

# **A Review of the Social Justice Concerns Related to the Integration of Palliative Care within the Kenyan Context**

**by**

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## **Abstract**

The World Health Organization (WHO) estimates that 40 million people are in need of palliative care worldwide, and of these, 37 million of them live in low- and middle-income countries (LMIC). Moreover, 98% of children who are in need of palliative care globally live in LMIC and almost half of them are living in Africa (WHO, 2015). Current palliative care needs are largely unmet and yet the need for palliative care is increasing due to the prevalence of HIV/AIDS, drug-resistant tuberculosis, and increasing rates of cancer, chronic conditions and non-communicable diseases (Sternswärd & Clark, 2004; Blinderman, 2009). Kenya is a key region to examine because it is a lower middle-income country, the burden of disease is high, public funding of palliative care is very limited, and yet with the combined efforts of national associations, dedicated healthcare workers, Non-Governmental Organizations and charities, Kenya is one of only three African countries that is approaching full integration of palliative care – ranked alongside several high-income countries worldwide.

Several international health and social justice agencies have highlighted that palliative care is a human right and should be recognized as a fundamental component of healthcare (Gwythner, Brennan & Harding, 2009); on the ground, the practice of this principal remains tenuous. In 2010 Human Rights Watch issued various hard-hitting reports on the state of palliative care in Kenya, highlighting a severe lack of governmental investments in palliative care service, particularly for children, and inadequate access or provision of essential palliative care medications such as morphine (Lohman & Amon, 2015). Since then, the

Kenyan Ministry of Health, in partnership with the Kenyan Hospices and Palliative Care Association (KEHPCA), has attempted to improve access to pain and palliative care services. Improvements such as including palliative care in the National Patients' Rights Charter, issuing detailed plans to integrate palliative care into the Kenyan public health system, publishing National Palliative Care Guidelines, and recent purchases of publicly funded opioid analgesic in the form of oral morphine (Ali, 2016).

Although there have been great strides in the establishment of palliative care services in Kenya, there are some overarching influential factors that complicate these efforts. There are also some key social justice concerns highlighted in the literature with regards to how inequity and stigma affect the facility of palliative care in Kenya. Through a comprehensive literature review in conjunction with my experiences from my internship with KEHPCA, I will discuss the hallmarks of palliative care in Kenya, the impacts of globalization, the increasing need for integrated services, the stigma and misconceptions that contribute to inequitable access, and finally explore the paradoxical relationship between social justice and this emerging public health issue.

**Keywords:** Palliative care, hospice, public health, cancer, HIV/AIDS, social justice, distributive justice, Kenya, East-Africa,

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## **Dedication**

To all of the clients, families and palliative care practitioners in Kenya who trusted me, guided me and welcomed me into their daily lives... I am ever grateful for the rich wisdom and experience you shared with me.

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## List of Acronyms

|        |   |
|--------|---|
| AIDS   | Acquired Immunodeficiency Syndrome                              |
| APCA   | African Palliative Care Association                             |
| ARVs   | Antiretroviral Drugs  |
| ART    | Antiretroviral Therapy  |
| CCP    | Cancer Country Profile  |
| CDC    | Centre for Disease Control                                      |
| COPD   | Chronic Obstructive Pulmonary Disease                           |
| EOL    | End-of-Life   |
| FBO(s) | Faith-based Organization(s)                                     |
| HIV    | Human Immunodeficiency Virus                                    |
| HRW    | Human Rights Watch  |
| ICECR  | International Covenant on Economics, Social and Cultural Rights |
| IAHPC  | International Association for Hospice and Palliative Care       |
| KEHPCA | Kenyan Hospices and Palliative Care Association                 |
| LMIC   | Low- to Middle Income Countries                                 |
| MDR-TB | Multi-Drug Resistant Tuberculosis                               |
| MOH    | Ministry of Health  |
| NGO(s) | Non-Governmental Organization(s)                                |
| PC     | Palliative Care   |
| PCU    | Palliative Care Unit / Clinic                                   |
| PLHIV  | People Living with HIV  |
| TB     | Tuberculosis  |
| WHO    | World Health Organization                                       |
| WHPCA  | Worldwide Hospice and Palliative Care Alliance                  |

## Introduction

From a population health perspective, healthcare systems must include services that address the needs of those living with a life-limiting illness, those nearing the end of their life, and the bereavement needs of the population (National Council for Palliative Care, n.d) – failure to do so encroaches on the human rights of the population. Palliative care offers a different perspective and approach to the care of people who face life-limiting illness – it is not a substitution or alternative to treatment, but rather a vital partner in the promotion of health and wellbeing throughout the life-course. While palliative care is most commonly associated with specialized care provided by specialized practitioners, the provision of palliative care is not limited to the tertiary level. In many parts of the world, palliative care is provided as a primary care intervention at the community level (Public Health and Palliative Care International [PHPCI], 2014). Most recently, palliative care has been integrated into the public health forum, arguably the level of intervention where palliative care has the most potential to enhance the overall quality of life of a population (PHPCI, 2014).

Efforts to integrated palliative care into public health systems are currently underway in various countries around the world. Kenya has made remarkable strides to integrated palliative care throughout their country, in urban and rural settings, enhancing existing healthcare amenities and building capacity with new facilities such as palliative care units and community hospices. The integration of palliative care in any setting is a large undertaking and presents many challenges from various sources, such as stigma and misconceptions about what palliative

care is, conflicting medical ideologies, and healthcare resource allocation. The central thesis of this paper states that for Kenya to achieve successful integration of palliative care the associated challenges and social injustices must also be addressed – the integration process must be contextually specific, equitable, responsive, and comprehensive.

In this paper I will explore this thesis within the literature and my experience in Kenya as an intern with the Kenyan Hospices and Palliative Care Association (KEHPCA). I aim to highlight the increasing need for integrated palliative care and the social justice issues associated with this emerging public health issue. I will begin with a comprehensive background to outline the complexities of palliative care, as a philosophy, as an approach to care, and the evolution of palliative care overtime. A brief overview of the integration of palliative care into the Kenyan public health system will also be included in the background. I will then describe the methods, results and key themes from my literature review, discuss the significance of these findings and compare them with my experiences during my internship with KEHPCA, outlining recommendations and exploring any gaps in the literature. Lastly, I will review the limitations of the research process as well as my personal reflections on my Master's project, this Capstone.

## **Background**

### **Definition of Palliative Care**

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families as they face problems associated with a life-threatening illness. Through the prevention and relief of suffering by means of early identification, thorough assessment and treatment of physical, psychosocial and spiritual symptoms, palliative care intends to neither hasten nor delay death, and regards dying a natural normal process (WHO, 2012). The term 'hospice' is often used interchangeably with palliative care, however this is incorrect as hospice care is principally for end-of-life, whereas palliative care can and should be integrated into the treatment plan as early as diagnosis of a life-limiting illness. This confusion between the two terms perpetuates the misconception that palliative care should only be implemented when there are no further curative treatments available. Palliative care can be helpful for adults and children alike, can be delivered in a wide range of settings, such as in hospital, in the community and at home, and should be equitably accessible to everyone who could benefit from it (Worldwide Hospice and Palliative Care Alliance [WHPCA], 2014).

In the early 1980s, it was widely accepted that palliative care was an essential part of cancer treatment, but over the years palliative care progressively became recognized for its broader applications in the treatment of a variety of life-limited diseases and chronic conditions. Table 1 outlines the list of diseases that the WHO and WHPCA (2014) recommend would benefit from palliative care.

**Table 1) Diseases requiring palliative care**

|   |  |
|---|--|
| <p><b>Adults</b><br/><i>15 years and older</i></p>      | <p>Alzheimer’s and other dementias, cancer, cardiovascular diseases (excluding sudden death), cirrhosis of the liver, chronic obstructive pulmonary diseases (COPD), diabetes mellitus, human immunodeficiency virus (HIV/AIDS), kidney failure (acute or chronic), multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, and multi-drug-resistant tuberculosis (MRD-TB).</p> |
| <p><b>Children</b><br/><i>younger than 15 years</i></p> | <p>Cancer, cardiovascular diseases (excluding sudden death), cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, kidney diseases (acute or chronic), neurological disorders and neonatal conditions.</p>   |

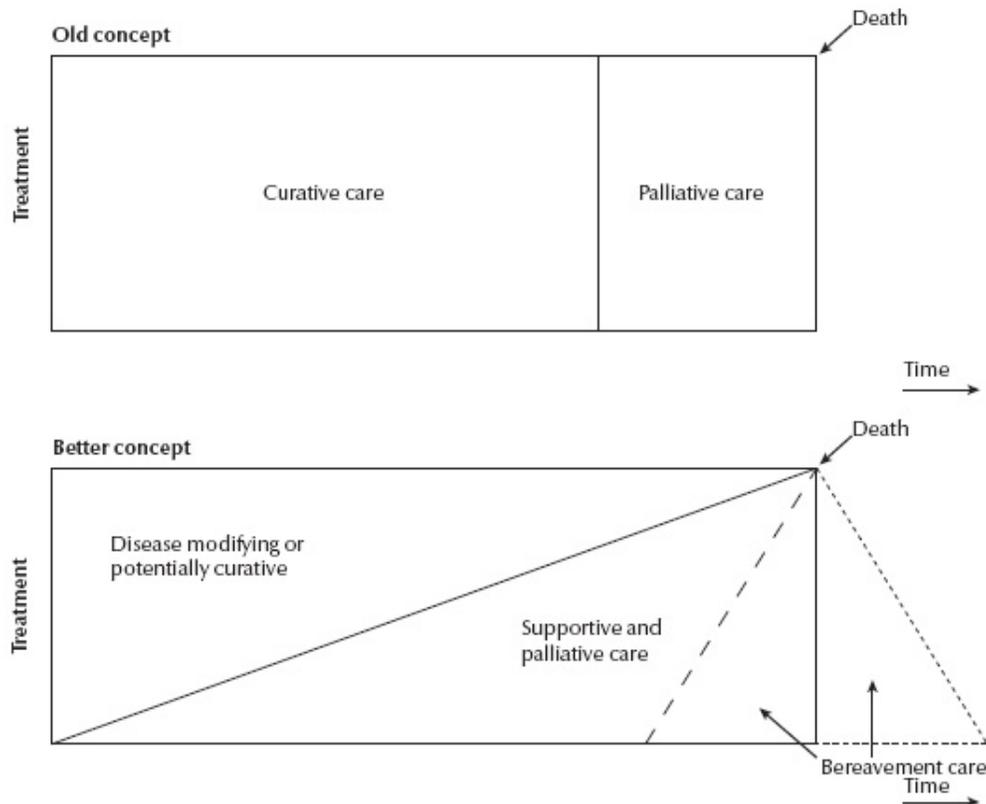
**Misconceptions and Pitfalls**

The course of an illness and the life-course of an individual are fluid and dynamic in their progression, and merit a model of care with a comparable level of flexibility and reflexivity. A troubling characteristic of contemporary biomedical healthcare is the rigid fragmentation of services, offered in distinct categories – illnesses grouped together by diagnosis, to be researched and treated by specialized practitioners. The fragmentation of services is also reflected in the silo-like categorization of healthcare funding and the overall structure of healthcare education and training (Selwyn, 2008). Palliative care is also often viewed as a specialized approach, with its own perceived parameters and boundaries. The trouble is that many of these parameters remain rooted in earlier conceptualization of palliative care noted in Figure 1 (Murray et al, 2005), which as mentioned before

perpetuate many of the misunderstandings that ‘palliative care should be reserved for the end of life’, or for ‘when there are no curative options are available’. The overall structure of healthcare specialization compounds the division between ‘curative’ treatment and ‘non-curative’ palliative care. It is a false dichotomy that neither serves the patient nor the health care systems charged with their care (Selwyn, 2008).

The current model of palliative care, also noted in Figure 1 “*better concept*”, illustrates how palliative care should be integrated into the overall care of the individual early on in their treatment, and gradually increased in correlation with the progression of disease and increase in symptoms (Murray et al, 2005).

Fig.1) Comparison between the old concept and the current model of palliative care



There are unintended pitfalls that emerge through reductionism and specialization in healthcare. For instance, by discretely focusing on the cause and control of disease and not accounting for the social determinants and broader context of the individuals affected by the disease, we end up with rather limited solutions for exceedingly complex problems. Palliative care is both a philosophy of care *and* a healthcare intervention (Payne, et al, 2009), but most importantly, palliative care is an approach that demands that the broader context of the individual be included in their plan of care, throughout the course of their illness.

### **Social Justice Aspects of Palliative Care**

Since the millennium, several international agencies such as the WHO, WHPCA, International Association for Hospice and Palliative Care (IAHPC), Human Rights Watch (HRW), and the International Covenant on Economics, Social and Cultural Rights (ICESCR), have highlighted that palliative care is a human right and should be recognized as a fundamental component of healthcare (Gwythner, Brennan & Harding, 2009). However, on the ground, the practice of this principal remains tenuous. The declaration of something being a human right has two main inferences – one being that it is “the minimum moral obligations owed to a human being”, and second, there is “a mechanism of accountability beyond the nation-state” (Wolff, 2012, p.16). Despite multiple acknowledgements of the human right to palliative care, the majority of countries around the world lack official palliative care policies or guidelines – and although many countries have

some level of palliative care provisions, the majority of hospice and palliative care services are supported by non-governmental organizations (NGOs), third-party partners, and are often not well represented in government healthcare budgets (Gwyther, Brennan, & Harding, 2009; Callaway et al, 2007). Perhaps Dr. Paul Farmer (2005: 201) states it best: “our practice has not kept up with our rhetoric”.

### **Brief Overview of Kenya’s Healthcare System**

Kenya’s in a lower middle-income country in East Africa, population of over 44 million (World Bank, 2014) and spends roughly 4.5% of their GDP expenditure on health (WHO, 2012). The Kenyan healthcare system is decentralized, where the Ministry of Health (MOH) establishes health policy, practice standards and sets the budget for allocation of funds, and the districts manage the delivery of services (Smart Global Health [SGH], 2016). There is both a public and private sector – the public sector manages 41% of the health facilities in Kenya and spends 5.9% of the general government expenditures on health, and the private sector manages 43% of the facilities and spends 60.4% - the remaining 15% of the healthcare facilities are run by NGOs (WHO, 2012; SGH, 2016). Per capita spending on health in Kenya ranges from 11 to 50, depending on the county, with higher per capita spending pooled around urban center (The Humanitarian Data Exchange, 2015). The healthcare system is structured for progressive referrals for higher levels of care, with access generally initiated at a local dispensary or private clinic, then a district or private hospitals, then a provincial hospital and lastly to one of the two national hospitals,

Moi Teaching and Referral Hospital in Eldoret, and Kenyatta National Hospital in Nairobi. Enrollment to the National Hospital Insurance Fund is required of all employed Kenyan and offers partial coverage of inpatient medical expenses; the policyholder is required to pay the balance of the bill directly to the medical facility. Fee waivers are possible for those who can prove their inability to pay for hospital bills, but it was reported to me during my time in Kenya that fee waivers could be cumbersome to obtain. There are several private health insurance companies that offer supplemental coverage for those who can afford it.

### **Overview of Palliative Care in Kenya**

Kenya is an important example in the pursuit of palliative care integration because the burden of disease is high, public funding of palliative care is very limited and yet with the combined efforts of national associations, dedicated healthcare workers, Non-Governmental Organizations and charities, Kenya is one of only three African countries that is approaching full integration of palliative care, ranked alongside several high-income countries worldwide. Kenya was the first country in East-Africa to open a hospice, has made tremendous progress with palliative care integration within the last decade, and has emerged as an active leader in palliative care internationally.

Historical influences on the establishment of palliative care in Kenya link back to faith-based organizations (FBOs) and colonialism. The first hospices in Africa were founded in the late 1970s, established by FBOs using a British model of care in Zimbabwe and South Africa (Stjernswärd & Clark, 2003). Kenya was

also colonized by the British and was the next country to open a hospice in 1990. Kenya's palliative care services have expanded greatly, but the majority of palliative initiatives and facilities are run with a faith-based approach and primarily funded by the private sector and non-governmental grants, such as the Diana, Princess of Wales Memorial Fund's Palliative Care Initiative (Clark, Wright, Hunt, & Lynch, 2007; Callaway et al, 2007). There are almost twenty hospices operating in Kenya, most of which are outpatient facilities offering palliative consultation, provision of palliative medications and outreach services. There are two inpatient hospices in Kenya, Kimbilio Hospice near Eldoret, and Our Lady Hospice in Thigio, both of which are primarily funded and operated by private FBOs.

In 2002 several hospice and palliative care professionals created a steering committee to discuss the foundation of a national association to represent the growing number of palliative care facilities and professionals, as well as a national advocate for awareness, training and investments in palliative care in Kenya (KEHPCA, n.d). The Kenyan Hospices and Palliative Care Association was officially registered in 2005, and since then has sparked a dramatic increase in palliative care awareness in Kenya. In a short amount of time, KEHPCA has establish a considerably high level of palliative integration, leading the way alongside the top 20% of countries in palliative services (WPCA, 2011). Countries worldwide are ranked into four groups based on the level of palliative integration; Group 1) no known activity, Group 2) capacity building, Group 3) provision of services, and Group 4) integration of services. Kenya is

ranked well on this scale, listed in Group 4 and approaching full integration status (WPCA, 2011; Wright, Wood, Lynch, & Clark, 2008).

In 2013, the MOH of Kenya, in partnership with KEHPCA, published the following documents outlining their efforts to integrate palliative care: the National Guidelines for Cancer Management, the National Palliative Care Training Curriculum for HIV/AIDS, Cancer and Other Life-threatening Illnesses, the National Palliative Care Guidelines, and finally The Kenyan National Patient's Rights Charter, which includes the right to palliative care. In 2014, the Kenyan government announced that it would include palliative care into the national healthcare budget in order to assist the current palliative care providers who are entirely dependent on private sector and charitable funding (eHospice, 2014). Over the years the government of Kenya made several declarations of support for the integration of palliative care and increasing access to essential palliative care medications, but governmental funding of services and medications has been slow to match the rhetoric.

KEHPCA reports that as of 2015, each of the provincial hospitals in the public sector have received pain management and palliative care education, and many of them have some level of palliative care services, such as a dedicated palliative care unit or a palliative consultation team on site. Kenya, like many LMIC, faces additional challenges of working to improve healthcare practices in resourced-limited settings. The current palliative care deficits in Kenya include inequitable access to services, particularly for children and rural or remote low-income communities, inconsistent access and provision of essential medications,

and limited palliative training in the baseline education of healthcare professionals (Lohman & Amon, 2015). It is important to note, that these deficits are also influenced by a broader context, such as gender dynamics, the vast diversity in religious beliefs, social customs and tribal traditions in Kenya, as well as stigma and fears related to death and dying, palliative care, and pain medications, held by patients, community members, the government and healthcare professionals.

## **Methods**

I conducted a foundational review of the literature and then included my own observed experiences, as stated in my extensive reflexive field notes, from my internship with KEHPCA in May through July of 2015. Building upon various systematic overviews of palliative care services in Kenya that were currently available online or in hardcopy, I aim to outline the social justice concerns regarding palliative care within the Kenyan context, including influential aspects and prevailing barriers to care.

I performed a literature review of my topic using six scholarly databases, searching assorted combinations of keywords and search terms such as public health, palliative, palliate, pain, cancer, social justice, ethics, human rights, Kenya, East-Africa, rural, urban, global health and globalization. It was important to include the terms *pain* and *cancer* in my search because palliative care is historical associated to pain management of cancer. It was also prudent to include HIV/AIDS in my search terms due it its prevalence in Kenya and to

capture literature that speaks to similar social justice issues, e.g. access to essential medications. I also did a thorough search of the grey literature published by international organizations such as the WHO, WHPCA, IAHP, HRW, ICESCR, African Palliative Care Association (APCA) and finally for more specific results on Kenya, I reviewed KEHPCA and the Republic of Kenya MOH's publications and reports, as well as the country profiles and data on Kenya published by the WHO, CDC, United Nations, and World Bank. In order to address the incipient nature of this issue, I also reviewed medical journals and books published by key leaders in oncology, global health and palliative care, who are spearheading practice recommendations globally.

The initial literature searches yielded 472 results (table 2), with several of the results overlapping in themes and with some duplication of results between the databases. Through a systematic analysis of the results, as noted in the methods section, the search results were reduced to 57 published articles, journals, grey literature reports, strategic plans, statistical profiles, news media source and books. Approximately half of my initial results were not specific to Kenya, but this did not automatically exclude them based on my criteria; I reviewed these titles and abstracts with a broader context and if it spoke to the state of palliative care or social justice in LMIC, Sub-Saharan Africa or the East-African region, it remained included in my search results.

**Table 2) Search Results**

| Database                 | Search words / terms                     | Results             |
|--------------------------|--|---------------------|
| Global Health<br>EBSCO   | Palliative / Pain + Kenya                | 19                  |
|                          | Palliative + Social Justice              | 2                   |
|                          | Palliative + Globalization               | 4                   |
| Science Direct           | Palliative + Kenya w/ refining filters   | 7                   |
| CINAHL                   | Palliative + Kenya                       | 42                  |
|                          | Palliative / Pain + Kenya                | 16                  |
|                          | Palliative + Hospice +Kenya              | 15                  |
|                          | Palliative + Social Justice              | 52                  |
|                          | Palliative + Globalization               | 4                   |
|                          | Palliative + Globalization + Kenya       | 0                   |
| Medline /<br>PubMed      | Palliative / Cancer + Kenya              | 59                  |
|                          | Palliative + Social Justice              | 92                  |
|                          | Palliative + Globalization + Kenya       | 9                   |
| Social Sciences<br>EBSCO | Palliative / Cancer + Kenya              | 6                   |
|                          | Palliative + Social Justice              | 10                  |
|                          | Palliative + Ethics                      | 134                 |
|                          | Palliative + Globalization               | 1                   |
| Cochrane                 | Palliative + Kenya OR Africa             | No relevant results |
|                          | <b>Total results (relevant results):</b> | <b>472 (52)</b>     |

I excluded all duplicate articles and sources from earlier than 1995, focusing primarily on sources from 2000 onwards. I screened the articles based on the titles, reading the abstracts and quick overview of the text, and then placing them in one of three files, 'relevant', 'somewhat relevant', or 'not relevant'. I then read the backgrounds, results and conclusions of the 'somewhat relevant' articles and moved some articles into the 'relevant' files for further review. I then read each of the 'relevant' articles in full and highlighted key elements that spoke to my search themes. I noted of any source citations connected to the highlighted key elements and made a list of articles to seek out

in my second search. I also reviewed the reference lists of the 'relevant' articles to identify common links, sources and prominent authors whose work is at the core of palliative philosophy, healthcare ethics and social justice theory. Once I had compiled a list of sources and articles that were not previously captured in my first review, I searched for them specifically. See Appendix for a flowchart outlining this selection process in more detail.

Upon completion of my literature review, I compared the results with my field notes from Kenya, looking for similarities and discrepancies between what's represented in the literature and what my experience was during my internship. My field notes include objective observations and extensive reflexive notes.

## **Results**

The literature used in this Capstone was current with 84% ( $n=44$ ) of the sources captured in my review from within the last ten years, and seven published within the last year. The literature captured in my review consists of articles found in peer-reviewed journals ( $n=31$ , 59%), grey literature ( $n=14$ , 26%), books, chapters or textbooks ( $n=6$ , 11%), and editorial reports ( $n=2$ , 4%). The captured scholarly articles are a variety of case studies, cross-sectional surveys, reviews and commentary. Most of the grey literature consisted of annual reports, evaluations, guidelines and statistical factsheets. The geographical setting of the literature breaks down as follows: 10% ( $n=5$ ) related to the region of Africa, 7% ( $n=3$ ) to East-Africa, and 17% ( $n=9$ ) Kenya specifically; more than half were from

a broader international perspective ( $n=30$ ) and 11% ( $n=5$ ) were focused on resource-limited settings.

## **Key Themes**

*The following key themes emerged from the review of the literature:*

- Rising burden of disease in Kenya with links to globalization
- Increasing need for palliative care with links to HIV/AIDS and cancer.
- Multi-faceted barriers to palliative medications (e.g. oral morphine).
- Social justice issues related to palliative care in general, as well as related to a lack of palliative care services in particular regions or for particular sub-populations of Kenya.

I believe what is most telling about these results is what is missing from the literature. There is a considerable amount of literature on the ethics and social justice concerns in palliative care overall, but very few specifically within the Kenyan context. Looking at the literature review, it is apparent that social justice is not a key theme in Kenya, or at least is it not effectively represented within scholarly research. This is in contrast to my experience in Kenya – key themes that emerged in my field notes include; social justice issues regarding a lack of paediatric palliative care, reluctance from physicians to prescribe opioids to palliative patients, including children, and profound legal rights violations against patients with a life-limiting illness (e.g. land inheritance violations, and being forced off family ancestry land after being diagnosed with a life-limiting illness).

## **Discussion**

### **Impacts of globalization**

Although palliative care worldwide has been enhanced by the increased collaboration and innovation that is a result of free-flowing global communication, the overall impacts of globalization have negatively affected the health of Kenyans. Resource-limited regions have suffered greater burdens of disease than resource-rich regions of the world, and this has only gotten worse since the onset of globalization (Boyle, 2006). LMIC carry two-thirds of the global disease burden, but yet have access to less than one-twentieth of the world's healthcare resources (Stjernswärd & Clark, 2003). Globalization is an influential contributor to NCD epidemics worldwide, for instance through the increased production and marketing of tobacco products (Beaglehole & Yach, 2003). Societal adaptations to globalization, such as the migration of people out of agricultural lands into urban centers, have led to profound changes in diet and lifestyle, as well as increased exposure to environmental carcinogens. Cancer patterns in new industrializing countries are changing dramatically, and much higher rates of lung, breast and colorectal cancers are occurring in countries where they were historically uncommon (Boyle, 2006). The same pattern changes are evident in the data from Kenya, where women are experiencing much higher rates of breast cancer than ever before, and men experiencing increases in rates in prostate cancer (WHO, 2014). Healthcare systems in LMIC are not equipped to deal with this new onslaught of cancer, and there are devastating social and economic consequences for families, communities, and regionally (Boyle, 2006).

Although the literature does not speak to any direct association between globalization and palliative care, I argue that the effect of globalization on patterns of disease and disease burden in Kenya, also contributes to the increased need for palliative care services. Globalization may be a somewhat circumstantial aspect of the issue, but it illustrates the overarching influences and challenges associated with palliative care in Kenya.

### **Increased need for palliative services**

Much of the literature highlights the importance of understanding the patterns of disease and how changes in disease prevalence greatly influence the need of palliative care. The two leading causes of death in Kenya are HIV/AIDS (41%) and cancer (8%) (CDC, 2015), but it is important to note that due to persistent and effective public health initiatives, communicable diseases are declining steadily and the Ministry of Health of Kenya (2014) projects that total deaths from non-communicable diseases (NCDs) will surpass communicable diseases by 2025. Approximately 20% of all cancers are caused by chronic viral infections, such as the human papilloma virus (WHO, 2006). In Africa, 36% of cancers are related to chronic viral infection, nearly twice the global average (Harding et al, 2014; Parkin, 2006). That said, simply acquiring the virus doesn't always lead to the development of cancer – immunosuppression brought on by HIV/AIDS or malnutrition can trigger the progression of chronic viral infection into cancer (Livingston, 2014). This is important information to consider due to the high prevalence of HIV/AIDS, malnutrition and the rise of virus-related cancers in

Kenya (e.g. cervical and prostate cancers). As the burden of disease increases, so does the need for integrated palliative care services.

Cancer is on the rise in many sub-Saharan countries, moreover, it is estimated that 80% of cancer patients in this region initially present to healthcare in the advanced stages of their disease, when curative options are limited (WHO, 2007). Oncology treatments are most effective when administered early on in the disease trajectory, which highlights why the above statistic speaks to the urgent need for integrated palliative care services. Chemotherapy and radiotherapy are essential aspects of oncology treatment, and can be offered as a curative measure *and* a palliative measure. Palliative chemotherapy and radiation are offered for the management of symptoms, for example controlling the size of a tumor that is impinging on other body parts, or decelerating the progression of an incurable cancer in order to improve quality of life. The WHO publishes Cancer Country Profiles (CCPs) outlining the cancer control efforts as reported by the MOH of each member state – according to the Kenyan CCP in 2014, the availability of publicly funded chemotherapy medications was limited, and there are only four publicly funded radiotherapy centers serving a population of over 44 million people.

During my time in Kenya, the main public radiotherapy center in Nairobi routinely had a waitlist of several months to a year, due to equipment breakdowns and overwhelming numbers of patient referrals. This is a two-fold issue because having timely access to radiotherapy is key to treatment success, and if radiotherapy is not provided when it has the potential to provide the most

benefit, there is an increased need for palliative services due to unmanaged tumor growth often accompanied by difficult symptoms such as pain, nausea, and shortness of breath. While consulting with patients at the various hospices in Kenya, it was not uncommon to see patients overly burdened by their tumors, waiting several months for a radiation appointment. For many of those patients, especially those who were diagnosed late in their illness, waiting several months can feel futile and be terribly detrimental to their quality of life.

With all of the above information considered, population health outcomes related to palliative care would improve in two ways if the government of Kenya invested in more cancer control services, such as chemotherapy and radiotherapy. It would reduce some of the need for palliative care from a quantity perspective, by improving patient outcomes and reducing cancer related deaths in Kenya. It would also improve palliative care services from a quality perspective, because palliative clients would have more timely access to the same cancer control services, enhanced symptom management and improved quality of life.

### **The vital role of access to medications**

Access to medications is essential when we look at the two leading causes of death in Kenya, HIV/AIDS and cancer (CDC, 2015). In parallel, the two leading indications for opioids are HIV/AIDS and cancer, and although LMIC carry the largest burden of these diseases globally, their opioid consumption rate is less than 7% of the world's consumption of medical opioids (O'Brien, 2015).

Both HIV and cancer have had great success with disease modifying treatments, and both still cause death, even with active treatment. Before anti-retroviral (ARV) medications were made readily available, people living with HIV (PLHIV) often died *with* an AIDS-related cancer, but *from* an AIDS-related infection (Livingston, 2014). Since ART was implemented in Africa, many PLHIV survive the acute phase of their HIV infection, but continue to struggle with a viral-related cancers made all the more resistant to treatment due to their HIV co-infection (Livingston, 2014). For example, KS is the second leading cancer in Kenyan males, and although the treatment for KS is helpful in managing the disease, HIV-related KS has a very high rate of recurrence and has the potential to be a very painful and persistent form of cancer. National policies to secure pharmaceuticals for treatment of an illness is vital, but in the example of HIV/AIDS, supplying ARVs and related cancer treatments to PLHIV is only one part of a very complex problem – without access to palliative medications, PLHIV will continue to suffer needlessly. Both disease modifying medications *and* palliative care medications need to be equitably accessible.

A measure of how well Kenya is meeting its palliative care commitments is noted in their procurements and provision of essential palliative care medications. The WHO's list of essential medications (19<sup>th</sup> ed. 2015) list two affordable opioid analgesics as essential to palliative care: the mild opioid codeine; and the stronger opioid morphine. Broader reports on opioid availability state that the African mean of opioid consumption is 0.33mg/person/year, which is far less than the global mean of 5.98mg/person/year (Powell, et al, 2010). The

literature speaks to this issue often, making links to multiple factors, such as issues with availability, access, governmental restrictions, lack of education, not enough prescribers, disinterest in dying patients, and misconceptions about opioids and addiction (Powell et al, 2010; Harding et al, 2010). In 2010 reports in the literature stated that Kenyan government had yet to fund the provision of essential palliative care medications, stating that 97% of the country's hospitals did not have pain medications available for palliative patients with moderate-severe pain (Human Rights Watch, 2010; Lohman & Amon, 2015). The Kenya Medical Supplies Agency (KEMSA) is responsible for the purchase of Kenya's stock of medications and reported various barriers such as governmental regulations and taxes on the importation of morphine powder (Human Rights Watch, 2010).

In 2013 the Kenya government made their first large purchase of morphine sulfate in power form (Ali, 2016). This was a significant move in the right direction, however, reports suggest that many healthcare sites rarely had the recommended minimum stock levels; palliative medications were frequently out-of-stock for many months or had expired on the shelf (Harding et al. 2013). Having medications expire on the shelves may lead to the assumption that the demand is much less than the stocked supply, but the literature clearly states there is a unmistakable need for opioid analgesics in Kenya, and that the discomfort and misconceptions of healthcare practitioners with prescribing and administering opioid medications, at times referred to as '*opioiphobia*', is the reason these crucial medications are left to expire on the shelf (Harding et al.

2013; WHO, 2012). Misconceptions about opioid side effects and addiction is a key barrier to the provision of these medications; as stated in the literature, healthcare workers routinely overestimated the risks associated with opioids, underestimate the effectiveness of the medications and underestimate the level of pain experienced by their patients (O'Brien, 2015).

In response to this issue, a multi-national initiative called "Treat the Pain" was rolled out to provide enhanced opioid education to physicians, nurses, and clinical officers. The Treat the Pain initiative, funded by the American Cancer Society, targeted resource-limited countries and partnered with local ministries of health in order to improve access to essential pain medications (O'Brien, 2015). Although this initiative was not specifically focused on palliative care, the target outcomes are the same; therefore many palliative associations such as KEHPCA offered staff and support to this important initiative. I attended a 'Treat the Pain' education session at Kenyatta National Hospital in Nairobi and was impressed with how thorough and engaging the session was, and practicality of the educational resources provided.

During my internship with KEHPCA, I attended a large stakeholders meeting to discuss developing a task-shifting program where specially trained palliative nurses were authorized to prescribe essential palliative medications. Members of the Kenyan MOH and our invited guest the Ugandan MOH were in attendance; Uganda spearheaded this initiative 2004 where specially trained palliative care nurses prescribe morphine, restricted to oral route of administration (Jagwa, & Merriman, 2007). This program is highlighted in the

literature for its achievements in improving access to essential palliative medications, as well as inspiring similar programs where registered nurses have been trained to initiate antiretroviral therapy in rural Uganda (Vasan, et al, 2009). It was prudent to invite Uganda's MOH members to share the challenges and successes of their task-shifting program in palliative care. The meeting was a success and a majority of the stakeholders agreed that a similar task-shifting program should be developed in Kenya.

### **Social Justice Issues**

While access to palliative care has been identified as a human right, the literature expresses concern regarding social justice issues stemming from the inequitable access to palliative services, medications, and deficits in palliative care resources, particularly in resource-limited settings (Harding, et al, 2014; Grant, Brown, Leng, Bettega & Murray, 2011). Even in resource-rich settings, where both treatment and palliation are widely offered, poverty still plays a role in the access to services; but when the needs are great and the resources limited, it becomes increasingly difficult to decide where public funds can be most effective and do the most good (Harding, 2008). In a region where HIV/AIDS prevalence is high, stigma is persistent, and adherence to treatment and access to ARVs remain issues of concern, one might argue the majority of funding should go to improving these issues first, to save lives, and yet many will suffer needlessly without palliative services and succumb to their illness long before these issues can be fixed. In a system where funding is given to programs that show

measurable improvements, such as number of lives saved, it can be a difficult pitch for funding when it come to palliative care.

Palliative care mirrors the ideal of human rights in that they are both based on principles of universality and non-discrimination (Gwyther, Brennen, & Harding, 2009). Rawlsian distributive justice also emphasizes the value in fair distribution of scarce resources, however in a manner that benefits the society at large, and therefore struggles with palliative care's focus on the needs of the individual (Knight & Alberstene, 2015). An extension to this, as explored by Norman Daniels work on restoring function and opportunity, also comes into conflict with justifying public funds for palliative care, as its purpose is not to restore function and opportunity in the traditional biomedical sense (Knight, & Alberstene, 2015). Many of the ethical underpinnings of healthcare funding are focused on preserving function for the stability of society, and less concerned with the wellbeing of the individual – shedding light on the paradoxical issue of offering a model of care when restoring function is not possible, for instance care of the severely disabled, lifelong mentally unwell, and advanced life-limiting illness. For this reason alone, there are inevitable social justice concerns worth exploring in how any government or organization implements palliative services.

Dr. Paul Farmer writes about this issue with regards to palliative care being used as a form of substandard healthcare for poor African with AIDS, in lieu of treatment (Farmer, 2007; Blinderman, 2009). In the early stages of the AIDS epidemic, prior to the role out of antiretroviral therapies, palliative care was the only option for many people living with AIDS, especially those living in

resource poor settings (Selwyn, 2008). Although palliative care is able to offer support to people when disease-modifying measures are not available, this should not be the primary application of palliative services. Palliative care practice standards and guidelines emphasize the need to integrate services along side disease-modifying measures, for example antiretroviral therapy (Blinderman, 2009). Dr. Farmer's statement, however, highlights some important discrepancies in quality of care and accessibility to care between those who can pay for services and those who cannot, and between those who live near services and those who must travel great distances, and lastly between the public and private health sectors.

As mentioned earlier, one of the key themes that emerged in my field notes included legal rights violations against patients with a life-limiting illness (e.g. land inheritance violations, and being forced off family ancestry land after being diagnosed with a life-limiting illness). To address this issue, the Nyeri Hospice partnered with Open Society Foundation East-Africa to pilot a monthly training clinic that offers people living with a life-limiting illness legal aid support and guidance. This program is an excellent example of how Kenya is tailoring their palliative care services to suit the specific challenges of the region.

One of the more distressing social justice concerns I noted while in Kenya was an apparent disinterest in treating palliative patients while in hospital and discharging patients with very advanced illness because they were deemed to be 'palliative' and therefore could 'no longer benefit from treatment'. The labeling of

patients as ‘palliative’ is customary in the literature and equally so in my practice experience in Kenya, and although the intention is well meaning, the ‘palliative’ label can marginalize people and limit their access to full breadth of integrated treatment that is their right. The labeling of people as ‘palliative’ patients likely stems from the old concept of palliative care illustrated in the background (figure 1), when people were either getting treatment or palliation, and by continuing to use these labels, we misrepresent what integrated palliative care really is – an inclusive cohesive plan of care for people living with a life-limiting illness.

## **Recommendations**

Recommendations by the WHO (2014) encourage all governments to integrate palliative care into their existing healthcare policies, and at a very minimum, the WHO recommends that palliative care should be provided even when curative measures remain unavailable – however, this treads dangerously into unethical provision of fragmented care, as Dr. Farmer warns. Although I agree with the WHO on encouraging the integration of palliative care, I think that the second recommendation perpetuates the misconceptions about palliative care and devalues the importance of integration. Kenya’s recent National Practice Guidelines for Palliative Care, Cancer, and HIV/AIDS, clearly state both disease-modifying treatments should be supported with integrated palliative care, as part of the overall pathway of treatment, and therefore should not be separated. Nations need to do more than simply add palliative care services, they need to integrate them into current treatment policies, *AND* if there are

deficits in treatment, the treatment deficits should be addressed with integrated treatment + palliative care solution.

The WHO goes on to recommends three foundational measures in the creation of a Palliative Care Integration Plan: government policy, education, and medication availability. These measures are not particularly expensive, nor do they require large investments in healthcare infrastructure. I agree that the three steps recommended by the WHO are needed, but I think a key aspect of integration is ensuring each steps are done with cultural sensitivity, and take into account the highly influential role culture, values and beliefs play in palliative care. It is important to ensure that the both national and state policies are developed to reflect the specific cultural of the people, that palliative education initiatives include conversations about death, dying, pain, family roles, and human rights.

I encourage Kenya to continue to promote a clear and salient understanding of what palliative care *is* and what is *offers* within their regions' context. It is vital that those who deliver the services as well as those whom use the services clearly understand the philosophy of care and what integrated palliative care entails. KEHPCA has already done so much in this pursuit and established close relationships with the various hospices and palliative care units (PCUs) around the country, and I applaud their efforts. However, the literature and my experience in Kenya as illustrated above show that there is still improvements to be made in how palliative care is perceived by healthcare workers and by the public.

## **Capacity building**

The integration of any new aspect of healthcare requires sufficient capacity among professionals. Capacity building can be achieved through creating connections and relationships to external organizations with well established fully integrated palliative programs (Clark & Wright, 2007). When a nation is trying to build new capacity, these connections are made with organizations from other countries, fostering cross-border relationships. There are many pan-national palliative care associations and alliances spearheading advocacy and advancement of palliative care globally; KEHPCA has a close links to many of these agencies and I believe these are fundamental partnerships worth maintaining.

Education and training are key aspect of capacity building; and as mentioned before, it is vital that the education and training be culturally appropriate and communicated effectively. Ethnography has a key role to play in this as well, both locally and within the global context. The culture of a group of people, their shared values and understandings of death and dying, can greatly influence how they perceived palliative care and alter their likeliness of reaching out for palliative care services. “The value systems of different cultures and socio-economic systems must continuously be addressed, as they will be of key importance for what type of palliative care ultimately can be delivered” (Stjernswärd & Clark, 2004, p.10). As mentioned earlier culture, values, and beliefs play a key role here because even if the services are highly advanced and

effective, you still need to get people to seek out the service – if they perceive a Hospice or Palliative Care Unit as a place of death, and that is not something openly discussed in their culture, then there may be a considerable reluctance to seek out palliative care services.

Kenya's MOH Health Sector Human Resources Strategy for 2014-2018, states its mission is "to promote and provide quality curative, preventative, rehabilitative and palliative health case services to all Kenyans", and yet there are no specific strategies were outlined in their report regarding palliative care training of their health sector human resources – it is time for the practice to match the rhetoric. Education is a key measure and should be delivered across various healthcare disciplines, such as to nurses, physicians, and pharmacists, and to all stakeholders, such as healthcare administrators and drug regulators (Stjernswärd & Clark, 2004). I recommend that KEHPCA's continue efforts on this front, partnering with Kenyan healthcare educators to offer palliative care specialty training as well as ensure that fundamental palliative care training is included into the baseline education of all disciplines of HCW; physicians, nurses, clinical officers, pharmacists, social workers, etc.

### **National policies and governmental support**

Kenya's neighbors to the east are strong partners in the pursuit of palliative integration in Africa. Uganda was the first African country to include palliative care in its National Health Plan (2001), and is the first East-African country to have National Guidelines for Handling Class A Drugs, which greatly

increased the availability of morphine, and allowed for specially trained nurses to prescribe oral morphine (Jagwe, 2002). Uganda's remarkable provision of palliative care is a great for improved access to medications in resource-limited settings (WHO, 2007). It is also an excellent example of the importance of effective collaboration between the government and community stakeholders, working together to achieve much more than either one could achieve on their own (Stjernswärd & Clark, 2004).

I recommend that Kenya continue with their collaborative partnership with other nations, for instance Hospice Africa Uganda, because of it an excellent model and shares similar population demographics as Kenya. There have been marked improvements in the procurement and provisions of essential palliative medications in Kenya – the government of Kenya and the Kenyan MOH need to stay the course and continue to address the urgent need of equitable, safe and universal access to pain and palliative medications through inclusive national health strategy and policies for palliative care.

## **Limitations**

Conducting a literature review of such a specific topic, across various databases as a single researcher is an evident limitation. It was not possible to ensure I have included all of the relevant literature, and so to compensate for this I searched a variety of sources, using a suitable assortment of search techniques to confirm a comprehensive cross-section of the literature. The table I used to track my search results was not an established tool for categorizing data results

however, I did search for methods, frameworks and tools designed for tracking search results, and found that for the purposes of this literature review, I required a custom method (e.g. excel spreadsheet) in conjunction with ample note taking on the hardcopy articles themselves.

As mentioned in the Results section, there was very little scholarly literature addressing social justice and palliative care in Kenya specifically, but plenty of current results examining the issue in broader contexts. I felt that with my personal experience and observation during my internship at KEHPCA, corroborated by 'grey' literature and editorial reports, and in combination with the broader literature of social justice issues with palliative care in resource-poor settings, allowed for enough triangulation of themes to extrapolate inferences of social justice issues in integration of palliative care within the Kenyan context.

## **Conclusion**

*“Looking back over the concept of human rights, we can see that social inequalities have always been used to deny some people status as fully human... the poor, women, black people, those of low caste, people with disabilities, children, or 'aliens' from other nations – you can fill in the blanks, depending to some extent on time and place – denied the full complement of human rights” (Farmer, 2005, p.206)*

The human right to palliative care is universal and without discrimination, however, because of its foundation in the alleviating suffering, palliative care has a special obligation to those who need it most (Krakauer, 2008). There is a great need for continued efforts to fully integrate palliative care services into the public

health forum in Kenya, in particular to address the needs of the most vulnerable with life-limiting illnesses. It is an ethical imperative that the government of Kenya, national agencies like KEHPCA, and healthcare professionals in various healthcare professions take on the challenge of addressing palliative care deficits, the social justice infringements associated with inequitable access to services and medications, and embrace the integration of palliative care as part of their advancing practice.

## Reflections

I found writing my Capstone to be a rather cathartic experience, particularly when I reviewed the competencies, and the many readings, references and notes I have compiled over the past three years. I entered this program not really sure if I had selected the right program for my learning interests, but in the end, I am so grateful for the diverse learning and outstanding opportunities that were made available to me throughout my time at Simon Fraser University.

In this paper I tried to highlight the complex nature of palliative care, particularly using global health and social inequity competencies to explain how many influencing factors impact the need for palliative care and how its perceived, accessed and provided. In reflection I am unsure if I was able to get my point across as I had intended, and wonder if I could have organized my Capstone differently to help the reader absorb each of the complex aspects of this public health issue. I also feel as though I have multiple subtopics that could have been a more focused Capstone – which may have been more specific, but give less of the overall picture. I struggled with this when I was planning my Capstone. I did quite a bit of planning and re-assessment before I began writing, with the intention of articulating the literature and my arguments clearly, and yet I re-arranged the paper several times after writing it. I am still not sure if this is because this topic was too complex, or if I am struggling with some indecisiveness in my work.

The gender dimension of palliative care is an important aspect of this issue that I failed to capture in my search of the literature. Interestingly, it wasn't represented in the literature that I did capture, which perhaps speaks to a lack of depth in the literature especially with regards to social justice, as gender is a key element of social justice assessment. Reflecting upon my experiences in Kenya, gender was a frequent component of many issues. For instance, the majority of the participants in the hospice support groups were women, most of the family caregivers were women, and most of the community health workers were also women. For me this illustrates that women bare a heavy burden of the perceived role of 'caregiver' because of their gender. In the educational workshops held at many of the hospices, (i.e. Legal Aspects at Nyeri Hospice) the majority of the participants were women, which may echo the aforementioned point, but I also think that it speaks to the desire for empowerment and knowledge that I observed of many women in Kenya. There is a tangible sense of women reclaiming power in certain regions of Kenya, a collective sense of emancipation from historical gender norms and being more outspoken about their needs, expectations and hopes for their future. Women were both a target of social injustices *and* catalysts for change.

Discussing social justice, especially in the context of people living with life-limiting illnesses requires considerable reflection and respect. There are many conflicting perspectives, with ethical justification for each, and so I felt it was imperative that I speak to the facts as stated in the literature and avoid making sweeping statements – there is so much variation, interpretation and context

involved. For that reason, the section on social justice was the most challenging section to write. Upon further reflection, I wish I had expanded on social justice theory more in my Capstone, and wish I had include a more thorough analysis of the gender injustices associated with palliative care in Kenya.

As a practicing palliative care nurse, I have considerable vested interest in this topic and I have explored it several times throughout my graduate studies. I have writing multiple papers, infusing palliative care into the various course topics, such as Social Determinant of Health and Globalization. I found these previous explorations of the topic to be very helpful in processing the results of my literature review – I notice the larger structural influence at play with more ease. I also wanted to shed light on an issue that I believe to be very important, but remained under the radar for sometime.

It was important for me to include some of the experiences and lessons learning during my internship with KEHPCA. It was my time in Kenya that truly tested my ethics and values, and my understanding of the true depth of suffering, indignity and pain experience by those who are denied access to palliative care. Remaining objective in the face of human suffering, hopelessness, and existential distress was a tremendous struggle for me. As an observer, researcher, life-long learner, it is so important to remain reflexive. Judgments, emotions and assumptions can easily pop into mind, but they do not serve the larger purpose of gaining a rich and full understanding of the experience of others. I utilized various techniques to maintain this focus on objectivity, such as reviewing my field notes with an objective eye later in the day, away from the

situation, and I also kept a personal journal as an outlet for my stress and worries. After considerable reflection, both during my internship and back at home months later, I recognize that my observations, struggles and experiences in Kenya greatly reinforce my desire to continue my career in palliative care and to be a catalyst for change in the field of public health.

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# Appendix

