Supportive and palliative care in the age of deferred death: primary care’s central role

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Mankind has never before witnessed a period with a greater proportion of older people. This will double in the next few decades to about a quarter of all people aged over 65 years.1 Absolute numbers of deaths will increase, and how people die will change significantly. Previously fatal illnesses have been largely tamed or even prevented. Medicine has virtually eliminated maternal mortality, and drastically reduced it from infections, accidents, cancer and cardiovascular disease. However, the frequent assertion that medicine has saved lives is wrong—all these advances have done is to defer death. It seems that society has limited the causes of death it tolerates to those from overwhelming accumulation of multiple ailments, dementia or (less frequently) organ failure or cancer.2

The structure of formal supportive and palliative care that has evolved—specialist palliative care—works best for people with cancer who only make up a fifth of those who die in old age.3 The trajectory of dying in progressive cancer is predictable and relatively short, so designing services for them is relatively straightforward. It is far more challenging to provide care for people with advanced diseases when the time frame is long and the course uncertain.

The prevailing service model of specialist single-organ care can unintentionally create exhausting treatment burdens, potential for error and care duplication, especially in multimorbid patients.4 Non-physical dimensions can be, and often are, neglected in a disease systems-centred approach. Crucially, often no one coordinates care where multiple specialists are involved. The well-being of those who shoulder the greatest burden of care—close family—can often be entirely ignored. Critical evaluation of the entire health system and the philosophies that underpin it are required urgently as many people still die without any access to palliative care at all.

What are the essential elements of care as the end of life approaches? First and foremost, it is essential that dying is seen as a normal, individual and wholistic process. Murray et al describe this as four dimensional—the physical, psychological, social and spiritual realms.4 Ideal palliative care pays appropriate attention to all four, and this requires integration and coordination across all levels of healthcare. At an individual and community level, this is the province of primary care.5 Both primary and palliative care emphasise comprehensive whole person care over time, and include care of the family in their wider community. Is primary care up to the task helping people to both live and die well? At a systems level, how can the specialist/hospital systems integrate seamlessly with care in the community?

Primary healthcare already exists in some form nearly everywhere. It makes sense to ensure a system with universal availability is tasked with supporting the universal experience of dying. At its best, primary care is already involved. In Catalonia, Spain, for example, high-quality palliative care is mandated by law. A single shared health record and a means of searching it for people at risk of dying in the foreseeable future ensures primary care is in a position to meet its responsibility as an integral part of the health system.6 In emerging countries, great examples exist of primary care in the lead. In Kerala, India, community palliative care is well developed,7 while Brazil has started to use its national primary care network to provide systematic palliative care previously confined to cancer units in tertiary hospitals.8 In rural and remote settings, primary palliative care is accepted as the norm, so more primary care practitioners state they perform palliative more commonly than in urban settings.9

So what supports and/or inhibits primary palliative care? The structure of countries’ health systems—reflective of their understanding and support of primary care—creates both fundamental facilitators and barriers to primary care doctors and nurses.10 Facilitators include ensuring sufficient primary care staff to provide appropriately in-depth care to the whole population. Community nursing resources11 and routine appropriate training in symptom and whole person care in undergraduate and vocational training are essential.10 Remuneration must support adequate time and resources for appropriate care, including the capacity to do home visits, which can improve outcomes for very ill people. A European Association for Palliative Care (EAPC) Toolkit for integrating palliative care into primary care10 was updated in 2019 with an infographic and video, which can be used by palliative care specialists and others to strengthen access to palliative care through primary care.

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There is frequently a lack of recognition of, or scepticism about the ability of primary care clinicians within the specialist health community. This is compounded by a perceived personal duty by some specialists to continue care to the greatest extent possible, which can prevent better sharing and integration of care.\(^1\) While there is a spectrum of skill (as in all professions), most primary care practitioners are willing to provide such care and do it competently.\(^1\)

Primary care practitioners can contribute to this lack of confidence by underestimating their skills.\(^1\) They may think supportive and palliative care is typified by specialist palliative care, hence that they do not ‘do’ palliative care.\(^1\) However, far more people die under primary care (and with a far wider range of conditions) than in specialist palliative care. With a small change in emphasis and by embracing a palliative approach, primary care practitioners can realise they are actually providing palliative care already. They must also be encouraged to understand that only non-specialists are in a position to identify patients requiring specialist palliative care, and thus have a key role as gatekeepers to either providing it themselves or to referring on should they determine the patient needs further support.

So what needs to happen to make supportive and palliative care both integrated and predominantly primary care-delivered?

First, virtually every health practitioner needs to recognise death is a routine and essential part of their practice—in particular primary care. WHO recently affirmed that palliative care is a core part of primary care provision.\(^1\) This requires primary health practitioners to acknowledge that deterioration to death is a possibility and to prepare for it alongside curative therapy—rather like carrying an umbrella on a cloudy day. This represents a paradigm shift from an ‘either curative/or palliative’ perspective, which may be considered counter-intuitive by some. All practitioners should be seeking out at-risk individuals actively so that their needs can be anticipated as they approach the end of life, alongside continuing to provide active attempts at cure. Early identification can be helped with a systematic approach to early identification of those approaching the end of life, including screening electronic medical records.\(^6\)

Preparation and planning then follow recognition. What complications are likely and what can be done to prepare for them when they occur? A team (primary care and specialist) appropriate to the possible issues should be built around the person, and their family and the team members understand what their roles will be when problems arise. As most people’s remaining time is spent at home, this requires coordination and communication between the patient and carer, specialists and primary care practitioners, so a comprehensive care plan is developed with input from all team members, and each person has defined roles. A single cross-disciplinary meeting to develop such plans provides excellent patient and health system outcomes.\(^1\) This approach requires deliberate investment in time and resources, so its value must be understood and embraced by health planners and actively pursued.\(^1\)

Inertia can impede change in complex systems like hospitals and hospices. Change usually occurs incrementally from established practices, unless a catastrophic event forces fundamental change. The COVID-19 pandemic shows how a seismic shock can usher in changes (like telehealth) that would otherwise take decades. We have seen what happens when systems change early and boldly, but also the catastrophic results of prevarication.

Where care is delivered by smaller administrative and less hierarchical units, better coordination may be evident. At a hospital level, can this be achieved? At a primary care practice level, management and practice owner attitudes to anticipatory care plans and time-intensive care can help (or hinder) effective palliative care. Working across specialist boundaries is essential, and has to be made administratively easier.

Finally, family carers for people at the end of life at home are widely neglected. Without them, the ill person’s care will often default to institutional or hospital care. Much more attention needs to be paid to carers’ needs, maintenance of their well-being, and preparing them for caring for their loved one through to death and bereavement.\(^1\) Proactive identification does allow needs to be anticipated and managed.

The pandemic nature of the coming burden of dying needs a ‘pandemic’ response at a personal, system and international level. COVID-19 has shaken the health system and forced innovative and rapid change. This current experience provides impetus to review health systems’ preparedness for other looming problems. The entire health system, including specialist palliative care, must grasp this opportunity. Comprehensive system and attitude change must occur now, before the number of deaths overwhelms our capacities.
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