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

Geoffrey Mitchell and Scott Murray.

Mankind has never before witnessed a period with a greater proportion of older people. This will double in the next few decades to about one quarter of people over 65 years.(1) Absolute numbers of deaths and their individual complexity due to multimorbidity will both increase. Previously fatal illnesses have been largely tamed or even prevented. Medicine has virtually eliminated maternal mortality, and drastically reduced it from infections, accidents, 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 accepts to those from overwhelming accumulation of multiple ailments, dementia or (less frequently) organ failure or cancer.(2)

The easiest to understand 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.(2) 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.(3) 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 wellbeing of

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3 those who shoulder the greatest burden of care- close family- can often be entirely ignored. Critical
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5 evaluation of the entire health system and the philosophies that underpin it are required urgently as
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7 many people still die without any access to palliative care at all.
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12 What are the essential elements of care as the end of life approaches? First and foremost, it is
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14 essential that dying is seen as a normal, individual and wholistic process. Murray describes this as
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16 four dimensional- the physical, psychological, social and spiritual realms.(4) Ideal palliative care pays
17
18 appropriate attention to all four, and this requires integration and coordination across all levels of
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20 health care. At an individual and community level, this is the province of primary care.(5) Both
21
22 primary care and palliative care emphasise comprehensive whole person care over time, and include
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24 care of the family in their wider community. Is primary care up to the task helping people to both
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26 live and die well? At a systems level, how can the specialist/hospital systems integrate seamlessly
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28 with care in the community?
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35 Primary health care already exists in some form nearly everywhere. It makes sense to ensure a
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37 system with universal availability is tasked with supporting the universal experience of dying. At its
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39 best, primary care is already involved. In Catalonia, Spain, for example, high quality palliative care is
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41 mandated by law. A single shared health record and a means of searching it for people at risk of
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43 dying in the foreseeable future ensures primary care is in a position to meet its responsibility as an
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45 integral part of the health system.(6) In emerging countries, great examples exist of primary care in
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47 the lead. In Kerala, India, community palliative care is well developed,(7) while Brazil has started to
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49 utilise its national primary care network to provide systematic palliative care previously confined to
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51 cancer units in tertiary hospitals.(8) In rural and remote settings, primary palliative care is accepted
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53 as the norm, so more primary care practitioners state they perform palliative more commonly than
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55 in urban settings.(9)
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3 So what supports and/or inhibits primary palliative care? The structure of countries' health systems
4 – reflective of their understanding and support of primary care, create both fundamental facilitators
5 and barriers to primary care doctors and nurses.(10) Facilitators include ensuring sufficient primary
6 care staff to provide appropriately in-depth care to the whole population. Community nursing
7 resources(11) and routine appropriate training in symptom and whole person care in
8 undergraduate and vocational training are essential.(10) Remuneration must support adequate
9 time and resources for appropriate care, including the capacity to do home visits which can improve
10 outcomes for very ill people. A [EAPC Toolkit](#) for integrating palliative care into primary care (10) was
11 updated in 2019 with an [infographic](#) and [video](#) which can be used by palliative care specialists and
12 others to strengthen access to palliative care through primary care.
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28 There is frequently a lack of recognition of, or scepticism about the ability of primary care clinicians
29 within the specialist health community. This is compounded by a perceived personal duty to
30 continue care to the greatest extent possible- which can prevent better sharing and integration of
31 care.(12) While there is a spectrum of skill (as in all professions), most primary practitioners are
32 willing to provide such care and do it competently.(13)
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41 Primary care practitioners can contribute to this lack of confidence by underestimating their
42 skills.(14) They may think supportive and palliative care is typified by specialist palliative care, hence
43 that believe they do not “do” palliative care.(15) However far more people die under primary care
44 (and with a far wider range of conditions) than in specialist palliative care. With a small change in
45 emphasis and by embracing a palliative approach, primary care practitioners can realise they are
46 actually already providing palliative care. They must also be encouraged to understand that only
47 non-specialists are in a position to identify patients for palliative care, thus have a key role as gate-
48 keepers to providing it themselves or to referring on should they determine the patient needs
49 further support.
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5 So what needs to happen to make supportive and palliative care both integrated and predominantly
6 primary care-delivered?
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11 First, virtually every health practitioner needs to recognise death is a routine and core part of their
12 practice- in particular primary care. WHO recently affirmed that palliative care is a core part of
13 primary care provision. (16) This requires practitioners to acknowledge that deterioration to death
14 is a possibility and to prepare for it *alongside* curative therapy - rather like carrying an umbrella on a
15 cloudy day. This represents a paradigm shift from an" either curative /or palliative" perspective,
16 which may be considered counterintuitive by some. All practitioners should be seeking out at-risk
17 individuals actively so that their needs can be anticipated as they approach the end of life, alongside
18 continuing to provide active attempts at cure. Early identification can be helped with a systematic
19 approach to early identification of those approaching the end of life, including screening electronic
20 medical records.(6)
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37 Preparation and planning then follow recognition. What complications are likely and what can be
38 done to prepare for when they occur? A team (primary care and specialist) appropriate to the
39 possible issues should be built around the person, and their family and the team members
40 understand what their roles will be when problems arise. As most people's remaining time is spent
41 at home, this requires coordination and communication between the patient and carer, specialists
42 and primary care practitioners, so a comprehensive care plan is developed with input from all team
43 members , and each person has defined roles. A single cross-disciplinary meeting to develop such
44 plans provides excellent patient and health system outcomes.(17) This approach requires deliberate
45 investment in time and resources, so its value must be understood and embraced by health planners
46 and actively pursued.(18)
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3 Inertia can impede change in complex systems like hospitals and hospices. Change usually occurs
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5 incrementally from established practices, unless a catastrophic event forces fundamental change.
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7 The COVID-19 pandemic shows how a seismic shock can usher in changes (like telehealth) that
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9 would otherwise take decades. We have seen what happens when systems change early and boldly,
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11 but also the catastrophic results of prevarication.
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16 Where care is delivered by smaller administrative and less hierarchical units, better coordination
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18 may be evident. At a hospital level, can this be achieved? At a primary care practice level,
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20 management and practice owner attitudes to anticipatory care plans and time-intensive care can
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22 help (or hinder) effective palliative care. Working across specialist boundaries is essential, and has to
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24 be made administratively easier.
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30 Finally, family carers for people at the end of life at home are widely neglected. Without them, the ill
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32 person's care will often default to institutional or hospital care. Much more attention needs to be
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34 paid to carers' needs, maintenance of their wellbeing, and preparing them for caring for their loved
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36 one through to death and bereavement.(19) Proactive identification does allow needs to be
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38 anticipated and managed.
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43 The pandemic nature of the coming burden of dying needs a "pandemic" response at a personal,
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45 system and international level. Covid-19 has shaken the health system and forced innovative rapid
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47 change. This current experience provides impetus to review health systems' preparedness for other
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49 looming problems. The entire health system, including specialist palliative care, must grasp this
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51 opportunity.. Comprehensive system and attitude change must occur now, before the number of
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53 deaths overwhelms our capacities.
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