person in a crisis dies, but we are equally unsurprised when they live. If they survive, our goal is that they should be as symptom-free and able as possible, and unburdened by medical treatments or adverse effects. This implies that palliative and geriatric care principles must become integral to all healthcare for frail older people regardless of diagnosis and prognosis.

But tensions are unavoidable. Frail older people are often aware of their mortality, but rarely see themselves as 'dying'. Many express a desire for recovery when ill, and to 'keep going' when frail or disabled [17]. Equally, there may be a strong desire to avoid the disruption of hospital admission or to receive life-prolonging therapies. Trying to prolong life when the attempt is clearly futile is wasteful, risks unnecessary harm and should be avoided. But medical hubris includes both over-confidence that medical treatment can help and unwarranted certainty that it cannot. Estimating the chances of success of proposed medical therapy for each individual requires both specialist medical knowledge and humility.

Delivery of medical care that is unwanted by individuals or those who are close to them makes no sense, but equally frail older people should have equitable access to appropriate medical investigation, treatment and acute care where this is wanted and can feasibly deliver health gain. We need to accept diversity and flexibility in what is wanted and delivered in the last phase of life, including different degrees of medical and therapy ‘aggressiveness’, and plans that change with time and circumstances.

The central role of communication and decision-making

Good communication, developing trusting relationships and rigorous shared decision-making is important to both palliative and geriatric practice. In palliative medicine ‘open and honest’ communication is often about acknowledging dying and articulating fears and priorities. In geriatric medicine the scope is wider, but less acknowledged or provided for. Many older people have difficulties communicating, including deafness, cognitive disorders and aphasia, so communication must be adapted. Hospitals and crises are disempowering and emotionally-charged, mitigating against effective communication. Collateral information from families or others is essential; families have expectations around information on wellbeing and progress, and play a key role in decision-making for medical and social care, especially around care transitions (e.g. moving to a care home).

Decision-making represents an intersection of law, ethics, professional duties and culture, which can lead to contradictions. English law emphasises autonomy and confidentiality; culturally we must embrace working with families. Medicine advocates evidence-based effectiveness; families may want efforts at life-preserving interventions which have little chance of success. Many people express the ideal of dying at home, but practicalities make it difficult or unwanted [18]. ‘Principlist’ ethics, taking account of benefits, burdens, autonomy and justice, can be applied to most decision-making, but are constrained by mental incapacity, uncertainty and practicality. Ethical frameworks that emphasise developing and maintaining relationships, especially by ensuring that all stakeholder viewpoints are heard, are particularly pertinent at the end of life. So too are virtue ethics, which define ideals for the disposition or values of the practitioner, who must advocate at the level of patients and their families, organisations and systems [19].

Advance care planning, including treatment escalation plans, using various legal or informal arrangements, can valuably help avoid unwanted elements of medical care. But in the light of uncertain prognostication and the unpredictable nature of decline in frailty, plans can be difficult to articulate, especially when crises or unexpected circumstances arise [20]. Rapid access to specialist, multi-professional, assessment and suitable non-hospital alternatives may be preferable.

Conclusion

For frail older people 'dying well' means minimising suffering, retaining independence for as long as possible, and maintaining dignity when independence is lost. There are tensions between potentially life-prolonging treatment or restorative rehabilitation on one hand, and basic symptomatic or personal maintenance care on the other. In practice, available options are often limited and determined by circumstances. Rigorous decision-making processes will best guide what we do. This balances what might be achieved through medical or therapy intervention, minimising treatment burden, and respecting the wishes and priorities of individuals, their families and advocates, within available resources. The pattern of care will be individualised and one size cannot fit all. It will require investment in time and skills to communicate and negotiate choices, and research to better quantify prognosis and treatment effects. It may mean rethinking hospital systems driven by efficiency and safety, which in the process have become increasingly 'system-centred' rather than 'patient-centred'.

Frail older people, and their family and professional carers, live with hope and uncertainty. Many accept that chronic and progressive diseases will not be cured, and that capacity to withstand acute illness or injury is diminished. Care of frail older people approaching the end of life is something for which geriatricians have the skills and a unique body of experience, enhanced by sharing care with palliative medicine, general practitioners, nursing and other allied health and social care professionals. Geriatricians can, and should, embrace this challenge.

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