Dying well in Haiti: a hospital-level needs assessment

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**BACKGROUND**

St. Luke Hospital – a private, Haitian-run tertiary care facility in the Tabarre area of Port-au-Prince, Haiti – approached the researcher with an interest in developing a hospital-level palliative care initiative. The World Health Organization defines palliative care as, “an approach that improves the quality of life of patients and their families facing the problems 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.” Currently, 80% of people requiring palliative care at the end of life, approximately 16 million people, live in low- and middle-income countries. Haiti is in the “capacity building” stage of palliative care work: focused on building the healthcare establishments, educated workforce, and organizational resources necessary to establish services in the future. The health system must begin providing basic palliative care services.

**OBJECTIVES**

In collaboration with St. Luke Hospital administrators, the researcher will:

1. Perform initial assessment of medical procedures and the current care climate relevant to end of life patients at St. Luke Hospital
2. Identify current hospital capacities that can form the foundation of future program development
3. Provide concrete data about the experiences and needs of stakeholders including:
   a. Patients near the end of life
   b. Family caregivers of these patients
   c. Medical staff members including physicians, nurses, and social services staff

**METHODOLOGY**

St. Luke physicians identified all enrolled patients as being within six months of end of life. Three surveys and consent forms were developed for each stakeholder group in the most appropriate language and format for each population. All-developed tools were initially translated by the researcher and back translated by native, Haitian Kreyol medical translators to ensure internal consistency and cultural sensitivity. Quantitative and qualitative data were collected through:

1. One-on-one structured interviews with
   - 6 patients approaching end of life (Kreyol)
   - 45 patient family caregivers (Kreyol)
   - Multiple local care experts (English)
2. Written surveys completed by
   - 12 St. Luke Hospital medical staff on their experience (French)
   - Medical staff members reporting patient metadata (French)
3. Researcher observation over a 3-month period

Interviews were completed through a native, Haitian Kreyol interpreter. All translations of French written survey responses were initially performed by the researcher and validated by a native French translator. Qualitative data were subject to open and axial coding, concluding in thematic analysis. Participant demographic information and quantitative data were analyzed via descriptive statistics completed in Microsoft\(^\circ\) Excel.

**FAMILY CAREGIVER ROLE**

Family members provide the majority of daily care for patients admitted to the hospital. These caregivers:

- Sit in plastic folding chairs by the patient’s bedside
- Reorient or move the patient reorient or move
- Help the patient relieve themselves
- Maintain cleanliness
- Address recurring care for wounds or specific illness symptoms
- Fan the patient to keep the bugs off and provide a respite from the heat
- Hold tubs for excess blood or spurt
- Cook the patient’s meals at home and feed them
- Purchase medications and medical supplies
- Transport biopsies/specimen/fluids to other hospitals or labs for lab testing

71.1% of family caregivers reported remaining in the hospital with the patient for the entire duration of their hospital stay. An additional 20.0% were in the hospital multiple times per week. 91.1% of interviewed family caregivers indicated that they believed their family member would recover.

**QUOTATIONS**

Family Caregiver Interview Quotes:

- “We’ve spent all of our money trying to treat [the patient’s] illness and now we don’t have any.”
- “If his father doesn’t get well, he doesn’t know what the family will do. His father is the only one that provides for them and has a job.”
- “[The patient] cannot speak, and she has a problem with her back. She cannot move her body. I am worried about taking care of her at home.”

Medical Staff Survey Quotes:

- “Palliative care would have a primary place in the Haitian healthcare system because of the significant number of patients who require this care.”
- “Palliative care: it’s care that we give to patients even though we know that it will not change the final prognosis (outcome).”
- “Without thinking that we can treat the patient, [palliative] care can make the patient comfortable and improve their life style.”
- “We don’t enough [economic] means or adequate staff – such as medications, support, training, etc.”
- “Sometimes we know what we are supposed to do for the patient, but sometimes we lack the [appropriate] materials and medications, so we lose the patient.”

**CONCLUSIONS**

**FUTURE WORK**

Initial St. Luke conversations regarding future palliative care involvement need to:

- Establish a standard operating definition of palliative care
- Ensure all appropriate staff have a common understanding of this definition
- Examine the role of palliative care services in the hospital and community
- Identify St. Luke’s current capacity to support palliative care development

If St. Luke administrators decide to develop hospital-level palliative care services, a palliative care development team should create a strategic plan for moving forward in service provision as well as community and international partnerships. All levels of St. Luke staff working with patients should be interested in these discussions.

**REFERENCES AND ACKNOWLEDGEMENTS**

References


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