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Review

Palliative care: When and how, and what are the implications for global cancer policy?

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ABSTRACT

The ageing global population increases the need for palliative care as an essential component of cancer programmes in all regions of the world.

This article provides an overview of the meaning of palliative and end-of-life care, and summarises the evidence for effectiveness and cost-effectiveness. Having established the need and effectiveness of palliative care, we identify the deficit in communication skills among clinicians, and the lack of investment in care and research. We then place palliative care in the global health context, with special reference to the gains made in sub-Saharan Africa. We conclude with the need for research investment to inform policy and to adequately respond to global need for effective palliative care.

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1. The concept and practice of palliative care

Palliative care is defined by the World Health Organization (WHO) as “an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual” [1]. The word palliative comes from the Latin *palliare*, meaning to cloak. The goal of palliative care is to ease the symptoms

and other problems associated with living with an incurable illness, rather than to try to extend the amount of time that the patient has left to live. In this article the term palliative care will refer to care delivered by health care professionals working in specialist palliative care teams. Specialist palliative care teams are multi-professional, including doctors, nurses, social workers, and other allied health professionals for whom palliative care is their core daily work. Specialist palliative care teams deliver care directly to patients, and indirectly by supporting other professionals to deliver care [2].

The term hospice is context dependent. In the UK, hospice most often refers to an institution within which the health care professionals are specialists in palliative care. Hospices in the UK usually have inpatient beds, as well as community teams who see patients

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in their place of residence. In the United States, hospice care is the term used for a Medicare benefit available to people with a prognosis of six months or less [3]. US hospice care is most often provided in the community, with inpatient units being less common.

Since the development of the modern hospice movement by Dame Cicely Saunders in the UK in the 1960's, it has become a global movement (for example the first hospice in Africa opened in Zimbabwe in 1979), and is often recognised as a medical and nursing speciality. Given the advances in the policy, practice and research of palliative care in the UK, in this article we will largely draw on the UK context. However, as an academic collaborative that has focused on palliative care as a global health need, we will also draw on further contexts and lessons learned from around the world. In 2004 the World Health Assembly passed its first resolution on palliative care and so now Governments have a responsibility to train health care professionals in palliative care, deliver appropriate and effective palliative care, and ensure an evidence base.

2. The benefits of palliative care

There is now a body of evidence from controlled trials that specialist palliative care teams provide improved symptom control, better satisfaction with care, and improved quality of life for patients, and better outcomes for care-givers [4–7]. Systematic reviews have shown that receipt of community-based palliative care is associated with double the odds of dying at home [8], and half the odds of cancer patients attending Emergency Departments in their last month of life [9]. In the United States, among people with cancer, hospice care was associated with lower rates of hospitalization, intensive care unit admission, and invasive procedures close to the end-of-life [10]. In Canada, community-based specialist palliative care is associated with reduced risk of acute hospital care use, and a higher rate of out-of-hospital death [11].

Paradoxically, although the aim of palliative care is not to lengthen life, there is early but growing evidence that early palliative care may also improve survival among people with cancer [12,13]. The mechanism of this is unclear but it may be a result of patients receiving less chemotherapy near to the end-of-life, having fewer hospital admissions, or due to improvement in patient depression [14]. In the UK, trial evidence has shown that a brief palliative care consultant advisory service can reduce symptoms and caregiver burden [15] and costs of care [16]. A further UK trial to integrate palliative care into a novel multiprofessional brief service to manage breathlessness found in addition to self-mastery of breathlessness, it also has a positive survival effect [17]. In an RCT evaluation from Africa, training and use of a basic assessment tool with a care plan in palliative care delivered by existing clinic nurses alongside treatment improved mental health and psychosocial problems [18].

3. Palliative care reduces the high costs of end-of-life care

Care costs for people in the last year of life account for a large proportion of total health care expenditure. In the UK, around 20% of hospital bed days are related to the last year of life [19]. In the USA, 25% of total health care expenditure is used in the last year of life [20].

Annual direct costs for cancer care are projected to rise in the USA from \$104 billion in 2006 to \$173 billion in 2020, driven by dramatic rises in the costs of therapy and the extent of care [21]. These are unsustainable increases. Better integration of palliative care has been suggested as a potential solution to reducing costs without depriving patients of benefit [21].

Evidence on the cost effectiveness of palliative care has lagged behind evidence on its effectiveness with respect to patient and

family outcomes. This is due to the complexity of capturing social care and informal care costs in addition to health care related costs. Emerging evidence suggests that palliative care is likely to be cost-saving overall. In a systematic review, Smith et al. examined 46 studies that reported on costs of palliative care [22]. They found a wide variety of study types, characteristics, and quality. Most of these studies were from the United States, and they included both cancer and non-cancer conditions. Despite these variations, they found a consistent pattern: palliative care was frequently found to be less costly than comparator groups, and in most cases this difference was statistically significant. This indicates that the expense incurred by having an extra team involved in the patient's care is offset by fewer tests and treatments, and less hospital-based care.

4. End-of-life communication

It has been said that if palliative care was a drug, patients and policy makers alike would demand it. Unfortunately, societal attitudes towards death and dying, and a reluctance to speak about end-of-life care issues, mean that palliative care does not always seem palatable. The 2013 Neuberger review called for a National conversation about death and dying, to dispel some of the taboos that still surround it [23]. Initiatives such as the Dying Matters coalition in the UK, the Death Café movement, and the US Conversation Project encourage the normalization of conversations about dying. However, many people still have a 'not yet' approach to talking about their own mortality.

This is compounded by health care professionals' reluctance to initiate conversations about end-of-life care preferences with their patients. A US study showed that 69% of patients with lung cancer (and 81% with colorectal cancer) were not aware that the intention of their palliative chemotherapy was not to cure their disease [24]. In one study, around half of medical oncologists preferred not to discuss resuscitation, advance directives, or palliative care until there were no more treatment options available [25]. Perhaps not surprisingly, cancer patients who have late end-of-life conversations are more likely to receive overly aggressive care [26]. In the US, recent provision of reimbursement to physicians who have end-of-life conversations with their patients is likely to lead to such conversations becoming more mainstream.

Good end-of-life communication must be initiated by health care professionals, who in turn require adequate education and training. Remarkably, given its ubiquity, it is only relatively recently that caring for people who are dying has become a mainstream part of medical education. While palliative care is slowly gaining prominence on the medical curriculum, still the average time devoted to palliative care is 20 h over five years [27].

5. Providing enough palliative care: a lack of investment

While there is now convincing evidence that palliative care can improve patients' quality of life and death, and frequently at lower costs, investment in palliative care services has been slow and often inadequate. In the UK, palliative care developed from the hospice sector, and historically much of its funding has been private or charitable. Currently, the charitable sector spends £950 million on hospice care annually, with state funding of around £460 million [28].

There is widespread geographical variation in investment in specialist palliative care services: in 2010/11 the average spend by Primary Care Trusts on specialist palliative care varied from £186 to £6213 per death [28]. Inequalities in palliative care provision are widespread, with evidence of disparity according to diagnosis, age and relative affluence in addition to geographical location [29].

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