Palliative care can be called the ‘heaven for the few’: how can we improve access to good palliative care?

Introduction

A few weeks ago, I spent time with a palliative care patient with breast cancer in Peterborough hospital. She was relaxed – in a secluded room, with her pain under control – and awaiting imminent transfer to a hospice. A few hours later, I saw another terminal palliative patient in agony, breathless and struggling to communicate this to us. I cast my mind back to my elective at the Uganda Cancer Institute. There were several children in their final days or weeks of life with inadequate symptom control, including uncontrolled pain, metastatic bowel obstruction, and hyperemesis. The stark contrast in access to good quality palliative care both globally, and within the UK is clear.

Palliative care aims to holistically improve quality of life for individuals facing life-threatening illness by addressing needs across four domains: physical, social, psychological, and spiritual.[1] This care is delivered through three core components: i) symptom prevention and management, ii) effective communication, focusing on care goals and planning, and iii) additional support for practical needs. Palliative care is explicitly recognised as a fundamental human right.[2] Despite this, only 14% of people requiring palliative care currency receive it globally.[1] This is not an issue isolated to low- and middle-income countries (LMICs) though; there are significant access issues throughout the UK which disproportionately affect marginalised groups. Indeed, 65% of UK adults worry about access to palliative care,[3] and recent reports suggest that although 90% of people are estimated to have a need for some palliative care, only 50% receive it.[4] Demand for palliative care is forecasted to continue to grow.[1] This essay will explore barriers to equitable palliative care access globally across four domains in a top-down approach: i) policy and systemic prioritisation, ii) workforce education and training, iii) availability of essential medicines, and iv) targeting sociocultural challenges. By addressing these areas, it outlines a roadmap for transforming palliative care into a universally accessible service.

Policy Decisions Must Prioritise Making Palliative Care Universally Accessible Throughout All Regions

Palliative care can be made universally accessible through integrating it into universal health coverage, and with policies being introduced to improve access to marginalised groups and rural areas.

Systemic political problems currently jeopardise delivery of high-quality palliative care as many countries lack a national palliative care strategy, with funding being prioritised for curative intent. According to a WHO survey on noncommunicable diseases conducted in 2019 over 194 Member States, palliative care funding was available in 68% of countries, and only 40% reported that the services reached at least half of patients in need.[5] To combat this, palliative care needs to be integrated into universal health coverage, so that all people – irrespective of income, disease type or age – should have access to a nationally-determined set of basic health services including palliative care. Most studies show at least cost neutrality of palliative care, with many showing substantial cost reduction by transfer of care from acute care settings to patients' preferred locations – typically at home or in residential hospice.[6] Therefore, arguments against providing palliative care on financial grounds are difficult to justify, as the cost savings from reducing hospital admissions and focusing on patients' preferred care settings outweigh the potential expenses.

In 2014, the World Health Assembly Resolution on Palliative Care[7] called for all countries to integrate palliative care provision into their national health care systems, to ensure access for all patients in need. However, desired outcomes have not yet been realised.[6] In the UK, a recent report found that 98% of practitioners believe commissioning specialist palliative services should be compulsory in every part of the UK, with 85% saying they strongly agreed.[8] Clause 16 of the Health and Care Bill provides Integrated Care Boards with duties to commission health services for the people they are responsible for. In 2021 there were calls from the Association of Palliative Care Medicine (APM) to amend clause 16 to include palliative care. This led to an amendment in August 2022,[9] which is an encouraging policy decision in the right direction. Even if national policies are established, measures need to be taken to ensure palliative care access regardless of geographical region within the country.

Palliative care access is significantly worse in rural areas.[10] However, palliative care access can be expanded to remote areas through increased adoption of telemedicine to provide virtual consultations.[11] Telemedicine usage in palliative care has previously been neglected as palliative care is considered a ‘high-touch’ speciality where sensitive communications cannot be done using remote technology. However, during the COVID-19 pandemic, several telephone-based palliative care studies were conducted, producing positive results for both patients and care givers. (12-14) This is encouraging and suggests there is scope for further usage in the future.

However, to make use of high-level policy decisions, there must be a trained workforce to enact these and refer patients in a timely manner.

Current Workforce Shortages Can Be Addressed Through Introducing More Palliative Care Training Programmes, and Upskilling Generalists

Education of healthcare staff - regarding awareness of available palliative care resources, patient selection for referral, and providing palliative care - is essential for making judicious use of high-level policy changes.

According to a 2021 UK survey, 66% of practitioners felt there was insufficient capacity to deliver high quality specialist palliative care in their locality.[4] This workforce shortage can be targeted two-fold. The number of palliative care specialists can be increased through developing and expanding specialist training pathways. Additionally, upskilling generalists by providing ongoing education to primary care providers, is key to integrating palliative care into routine and community-based practice. Both by increasing palliative care competencies among generalists and by providing increased education opportunities in telemedicine, this can help reduce palliative care access barriers in remote and rural regions.

Lack of referral to palliative care is a serious barrier to equitable palliative care access, which can be targeted through education. There is referral reluctance, which may be attributed to fear of upsetting the patient, an admission of their own failure, or not understanding the benefits of palliative care.[6] This may account for late referrals – a known issue.[4] Indeed, a recent UK-based report found that only 17% of practitioners felt patients were referred in a timely manner to fully benefit from specialist palliative care.[4] Perhaps more seriously, is discriminatory selection criteria for palliative care referrals. There are significant inequalities in access to hospice care, where white, middle-class, middle-aged cancer patients are traditionally overrepresented. Recent research reaffirms that inequalities in hospice care provision persist. Patients without cancer, ethnic monitories, and those from rural or deprived areas are still under-represented.[15] Other reports on palliative care more generally highlight other structural and social determinants of health affecting health inequalities for disadvantaged populations across high and low-income countries,[16] including poverty, social isolation, learning disabilities, imprisonment, and LQBTQ+ groups.[17] This can be targeted by developing baseline palliative care knowledge across healthcare staff through integrating palliative care modules into medical and nursing curricula. Additionally, automatic triggers to refer patients to palliative care when transitions in care are documented (i.e., on metastases detection or screening tools detecting distress) could be integrated into systems to reduce bias.[6]

Even with sufficient capacity of well-trained staff, access to good quality palliative care is limited without access to essential palliative care medicines.

Shortages of Essential Palliative Care Medicines Can Be Combated Through Regulatory Reform and Local Manufacturing

Unnecessarily restrictive regulations for morphine and other essential controlled palliative medicines deny access to adequate palliative care.[1] These stem from misconceptions that improving access to opioid analgesia will result in increased substance abuse. These global disparities are evident by 2018 results from the International Narcotics Control Board, which found that 79% of the global population (predominantly based in LMICs) account for only 13% of total morphine consumption.[18] Though this is an improvement from 2014, this significant global disparity remains a concerning matter.

There have been significant strides in policy to establish the recognition of palliative care medicines as essential. As of the 2019 release of the WHO Guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents,[19] palliative care medicines are included in the WHO Essential Medicines List. Despite this, shortages of essential palliative care medicines continue. This can be combated through improving drug importation or reducing the need to import medicines altogether. Regulatory reform can streamline importation and distribution processes for essential medicines. Low-cost locally manufactured palliative medicines can also cut costs and reduce reliance on imports, thus helping circumvent palliative care medicine shortages.

However, there cannot be palliative care treatment, whether pharmacological or not, without consent. This relies heavily on public awareness and community engagement.

Sociocultural Barriers Need to Be Addressed Bidirectionally Through Education Campaigns and Leveraging Community Health Workers

Cultural barriers and awareness challenges - including taboos surrounding death and dying, fears about palliative care, and low awareness among patients and families about their rights to receive palliative care - impede palliative access.

Many individuals fear that palliative care may shorten their life expectancy, however, there is growing evidence that patients who receive concurrent palliative care tend to live at least as long as those whose care is directed at disease management alone.[6] Through increased education campaigns, this can help to target such misconceptions, and encourage earlier referrals.

Community engagement is bidirectional and relies on leveraging community health workers, linking to improved education and upskilling generalists. Lack of awareness about rights to receive palliative care has recently been attributed to marginalised groups assuming that services are for other people, rather than for them.[20] Increased work on introducing visible representation aims to act on this, including the work of Mary Lou Kelly in Canada working with remote indigenous populations, and the work of Suresh Kumar in developing Neighbourhood Networks in disadvantaged Indian populations.[21–22] In both cases, efforts to encourage individuals and communities to take an active role in providing palliative care themselves has led to successful and innovative community-based care initiatives.[20] Such a public health approach to palliative care, which is driven primarily by community development, requires leadership that empowers community involvement, rather than focusing solely on providing professional services. Like healthcare generally, palliative care is not just about delivering services to people treated as passive recipient; it is about actively engaging and enabling communities to play a role in their own care. Therefore, geographic (remote and rural), institutional (prisons and homeless) or social (ethnic or sexual identities) differences can be addressed by asking what they can offer us within a partnership, rather than what we can provide.[20] By centering around communities, this can help overcome issues with palliative care access in the marginalised groups who are most underrepresented.

A Path Forward: Achieving Universal Access to Palliative Care

Palliative care is fundamental human right, yet only 14% of individuals in need receive it, highlighting a significant disparity in access and a critical gap in healthcare provision. The global need for palliative care will only continue to grow due to the ageing of populations and the rising burden of noncommunicable disease.[1] In the UK, models predict that there will be over 100,000 more people dying annually by 2040.[4] Therefore, improving access to palliative care is not only necessary, but increasingly urgent. Achieving universal access to palliative care requires a holistic approach that addresses key barriers across policy, workforce development, medicine availability, and sociocultural factors. Only through concerted global action can we transform palliative care into a universally accessible service that truly serves the most vulnerable.

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