# Interdisciplinary End of Life Symposium

### International Perspectives on End-of-Life Care – Mozambique Layne Heller, MS, PhD Student

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I do not have any relevant financial relationships.

This presentation and/or comments will provide a balanced, non-promotional, and evidence-based approach to all diagnostic, therapeutic and/or research related content.

# Cultural Linguistic Competency (CLC) & Implicit Bias (IB)

#### **STATE LAW:**

The California legislature has passed <u>Assembly Bill (AB) 1195</u>, which states that as of July 1, 2006, all Category 1 CME activities that relate to patient care must include a cultural diversity/linguistics component. It has also passed <u>AB 241</u>, which states that as of January 1, 2022, all continuing education courses for a physician and surgeon **must** contain curriculum that includes specified instruction in the understanding of implicit bias in medical treatment.

The cultural and linguistic competency (CLC) and implicit bias (IB) definitions reiterate how patients' diverse backgrounds may impact their access to care.

#### **EXEMPTION:**

Business and Professions Code 2190.1 exempts activities which are dedicated solely to research or other issues that do not contain a direct patient care component.

This presentation is dedicated solely to research or other issues that do not contain a direct patient care component.

# Introduction

- Moved to Mozambique in 2009
- Co-founded Casa Ahavá Mozambique in 2013 convalescent/hospice home for cancer patients
- Earned a Master's degree in Palliative Care from the University of Maryland Baltimore 2020
- Currently a PhD student at the University of Maryland Baltimore pursing a doctorate in Palliative Care focusing on end-of-life priorities and preferences among community-dwelling Mozambicans

# **Brief Overview of Palliative Care in Africa**

- 1979 The first hospice, Island Hospice Zimbabwe<sup>1</sup>
- 1980 -St. Luke's Combined Hospice South Africa<sup>1</sup>
- 1990- Nairobi Hospice Kenya<sup>1</sup>
- 2002 Meeting of 28 palliative care providers in Cape Town, South Africa
- 2004 The African Palliative Care Association (APCA) was founded in Tanzania<sup>2</sup>
- 2017 Half of Africa's nations had a designated person for palliative care within the health departments<sup>3</sup>
- 2020 As many as 1085 palliative care departments were founded

# Mozambique

- Size: 800,000 km<sup>2</sup>
- Population of almost 34 million people
- Life expectancy is 62 years old
- Illiteracy rate of women at 49.4% and men at 27.2%<sup>4</sup>
- Ratio of one doctor to 11,232 Mozambicans<sup>5</sup>
- 1 nurse to 1,754 Mozambicans<sup>5</sup>
- Consult wait time at least two months, which rises to six months in cases where the patient needs a specialist<sup>5</sup>



# **Palliative Care in Mozambique**

- 1997 First pain unit -focus on neuropathic pain in amputees/ victims of war mines
- 2007 First stand alone pain unit
- **2009** Creation of the Mozambican Palliative Care Association, PC Policies, the Curriculum Design<sup>6</sup>
- 2012 PC Reference Manual in 2012<sup>6</sup>
- 2013 Mozambican Pain Study Association<sup>6</sup>
- 2019 PC added to Pain Unit<sup>6</sup>

As of 2020:

- 1 of 11 African countries with palliative care policies<sup>7</sup>
- 1 of 6 African countries with a stand alone palliative care unit<sup>7</sup>

# **Challenges to PC Implementation in Africa**

- Lack of trained professionals
- Lack of resources essential medicines
- Lack of government partnership funding
- Lack of monitoring and evaluation
- Rural based-patients

# **Palliative Care Philosophy**

- Rooted in patient-centered care and shared decision making<sup>8</sup>
- Autonomy is often considered a cornerstone of palliative care<sup>8</sup>
- Is best when the patient and family recognize their power to determine and guide their own goals of care<sup>3</sup>

# **Prioritization of Autonomy is not Universal**

Many cultures expect the medical provider:

- to have more knowledge than them
- to tell them what is wrong
- to tell them what to do.

When not followed, the competency of the provider is doubted.



Paternalism is the leading model of patient-provider relationship in Africa

#### **Reasons for Paternalism:**

- Cultural Views
- Language
- Education
- Time constraints

Opposed to Western belief, the paternalistic approach can be empathetic and caring.

## **Need for African-based modifications in PC**

"The concept of palliative care within Africa has its roots in the UK model, we believe that it must be adapted to African traditions, beliefs and cultures – all of which vary between communities and countries."

-African Palliative Care Association<sup>9</sup>

# **Healthcare and Personhood**

- Patient is center and focus of medical world view
- No patient, no need for medicine
- Medical worldview guides how we perceive patient, and then nature of disease and health<sup>10</sup>

# WHO IS THE PATIENT?

### Personhood in Africa vs. Western Philosophies

African Personhood	Western Personhood
<ul><li>Communal</li><li>Achieved in stages</li><li>Continues after death</li></ul>	<ul> <li>Individual – rooted in autonomy</li> <li>Born with it</li> <li>Ends in death</li> </ul>

# "I am because we are, and since we are, therefore I am."

#### - John Mbiti

# **African Personhood & Health and Illness**

#### **Communal lens -**

Health:

- Physical state of the body and mind,
- Well-being of the emotions and spirit of individual
- Well-being of the family, community, and ancestors, as well as the environment<sup>11</sup>

Illness:

- Disharmony, physically and relationally, both with the living and the dead
- Both natural and supernatural<sup>12</sup>

# **Diagnosis and Treatment**

- Starts by examining a lack of balance between oneself and one's social environment or spiritual world<sup>13</sup>
- Secondly thinks about natural causes
- Illness can be caused by: curses, ghosts, ancestral spirits, bacteria, viruses, parasites, emotional or relational factors, etc. or any combination of these<sup>14</sup>
- Family considers illness "our illness"<sup>15</sup>
- Holistic approach using traditional medicine, orthodox medicine, or a combination

# **Thoughts About Adaptations for African PC**

- Palliative care IS holistic
  - Usually led by the physician or nurse those that attend to the physical body
  - Restructure?
- Mozambique PC: a physician, nurse, and psychologist. The psychologist takes on the spiritual care. Does this work? How can we incorporate spirituality?
- Time constraints
- Role of traditional doctors/medicine
- Massive need/rural patients
- Resources/medications
- Communal decisions, preferences and priorities Who has the final say?

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