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PERSPECTIVE

DIGNIFIED COMMUNICATION IN A TIME OF CRISIS: COVID-19 AND THE ROLE OF PALLIATIVE CARE IN ETHIOPIA

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As the COVID-19 pandemic continues, it is recklessly, indiscriminatingly, highlighting the need for an often neglected yet vital component of any health system: palliative care. As we write this, recorded global infections have passed 23 million with 800,000 recorded deaths (1)**.** At the height of the crisis in New York City, Emergency Departments were in chaos, with refrigerated trucks serving as mobile morgues set up outside hospitals to accommodate morgue overflow. In Ethiopia, the alert by the World Health Organization was taken very seriously and we have seen major evidence of political commitment to mitigate the pandemic. The covid-19 pandemic has, however, brought forth unprecedented social challenges, with Ethiopians being traditionally communal in worship and daily transactions. Mass activities like funeral processions, church and mosque attendances, mass open markets, an overwhelmed public transportation system and the daily subsistence income of the majority of our population has made lockdown unthinkable. Life is now defined by social distancing, hand sanitization and mask wearing.

Currently over 600,000 Ethiopians have been tested. Of these 32,722 were positive with 572 deaths (2)**.** Initially testing was for those at high risk due to the expense associated with the PCR method , which is resource intensive, but most recently a house to house survey is being carried out which should help to better assess total population prevalence.

End of life preferences are both a highly personal and global, human phenomenon. Whether you live in New York City or Addis Ababa, most of us want the same things at the end: to be with family, to be at peace, at home; in short 'a good death (2). Yet more and more of us are dying apart from families, in hospitals. This is especially true now, in the midst of the covid-19 pandemic. In Ethiopia, having advance directives, or instructions that ensure a doctor acts in a way that honours your wishes, is extremely rare, for a number of important reasons.

Palliative care is a poorly understood, indeed often misunderstood, treatment modality for when curative options are exhausted or not available. It is an often neglected yet vital component of any health system. Palliative care, and its terminus, end-of-life care, aims to decrease suffering and promote dignity and a "good" death, *whatever that means to you*. This last point is critically important. COVID-19 is especially lethal for older adults, and those with underlying health conditions, there are no proven treatments, it is indiscriminate and advances quickly. It is so important right now, that all of us and especially the most vulnerable among us think about and verbalize what we would want, if we were suddenly, critically ill.

COVID-19 has highlighted the need for increased awareness and access to palliative care. Globally, over 19 million people are in need of palliative care, yet just 14% will receive it, largely in high income settings. In Ethiopia, palliative care is in its infancy. The hospice and palliative care movement in Ethiopia started as a response to the health system's inadequacy to respond to the HIV/AIDS epidemic. The first case appeared in 1984 and infection spread rapidly with hospitals and clinics quickly filling up and overflowing bed capacity. Home based hospice-care were, hence, the only alternatives in the absence of anti-retroviral therapy (ART). Community members and minimally trained home care workers filled the void by providing basic services.

More organized initiatives in HCBC were introduced in the year 2000, when care and support services began to be delivered by Organization for Social Services for AIDS (OSSA), and others through Idirs (community self-help associations), and Kebeles (smallest unit of Urban dwellers self-help public associations). The establishment of the Addis-based non-profit organization Hospice Ethiopia in 2003 has further boosted the advocacy for home based palliative care services. The Ethiopian Ministry of Health is also working to improve access to palliative care in Ethiopia.

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In the best of times, and again no matter where you live, it is hard to talk about death. The COVID-19 pandemic is fast-moving, dynamic and has magnified the need for these difficult conversations. Communication of bad news and empathy are a well-organized, cultural practice in Ethiopia 'packaged as *merdo*'. Yet despite this traditional skill, bad news communication is commonly shunned duty by Ethiopian health providers and still much abhorred by the community. Culturally, the collective will of community prevails over the personal autonomy of patients. Individual autonomy is further undermined by critical illness at end of life. A healthcare worker is often instructed by family not to communicate bad news to the patient for fear of inability to cope or even widespread belief in acceleration of death after such a disclosure. Healthcare professionals must learn how to communicate bad news within our accepted cultural context. Assessing what the patient already knows and how much he/she would like to know is a good starting point. As healthcare providers, this is our responsibility, always, but especially now, during this time of crisis. For tips on how to incorporate palliative care into your practice, please visit https://ethiopianpalliativecare.com/, where under the "Resources" tab, you will find links to guides for healthcare providers.

The cloak of palliation, a crucial yet often non-existent component of fragile health care systems and humanitarian response efforts, is a critical adjunct which both reduces suffering and spares resources. There are no second chances in decisions surrounding end of life care, whether we make them for ourselves, a loved one, a patient or whether the decision is made for us. It is time to start having the difficult conversations. We owe this to ourselves, to our families and at challenging time, to our country as well.

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