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How can palliative care deal with overzealous treatment?

Abstract

Palliative Care has an important role to play in preventing overzealous treatment. Active palliative care approach should be applied early in the disease and in all conditions, not only in cancer. Palliative Care specialists should be involved in the support and educating generalists, family members and general public. The holistic approach including the existential issues is able to foster new hope and stop patient and the family to insist on more treatments which may bring more harm than benefit. By gathering evidence through research and audit about the prevalence and costs of such iatrogenic activities, we may and advocate for a redesign of end-of-life care services so that patients can routinely access reliable care.

Key words: overzealous treatment, futile therapy, iatrogenic damage, palliative care

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Introduction

Palliative care has a major part to play in preventing overzealous treatment. To do this however, palliative care must extend and progress in three directions. Firstly it must become more involved with all progressive, life threatening illnesses — not just cancer, strategically training and supporting generalists in the palliative care approach. Secondly, palliative care must also become involved earlier in the course of the life-threatening illness, to offer, from the beginning, an active palliative approach and continuity of care as a real alternative to disease orientated treatment. Finally palliative care practitioners, again probably through training and supporting generalists, must help patients gain a realistic hope at the end of life, by supporting the patient and family carer in all dimensions of need: physical, psychological, social and spiritual. As well as advancing in these three dimension clinically, by promoting a greater

public discourse about death and dying in society, palliative care could also help de-stigmatise and de-medicalise death and dying, and help promote more effective, patient-centred treatment.

How can palliative care get more involved with all life threatening illnesses?

The mortality rate of being a human is 100% — a fact that many doctors appear to forget. Diagnosing dying is often done late if at all before death. Recent conceptual work describing patterns of physical decline at the end of life suggest that the clinical course of patients with eventually fatal chronic illnesses seem to follow three main patterns [1, 2]. These trajectories provide a way to describe generalities about large and discernable groups of people each with different illness time courses, service needs, priorities for care, barriers to reliably high quality end of life, and

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when overzealous treatment may occur during these different trajectories (Figure 1).

The first trajectory is the maintenance of good function until a short period of relatively predictable acute decline in the last weeks or months of life: lung cancer typifies this. The second trajectory, with slow decline punctuated by dramatic exacerbations which often end in sudden death is seen more typically in organ failure such as in end-stage chronic obstructive pulmonary disease and in heart failure. The third trajectory is poor long term functional status with slow decline. Elderly patients with dementia, frailty, or multiple co-morbidities fit into this category [3]. A general practitioner in the UK with 2,000 patients registered in his or her name on average each year has 20 deaths. Five of these are from cancer, six are from organ failure and seven from the dementia or frailty trajectory. Only two per general practitioner per year nowadays are deaths following an acute event, so sudden unexpected deaths are rare.

The first "cancer" trajectory has a generally predictable course and the needs of such patients in economically developed countries are currently usually well met by hospices and palliative care. However, patients with organ failure who follow the second trajectory often receive less and poorer care at

the end of life [4]. The needs for such patients are for planning to prevent acute exacerbations and then available acute care for the exacerbations. Similarly palliative care as it is currently configured contributes little to support those dying on the third of these trajectories, the frailty trajectory [5]. Thus, the urgent challenge of palliative care is to help address the palliative care needs of patients on the second and third trajectories, and to prevent overzealous treatment in these large increasing groups of elderly patients. It is likely, because of resource constraints, this palliative approach will be delivered through palliative care specialists training and supporting generalists in hospital and in the community rather than rendering clinical care themselves [6]. For every palliative medicine specialist in the UK there are at least 70 hospital doctors and 70 general practitioners. Thus a strategic approach to promote accessible care is to train and support generalists.

When in the illness trajectory should a palliative care approach start?

Recent systematic reviews suggest that predicting time to death, especially prognostication about a year before death, is very difficult and almost impossible in non-malignant illnesses [7, 8]. "Prog-

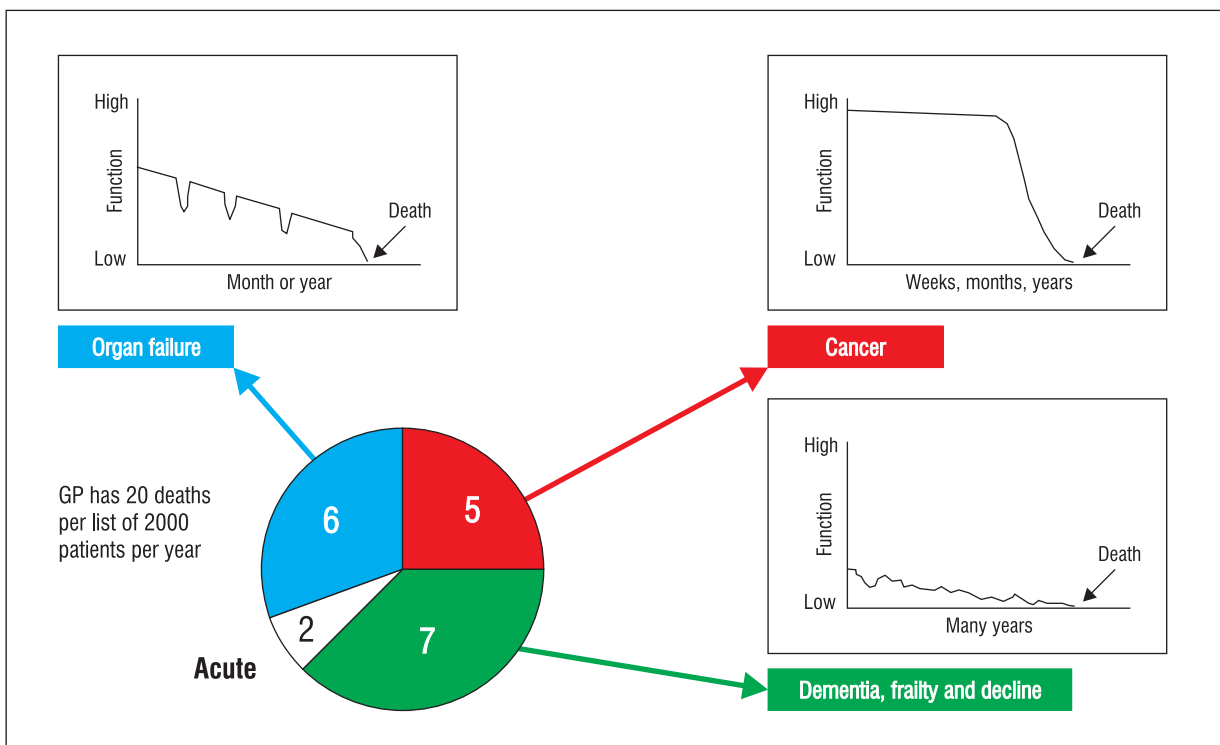


Figure 1. Typical trajectories of physical decline at the end of life: acute, intermittent and gradual decline [2]

nostic paralysis” indeed has been described whereby a doctor does not plan care because he or she does not know what might happen [9]. It is thus vital that palliative care is not restricted to a specific prognosis or diagnosis as mentioned above. It should be according to the needs of the patient and specifically their capacity to benefit.

In cancer the old paradigm was that there was curative care until a specific time when cure was no longer possible. The patient would be told “there is nothing more that we can do”, and then palliative care would begin (Figure 2). The newer and better concept however is that at diagnosis of a life threatening illness, while disease modifying treatment continues, supportive and palliative care is started and gradually increased throughout the course of the illness. Thus patients can receive disease modifying treatment and palliative care at the same time [2]. These are not mutually excluded, but complementary.

In the organ failure and frailty trajectories it has previously been more difficult to conceptualise and decide when a palliative care approach might be clinically appropriate. However, examining a typical organ failure trajectory (Figure 3) it is evident that events or triggers such as a hospital admission might be utilised to consider if this approach is now appropriate for that individual patient. Alternatively, there might be clinical indicators such as grade 4 heart failure (i.e. breathlessness at rest) to trigger this approach, or even the “surprise question”. This question is where a physician asks himself or herself the

question “would I be surprised if this patient were to die in the next year”? If the answer is “no” this means that the patient might die and therefore a plan should be started “just in case”. Patients can hold together preparation for the inevitable death and hope for the future, having dual, competing narratives in their mind [4]. For more details about indicators for identifying people on the frailty and organ failure trajectory please see the Gold Standards Framework website (<http://www.goldstandardsframework.nhs.uk/>). Overzealous treatment later in the course of the illness, in the very last days of life (see Figure 3 stage 3) can be prevented by diagnosing imminent death, and starting the patient on an end-of-life care pathway, such as the Liverpool Care Pathway [10]. This ensures among other things the consideration of stopping any unnecessary treatments and tests

In summary, early identification that the patient may die may well allow a palliative and supportive care approach to be started instead of, for instance, palliative chemotherapy which in some cases result in a poorer quality of life. Of course the doctor and patient and carer must buy into this and a number of questions can be raised to help the clinician and patients come to this understanding (Table 1).

How can palliative care foster hope and support the patient in all dimensions of need?

We conducted a study comparing the experience of dying in Kenya and Scotland [11]. In both

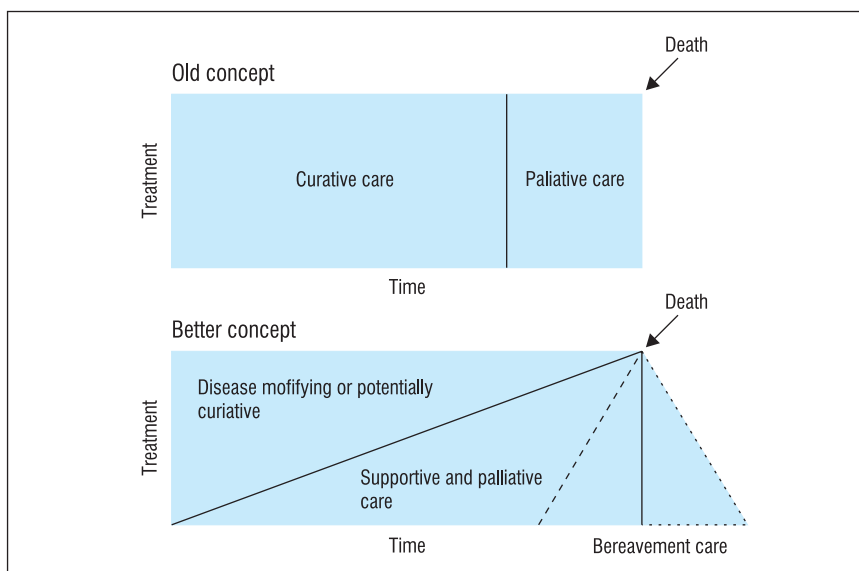


Figure 2. Appropriate care near the end of life: from disease modifying to active palliation [2]

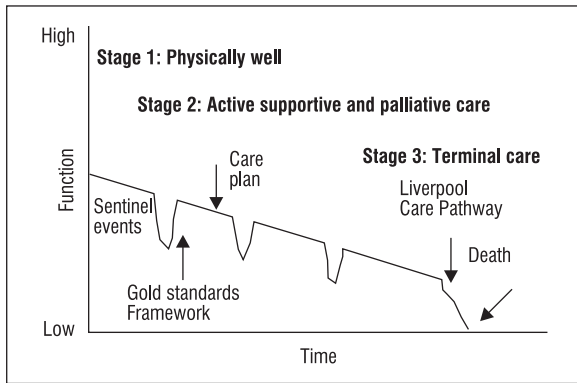


Figure 3. Three stages in organ failure trajectory

Table 1. Adopted patient-centred supportive care: possible questions [9]

What's the most important issue in your life right now? What helps you keep going? What is your greatest problem? You usually seem quite cheerful, but do you ever feel down? If things got worse, where would you like to be cared for?
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situations patients were asked to say what their main problem actually was. In Kenya it was consistently physical suffering, especially pain, as analgesia was frequently unavailable and inaccessible. But in Scotland the main issue that people spontaneously raised was existential in nature, it was about the meaning of life and why they were in such distress. Thus it was evident that many people dying in Scotland had existential issues that were frequently more significant and pressing to them than physical symptoms. The study, and further ones exploring more specifically spiritual needs of those who were in the last months of life, identified that in many cases the existential or spiritual issues were not being addressed by services. This highlights the importance of assessing all dimensions of need. It is also now accepted that everyone when faced with a serious illness, will have spiritual issues, relating to the meaning and purpose of life. A balanced or "holistic" assessment, and then addressing the dimension of need most pressing to the patient might result in less overzealous physical treatment.

Further research carried out by our palliative care research team in the community in Edinburgh has shown that as well as a typical physical trajectory of decline at the end of life in cancer there are also characteristic social, psychological and spiritual trajectories [12]. The social trajectory tends to run in parallel with the physical but there appear to be

four stages — at diagnosis, end of treatment, disease progression and terminal stage when psychological and existential distress are most likely to occur in patients (see Figure 4). I think you need to unpack these trajectories a bit more to show how they work in parallel. This of course has implications that we should attempt to meet these psychosocial needs from diagnosis, and be alert at other stages, and not just before the actual death. To do this we must be involved early in the illness, often when disease-modifying treatment is also occurring. Overzealous physical treatment is sometimes used as an alternative to appropriate social/psychological and spiritual treatment.

Similarly research indicates that when a patient is acutely breathless at home with heart failure, the patient is likely to also have psychological distress and social problems [12]. Thus an appropriate response to the acute exacerbation would be to consider not just the physical dyspnoea (rushing the patient into hospital) but also that psychological and social responses might also be appropriate. Thus overzealous rushing a patient into hospital might be prevented if this is understood and especially if plans are made in advance both to prevent the acute event, and to plan what to do if it were to occur. This over-treatment is encouraged by a system where health and social care are not well co-ordinated, a system that is not set up to routinely deal well with this most common reason for hospital admission currently in the UK.

Another area which needs to be addressed is the lack of understanding of the natural progression of life to death. This results in futile admissions from

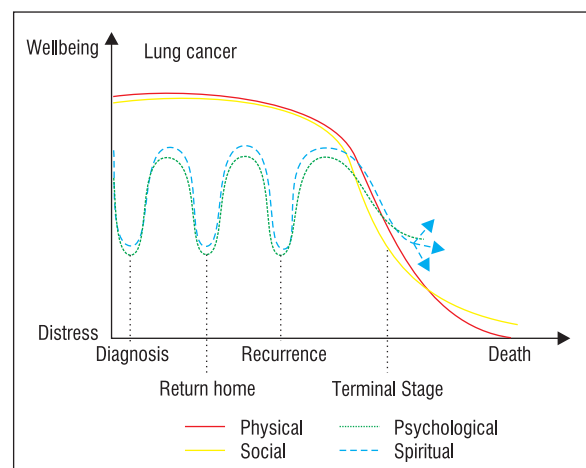


Figure 4. Typical physical, social, psychological and spiritual end of life trajectories in people with lung cancer

care homes when a patient collapses, even if it is a natural death. Where advance care plans and Do Not Attempt Resuscitation (DNAR) orders are routinely considered on or soon after admission, and staff are trained to recognise and be comfortable in dealing with dying, hospital admission rates from care homes can decrease by 50%, and bereaved carers also report much improved care and communication of themselves and the patient [13, 14].

Call for a public discourse on death and dying

An exciting development which palliative care is starting to embrace is "Health promoting palliative care" [15]. This calls for community involvement in end-of-life care and calls for people and the community to generally talk and be more involved in many aspects of care at the end of life. Death has been institutionalised and medicalised in the West. Health Promoting palliative care argues that if it were brought more into the open it would of course be much easier to plan for a good death. Talking more about death and dying could also facilitate a reduction in futile treatment options, as realistic plans are made ahead of time as to what to do. Practical guidelines for this approach are available at <http://www.latrobe.edu.au/pcu/guide.htm>

Conclusions

Overzealous treatment appears in many guises from relatives demanding futile (according to the current evidence base) chemotherapy to maintain hope, to people being rushed into hospital unnecessarily at the end of life due to the way the system is geared to respond. We must gather evidence through research and audit about the prevalence and costs of such iatrogenic activities, and advocate for a redesign of end-of-life care services so that patients on all three of the trajectories can routinely access reliable care. We must educate the public and doctors about the inevitability of death. We must get involved with all diseases beyond cancer and we must get involved early in the illness rather than just in the terminal stage. And if we intervene early and seek to address existential as well as physical needs it is likely that we can do much to obviate overzealous treatment and the suffering it causes to patients.

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Editorial note

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