

The evolution of hospice and palliative care in Ethiopia: From historic milestones to future directions

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Abstract

Introduction: This article reviews the genesis of hospice and palliative care in Ethiopia, examines recent progress, and makes recommendations for the way forward.

Result: Although the delivery of palliative care in Ethiopia has shown significant progress over the past two decades, it remains patchy, with the interdisciplinary components of psychological, social and spiritual support lagging behind the primarily medical approach.

Discussion: As a pillar of healthcare provision, and in conjunction with health promotion, disease prevention, curative services and rehabilitation, PC awareness and its development should be a high priority

Conclusion: More research on the root causes of lack of integrated services for PC and genuine conversation is required [*Ethiop. J. Health Dev.* 2020; 34(4):000-000]

Key words: Palliative care, Ethiopia, life-threatening chronic illness, hospice, end-of-life care

Introduction

The World Health Organization defines palliative care (PC) as ‘an approach that improves the quality of life of patients and their families facing the problem 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, physical, psychosocial and spiritual’ (1). Recent efforts to incorporate PC into the continuum of care in Ethiopia and other low- and middle-income countries indicate that they have been both efficient in terms of improving the quality of care, and cost-effective (2).

In 1967, Dr Cicely Saunders, widely regarded as the founder of the modern hospice movement, opened the first team-based facility in the United Kingdom. The term ‘palliative care’, used synonymously with ‘hospice care’, was later coined by the Canadian physician, surgeon and academic, Dr Balfour Mount (3). PC then evolved into an alternative to traditional care for patients who were either disillusioned with what modern medicine had to offer, or felt they had been ‘abandoned’ by their professional care providers, as there was ‘nothing more that could be done for them’. While PC allows patients and families to navigate various treatment and care modalities following their prognosis, it has been also proven to be cost-effective (3,4).

This brief communication intends to provide an overview of the historical and cultural underpinnings of ‘comfort care’ in Ethiopia, chronicle the advances over the past two decades, and make recommendations for future directions. The content of this communication is based on an established program and the research

experiences of the authors. It is hoped that it will provide a quick reference resource for future research, policy making, service provision and advocacy for PC.

Results

In Ethiopia, the modern hospice and PC movement started more as a response to the health system’s inadequacy to respond to the HIV/AIDS epidemic than a desire to provide an alternative care setting. HIV spread rapidly, with hospitals and clinics quickly filling up and overflowing (5). Often, sick patients had to be turned back and sent home. Home-based care (HBC) was then the only alternative in the absence of anti-retroviral therapy (ART), but was not recognized by the national healthcare system at that time. Prior to ART, patients with HIV experienced a rapid downward trajectory, with care focused on comfort and the alleviation of suffering, similar to hospice care. Community members and minimally trained HBC volunteers filled the void by providing basic services, dispelling myths about HIV/AIDS, and reintegrating patients into the community. In a noteworthy paradigm shift, *iddirs* (community self-help associations), which traditionally limited their services to the dead, started being involved with the sick and the dying, thus providing support to patients and families. More organized initiatives in HBC were introduced in 2000, when care and support services began to be delivered by civil society agencies, such as the Organization for Social Services for AIDS (OSSA). The establishment of Hospice Ethiopia in 2003 further boosted advocacy for HBC services. The past two decades have shown significant progress in the delivery of PC in Ethiopia (see Figure 1), although an integrated and truly interdisciplinary approach is still lacking.

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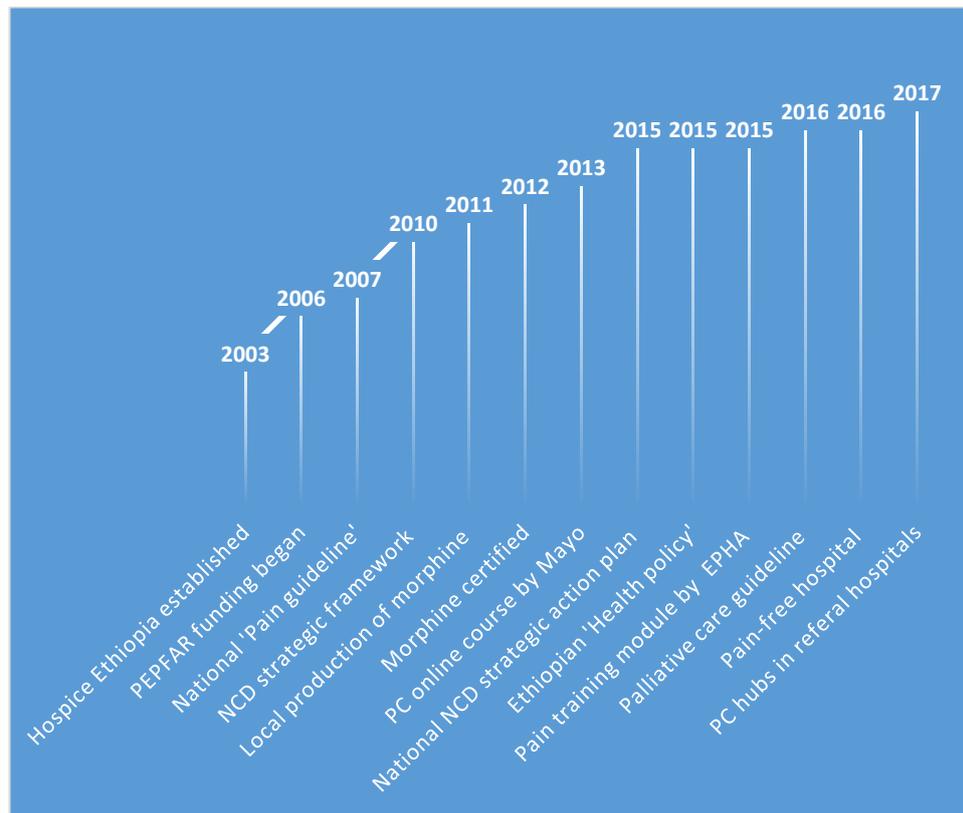
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Figure 1: **Milestones of palliative care involvement in Ethiopia**

Discussion

As a pillar of healthcare provision, and in conjunction with health promotion, disease prevention, curative services and rehabilitation, PC awareness and its development should be a high priority for Ethiopian policy makers, health providers and advocates for patients suffering from life-threatening chronic illnesses (LTCIs), such as cancer and other non-communicable diseases (NCDs). Many Ethiopian medical practitioners feel bound to the false dichotomy of aggressive and invasive intervention on one hand, and the sense of futility of 'having nothing to offer' on the other. However, there is much that can be offered to patients with incurable diseases, and this responsibility falls squarely on the shoulders of those of us who have taken an oath 'to first do no harm'. Indeed, it is our responsibility to care for patients from birth through to death, promoting health and minimizing suffering at every stage. Yet in Ethiopia, pain management, end-of-life care (EOLC), communication of bad news, the role of family in the multidisciplinary team, and the HBC approach, are not embraced and emphasized in healthcare providers' training. When the practitioner is faced with a multitude of problems in patients treated with LTCIs, the system appears to falter, with poorly organized responses to the challenge (6,7).

In Ethiopian culture, stoicism is highly valued and the expression of pain is equated with weakness and a lack of courage. As a result, pain management is given little consideration during child birth and surgical procedures, such as circumcisions and uvulectomies performed by traditional healers in some areas of the country (8). Inadequate management of moderate to severe pain, even within established institutions, can be inferred from the low per capita use of opioids in Ethiopia (less

than 0.0004 mg, ranking bottom of the league of 152 countries surveyed in the year 2003) (9). The training of clinicians lacks adequate emphasis on pain management, and there is often a flawed assumption that pain should only be treated within the context of the underlying disease and not as an isolated symptom.

End-of-life preferences are both a highly personal and universal phenomena: to be with family, to be at peace, at home – in short, 'a good death'. Yet more and more of us are dying apart from families and in hospitals. In Ethiopia, having advance directives or instructions that ensure a doctor acts in a way that honors one's wishes is extremely rare for a number of important reasons. Despite traditional community practices of breaking bad news (*merdo*), its communication is a commonly shunned duty by Ethiopian health providers and still much abhorred by the community. Culturally, the collective will of community prevails over a patient's autonomy. Individual autonomy is further undermined during critical illness and at the end of life. A healthcare worker is often instructed by families not to communicate bad news to the patient for fear of the patient's inability to cope or because of the widespread belief in acceleration of death after such a disclosure.

In Ethiopia, the conflict between spirituality, faith and modern medical interventions is a common dilemma in chronically ill patients. For example, refusing to take medication while opting for holy water, or the yearning for miraculous cures or healing, can undermine medical efforts to control or treat disease. Mental health issues, such as anxiety and depression, commonly affect both patients and their care-giving family members as end of life nears, yet historically these conditions have not been addressed by medical practitioners. Due to a lack of

support in decision-making and honesty surrounding poor prognosis, and catastrophic out-of-pocket health expenditure on expensive and often futile medical interventions, families can often be forced into economic bankruptcy (2,7).

Integrating PC delivery early into the chronic care of those with incurable disease allows patients and physicians to navigate through the disease trajectory with appropriate adjustment of treatment goals as the disease progresses and function declines. The alleviation of pain and suffering becomes paramount towards the end of life, with the active management of other distressing symptoms. In Ethiopia, there is a great need for value- and norm-sensitive, culturally appropriate PC and EOLC that balance respect for family preferences and patient autonomy. Healthcare professionals must learn how to communicate bad news within the accepted cultural context. Assessing what the patient already knows and how much they would like to know is a good starting point. We must empower family members with the above skills, as they have an important role as caregivers, while also teaching self-care, as we know the caregiver role is extremely taxing. We also must employ a multidisciplinary approach using psychologists, social workers and faith counsellors, as this is crucial to address the holistic needs of patients and families.

Conclusions

In Ethiopia, available evidence and cumulative experience over the years reveal that PC services mainly focus on pain management, while the other components – such as social, economic and spiritual support – remain patchy, underdeveloped and uncoordinated. In a country where NCDs are on the rise and where support mechanisms are not established, the care needs of patients are highly compromised.

As a way forward, key steps in advancing the cause of PC in Ethiopia include: awareness of PC among policy makers, healthcare providers and advocates; research into culturally appropriate PC approaches; task shifting to primary care for better access; translating the concept of PC and core terminologies into working (official) language to help community ownership; building alliances between HIV and Chronic Non-communicable disease sectors; integrating PC into the continuum of care of all LTCIs; incorporating the discipline into pre-service curriculums; and, most importantly, committed leadership by the Federal Ministry of Health and active engagement by all stakeholders. More research on the

root causes of the lack of integrated services for PC and genuine conversation is required to improve awareness among policy makers, healthcare providers and patient advocates to make PC a high priority.

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