Miranda Olson
Global Health Narrative
Honors Thesis

Palliative Care Capacity Building to Community-Level Service Provision: St. Luke Hospital Case Study

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Chapter 1. Palliative Care Introduction and Research Study Overview

In 2000, the Committee on Economic, Social, and Cultural Rights, in a document adopted by the United Nations (UN) declared, "preventative, curative, and palliative health services to be a human right."[i] Although the fundamental intention behind palliative care is not new, the standardization and acceptance of the human right to palliative care are relatively recent. The World Health Organization (WHO) 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."[ii] Every year, over 20 million people are estimated by the WHO to require palliative care at the end of life.[iii] Approximately 80 percent of this population, 16 million people, live in low- and middle- income countries.[iv]

Palliative care system design is based on the following primary themes: 1) provide symptomatic relief, 2) regard death as a natural process, 3) incorporate spiritual and psychological care, 4) maximize the patient's remaining time based on patient values, 5) offer the family support for coping with the patient's illness and death, 6) use a care team approach, and 7) apply palliative practices early in the course of illness.[ii] Although this array of themes indicate that palliative care is widely applicable, it is typically implemented in two circumstances – chronic, life-affecting illnesses and end of life care. Examples of chronic, life-affecting illnesses that may benefit from palliative care include HIV, AIDS, cancer, heart disease, chronic pain syndrome, and diabetes. Care provided by a palliative expert or team changes throughout the chronology of illness. The aspect of care provided in late illness stages is traditionally

described as hospice. Hospice is one specific component of palliative care provision.

Many high resource countries are developing and implementing palliative care services as an integrated initiative within their overarching national health systems.[v] Thus far, high resource countries have produced most of the existing international palliative care research and service provision programs. In the United States (US), an example of a high resource care environment, 65 percent of hospitals with 50 or more total facility beds reported a palliative care program 13 years after the UN declaration. The number of hospital palliative care programs in the US is increasing steadily, with almost universal access to services in large hospitals and academic medical centers.[vi] However, many low resource nations do not have an effective, nationally supported health services framework. These low resource care environments are characterized by different variables, challenges, and strengths than high resource settings. Although the increasing body of research produced in high resource environments is providing data and care models necessary for the implementation of evidence-based palliative care development in comparable settings, this research does not provide appropriate data to allow for evidence-based development and decision making in low resource countries.

However, in recent years, low resource nations across the globe have begun partnering with WHO and international palliative care organizations to close this research data gap. Research emerging from countries including Uganda, Malawi, Chile, India, Mongolia, and Egypt have produced promising results showing the efficacy of palliative care provision in low resource settings. Beginning in 2006, following the emergence of low resource setting palliative care research data, the International Observatory on End of Life Care began producing a palliative care development index, ranking every country in the world and creating a, "world map of hospice-palliative care development."[vii] This analysis framework originally categorized

countries into four development Groups. However, a global update released in 2013 defined the following six functional development Groups: Group 1) No Known Hospice-Palliative Care Activity, Group 2) Capacity Building Activity, Group 3a) Isolated Palliative Care Provision, Group 3b) Generalized Palliative Care Provision, Group 4a) Countries Where Hospice-Palliative Care Services Are at a Stage of Preliminary Integration into Mainstream Service Provision, and Group 4b) Countries Where Hospice-Palliative Care Services Are at a Stage of Advanced Integration into Mainstream Service Provision. The Group categories represent palliative care system maturity milestones with Group 4b characterizing countries with the most developed palliative care services successfully integrated into general medical care provision.

Although each Group characterizes palliative care provision maturity, a nation does not need to progress through these Group categories in a linear fashion. A country may skip one or many of these Group characterizations in the development of its palliative care services. This international index provides a potential method for examining the comparative growth through time of a nation's palliative care development. However, little to no research data has been produced to describe approaches and necessary implementation steps for transitioning between Group classifications. One of the most drastic Group transitions is for a country to move from providing no palliative care (Group 1 and Group 2) to providing some palliative care services (Group 3 a, b and Group 4 a, b). As of 2013, 98 countries needed to make this challenging transition, including 60 low or middle resource countries.[viii] Most of the high resource nations in this position are commonwealths or territories of countries currently providing palliative care. To close this specific research and implementation method gap, Group 2 countries that successfully transition to providing some palliative care services can be used as case studies and development models for comparable nations.

Haiti is a Group 2 country with the opportunity to transition to providing palliative care services. Haiti spans the western-most third of the island of Hispaniola bordered on the east by the Dominican Republic, the Caribbean Sea to the west and south, and the Atlantic Ocean to the North. In general, Hispaniola has a very mountainous landscape with few plateaus or flat lands. The few plains that Haiti does have are the most productive agricultural lands in the nation and are also the most densely populated areas.[ix] Haiti's capital city, Port-au-Prince, is situated on the northern side of the island on the Atlantic Ocean.

The United Nations Development Programme currently ranks Haiti 168 out of 187 ranked countries on the Multi-dimensional Poverty Index, indicating that it is one of the poorest nations in the world.[x] The WHO estimated life expectancy at birth in Haiti to be 65 years compared to the entire WHO region estimated to have a life expectancy of 76 years.[xi] The Human Rights Watch report *Global State of Pain Treatment: Access to Medicines and Palliative Care* states that all of the opioids consumed in, "Haiti could treat pain in less than 1 percent of its terminal cancer and HIV/AIDS patients."[xii] In comparison, the same article reports that all of the opioids consumed in the United States could treat 6,488.8 percent of the US's terminal cancer and HIV/AIDS patients. As far back as 2009, the US, Canada, and Europe accounted for 18 percent of the global population and 90 percent of global morphine consumption, according to the International Narcotics Control Board.[xiii] These statistics illustrate the critical disparity in access to pain management medications and palliative care for patients living in Haiti.

Conceptually, Haiti is currently classified as a country in the Capacity Building stage of palliative care development. Capactity building means there are efforts within the nation to build the healthcare establishments, educated workforce, and organizational resources necessary to establish future palliative care services. However, there are currently no identified palliative care

initiatives in Haiti.[xiv] Through archival research, historical contextualization, and analysis of existing palliative care country case studies; this thesis provides a broad outline of the historical and cultural forces that have, in large part, shaped Haiti's current medical care provision system. This background research also examines the country's current palliative care development stage and is used to suggest potential national and community-level components of future palliative care development initiatives.

To meet the needs of the large number of residents requiring palliative care, Haiti may need to transition from solely curative and preventative measures to a system providing basic palliative care services. This thesis presents a private Haitian-run hospital in Port-au-Prince, St. Luke Hospital, as a potential palliative care champion. If the hospital were to assume the role of palliative care champion, St. Luke would lead the transition to community-level palliative care service provision. Prior to the initiation of this research, administrative staff at St. Luke Hospital expressed interest in developing and implementing palliative care services within the hospital setting.

In collaboration with hospital staff, the researcher completed on-the-ground survey, interview, and observational research with St. Luke patients, family caregivers, and medical staff members from June to August 2016. This research study provides an initial assessment of participant needs, perspectives on various palliative care concepts, identified barriers to accessing care, and symptom management and illness trends in patients designated as needing palliative care. Specifically, this study includes patients within the end stages of illness, estimated to be within six months of end of life by medical staff members, and their family caregivers. Therefore, the collected data is only valid as a starting place for discussion regarding hospice, end of life palliative care, services at St. Luke Hospital.

This research data is provided as an initial needs assessment to facilitate evidence-based discussions on palliative care service development within St. Luke Hospital and the surrounding community. Overarching analysis themes are identified through the collected data and organized as potential discussion points for palliative care service stakeholders within the hospital and potential community partnership conversations.

Presenting a brief history of western medicine in Haiti, this thesis will begin with the analysis of eighteenth-century texts written by colonists when Haiti, known then as Saint Domingue, was under French occupation. Due to limitations of time, this thesis will briefly discuss nineteenth and early twentieth-century developments to examine the current climate of western medicine in Haiti. This discussion of current Hatian medical care services will focus on the influence of international humanitarian aid organizations and the establishment of westernized medical hospitals in the aftermath of the 2010 earthquake.

After presenting this brief introduction to the colonial history of Haiti, this thesis will establish a platform for discussing palliative care service development based on the fundamental components of existing Western palliative care systems. Successful palliative care programs in other nations are analyzed to contextualize the site-based needs assessment results. Palliative care service structures implemented in high and low resource nations provide case studies to identify necessary palliative care system components and service models applicable in the Haitian healthcare context. Developed primarily in high resource countries, features of these Western programs represent the most widely accepted modern palliative care model.

Following this review of exisiting programs, the thesis will focus on the site-based palliative care needs assessment research completed at St. Luke Hospital throughout the summer of 2016. A general overview of the hospital is followed by a thorough introduction of the

completed research study including: the aims, population inclusion criteria, data collection and analysis methods, and participant demographics. The qualitative and quantitative research results are then presented within analytical categories defined through qualitative thematic analysis techniques.

As a low resource nation with a complex history influenced by colonization, revolution, natural disasters, political instability, and humanitarian aid relief efforts, Haiti can provide a window into the needs of patients near the end of life and their family member caregivers in similarly effected low resource nations. The needs and existing barriers to accessing end of life care must be assessed before palliative care services can begin to be designed and implemented in these low resource healthcare environments. Haiti's distinct cultural and religious environment also provides a limited snapshot of the challenges of applying western medical models in other cultural healthcare settings.

Chapter 2. Beginning of Western Biomedical Influence in Haiti: 18th Century Saint Domingue

Colonial History of Haiti

Recorded history of Haiti first began when Christopher Columbus landed on the island of Hispaniola in 1492, when the island became the first permanent European settlement in the New World. Following discovery by the Spanish, all the island's native inhabitants, the Taino, were either killed or enslaved by the Spanish conquistadors within 25 years.[xv] A large battle between the Taino and the Spanish introduced the native populations to warhorses, guns, dogs trained for killing, and the European approach to warfare in which the primary objective was to kill as many of the opposing people as possible; which was not the traditional approach to warfare on the Islands. The Taino people that survived the war with the Spanish either succumbed to illnesses introduced by the Spanish or were forced to support the Spanish by providing food, lodging, cotton, and gold. The burden of feeding the Spanish conquistadors led to mass famine and food shortages for the Taino people.[xvi]

Recognizing that Hispaniola would not be an abundant source of gold for Spain, the Spanish conquistadors quickly transitioned the island into fertile farming lands to cultivate crops to feed the Spanish in other areas of the New World. Beginning in 1508, when the Taino people were no longer populous enough to sustain the required crop yield, African slaves were imported to Haiti as the primary source of labor. This influx of African slaves was the foundation for the current population inhabiting Haiti. Sugar was quickly introduced as a cash crop to accompany the tobacco and coffee beans already produced on the island.[xvii]

As the Spanish began to settle in different regions of the Caribbean and Central and South America, Hispaniola became of lesser value to the Spanish. After a period defined by the

presence of European privateers, pirates, and "boukanniers," the Spanish abandoned the western part of the island, concentrating in the Spanish settlement in Santo Domingo.[xvii] While the French first established a presence in Hispaniola in the early 17th century, the Spanish ceded control of the region now known as Haiti to the French in 1697, creating the colony of Saint Domingue.[xv]

For the next century, the colony became one of the richest in the world under French rule. The French colony initially produced cash crops such as coffee, indigo dye, cotton, tobacco, and exotic spices.[xvi] However, the plantations quickly turned their attention to the cash crop their neighboring British colonies were successfully producing – sugar cane. At Saint Domingue's peak production in 1791, the colony exported 78,696 tons of sugar cane, making it the most productive French colony.[xviii]

To produce these immense quantities of sugar cane, the colony relied heavily on a plantation structure demanding a large amount of slave labor. This plantation system was enforced by the French military presence on the island ruling in the interests of the French crown. The French slave trade was one of the most brutal in the Western world. With a slave life expectancy of seven to ten years after arrival in Saint Domingue, the colony was always in need of more slaves to put to work.[xix] Saint Domingue was one of the primary destinations of the Transatlantic slave trade during the eighteenth century. France's dealings in the Transatlantic Slave Trade accounted for approximately, "20 percent of African slaves imported to the Americas." [xx] Even though it is estimated that Saint Domingue's slave population made up almost nine-tenths of the colony's total population in 1789, the majority of the colonial experience preserved in historical texts is written from the perspective of the Western travelers and colonists inhabiting the island.[xxi]

As France and other European countries expanded their colonies during the eighteenth century, they were faced with unfamiliar climates, geographical environments, and cultures. These and other unfamiliar conditions that accompanied colonial expansion were quickly associated and imbedded with European understandings of foreign illnesses and medical issues. As the French colony continued to develop, these unfamiliar conditions threatened human and economic welfare in Saint Domingue and, as an extension, in France. Saint Domingue exemplifies the colonial quest to identify, understand, and solve these newfound threats. The investigation, study, and experiments completed in this period continue to have relevancy in the twenty-first century.

Medicinal investigation, infrastructural changes, and sociocultural interactions in eighteenth century Saint Domingue form the basis of biomedicine currently practiced in the contemporary nation of Haiti. The first step in this analysis is to canvas eighteenth century texts pertinent to the evolution of medical care in the French colony. This initial survey of primary source materials, augmented through secondary research, provides a framework to inform future discussion regarding the current state of health in Haiti.

After the French colonization of Saint Domingue in 1700, European naturalists flocked to the West Indies to explore local herbs, identify possible cures for "hot climate" illnesses, and ascertain cash crops suitable for growth in the New World.[xxii] As, "botanical exploration accompanied colonial expansion," European naturalists discovered medicinal plants to help European troops and planters survive in the New World as standard pharmacy proved ineffective in the new, tropical climate. [xxiii] Early eighteenth century European naturalists respected and sought the knowledge of Saint Domingue's native population, later expanding this interest to the imported slave populations, primarily from Western Central Africa.[xxii] French botanist Nicholas-

Louis Bourgeois even stated, "the negroes had more knowledge of these cures than the whites."[1] Both the imported African slaves and the native Taino people often acted as a starting point for European naturalists' botanical exploration.[xxiv]

The eighteenth century also saw an increase in public health awareness and open dialogue exchange regarding medicinal remedies. As the French colony continued to develop and France began to rely heavily on cash crop exports such as sugar cane, the healthcare infrastructure and population access to medical treatments was increasingly scrutinized. Criticisms escalated near the end of the eighteenth century in Saint Domingue, especially related to the high loss of French soldiers and Black slaves to endemic illnesses, as the Haitian revolution began to apply pressure to both the French military and economic exchange system.

Primary Source Analysis

To further explore health and medicine themes in eighteenth century Saint Domingue through primary sources, the analyzed texts were selected based on significance and accessibility criteria. The John Carter Brown (JCB) Library at Brown University has one of the world's largest Haitian historical writing collections. The digitized "Haiti Collection" is comprised of 1,064 texts. Of these texts, less than thirty pertain directly to medical treatments, health status, and the sociopolitical climate surrounding health in this period.

As these texts were analyzed, a clear theme emerged after 1802 – almost all the medical treatises primarily focused on Yellow Fever. These documents illustrate a marked change in medical dialogue and interests in Saint Domingue and the broader eighteenth century medical community. As this chapter seeks to illuminate understandings of health, medical treatments, and some of the sociocultural perspectives surrounding health in eighteenth century Saint Domingue,

all texts from 1803 on are excluded from this analysis and no pertinent texts before 1700 were identified. Thus, this is an exploration of texts published after 1700 and before 1803 in the JCB Library's Haiti Collection. Most of these texts are written in French and all translations to follow are the researcher's own.

Botanists and Pharmacology

Although many of the botanists and naturalists writing on plants with medicinal properties were also physicians, these early botanical investigators approached medicine in Saint Domingue from a distinct perspective focused on the use of native plants and wildlife.

Jean-Baptiste-Renè Pouppé-Desportes (1704-1748) published many of these botanically oriented works. His three-volume work titled *Histoire des Maladies de S. Domingue*,[1] published in 1770, addressed tropical medicine, the importance of "Black slave medicine," and pharmacology. Pouppé-Desportes presents a list of botanicals and herbs, their medicinal properties, and instructions for preparing remedies as well as further discussions on "Black medicine" and larger-scale epidemic medicine. These volumes are cornerstone works representing the early pharmacological perspectives of French naturalists in eighteenth century Saint Domingue.

The *Lettres a M. de Jean, docteur-regent de la faculté de medecine, en l'Université de Paris: I. Sur les maladies de St. Domingue. II. Sur les plantes de la même île. III. Sur le remora et les halcyons*[2] by Jean Damien Chevalier (1682-1755) represented a similar presentation of this early botanical perspective. Chevalier was the, "Faculty of Medicine at the University of Paris,

[1] *History of the Diseases of Saint Domingue*
[2] *Letters to Mr. Jean, doctor-regent of the faculty of medicine in the University of Paris I. On the diseases of Saint Domingue. II. On the plants of the same island. III. On the remora (fish) and halcyons*

former professor of the same faculty, and heretofore Physician of the King at St. Domingue."[3] Chevalier's official positions within both the higher educational system of Paris, France and as a chief physician within the colonial French infrastructure in eighteenth century Saint Domingue gave Chevalier the international credibility, connections, and unique perspective to provide a more specific representation of medical practices in Saint Domingue.

In addition to presenting botanicals, Chevalier's work discusses the medical geography of Saint Domingue and the limited use of animals, such as fish, within medical remedies. Published in 1752, this work provides valuable insight into the common illnesses that concerned medical physician leaders in Saint Domingue as well as the medical practices used to treat the presented illnesses. In contrast to Pouppé-Desportes, Chevalier organized his work by separating illnesses of concern from the remedies and botanicals. This structure may suggest a more clinical approach to botanical inquiry rather than the plant-based analysis provided by Pouppé-Desportes.

The final work connecting botanicals and remedies to corresponding illnesses presents the potential medicinal properties of various lizard species and their applications to treating venereal and skin diseases. *Expériences faites sur les propriétés des lézards: tant en chair qu'en liquers, dans le traitement des maladies vénériennes et dartreuses*[4] is assumed to be written by the Swiss naturalist and student of tropical medicine Girod-Chartrans. Published in 1787, this text is unique because it focuses on one source of medical remedies – the lizard, and it provides multiple descriptions of venereal disease within the Black[5] population in Saint Domingue. Girod-

[3] "De la Faculté de Médecine, en Université de Paris. Docteur-regent, ancien professeur de la même faculté, & ci-devant medecine du Roi à St. Domingue." (title page)
[4] *Experiences on the properties of lizards: so flesh that "liquers," in the treatment of venereal diseases and dartrous*
[5] "les Negres"

Chartrans progresses through various lizard-based remedies and the possible implications of each to the health of the Black population that were dying at very high rates from these illnesses. These Black slaves were of great value to French plantation owners, motivating them to try to maintain the health of their labor force.

The narratives and applications of medical remedies in this text prove unique in eighteenth century literature on Saint Domingue, providing a window into some of the sociocultural aspects of medicine in this time period. Due to the lizard species' indigenous statuses and the various uses for these lizards within the Black community, Girod-Chartrans strongly hints at learning these included remedies from Saint Domingue's Black slave population.

Europeans Exposed to Foreign Illness

As the French Colony continued to develop, French citizens – including plantation owners, curious travelers, sailors, soldiers and elected officials – took up residence in the Caribbean. Beginning with the initial sailing journey from Europe to the hot climate areas of the New World, the long distance foreign travel began to significantly affect the health of French and other European travelers.

The increasing frequency of European travelers between the Old and New World in the eighteenth century spurred interest in an area of medicine combining the new area of "hot climate" medicine with naval and sailing medicine. Antoine Poissonnier-Desperrières (1722-1793) was a French physician that began writing on the intersection of these eighteenth century colonial medical issues. His work, published in 1780, *Traité des fièvres de l'isle de St.-Domingue: avec un mémoire sur les avantages qu'il y auroit à changer la nourriture des gens de*

mer[6] discusses the emerging area of "hot climate medicine," currently recognized as tropical medicine, as well as interventions that could be enacted in the context of sailing vessels.

Poissonnier-Desperrières was in a powerful position within the French medical hierarchy as, "Squire, Knight of the Order of Saint Michael, former. Ordinary Doctor of the King, Doctor of the Grand Chancellery & of the Generality of Paris, Inspector General Deputy Navy Hospitals & Colonial Royal Cenfeur, the Academy of Dijon & Company Royal Medicine."[7] His position as an Ordinary Physician of the French King as well as Inspector General Deputy of the French Navy Hospitals illustrates the invested interest that France developed throughout the eighteenth century on naval medicine in the New World. His work primarily discusses the importance of diet in treating and preventing disease, such as scurvy. However, Antoine also presents a discussion on fevers in the New World as well as a brief section on medicine and health in the Black slave community.

As a French physician looking remotely at illness in the New World, Antoine's subject choice depicts the interests of the French government in this period as a distant colonial leader – keeping sailors healthy, managing foreign illnesses that traveling Europeans face in the New World, and maintaining the health of their imported Black slaves. His other work *Mémoire sur les avantages qu'il y auroit a changer absolument la nourriture des gens de mer*[8] followed the, "State of the sick of the frigate (type of military warship) La Belle-Poule, commanded by M.

[6] *Treaty of the fevers of the island of Saint Domingue: with a thesis on the advantages there have been at the changing of the food of seafarers*

[7] "Par M. Poissonnier Desperrières Écuyer, Chevalier de l'Ordre de Saint-Michel, ancien. Médecin ordinaire du Roi, Médecin de la Grande Chancellerie & de la Généralité de Paris, Inspecteur général adjoint des Hôpitaux de la Marine & des Colonies Cenfeur royal, de l'Académie de Dijon, & de la Société royale de Médecine."

[8] *Thesis on the advantages there have been at the complete changing of the food of seafarers*

Dorves in 1771 during the trial of vegetable diet."[9] Through this observational approach, Antoine focuses in even greater detail on dietary changes as a medical treatment method. Diet-based medicine has been a staple of the Western medical system since the Hippocratic writings in the 5th century BCE.

Prior to Poissonnier-Desperrières's works, G. Mauran published a work in 1766 titled *Essai sur les maladies qui attaquent le plus communement les gens de mer, contenant une méthode courte & facile pour les connoître, les guérir, & même en préserver*.[10] This publication focused directly on illnesses that befall seafaring individuals, especially sailors and the navy. Mauran extends his discussion beyond Saint Domingue to other Islands in the Caribbean, commenting specifically on, "fevers prevailing in the French colonies of Saint Domingue, Martinique, and the other Antilles islands."[11] These "hot climate" fevers are a common theme throughout all the eighteenth century works regarding illnesses effecting foreigners on their way to or living within the New World.

An essay on diseases incidental to Europeans in hot climates by James Lind (1716-1794) and Clause Esprit Thion de la Chaume (1750-1786) provides a different perspective on foreign travel to Saint Domingue. This two-volume work addresses medical topics of concern in the eighteenth century from the prospective of geographically and culturally distinct English physicians. Although Lind and Thion de la Chaume are from a different European country, they

[9] "État des malades de la frégate la Belle-Poule, commandée par M. Dorves, en 1771, pendant l'essai du régime végétal." (Page 28-31)
[10] *Essay on the diseases that most commonly attack seafarers, containing a short & easy way to know, heal, and even prevent them: work useful to naval ship surgeons, and even to all seafarers who travel in ships that have no surgeon. We have attached some observations on the safest way to rescue the drowned, and to treat the fevers of the Isle of Saint Domingue & other French colonies in the Caribbean.*
[11] "Des fiévres qui regnent dans les colonies françoises, à Saint-Domingue, à la Martinique & aux autres isles Antilles" (Page 150-170)

share many of the same interests in foreign travel medicine as the French physicians Poissonnier-Desperrières and Mauran. Each of their works canvases "hot climate" diseases, fevers, and different dietary medicinal "treatments" useful for long course sailing navigations.[12] However, Lind and Thion de la Chaume discuss these topics in the context of a much larger geographical area in the New World including regions now recognized as New England, Maryland, Virginia, South Carolina, Georgia, Florida, and Haiti. These additional colonies beyond the Caribbean represents the vested interest of England in other areas of the New World as well as the cultural distance between the authors of this text and Saint Domingue in comparison with the French physicians.

Tropical Illnesses, Prevention and Cures

Tropical medicine texts formatted to list tropical diseases and illnesses accompanied by known preventions and cures for the specified illness also began emerging in this period. *Avis aux habitans des colonies, particulièrement à ceux de l'Isle S. Domingue: sur les principales causes des maladies qu'on y éprouve le plus communément, & sur les moyen de les prévenir*[13] written by J.F. Lafosse was published in 1787 and focused entirely on New World illnesses and their prevention. As the "Doctor of Medicine from the University of Montpellier (France), Correspondent of the Royal Society of Medicine,"[14] Lafosse was geographically removed from Saint Domingue,[15] but his work still illustrates a vested interest in colonial diseases. However,

[12] "les navigations de long cours"
[13] *Notice to the inhabitants of the colonies, particularly those in the Isle of Saint Domingue: on the main causes of the diseases that are most commonly experienced, and on the ways to prevent*
[14] "Docteur en Médecine de l'Université de Montpellier, Correspondant de la Société Royale de Médecine." (Title Page)
[15] "de l'Isle S. Domingue"

the format and structure of Lofosse's writtings present a more academic, less narrative, approach to tropical medicine than exhibited by either the botanical or foreign travel authors previously described. Lofosse presents a long list of common illnesses and then focuses on prevention. He does not focus on curing illnesses but rather better understanding their natural histories – the origin and progression that marks a specified disease.

A similar work, *Observations générales sur les maladies des climats chauds: leurs causes, leur traitement, et les moyens de les prévenir*,[16] written by Jean-Barthélémi Dazille and Jean Sédillot discusses tropical medicine and medical climatology in the French West Indies with a focus on Saint Domingue. This work was "found in Saint-Domingue, …, printer of the King in the Cap."[17] Like Lafosse's work published two years later in France, this medical text presents illnesses with their associated preventions and treatments in a methodical, biological format. These eighteenth-century documents do not include experiential health testimonies.

This subject-based organization structure resembles a reference medical text used by practicing physicians or heads of households responsible for managing the presented illnesses rather than an explorative scientific text. *Apperçu sur les maladies de Saint-Domingue: avec les remedes qu'il faut y appliquer*,[18] published in 1797, supports such a purpose. While writing this medical text, Decout worked as the "Master in Surgery, Associate of the Academy of Sciences and Arts of Cap français, and Chief physician of the southern department of hospitals."[19] "Cap français," later referred to as Cap-Haïtien, was a commune in the north of the French Saint

[16] *General observations on the diseases of warm climates: their causes, their treatments, and the ways to prevent*
[17] "Se trouve a Saint-Domingue, chez M. Dufour de Riams, imprimeur du Roi au Cap."
[18] *Overview on the diseases of Saint Domingue: with the remedies that are to be applied*
[19] "Maître en chirurgie, associé de l'académie des sciences et arts du Cap français, et médecin en chef des hôpitaux du département du sud." (Title Page)

Domingue colony, acting as the capital until 1770 when governmental power was moved to Port-au-Prince.[xxv] As acting Chief physician in southern Saint Domingue hospitals, Decout compiled this medical "dictionary."

Throughout the work, Decout discusses a list of illnesses presumably prevalent in Saint Domingue near the end of the eighteenth century. These include cancer, cholera, fevers, fistulas, hernias, hysteria, jaundice, upset stomach, migraine headache, and rheumatoid arthritis. The dictionary format presents a defined illness[20] and related remedies,[21] or treatments. The pages are marked at the top with letters, indicating the alphabetical subsection of illnesses discussed on the corresponding page. This format would allow physicians and other text users to search alphabetically for illnesses and their corresponding treatments as necessary. Decout's work was the only text studied that presented this dictionary format. However, Decout's dictionary seems to be a progression of earlier texts listing illnesses and their treatments.

Infrastructure: Military, Government, and Hospitals

As the end of the eighteenth century drew nearer, more of the Saint Domingue medical texts mentioned aspects of the French colony's infrastructural components, especially the interaction between these structures and population health. One of the primary concerns of the absentee French government was maintaining military control of Saint Domingue. However, after seizing control of the colony, French military troops faced the same challenges as other foreign European travelers. As an increasing number of soldiers fell ill, physicians in Saint

[20] "les maladies" (Page 1)
[21] "ses remèdes" (Page 14)

Domingue began to focus specifically on the health of French troops and the structural systems that directly affected soldiers.

In 1797, Hector McLean published a medical text specifically on this issue titled, *An enquiry into the nature, and causes of the great mortality among the troops at St. Domingo: with practical remarks on the fever of that island; and directions, for the conduct of Europeans on their first arrival in warm climates*. Like other foreign European travel medical works such as James Lind's volumes on colonial medicine, McLean discusses the fevers of Saint Domingue as well as a general overview for preventative measures all European travelers to the New World should take. However, McLean considers this topic in the context of French colonial military soldiers.

As the, "M.D. Assistant inspector of hospitals for St. Domingo," McLean worked closely with the hospitals in Saint Domingue that treated the French soldiers. He examined the high death rates in the French military as an informal case study on the illnesses of Saint Domingue. As a physician working in the French colony, his focus was on identifying the causes of the high prevalence of illness among the soldiers as well as describing the specific illnesses that were responsible. McLean's observational approach resembles methods used in the earlier naval and sailing texts.

French soldiers were critical to maintaining the strength and infrastructure of the French colony throughout the eighteenth century. However, at the time of McLean's authorship, the hospitals observed in his work began to fall under the substantial criticism of other physician scientists. Concurrently, Charles Arthaud was "…the first royal physician *per interim* in Cap

François…"[22] His medical text, *Description de l'Hôpital général du Cap*,[23] published in 1792 focused on the structure of the General Hospital of the Cape. After describing the hospital, his work focused on critiquing current practices, hospital layouts, and the potential implications for patient health of the geographic location of wetlands surrounding the hospital. Arthaud's work clearly moves beyond medical consideration to infrastructural analysis and public health exploration.

Jean-Barthélémi Dazille's 1788 publication provides a more gradual transition from the illness and treatment-oriented medical texts to this more general, public health discussion. His work, *Observations sur le tétanos: ses différences, ses causes, ses symptômes, avec le traitement de cette maladie & les moyens de la prévenir*,[24] provided an etiological description for tetanus along with the known preventions and treatments. However, this disease-specific analysis is surrounded by significant public and population health discussions. As the "royal physician in Saint Domingue during the upheaval of revolution…," Dazille was faced with a floundering health infrastructure, including the hospital system.[xxvi] *Observations sur le tétanos* outlines many of the accompanying frustrations and challenges facing him as a head physician at the turn of the century. Ideas for improving medical care in the upheaved colonial environment precedes his

[22] McClellan, James E., III. *Colonialism and Science: Saint Domingue and the Old Regime*. Baltimore (Md): John Hopkins UP, 1994. Print.
[23] *Description of the General Hospital of the Cape: in which an idea of the influence of the air of the marshes on endemic diseases that are observed, with an overview of the inconveniences of the situation of the current cemetery, and those which can still result from too great reconciliation of the General Cemetery that we just established*
[24] *Observations on tetanus: its differences, causes, symptoms, with the treatment of this disease and the means to prevent it. Proceeded by a speech on ways to improve the medicine practice in the torrid zone. Followed by comments on the health of pregnant women in these regions; their illnesses at different periods of pregnancy; delivery & suites; conservation of newborns through adolescence. Completed by the approximation of vices and abuses of the hospitals of the tropics, and the means to address them.*

discussion of tetanus. This disease-specific section is then succeeded by a discussion of the health of pregnant women and birthing rooms as well as the welfare of children through adolescence. Dazille concludes with final remarks on the, "vices and abuses of the hospitals of the tropics, and the means to address them." This text begins and ends with primary public health concerns of the period.

A government text signed by the Military General of Saint Domingue was the final work analyzed. Published in 1802, *Arrêté sur le service de santé dans la colonie*[25] mentions the island's medical system, public health challenges, and hospitals. This work is a government act for the establishment and regulation of medical services, both military and civilian, throughout the island. This document illustrates that the ruling class in this time, most notably the military, had a vested interest in indigenous medications, natural history, and an analysis of mineral waters.[26]

Discussion

Throughout this analysis of texts relevant to this thesis' focus, some general themes emerged that are significant when contextualizing the contemporary state of medicine and healthcare in Haiti. Many of the authors discussed attempted to decontextualize native wildlife, botanicals, remedies, treatment methods, and prevention ideas from the surrounding sociocultural environment of eighteenth century Saint Domingue. Taking this medicinal information out of context misleads the reader. Many of the presented remedies originated with

[25] *Ordinance on the health service in the colony*
[26] "Dans l'analyse des remèdes nouveaux, sur lesquels le Général en chef demandera au Conseil son avis, dans la substitution des médicamens indigènes aux exotiques, dans la continuation de Saint-Domingue et dans l'analyse des eaux minérales." (pg 2)

native and salve populations in Saint Domingue, but the authors of these works present them as European discoveries. Also, many of these authors, such as Pouppé-Desportes in *Histoire des Maladies de S. Domingue*, defined patient populations based purely on skin color.[27] These authors further illustrate inherent racism by discussing Europeans as foreign travelers while the Black slave population is discussed in relation to island natives. The social divisions of the colony portrayed in these texts indicate a historical inequity in medical care and illness discourse based on race and class.

We also observe that, as these European works progressed throughout the eighteenth century, medicinal herb and drug descriptions; disease descriptions; and treatment and prevention recommendations became increasingly uniform. In the mid to late eighteenth century, a shared medicinal dialogue emerges throughout the analyzed texts. However, an individual's understanding of and ability to enter this medical communication was reliant upon literacy and a thorough knowledge of the French language. A large majority of the native peoples and slaves in Saint Domingue who contributed significantly to the presented medicinal knowledge were excluded from this emerging medical dialogue.

This compilation of texts also identifies the illnesses and diseases of most concern in this period. Many illnesses reappeared in several of the analyzed texts including: "the fevers of Saint Domingue," references to an illness symptomatically similar to malaria, arthritis and other "stiffening joint" illnesses, cholera, various illnesses suspected as the cause of stomach illness, fistulas, anxiety disorders or hysteria, severe headaches, venereal diseases, and symptoms of dietary malnutrition such as scurvy. This list of illnesses provides important information about

[27] "… j'en ai peu observé dans cette constitution parmi les blancs; elles ont été communes parmi les negres." (pg 33)

the infrastructural challenges of eighteenth century Saint Domingue, and it also includes many of the illnesses that have only recently begun to decrease in prevalence in the past decade in contemporary Haiti.[xxvii] These include diarrheal illnesses, malaria, cholera, nutritional and dietary concerns, venereal diseases, and neuro-psychiatric conditions.[xxviii] Many of these illnesses remain a prevalent challenge for Haiti, directly effecting daily health.

Finally, the texts analyzed illustrate a distinct transition from individual treatment perspectives to population-based inquiry by the end of the eighteenth century. The earlier works, primarily written by European botanists and naturalists, focused on individual plants and their potential for treating specific illnesses. In contrast, works written near the end of the eighteenth century, primarily regarding the health infrastructure in Saint Domingue, present a more public health-based approach to medical investigation. Population-based observational findings, such as Hector McLean's exploration of the prevalence of illness in the French military troops, illustrate a maturation of the medical field in Saint Domingue beyond individual-level concerns to community-level health interests.

The Haitian Revolution significantly altered the sociopolitical dynamics within the country at the turn of the century. Prior to the Haitian Revolution, the French government began discussing population health measures and implementing systematized healthcare. However, the destruction and change in country leadership resulting from the Haitian Revolution caused this momentum toward systemic progress to reverse. Minimal evidence of the French population health perspective is observed in the current medical system, illustrating a discrepancy between the historical health trajectory of Saint Domingue and the resulting status of modern healthcare in Haiti. Colonial history and revolutionary perspectives preceded Haiti's current lack of resources, racial disparities, and complex sociocultural interactions with western biomedicine.

Chapter 3. Sociopolitical History of Haiti: Influences on Healthcare

At the end of the eighteenth century, Saint Domingue was divided into three distinct social classes: 1) wealthy, white colonists primarily from France, 2) free mulattoes and blacks who were not considered equal in status with the white elite but could own land and slaves, and 3) slaves imported to the island, primarily from western Africa.[xxix] In this time period, there were approximately 32,000 whites, 28,000 free people of color, and 500,000 slaves living in Saint Domingue.[xxx] Slaves in Saint Domingue were considered "property of the public" with only their basic necessities met by their masters.[xxix] After over a century of mistreatment, hard labor, and brutality inflicted on the imported slaves by their white masters, Saint Domingue was primed for the flame of revolution.[xxxi]

Concurrently, the French Revolution was raging overseas, causing the frequent European travelers to bring radical thoughts and conversations to the colony. In 1789, the French issued the Declaration of Rights of Man, stating that, "In the eyes of the law all citizens are equal." Although France planned on maintaining the enslavement supporting their oversea colonial economies, including Saint Domingue, the philosophical, moral, and ethical questions raised by this statement of equality for all rapidly began to spread throughout the island. French Revolutionaries such as Amis des Noirs supported the movement, directly spreading concepts such as abolition.[xxxii] However, the pro-slavery plantation owners also helped spread the radical ideas that fueled the French Revolution by discussing these issues in front of their slaves, who then formed their own opinions about "liberty, equality, and fraternity."[xxxi]

As ideas stemming from the French Revolution flamed increasing hostility, the Saint Domingue slave population recognized an opportunity for a revolution of their own as the,

"white minority split into Royalist and Revolutionary factions, [and] the mixed-race population campaigned for civil rights."[xxxiii] Although there were small revolts led by slaves throughout the prior decade, an organized full-scale slave rebellion began in August of 1791. Under the guidance of rebellion leaders such as Biassou, Boukman, Cristophe, Dessalines, Francois, Jeannot, Macaya, and Toussaint, this rebellion continued for the next twelve years as slaves fought for liberty from the colonial institution of plantation slavery that had oppressed them for over a century.[xxxi, xxxii] After the only successful slave revolt in history, the French were defeated, and Haiti was declared an independent country in 1803, making Haiti, "the first independent black state in the New World." [xxxii]

Immediately following the Haitian revolution, the revolutionary leader at the time, Dessalines, assumed the role of self-appointed Emperor of Haiti. However, he was promptly assassinated in 1806 which led the nation into a period of monarchs and presidents, with multiple parties continuously contending for political control of the country. Until 1820, the north and south of Haiti were divided as two distinct political halves creating regions with differing economies and policies. Most people living in the North became fairly prosperous but unhappy, while the average person in the South was poor but fairly content. After the reuniting of north and south, Haiti also conquered the Spanish portion of the Island, placing the entire Island of Hispaniola under Haitian rule. In 1844, Spanish troops once again took control of the area now known as the Dominican Republic.[xxxiv]

Complete disintegration of political control in Haiti occurred in 1915 after President Guillaume Sam executed 167 political prisoners, eliciting anger throughout the capital city, Port-au-Prince. This incident led a mob to, "tear him apart and parade through the streets displaying the parts of Sam." This state of complete collapse of political control led the United

States to intervene, acting as Administrators running the Haitian government until 1934. US control was initiated for a multitude of conflicting reasons, but during this time, the US errected significant infrastructure and encouraged stability in Haiti.[xxxiv]

In 1957, François Duvalier won a democratic Presidential election by public vote. However, once elected, Duvalier ruled Haiti until 1971 through force and bloodshed, estimated to have killed approximately 30,000 Haitians in that period for opposing his rule. His son, Jean-Claude Duvalier, then ruled after his death until 1986.[xxxiv]

The political history of both the colony of Saint Domingue and the Republic of Haiti is filled with upheaval, uncertainty, military confrontations, and contentious leadership. Although some conversations regarding public health initiatives were started at the end of the eighteenth century, this progressive dialogue was hindered during the Haitian revolution and the political instability following the slave uprising. After Haiti declared independence at the beginning of the nineteenth century and the slave trade in Haiti was abolished, the economic stability provided by the French export trading system also collapsed.[xxxiv] Exacerbating this loss of income due to decreased exports, the French demanded compensation for the colonists' lost slave holdings in what is known as the "Independence Debt." Imposed in 1825, Haiti continued repayment efforts through 1947, paying a total estimate of 21 billion dollars in modern US currency to France.[xxxv] Since many of the same challenges that existed in the eighteenth century are still prevalent today, this historical context provides a critical framework to better understand contemporary medical services in Haiti.

After centuries of unstable government structures, environmental emergencies, and underdeveloped medical and sanitation systems; Haiti's already perilous situation was instantaneously exacerbated by the highly-publicized destruction of the 2010 Earthquake. On

January 12, 2010, Haiti was hit by a 7.0 magnitude earthquake with 5.9 and 5.5 magnitude aftershocks. The epicenter of the Earthquake was only 15 kilometers outside of Port-Au-Prince. As the nation's largest city, Port-au-Prince housed approximately 1 million people at the time of the Earthquake.[xxxvi] Haiti's already weak and disorganized infrastructure, including unregulated building construction; the decentralized, distrusted government; and overcrowded and impoverished urban areas housing 52 percent of Haiti's overall population, compounded the consequences of this natural disaster. With an official death toll of 316,000 people, an estimated displacement of 1.5 million Haitians into temporary settlements, and approximately 10 million cubic meters reduced to rubble, the Haitian Earthquake in 2010 initiated, "an unprecedented relief effort for what was the worst recorded natural disaster in the Western Hemisphere."[xxxvii] This immediate, large-scale international humanitarian aid effort has defined twenty-first century Haitian healthcare. In the wake of the Earthquake, many of the nation's hospitals were left inoperative, leaving a heavy burden of caring for the injured, sick, and dying to hospitals spontaneously established by international aid organizations.

Now, seven years after the earthquake, Haiti is populated with a diverse array of internationally funded hospitals and other aid organizations such as orphanages, religious associations, and schools. The decentralized, piecemeal medical system currently serving the country directly demonstrates the effects of western biomedicine in Haiti, introduced through both colonialism and international aid efforts. Many of the established medical centers are staffed or run by international personnel, including: Médecins Sans Frontières (MSF) International, Sisters of Charity, Le Groupe Haïtien pour L'étude du Sarcome de Kaposi et des Infections Opportunistes (GHESKIO), Hosptial Bernard Mevs, and St. Luke Hospital. Although many Haitians still maintain health-related traditions and superstitions, Hatian medical services

are heavily influenced by western biomedicine and most medical centers do not incorporate traditional healing practices or providers into their treatment methods.

Disaster relief medical aid structure is typically modeled after healthcare systems developed in high resource care environments. With relief aid commitments ending and the resulting reallocation of international support, Haiti is experiencing a drastic decline in healthcare funding. As resources continue to diminish, health centers like St. Luke Hospital are left with defficient staffing and monetary support to treat all the patients that require free or low-cost, quality healthcare. In an interview, Wynn Walent, International Liaison and Volunteer Coordinator for St. Luke Hospital, explained that hospitals like St. Luke must respond to this decrease in resources by restructuring their healthcare provision approach. St. Luke Hospital is reducing costs and practitioner demands by transitioning from a mostly in-patient clinic to mostly out-patient services. The previous inpatient care model, used at most high resource care hospitals, was only sustainable with consistent international funding support due to the high overhead expenses associated with inpatient care. Many countries across the globe have established palliative care models, in a diverse array of low to high resource settings, demonstrating the cost-effectiveness of integrated palliative care services. These exemplary models can be used to discuss location-specific best practices in palliative care service standards.

Chapter 4. Palliative Care Strategies: Lessons from International Case Studies

Since the United Nations adopted palliative care as a human right in 2000, the generation of research literature discussing palliative care systems and the implementation of program models has increased drastically. Many high resource nations are now facing the consequences of institutionalizing end of life care and shifting from a primary care-based model to a system heavily reliant on emergency medicine services. Both academic journals and popular novels, such as Atul Gawande's book *On Being Mortal*, are increasingly exploring the role palliative care services should play in the healthcare systems of high resource countries. Similarly, the volume of texts presenting a low and middle resource perspectives on palliative care systems has also begun to increase. While some of these literature sources discuss underlying palliative care philosophies, there are also examples of care systems being implemented in a variety of sociocultural contexts.

Palliative care models implemented in all resource environments can inform future palliative care development. This chapter will specifically discuss three country case studies with very different care environment characteristics – Spain, Mongolia, and India. These successfully implemented models illuminate necessary palliative care system organizational structures, the importance of tailoring an intervention to specific healthcare environments, fundamental components of all successful palliative care programs, and the varying institutional levels on which palliative care services can be implemented (i.e. national or local government, a hospital ward, or within a specified geographic area). Existing palliative care programs in each of these countries illuminate approaches for strategic planning and development of future palliative care programming in Haiti.

Twenty-four years ago, in collaboration with the Catalan Department of Health and the Catalan Institute of Oncology, WHO initiated a demonstration project in palliative care (PC) in the Catalonia region of Spain. The project's twenty-year report provides an excellent model for understanding the WHO goal for national palliative care systems. The demonstration project article states that, "Catalonia has a publicly funded NHS [National Health System] providing care that is free of charge at the point of access for all citizens… The aims were to introduce wide coverage, equality of access, and quality in the provision of PC and to stand as a reference for accountability." To provide quality palliative care free of cost to all residents, the Catalan Department of Health has established a combination of palliative care units, hospital support teams, home care support teams, outpatient clinics, psychosocial support teams, and nonclinical services throughout the region, "…with the relief of suffering and adjustment to loss and grief as the main goals of care."[xxxviii] Each of these services attempts to fill a different role in the palliative care service network, and the primary goals of this WHO demonstration project may help establish attainable long term objectives for palliative care development in Haiti.

The self-evaluation of the demonstration project results states that:

> The most relevant strengths and characteristics of the Catalan model are the systematic NHS approach to planning, the high coverage for cancer patients, the geographic spread, the rapidly growing coverage for non-cancer patients, and the systematic evaluation of implementation of PC services. The most relevant weaknesses include aspects of the model of care, continuity, and development of models in practical settings and in academia.[xxxvii]

Although this type of comprehensive, national palliative care system is not currently attainable for many low resource nations, aspects of this successful WHO initiative may demonstrate characteristics or approaches applicable in low resource environments such

as Haiti.

Qualitative and quantitative data, collected in five-year intervals, evaluate the Catalonia demonstration project's patient demographics, cost-effectiveness, teaching and educational strategies, and patient experience and satisfaction with care. Data results show that, "…the PC network saves more than it costs, as a result of the striking reduction in the use of hospital resources." Spain's successful data collection strategies and evaluation methods illustrate the importance of measurable outcomes and program assessments in evaluating service provision success and providing data for evidence-based programmatic growth. Adapting existing evaluation methods, such as those used for the Spain demonstration project, will allow Haiti to produce standardized and comparable program data that is valuable within the international palliative care discourse.

Individual province demographic and health system data were used to inform the methods implemented within specific regions of the national health system. For example, the proposed model for palliative care services in "metropolitan" areas, with a population greater than 500,000 people, is a combination of palliative care units, outpatient clinics, hospital support teams, training, and research at the primary University hospitals as well as a few smaller social health centers with palliative care units. In contrast, the suggested model for rural populations with less than 50,000 people is a comprehensive system with a hospital support team and home care support team working on all levels.[xxxvii] These demographic-dependent palliative care system designs highlight the diverse needs of different populations and establish basic palliative care service models which may be adaptable for various circumstances. This service approach also emphasizes the critical importance of spending time and resources on understanding the unique needs of the target population in establishing appropriate palliative care programs. For

leaders in Haiti, these metropolitan and rural system design structures may provide a starting point for identifying necessary palliative care implementation partners.

The article "Mongolia: Establishing a National Palliative Care Program" discusses the necessary components of establishing an integrated, country-level palliative care program in Mongolia. Four things needed to happen simultaneously to make this national plan possible: 1) create national palliative care policies and standards of practice; 2) change policies to increase opioid availability by allowing the importation of low-cost, oral morphine and general practitioners to prescribe up to a week of these oral analgesics; 3) educate doctors about general aspects of palliative care and proper oral analgesics prescription methods through hands-on teaching experiences; and 4) supply analgesics to the health centers where they are most needed. In describing the necessity for simultaneous action, this article states that:

> Intensive follow-up bedside training is critical in order to provide hands-on experience with opioid prescribing… Seeing positive effects in patients created enthusiasm for opioid use and helped the participants overcome their opiophobia…Therefore, it is imperative that training and availability of opioid analgesics be coordinated.[xxxix]

Through these coordinated international and national efforts, Mongolia was successful in increasing the amount of imported oral morphine to address pain management as well as establishing a functioning national palliative care program.

However, unfortunately, Haiti does not currently have a strong national healthcare system. In her article "Surgical Palliative Care in Haiti," surgeon Dr. Joan Huffman writes about her experience providing medical care immediately following the 2010 Haiti earthquake. In summarizing the effects of the disaster on vulnerable patient groups, Dr. Huffman states:

> Following an MCE [Mass Casualty Event], there are 4 groups of patients who

> fall into the 'not expected to survive' category: patients already under hospice/palliative care; vulnerable patients in long-term care facilities with an advanced disease (1%–2% of normal population); individuals exposed to the MCE who are expected to die; and other patients triaged due to scarce resources. Suddenly, because of an abruptly austere environment, all these patients are shifted to palliative care.[xl]

Huffman continues to discuss the challenging situation that arises when this critical spike in palliative care need clashes with current disaster response strategies. These humanitarian aid strategies tend to focus on helping the most people as efficiently as possible and often do not immediately work to incorporate the local cultural and historical context of the emergency situation. In contrast, quality palliative care services rely heavily on local context and designing an individualized care plan for each patient. Unfortunately, the Haitian healthcare system is still primarily composed of these international humanitarian care facilities. Almost seven years after the 2010 earthquake, the westernized biomedical health systems established during the crisis by international organizations and volunteers – most of which are based in high resource nations – have proven unsustainable for Haiti. These quickly erected healthcare systems fail to meet the palliative need constantly present in the low resource environment.

However, both the Spain and Mongolia palliative care models emerged as collaborative efforts between an organization currently providing an established, western model of palliative care and an in-country network of physicians, policy makers, nurses, and educators. Although many countries, like Haiti, do not yet have a national palliative care model as described in the WHO Catalonia demonstration project, some countries have small groups of invested professionals and community members who have successfully established smaller-scale, community-based projects. India, a middle resource nation, is one country establishing

community-based palliative care programs. India's sociocultural, economic, and family care structures most closely resemble those identified in Haiti; making India and similar community-level palliative care development trajectories most directly applicable to Haitian service development.

In the article "Hospice and Palliative Care Development in India: A Multimethod Review of Services and Experiences," researchers summarize and analyze palliative care initiatives in India before 2008. India presents a unique sociopolitical, economic, and cultural landscape for palliative care because the subcontinent is made up of 25 diverse union territories – 16 with palliative care and hospice services and 19 without. Regarding establishing these programs in a diverse, middle income, mostly-rural country; Dr. M.R. Rajagopal, a founder of Pain and Palliative Care Society in Kerala, explains:

> Our suffering people need a system of palliative care delivery that is suited to our social and cultural milieu. It has to be inexpensive; we cannot possibly have enough expensive inpatient facilities for a million people. We can learn from the hospice system of the West, without duplicating it in its entirety. We have a strong point in our favour and that is the family structure in India. People generally prefer to live and die at home. If we have a system of delivery of palliative care based on treatment at home, with the relatives being empowered in the care of the patient, it has a definite chance of succeeding (pg. 589).[xli]

Dr. Rajagopal elegantly expresses the view of western palliative care model adaptation shared by many other palliative care stakeholders in countries such as Sudan, Nepal, Uganda, and Brazil.[xlii,xliii,xliv,xlv]

According to these and related studies, countries that have implemented palliative care programs as part of national health systems and community-based programs have seen great success. Implemented programs have resulted in unanimous cost savings, improved experiences

with end of life care and pain treatment, and a lower burden on traditional medical care services. However, to establish a successful national palliative care system, there must be international collaboration as well as inter-professional teamwork within the country. Palliative care is, by definition, an interdisciplinary initiative. In global perspective, WHO guidelines establish that palliative care program:

> Recommendations are tailored to different resource settings, and priority is given to initiatives that are well integrated into the existing health system and related programs. Policy development, education and training, provision of good quality care (including home-based care), and drug availability are considered key components of a comprehensive palliative care program.[xlvi]

Based on the success and required collaboration of these palliative care models, Haitian medical care providers may be able to use palliative care to transition from the current short term, internationally funded healthcare facilities to a more sustainable, long term healthcare network. If a palliative care program were to be established in Haiti, fundamental aspects of the program would include: 1) identifying an organization to provide the location and initial leadership for program development and strategic planning; 2) listening to patients near the end of life and their family members to begin understanding the specific needs of the target population; 3) identifying highly motivated individuals in a variety of job positions as program leaders and in-country palliative care advocates; 4) training physicians, nurses, and hospital support staff in palliative care provision; 5) organizing and fortifying international collaborations and relationships with specialists for training; 6) changing opiate importation and distribution policy as well as prescription practices.

Working toward a national palliative care program may unite disparate entities within Haiti around a common, attainable goal. Establishing discourse on policy, education, and health

practices will help the nation move toward a goal of a more sustainable, nationally-operated infrastructure. The connections between these stakeholders will also translate into future infrastructural progress being implemented more easily for other systems in Haiti. Working toward these goals within the humanitarian aid response, or immediately after, may help create long term capital in community networks, an educated work force, and movement on reestablishing public policies.

Many high resource countries are establishing palliative care systems in response to the effects of implementing a national healthcare system. Many countries with an effective, organized national system are now facing the consequences of institutionalizing death. As more individuals choose to die in the hospital rather than at home, medical care costs increase drastically. Palliative care is one cost-effective method proven in high resource countries to reduce these costs and begin decentralizing death. Developing a palliative care service in Haiti may prevent this effect as medical care access continues to increase. High resource countries are also trying to use palliative care services to mitigate the consequences of an inequitable primary care system. In nations where not all citizens have access to primary care, such as the US, the burden of these unmanaged and belatedly diagnosed conditions falls on the emergency medical services. A similar phenomenon is observed in Haiti due to the lack of patient access to consistent primary care. Individuals requiring care near the end of life are a burden on the Haitian healthcare system, indicating the need for palliative care-hospice service provision.

Haiti has the unique opportunity, created by past experiences with international aid relief and the current need for health system redefinition, to learn from countries that have successfully established palliative care programs and potentially augment the international palliative care development conversation. If work begins to design a Haitian-specific palliative care system,

Haiti will be a new case study in how Group 1 and 2 countries can transition to providing palliative care. The nation is currently in the capacity building stage, meaning that they need to work on strengthening organizational frameworks and identify a palliative care leader. There is a clear need for palliative care and symptom management near the end of life for patients in Haiti. However, economic factors and funding will need to be considered as a key factor in palliative care service design.

As observed in archival primary source analysis, international stakeholders have written and heavily influenced the history of medicine in Haiti since the first introduction of European Colonists. To foster national ownership of any developed palliative care program and less dependency on international funding schemes, the design of palliative care services must be placed in the hands of Haitian healthcare workers and community leaders rather than international partners with experience designing palliative care services. The current medical care system, with disjointed non-profit and internationally-funded private hospitals, is the result of internationally led development and implementation of traditional western biomedical systems. To prevent this from reoccurring and capitalize on the opportunity of palliative care system development to provide stronger intra-country health frameworks, Haitian organizations and community members must lead program development.

The previous French attempt in the late 1700s to establish public health services in Haiti exemplifies the importance of generating a universal terminology and dialogue around a population health issue before moving forward with program development. To prevent the inherent structural biases in the previously established French healthcare system, movement leaders must ensure the involvement of all members of Haitian society in designing and

developing the terminology surrounding palliative care issues in Haiti. This includes patients and their family caregivers of all educational and socioeconomic backgrounds.

With the lack of effective national healthcare infrastructure, palliative care program provision must be moved forward on a community or individual clinic level. Establishing a palliative care network can be an opportunity to step back and foster local connections and dialogue while understanding and assessing current community stakeholders and strengths. Palliative care is an interdisciplinary initiative, requiring the collaboration of experts and workers from many backgrounds and disciplines. To be financially feasible, palliative care also requires the centralization of community resources and standardization of treatment approaches.

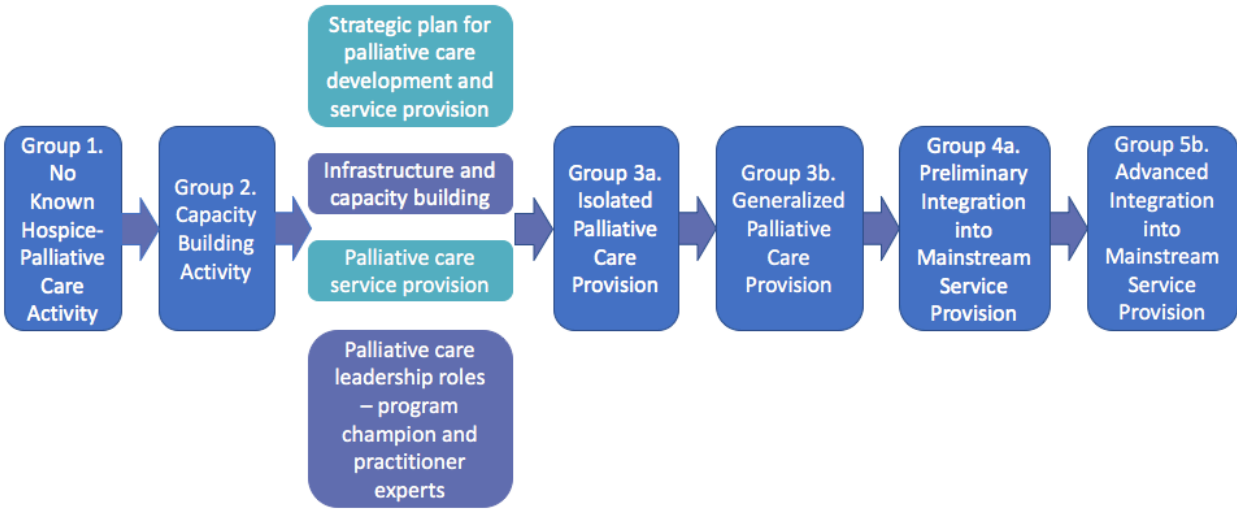


Diagram 1. Palliative care system maturity Groups and the four building blocks necessary for transitioning from capacity building activity to palliative care service provision.

Examining the International Observatory for End of Life Care's method for grouping countries based on palliative care development maturity, four primary building blocks for palliative care programs emerge, including: 1) a strategic plan for palliative care development and service provision, 2) infrastructure and capacity building, 3) palliative care service provision, and 4) palliative care leadership roles which include a program champion and practitioner

experts (Diagram 1). The design of palliative care programs must vary based on country dynamics, sociocultural context, current capacities, and challenges including feasibility of service provision. While there is existing research on the specifics of palliative care program design, countries that must transition from Group 1 and 2 to some provision of palliative care services require more front-end work on strategic planning and capacity building before service design can occur.[xlvii]

Thus, one of the next steps in furthering palliative care development in Haiti is to identify a palliative care champion and practitioner experts within the country. St. Luke Hospital administration expressed an interest in providing palliative care services at the clinic level and, with support, may be able to act as the necessary palliative care champion. If St. Luke were to take on this role, the hospital staff and organization would be on the cutting edge of palliative care development as well as resource centralization, health infrastructure building, and the standardization of end of life care in Haiti. To provide St. Luke with the necessary initial data assessment to make an evidence-based decision regarding the hospital role in future palliative care efforts, the researcher collected qualitative and quantitative data in collaboration with hospital staff. The researcher collected needs assessment and topic-specific data in a three-month study interviewing and surveying patients estimated to be within six months of end of life, their family caregivers, and the hospital medical staff members. This initial assessment data is analyzed for thematic trends that can be used as talking points in future partner meetings and collaboration attempts.

Chapter 5. Introduction to Needs Assessment Study at St. Luke Hospital

Study Introduction

In collaboration with St. Luke Hospital, the researcher interviewed six patients and 45 family caregivers of patients near the end of life and surveyed 12 St. Luke medical staff members, gathering quantitative and qualitative data. The researcher also collected observational data and interviewed relevant in-country experts. These collected data provide an initial needs and capacities assessment for St. Luke Hospital administrators to make evidence-based decisions regarding the Hospital's future role in palliative care development. Qualitative coding and thematic analysis were also utilized to identify potential topics to guide strategic planning and community partnership conversations regarding palliative care development and program design.

Research Location Description

St. Luke Hospital (l'Hopital St. Luc) is a private tertiary care hospital located in the Tabarre area of Port-au-Prince, Haiti. The hospital was first established in the aftermath of the 2010 Earthquake as a partner organization to an already existing pediatric hospital, L'Hopital St. Damien. After the Earthquake, there was an influx of adult patients that needed and were not receiving critical care, especially when the Cholera epidemic began in November 2010.[28] St. Luke has two emergency wards which collectively hold 45 in-patient beds. The hospital employs over 15 physicians and many more nursing staff to care for patients and hosts international medical volunteers in key specialty areas including neurology, plastic surgery, cardiology, and

[28] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3310575/

endoscopy. According to St. Luke medical staff, the hospital tries to limit in-patient care to less than one week.

St. Luke medical staff host daily clinics Monday through Friday to provide patients not staying in the hospital with ongoing or less emergent care as well as provide wound care. In May 2016, in collaboration with non-profit Equal Health International, St. Luke opened an oncology center employing one part-time physician. The oncology center provides patient diagnosis, chemotherapy (including palliative chemotherapy), referrals for surgical intervention, medications, and symptom management support. Finally, St. Luke Hospital is also affiliated with Kay Germaine, a neurological mobility deficit center primarily treating adult stroke patients after hospital discharge.

Study population

All participants were recruited from St. Luke Hospital from June 2016 to August 2016. Patients were considered for inclusion in the study if the attending physician identified a life-threatening condition with risk of end of life within six months. Three categories of participants are included in the study: 1) patients with life-threatening conditions, 2) family members caring for a patient with a life-threatening condition, or 3) physicians and nurses on the patients' medical teams. Potential study subjects meeting the inclusion criteria were identified each morning after physician rounds. Excluded from the study are patients with an unclear prognosis as determined by the physician team, an age less than eighteen years old, and the inability to provide consent or locate a designated surrogate decision-maker. Selected eligible patients were first offered the opportunity to participate via face-to-face conversation with the researcher

[M.O.]. If the patient was unable to provide consent, then a family member providing care for the identified patient in the hospital was offered the opportunity to participate in the study.

All medical staff were given the opportunity to complete the medical staff survey. Two family member caregivers chose not to participate in the study when offered, stating that they were too tired to talk. Three medical staff members also chose not to participate in the study when offered, stating that they, "did not know anything," about the hospital.

Communication between the medical care provider, patient, and patient's family members is a fundamental component of palliative care. Clear and consistent communication ensures all parties understand the patient's illness diagnosis and prognosis, a necessary precursor to developing an individualized patient palliative care plan. Thus, the primary outcome of interest was identifying current patient and family caregiver needs within the relevant patient population. One method of measuring this was comparing the caregiver and patient understandings of a patient's diagnosis and prognosis with the medical staff's official diagnosis and prognosis for agreement. Secondary study outcomes included identifying barriers to accessing or providing palliative care services, recognizing existing hospital capacities, and generating underlying categorical questions that must be discussed by stakeholders before initiation of palliative care program development.

Process of Consent

An explanation of the study purpose, survey process, and participant's role was provided to each study candidate in their native language by an interpreter. The patient and family member consent form was translated into Haitian Kreyol, and the medical staff consent form was translated into French, the official language of medical education in Haiti. All consent forms

were translated using forward- and back-translation procedures. In addition to the written forms, a Haitian Kreyol interpreter read the Kreyol consent forms out loud to overcome any literacy barriers. Participation agreement was signified by a verbal decision and a signature or personal marking on the form.

Study Methods and Data Collection

This study employs a mixed methods approach. Data were gathered using one-on-one interviews with patients and family member caregivers. St. Luke medical staff completed related surveys. Questions to gather quantitative data identify the demographics of study group participants and analyze the frequency of provided survey answers. Qualitative data were collected through semi-structured, open-ended questions and were used to contextualize the quantitative data and identify health experience themes.[xlviii]

All interviews were conducted by the researcher, a female undergraduate student participating in Biomedical Engineering and Global Health Narrative programs at Brown University. She has completed prior research in public health methods including conducting one-on-one semi-structured interviews, focus groups, ethnography, survey design and data collection, and qualitative data analysis. A relationship was not established between the researcher and study participants prior to beginning the on-site study. In the consent form, the participants were informed of the motivation and goals behind the research initiative as well as the researcher's affiliation as a collaborator with St. Luke Hospital.

Data were collected from Caregivers and Patients through structured interviews, from St. Luke medical staff via written survey, and from affiliated hospital partners via semi-structured interviews. Data was also collected through observational methods and content analysis. All data

was collected within St. Luke Hospital. If the participant was mobile and able, the researcher offered to move to a more private area of the hospital to conduct the interview. Most interviews were conducted in a space removed from the primary urgent care wards not directly used to care for patients. However, some patients that were unable to move or family members that did not want to leave a patient's bedside, chose to complete the interviews in the ward. For these interviews, privacy screens were erected and reasonable considerations were made to protect the privacy of the participant. Some participants were accompanied by other family members during the interview.

All interviews with family caregivers and patients were completed using standardized surveys. A trained, native-speaking Kreyol translator followed an established script, reading the survey questions verbatim to the participant. If the clarification was required, the participant's questions were translated to English, so that the researcher could provide a response to be translated. No repeat interviews were conducted and no audio or visual recordings were collected. Field notes were written during and following each interview. Each interview took between twenty and sixty minutes, depending on participant pace.

Patients

Patient Critical Care Survey [Appendix A1]

Patients were interviewed to collect demographic information, quantitative data on their perspective of healthcare access and unmet needs, and qualitative data regarding their concerns and experience in the hospital.

Family Member Caregivers

Family Member Critical Care Survey [Appendix A2]

Family members providing care to a patient in the hospital were interviewed to

collect quantitative data for demographic information and their perspective of healthcare access and unmet needs; and qualitative data identifying their primary concerns and additional resources they wished the hospital would provide.

Medical Staff

Medical Staff Critical Care Survey [Appendix A3]

Physicians and experienced nurses completed the survey by hand to provide quantitative yes/no and multiple choice data regarding staff demographics, current hospital resources, medical staff satisfaction, and perspectives on palliative care; and qualitative data on their impressions of and feelings about palliative care and the healthcare services that they currently provide.

Integrative Palliative Outcome Scale (iPOS) [Appendix A4]

The attending physician in each Hospital ward completed an iPOS survey for each patient participant in their ward that was either interviewed or had a family caregiver interviewed. This survey collected quantitative data on the health condition, symptoms, and current state of treatment management for each patient participant.

Additional Qualitative Data Collection Methods

Clinical Observation

The researcher observed clinical interactions with patients that qualified for this study as well as the day-to-day hospital operations structure.

Semi-Structured Interviews

The researcher held informal, semi-structured interviews with other related stakeholders including the Hospital Administrator, Social Services team members,

and Physical Therapy team members to explore the role of non-medical resources in the treatment of patients with life-threatening illnesses.

Data analysis

Demographic data for each participant category were tabulated and analyzed with frequency distributions. Data corresponding to each participant category were considered separately. However, the primary unit of the analysis remained the individual patient.

The researcher was the only data coder. Coding themes used in this analysis were derived from the collected data. Narrative responses were categorized into themes, which were assessed to determine patterns and identify outlier responses. The open-ended questions were subject to content thematic analysis. Descriptive statistics were used to analyze the yes/no and multiple choice quantitative responses as well as the participant demographic information.

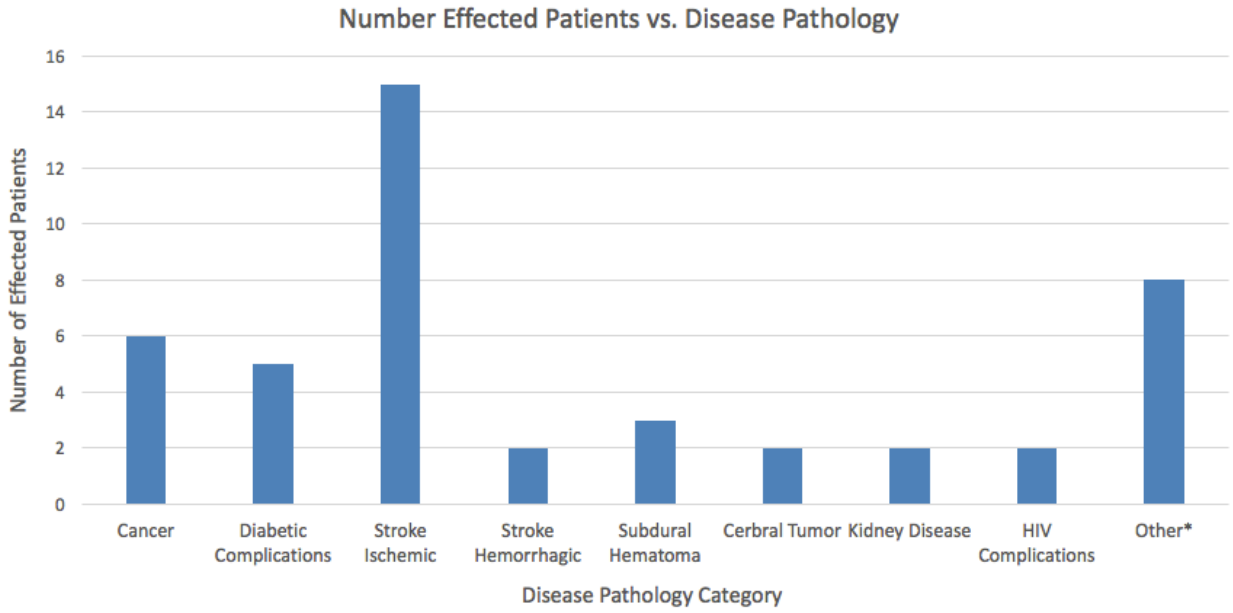
Measures from the completed iPOS assessments were tabulated, and diagnosis data were stratified into illness categories to better understand the frequency of each illness type. Descriptive statistics were used to analyze the collected symptom management data to understand the hospital's current capacity for managing the primary symptoms associated with end of life care. Microsoft® Excel was used for data analysis. All aspects of the study were approved and monitored by the hospital research review board.

Participant Role Summary and Demographics

Patients:

Six patients were interviewed in this study, four female and two males. Demographics for the interviewed patients are presented in Table 1. However, due to the inclusion criteria of this

study, many patients identified as within six months of end of life were unable to participate because of their cognitive or physical condition. For patients recommended for this study who were unable to participate, the family members caring for them in the hospital were asked to participate. For all participating patients and patients with participating family caregivers, the attending St. Luke physician completed an iPOS form with information regarding disease pathology (Graph 1).



Graph 1. Number of patients effected by each disease pathology category based on physician iPOS records.

In the duration of this study, the primary researcher observed that a significant number of patients arrived at the hospital with no family members to care for them. Many of these patients were identified as possible candidates for palliative or hospice care. Because family members complete so much of the patient care, the hospital has a social services group that provides for the basic needs of patients without family members including making food at the hospital and providing feeding assistance, helping them shift beds or positions a couple times a day, and

completing any necessary basic sanitary care. These patients, referred to as "abandoned," are unrepresented in the data collected in this study.

Table 1. Demographic information for interviewed patients.

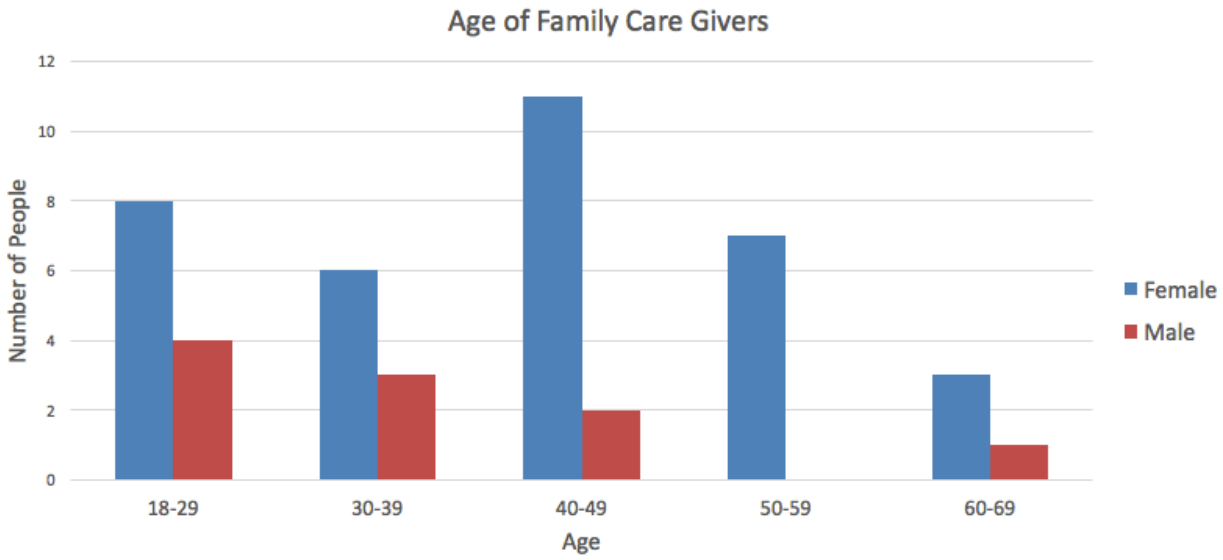
Patient	**Sex**	**Age**	**Marital Status**	**Level of schooling**	**Religion**	**Who helps make medical decisions?**	**Length of medical treatment for current illness**	**Length of current hospital visit**
1	Female	58	Married	Never went to school	Christian	Daughters	4 years	4 days
2	Female	34	Single	12th grade	Baptist	Nobody	2 years	More than a week
3	Male	65	Married	Primary school	Protestant	His family	1.5 months	More than a week
4	Female	35	Single	Never went to school	Protestant	Her family	2 years	4 days
5	Male	19	Single	9th grade	Protestant	Mother	1 year	5 days
6	Female	31	Married	12th grade	Baptist	Herself	5 days	5 days

Family Member Caregivers

Patient Support Role: Family members provide most daily care for patients admitted to the hospital. These caregivers sit in plastic and/or folding chairs beside the patient's bedside to help the patient reorient or move, relieve themselves, and maintain cleanliness. Family caregivers also: address recurring care for wounds or specific illness symptoms, fan the patient to keep the bugs off and to provide a respite from the heat, hold tubs for excess blood or sputum, cook meals at home for the patient, purchase medications and medical supplies, and run to other hospitals or labs to get medical tests completed for biopsies/blood/fluids or to pick up blood from a blood bank. Nurses do not perform this type of supportive care. Family members provide almost all personal patient care in the hospital.

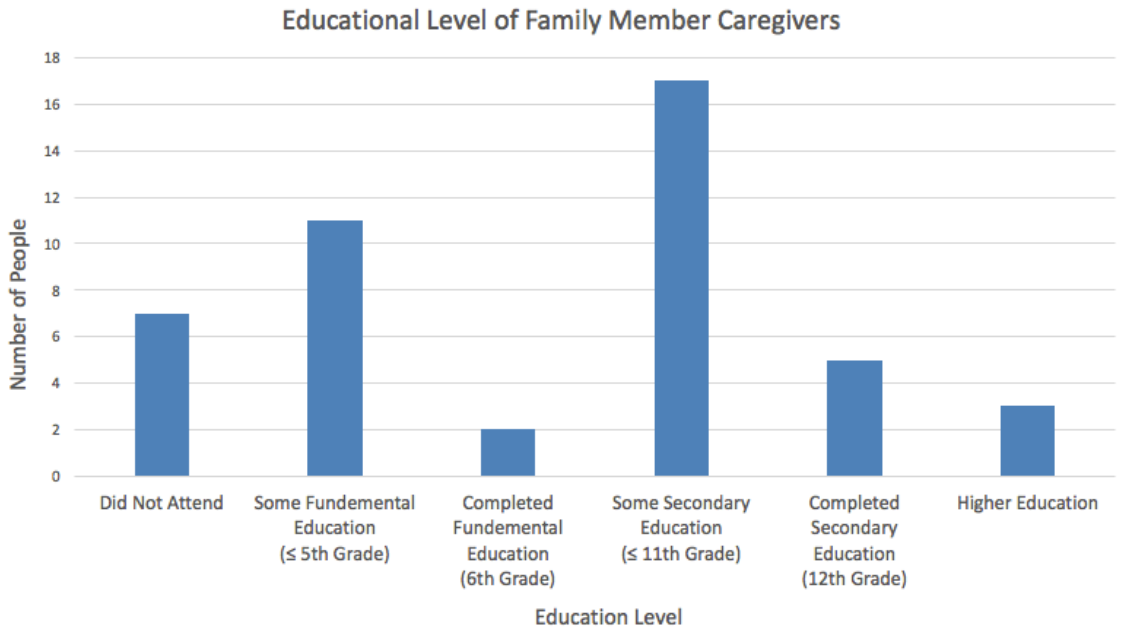
The researcher attempted to interview the family caregiver that spent the greatest amount of time in the hospital with the patient. In multiple instances, this family caregiver was female and, when approached by the researcher, she referred the researcher to the primary male head of their household. In one instance, the male head of household was interviewed and then, with his permission, the initial female family member was interviewed separately. In three instances, the male family member demanded to be present for the interview. Although any data recorded was the response of the family care giver present, a few responses may have been influenced by the presence of male family members.

In this research study, 35 female and 10 male family caregivers were interviewed. The age distributions of interviewed family caregivers stratified by sex are presented in Graph 2. Of the interviewed family members, 32 responded that they stayed with the patient in the hospital throughout the entire duration of their hospital stay, 9 spent multiple days a week with the patient, 2 visited the patient once a week, and 2 were "rarely" with the patient. The relationship between family caregiver and patient was also collected as part of the demographic data. The most frequent relationships are: family caregivers were the patient's child (20), spouses (6), and parents of the patient (6). Other designations include grandchildren, siblings, non-traditional or informally adopted family members, in-laws, and member of the patient's church congregation. Forty-two out of the 45 family caregivers interviewed stated that they do assist the patient with medical decision making; the three participants that reported they do not assist in medical decision making were female family members.



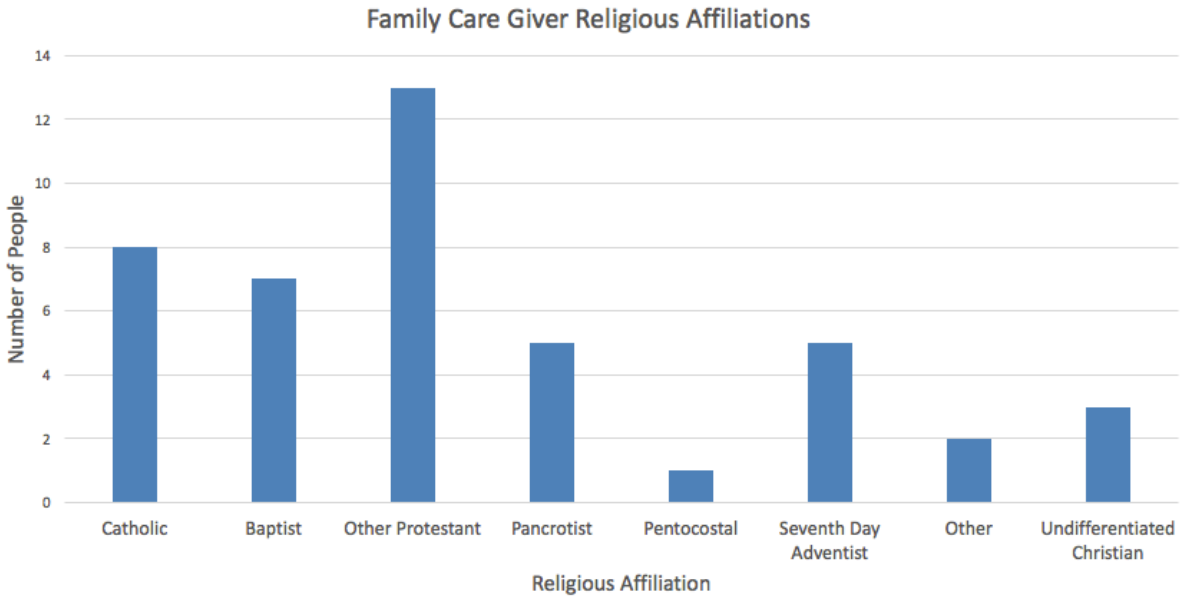
Graph 2. Number of family care givers in each age range, stratified by gender.

In addition to the above demographic information, the education levels of the family caregivers were collected. In Haiti, the educational system is divided into three main categories: Fundamental Education, Secondary Education, and Higher Education. Fundamental Education is comprised of nine years of schooling divided into three-year cycles – the first, second, and third cycles. Per law, education is compulsory for students six to eleven years old. After completion of the second cycle, or approximately six years of schooling, students may enroll in vocational training programs. However, any other form of Higher Education, such as University, requires the completion of Secondary Education. Secondary Education is a four-year long sequence. In interviews, many participants referred to "Primary School" as completing the first two cycles of the Fundamental education sequence. For the purposes of this research project, vocational school and University are grouped together within the Higher Education category. The education data for the family caregivers are grouped accordingly in Graph 3.



Graph 3. Completed education level of interviewed family caregivers.

Research participants were also asked their affiliated religion. Only one family caregiver interviewed did not associate with a religion. Of the 44 family caregivers that do affiliate with a religious group, the most common affiliation category is undifferentiated Christianity or a denomination of Christianity (37). Undifferentiated Christianity in this research study is used to describe religious affiliations in which the participant did not self-differentiate their denomination. With five affiliates, Pancrotist is the next most frequently represented religious identity. Although the researcher was unable to find literature on this religion, both native-speaking medical interpreters translating participant responses and a Catholic Priest who has been working and living in Haiti for more than three years described Pancrotism as a religious movement that became prevalent following the Earthquake. Based on their amalgamated descriptions, the religion seems to be a form of syncretism, combining the beliefs and perspectives of multiple world religions. Differentiated categorical data of collected religious demographic information is presented in Graph 4.



Graph 4. Religious affiliations of interviewed family caregivers.

Medical Staff

More than ten physicians and many more nursing staff work in the St. Luke Hospital wards providing medical care to emergent inpatients as well as running outpatient and wound care clinics. During the duration of this research study, the public hospitals in Port-au-Prince were closed due to staff member striking, creating an overflow of patients for private hospitals including St. Luke Hospital. In response to this large influx of patients, the inpatient capacity of the hospital – including beds and medical staff – doubled throughout the three-month duration of this research project. Although asked to participate by the lead physicians, recently hired physicians and nurses chose not to participate in this study. Thus, medical staff surveys were limited by high staff turnover and associated inexperience. Another limitation was the hesitance some experienced staff members showed about completing the survey. For example, a head physician asked a nurse with four years of experience working at St. Luke if she would be willing to complete the survey. Although the nurse initially told the doctor she was willing, once

the doctor walked away, the nurse declined to participate stating that she, "[knew] nothing about the hospital." The underlying reason for her hesitation to participate was unclear.

Social services play a significant role in relieving patient and family member suffering which is just as important as primary medical treatment. Most of the observed illness in Haiti was not curable due to presentation at an advanced or terminal stage of disease, especially with the limited resources in this setting. In this environment, palliative care may simply be basic care, pain and symptom management, finishing life with dignity, and having the patient and caregivers know that everything that could be done was attempted. Social services work toward this goal by meeting with each patient's family members, offering resources as needed for purchasing bed sheets, food, and necessary medications. Each afternoon, they host a family member session to provide basic information about the hospital and answer questions from family members. These activities contribute significantly to the contextualized definition of palliative care services.

In this study, four men and eight women completed the medical staff survey. Nine participants were between 30 and 40 years old. Of the remaining participants, one was 28 years old and another was 47. The final participant did not provide a response. Two staff members specialized in Family Medicine, four in Internal Medicine, two in General Medicine, and four were certified Nurse Practitioners. At the time of data collection, the ten participants that responded had practiced medicine in their field for an average of 6.2 years (± 2.44 years). Eleven out of the 12 medical staff participants worked at St. Luke Hospital for at least two years. One participant had only worked there for 4 months (Graph 5). The medical staff interviewed were all Haitian except for one participant that was American by nationality but has always lived in Haiti. All but one staff member interviewed attended medical school in Haiti. Seven out of the 12

medical staff interviewed reported working with patients near the end of life often, and the remaining five participants reported always working with this population. This information is summarized in Table 2 below.

Graph 5. Number of years each medical staff participant had worked at St. Luke Hospital.

Table 2. Demographic information for participating St. Luke Hospital medical staff.

Medical Staff	Sex	Age	Medical specialty	Time practicing medicine	Time working at St. Luke's	Religion
1	Female	32	Family Medicine	3 years	4 months	Baptist
2	Female	37	Internal Medicine	7 years	4 years	Baptist
3	Female	39	Internal Medicine	11 years	3 years	Catholic
4	Female	37	Internal Medicine	9 years	5 years	Baptist
5	Male	31	General Medicine (no specialty training)	5 years	3 years	Catholic
6	Male	34	General Medicine (no specialty training)	7 years	2 years	Pentecostal
7	Male	30	Internal Medicine	6 years	2 years	Adventist
8	Male	40	Family Medicine	6 years	5 years	Catholic
9	Female	28	Nurse Practitioner	4 years	4 years	Catholic
10	Female		Nurse Practitioner		5 years	
11	Female	39	Nurse Practitioner		6 years	Baptist
12	Female	47	Nurse Practitioner	4 years	5 years	Protestant

Chapter 6. Family Caregiver Interview and Medical Staff Survey Data

The following chapter is a summary of the collected quantitative and qualitative caregiver interview, medical staff survey, and iPOS data (Appendix E). These data are the result of an initial needs assessment at St. Luke Hospital. Related observational data collected by the researcher is included in Appendix F. Results are categorized by palliative care discussion topic to aggregate data associated with the guiding conversation questions presented in Chapter 7.

Palliative Care Definition

When asked to define palliative care, the St. Luke medical staff provided diverse responses, illustrating varied understandings of palliative care goals and practical applications. Many of the physicians stated that palliative care was provided in the final stages of illness. A few physicians discussed the role of palliative care in preserving the patient's "dignity" as they pass away. Many physicians also mentioned pain management. Only one physician commented on the role that palliative care should have in Haiti, stating that, "Palliative care would have a primary place in the Haitian healthcare system because of the significant number of patients who require this care." There was a large discrepancy between the responses of the physicians and the nurses. The nurses wrote very little, if at all, while every doctor described at least the basic definition of end of life hospice care. A couple quotes include:

> "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 lifestyle."

In response to the survey, 63.6% of the medical staff reported that St. Luke provided some form of palliative care to patients (N=11). Treatments that were used as examples include: providing oxygen, pain medications, family member counseling, and blood transfusions. Medical staff that indicated they did not think St. Luke provided palliative care discussed limitations such as lack of resources, trained staff, and space including hospital beds to keep patients for longer hospital stays.

When asked about practical problems resulting from the patient's illness, 22.2% of family caregivers reported that these problems were being addressed. However, three of those family caregivers reported receiving help from their church or family members. Therefore, only 15.6% of caregivers reported that the hospital had helped them address practical problems resulting from the patient's illness.

Additional support from the hospital was desired by 93.3% of family caregivers. Common needs that emerged through the family caregivers' open-ended responses included: 1) food provided for both the patient and family caregiver; 2) financial support to buy medications; 3) the opportunity for family caregivers to stay in the hospital without needing to sleep in a folding chair; 4) more frequent check-ins from the doctor; 5) support for the family after a patient dies; 6) better medical information; 7) provided transportation between hospitals for taking samples to be tested, getting blood for a transfusion, or transporting a patient between hospitals; 8) medical care at home; 9) more "caring" nurses and doctors; 10) psychological, physiotherapy, and spiritual support; 11) better initial understanding of the total cost of the hospital visit as well as the payment date; 12) free water supplied for patients and family caregivers; and 13) help caring for (i.e. washing) the patient.

Approximately half (48.9%) of family caregivers reported that the patient currently

receives psychological care. However, 13 of those patients were receiving psychological care from family members, not the hospital. Only 28.9% of family caregivers reported that the patient was currently receiving psychological care from medical staff at the hospital. In comparison, 95.6% reported that the patient would like to receive psychological care. Similarly, 62.2% reported that the patient currently receives spiritual care, but only 24.4% of those reported that the patient currently receives spiritual care in the hospital. One family caregiver said that her pastor tried to come pray with the patient, but it was not visiting hours, so he was not allowed into the hospital. Many of those with spiritual care in the hospital received it from a family member or religious church member visiting another patient in the hospital. Only one family caregiver reported their patient receiving spiritual support in the hospital directly from a religious figure. Almost all the family caregivers (97.8%) reported that the patient would like to receive spiritual care in the hospital. Only 13.3% of the family caregivers reported that the patient currently receives social care, and 91.1% reported that the patient would like to receive social care.

According to the family caregivers, 80% of the patients had no access to in-home medical care. Additional barriers to regular medical care include: 1) financial difficulties (77.8%), 2) lack of medical information provided to caregivers (62.2%), 3) difficulty getting medications (55.6%), and 4) difficulty traveling to or from the hospital (44.4%). Only 15.6% of family caregivers reported not understanding the doctor. However, interviewed caregivers may have interpreted this question as, "Do you understand the language *dialect* that the doctor speaks?" rather than understanding the *content* of their discussions with medical staff members.

When asked what they would like to have the capacity to provide for patients, the primary themes that emerged in the medical staff's qualitative responses included: 1) better

psychological care for patients and family members by training current staff and integrating a psychosocial support team, 2) improved pain management, 3) a ward designated for end of life patients, and 4) awareness campaigns for common preventable illnesses (i.e. stroke and cancer).

Internal Medicine physicians are necessary for treating end of life conditions according to 91.7% of medical staff responses. In addition, 83.3% of medical staff indicated that spiritual care, social services, and trained palliative specialists are necessary for meeting end of life needs; and 75% felt the same about physical therapists. In qualitative responses, the medical staff indicated that they felt the following were also necessary for meeting patient needs: the patient's family members, psychologists, family educators, and nurses.

One section of the iPOS survey, completed by medical staff members as a summary of each patient's condition, recorded the severity of various symptoms that must commonly be managed near the end of life. Each symptom's severity for the specified patient was recorded on a scale from 0 to 4 – 0 meaning that the symptom was absent and 4 meaning that the symptom severely impaired the patient's daily functioning or quality of life. Although some medical staff did not complete the assessment for every symptom, the data set was complete enough to calculate an average score for each symptom. These average score estimates are presented in Table 3 below. Of the surveyed symptoms, the most debilitating symptoms were poor mobility and weakness or lack of energy with average scores of 3.0 and 2.9, respectively. The least common or best managed symptoms were nausea and vomiting with average score estimates of 0.5 and 0.2, respectively. In the qualitative notes section of the survey, St. Luke physicians commonly listed "decline of mental status" as a severely debilitating symptom.

Table 3. Average scores (rated from 0-4, least to most severe) for common symptoms of patients near end of life.

Symptom (Scored 0-4, least to most debilitating)	**Average Score Estimate**	**N (data set size)**
Pain	1.3	22
Shortness of breath	1.7	38
Weakness or lack of energy	2.9	33
Nausea	0.5	29
Vomiting	0.2	38
Poor appetite	2.0	25
Constipation	1.2	37
Sore or dry mouth	1.3	23
Drowsiness	1.4	19
Poor mobility	3.0	39

Doctor-Patient and Family Member Communication

Approximately half of family caregivers (51.1%) accurately described the fundamental physical manifestations of the patient's diagnosis. Although some family caregivers could repeat the official medical language for the diagnosis (i.e. Ischemic Stroke), if they were unable to describe what that definition implied about the patient's condition (i.e. something is wrong in their head and is hurting them), they were categorized as not understanding the patient's diagnosis. Conversely, many family caregivers understood the physical condition of the patient but did not know the technical medical terminology. These caregivers were categorized as understanding the patient's diagnosis. No significant relationship was found between family

caregivers talking with a doctor about their goals for their family member's care in the past week and family caregiver understanding of the patient's diagnosis.

Regarding acquiring patient information, 80% of family caregivers reported receiving medical information about the patient's illness from the medical team at the hospital; 55.6% reported receiving information from a community or mobile clinic; and 51.1% reported receiving information from family members. No family caregivers reported receiving information from a traditional healer. However, in Haiti, seeking help from a traditional healer is often stigmatized. Especially when talking with a non-Haitian researcher, the family caregivers may have chosen not to disclose their interactions with traditional healers.

When answering questions about recovery expectations, 71.1% of family caregivers thought the patient would make a "full recovery without any disability," 11.1% thought the patient would recover with "limited disability," 8.9% thought the patient would recover with "severe disability," and 8.9% thought the patient would pass away.

Throughout the interviews, most family caregivers expressed belief in the patient's ability to recover. All patients enrolled in this study were classified by a St. Luke physician as being within six months of end of life. In contrast, 91.1% of interviewed family caregivers indicated that they believed their family member would recover. Qualitative responses regarding patient recovery had a clear, overarching religious theme. When asked who they most trusted to care for the patient, 60.0% of family caregivers placed the most trust in God while only 28.9% placed the most trust in medical doctors. Of the 32 qualitative responses recorded, 19 family caregivers mentioned God in their response, or 59.0%. A couple family caregiver responses include:

> "In the name of Jesus Christ, she will completely recover."
> "She's sure that he will be completely recovered because God and the

doctors are working together."

Common themes throughout the qualitative responses included God working miracles, the grace of God, God can heal anything, and that the patient's illness was a trial sent by God to make the patient stronger. Many family caregivers also shared stories of family members or friends that have had a healing dream or vision, miraculous recovery, or no pain because of God. While talking with a family member that was studying to be a lawyer, he paused before answering the question. Shifting in his seat and looking uncomfortable, he said, "Before I tell you my answer, I have to tell you a story." The story was about his mother having a dream from God right before a major surgery for cancer. His mother fully recovered. Therefore, he believed, "God is trying to tell my father something, but then my father will get completely better."

Low Capacity Concerns

In addition to medical care, 25.0% of medical staff members reported addressing psychological, spiritual, occupational, social, or emotional needs for their terminally ill patients.

In qualitative responses, the medical staff identified barriers preventing them from meeting patient needs. Throughout these responses, common themes include: 1) lack of appropriate medication or the patient cannot afford the necessary medications, 2) lack of trained medical staff, 3) not enough training for the medical staff regarding the psychological aspects of care, 4) economic limitations, 5) lack of education for the patient and family members, and 6) lack of psychologists. Only 25% of the medical staff members felt they had the necessary resources to manage life-threatening conditions. Regarding associated resources, 41.7% of the medical staff felt they had adequate preventative measures while only 8.3% felt the hospital had adequate diagnostic tools and testing capabilities.

Pain, nausea and vomiting, lethargy, and challenge breathing are four of the most common end of life symptoms that medical practitioners must manage. One of the primary goals of palliative care is to provide as much symptom management as possible to relieve suffering near the end of life. Most of the medical staff members (83.3%) felt they had sufficient medication to manage patient nausea and vomiting; half (50%) indicated sufficient medication for managing patient pain and weakness, or lack of energy; and only about one-third (36.4%) felt they had the medications necessary to manage shortness of breath.

Role of Family Caregiver

Survey results show that 64.4% of family caregivers would prefer the patient receive future treatment at home rather than in the hospital. For those family caregivers that reported they would like the patient to continue receiving care in the hospital, the most common reason for their decision was the belief that the hospital provided better care than could be provided at home.

Regarding inpatient support, 71.1% of family caregivers reported remaining in the hospital with the patient for the entire duration of their hospital stay, providing critical daily care for their family member during that time. An additional 20.0% of caregivers were in the hospital with the patient multiple times per week.

Interdisciplinary Palliative Care Team and Care Networks

End of life care involves a diverse array of needs that extend beyond the patient and the hospital. When asked about their primary concern while the patient was in the hospital, common themes in family caregiver responses include: the patient's suffering, the future for children left

behind by the death of an only parent or family breadwinner, worried about caring for a physically or mentally impaired family member at home if the patient recovers, financial concerns for when the patient is released and full payment is due, worry that the patient may die, and worry about the patient's declining health with no explanation for it. A few quotes from the family caregivers include:

> "[The patient] has two daughters of her own with no one to help her. [The patient's] sister is currently taking care of the kids, but that is not a long-term solution."
>
> "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."

When asked about hospital resource connections, one-third of the medical staff (33.3%) indicated that St. Luke was connected with other international non-governmental organizations (NGOs) and other hospitals. Only 8.3% of medical staff indicated the hospital was connected to community health clinics, government programs, and local organizations. Palliative care services are an interdisciplinary, broad ranging endeavor that requires resource sharing and partnerships. These low estimations of hospital connectedness indicate that many medical staff may not be aware of St. Luke's potential resource connections for treating patients near the end of life.

One-fourth of the medical staff (25%) indicated that medical treatment extends beyond the hospital for terminally ill patients. Common reasons provided for care not being able to extend beyond the hospital included nurses being unable to make home visits and the patient's

family being unable to afford necessary medications. Medical staff that reported medical care extending beyond the hospital referenced the psychological, spiritual, and social support that the patient's family provides, longer-term treatments for illnesses such as HIV and TB, and the support provided by social services.

According to family caregivers, 77.8% of patients received regular healthcare from family members, 73.3% from a hospital, and 55.6% from a community or mobile clinic. 15.6% of caregivers reported that the patient only received regular medical care from family members or received no regular medical care.

Internal Staff Communication

Only 36.4% of the medical staff members were satisfied with the care that they provide patients. Similar themes as discussed earlier emerged in the open-ended expansion of this question. A couple of medical staff quotes include:

> "We don't have 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."

Chapter 7. Topics to Facilitate Palliative Care Development Strategy Conversations

This chapter is intended to help the St. Luke Hospital team prepare for decision-making regarding palliative care development via intra-organizational dialogue. The following questions apply specifically to the service provision population of patients and family caregivers of patients near the end of life. Initially, the following question structure is intended to facilitate internal hospital discussion of relevant topics to begin program development efforts. The multi-question format may be used to guide a palliative care discussion group through the identified topics.

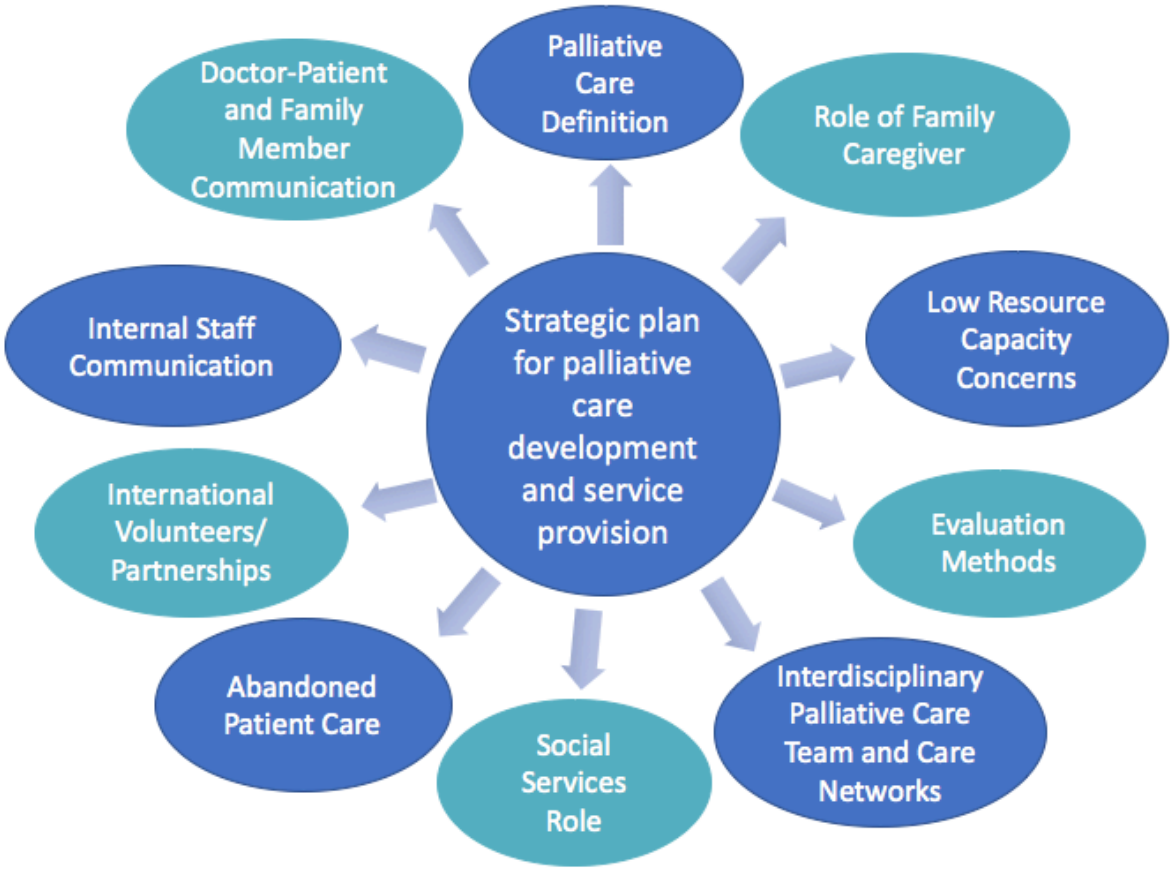


Diagram 2. Topics to facilitate palliative care development strategy conversations.

Some questions may be deemed irrelevant for the care environment and other questions may need to be added. This research was completed by an international student in a short duration. The St. Luke Hospital staff have a much more encompassing and informed understanding of the medical care environment that this research examined, and any interventions should be tailored accordingly.

If St. Luke decides to move forward as a palliative care champion in Haiti, these questions may also guide future community partnership conversations. The conversational objective would be to establish agreed upon terminology and guidelines surrounding these topic categories. This agreement of definitions and basic policy statements can be used to design a collaborative palliative care strategic plan for Haiti and identify initial targets for establishing infrastructure and capacity for palliative care services.

Discussion topic categories and associated questions:

Palliative Care Definition

- How is quality of life near the end of life defined for St. Luke Hospital? How is quality of life near the end of life defined for the surrounding community? How is quality of life near the end of life defined for Haiti?
- What is the definition of palliative care for St. Luke Hospital? What is the definition of palliative care for the surrounding community? What is the definition of palliative care for Haiti?
- What value does palliative care add when providing care for patients near the end of life?
- What should the priority be for this patient population in St. Luke Hospital?
- What are essential components for a palliative care service?

- How should this list of service components be prioritized based on community needs, current capacity, and available resources?
- What should be the role of palliative care in St. Luke Hospital? What should be the role of palliative care in the surrounding community? What should be the role of palliative care in the Haitian medical system?
- How will individual patient palliative care needs be identified in St. Luke Hospital?

Doctor-Patient and Family Member Communication

- What value does doctor-patient communication provide? What value does doctor-family member communication provide?
- What are frequently raised concerns during doctor-patient conversations? What concerns are frequently raised during doctor-family member conversations?
- What are best practices for responding to these concerns?
- What are useful methods for structuring doctor-patient conversations? What are useful methods for structuring doctor-family member conversations?
- What are the desired outcomes of doctor-patient communication? What are the desired outcomes of doctor-family member communication?
- What are minimum standard outcomes to achieve in doctor-patient communication? What are minimum standard outcomes to achieve in doctor-family member communication?
- Should medical staff members prioritize speaking directly with the patient about their diagnosis and treatment regimen?

Low Resource Capacity Concerns

- What is the role of diagnostic tools within end of life patient care?
- What is the role of preventative measures within end of life patient care?
- How can we leverage intra-country partnerships to establish a network of Haitian health providers that will be involved with palliative care development?
- How is the needed care for emergency patients different from or similar to the care needed by this patient population?
- Should this patient population be in the continuous emergency care environment?
- To consolidate resources targeted toward this patient population, should the hospital create a specific palliative care ward?

Role of Family Caregiver

- What services do family caregivers currently provide?
- What should be the role of family caregivers in palliative care?
- How can we support family caregivers in this role?
- How can we encourage family caregiver self-care?
- Should the hospital support family care at home, potentially through an in-home community worker program?
- Should the family caregiver staying in the hospital with the patient be included in all medically-related conversations?
- How will the training and information provided to the in-hospital family caregiver effect the efficiency of care provision?

- How can in-hospital family caregiver training be incorporated into the evaluation of palliative care services at St. Luke Hospital?

Interdisciplinary Palliative Care Team and Care Networks

- What personnel specialties are needed for an in-patient palliative care team? What personnel specialties are needed for a community-level palliative care team?
- How should this list of specialties for an in-patient palliative care team be prioritized based on current capacity and available resources? How should this list of specialties for a community-level palliative care team be prioritized based on community needs?
- St. Luke Hospital staff can currently provide which of the specialties needed for an in-patient palliative care team? St. Luke Hospital staff can currently provide which of the specialties needed for a community-level palliative care team?
- Which of the specialties needed for an in-patient palliative care team can St. Luke access through community partnership building? Which of the specialties needed for a community-level palliative care team can St. Luke access through community partnership building?

International Volunteers/Partnerships

- What is the current role of international volunteers in patient care at St. Luke Hospital? What is the current role of international volunteers in patient care in the surrounding community?
- Based on previous discussion, what specialty skills need to be accessed through international partnership building to move forward with palliative care development?

- How can international partnerships and volunteer specialties be effectively utilized for maximum benefit?
- What is cultural competency in the context of St. Luke Hospital and this patient population? What is cultural competency in the context of Haiti and this patient population?
- How can the hospital ensure the cultural competency of international volunteers?

Abandoned Patient Care

- Why are patients abandoned at St. Luke Hospital? Why are patients abandoned in the surrounding community?
- How can palliative care services address these reasons for abandonment?
- How can palliative care services improve inpatient care for abandoned patients?
- How can palliative care services decrease the burden abandoned patients place on hospital resources?

Social Services Role

- What services does social services currently provide?
- What role does social services have in palliative care provision and development at St. Luke Hospital?
- How should social services be expanded in the palliative care development process?

Internal Staff Communication

- What is the existing authority hierarchy of medical staff in St. Luke Hospital?
- How is information currently passed between staff members at different hierarchy levels?

- What processes should be implemented to better ensure communication consistency and accuracy between staff members to facilitate the interdisciplinary teamwork needed to address patient needs?
- What processes should be implemented to ensure development and planning team members represent diverse perspectives? What processes should be implemented to ensure palliative care service provision team members represent diverse perspectives?
- Which hospital staff members should be involved in palliative care development and strategic planning? Which hospital staff members should be involved in palliative care service provision?
- What value can open and honest staff dialogue add to palliative care development and service provision in St. Luke Hospital?
- How can open and honest staff dialogue be facilitated in St. Luke Hospital to encourage feedback on palliative care development and implementation?
- How can St. Luke Hospital provide support for their staff members working with this patient population?

Evaluation Methods

- What is the importance of evaluation in palliative care development and service provision?
- What specific programmatic components need to be evaluated?
- How should these component evaluations be prioritized?
- What methods should be used for evaluating each component?
- How should evaluation results be utilized?

These questions are meant to encourage critical dialogue on a few key palliative care strategic topics and are intended to inspire development of additional questions through a structured planning process. Discussion results can be used to formulate pieces of the strategic plan including a working definition of "palliative care," long-term and short-term palliative care mission statements; and service provision approach – clinic-level or community-level. This is groundbreaking work that can provide a foundation to establish a unified understanding of palliative care within the hospital and build collaborative partnerships beyond the hospital walls.

Chapter 8. Conclusions

Currently in the capacity building stage of palliative care development, Haiti will require a focused effort to transition to palliative care service provision. Due to the decentralized structure of existing medical services in Haiti, initial palliative care development will most likely be unsuccessful at a national level. However, a concerted effort to progress development may be successful on either the hospital or community level. At the commencement of this research, St. Luke Hospital administrators expressed interest in providing palliative care services within the hospital setting. This thesis provides basic needs assessment data, identifies existing hospital capacities, and suggests question topics to be discussed with the palliative care development team. These study data and the associated thematic analysis are intended to help St. Luke Hospital administrators make evidence-based decisions regarding the hospital's involvement in future palliative care development.

St. Luke Hospital has multiple existing capacities that could be leveraged to initiate successful hospital-level service provision. The most fundamental of these capacities is the trust that St. Luke patients have in the care provided at the Hospital, as demonstrated by the qualitative patient and family caregiver survey data. This underlying trust in the hospital will allow St. Luke more leeway during program development and implementation. The patients and their family members feel confident that St. Luke has their best interests at heart, so fewer resources will be required to acquire patient and family member support for palliative care programming. A second crucial capacity is the reported interest St. Luke staff members have in providing palliative care services. Medical staff and supplemental collaborators invested in developing palliative care programming will facilitate program design and implementation,

provide guaranteed personnel support for related efforts, and make it easier to acquire constructive feedback throughout the process. Similarly, the staff members' interest in increasing and diversifying their continued education training will allow administrators to use palliative care development to directly respond to a need identified by trusted Hospital employees.

As exemplified by international case studies, specialty expertise is critical to successful development efforts. St. Luke is uniquely positioned for program development because the Hospital has an established relationship with a United States palliative care physician, Dr. Nicole Shirilla, interested in supporting program development. In addition, a Haitian physician in the surrounding community was recently trained in Uganda by Hospice Africa Uganda, a leading international palliative care educational facility. Both partners will be invaluable in establishing palliative care services.

Although medical services remain decentralized, reliance on patient family members for caregiving support is a unifying feature of Haitian healthcare, exemplified by the role of family caregivers at St. Luke Hospital. Although this presents a large burden for patient family members, this care model has the potential to streamline the Hospital's transition to palliative care service provision. Developed programming can leverage this foundational structure to empower family caregivers rather than placing additional patient care burden on limited medical staff resources. As mentioned by multiple medical staff in their qualitative survey responses, this family-based care environment also allows patients to be surrounded by the social, psychological, and spiritual support of their loved ones.

Many research participants reported interacting with religious and supplemental health resources in their communities. Most patients and family caregivers self-identified as affiliated with a denomination of Christianity. Although many Christian denominations were represented,

observational notes and family qualitative responses suggest that Haitians identifying as Christian welcome religious support from individuals affiliated with a diverse array of denominations. This inherent religious unity enables the Hospital to improve spiritual care for patients and family members with minimal resources. Given participant responses, the spiritual aspect of service provision will be an essential component in any palliative care program implemented at St. Luke. In addition, this population characteristic provides the opportunity to involve community religious leaders and organization staff members in the care resource network. The data also show that more than half of the patients received regular healthcare from community or mobile clinics. These local health centers caring for intersecting patient populations may act as collaborative palliative care partners – presenting a first contact point for patients and potentially providing community-based family caregiver support.

Initial conversations regarding St. Luke's future involvement in palliative care efforts must establish a standard operating definition of palliative care, ensure all appropriate staff members have a common understanding of this definition, examine the role and importance of providing palliative care at the hospital and community levels, and evaluate the Hospital's existing capacity to support palliative care development and service provision. If St. Luke administrators decide to develop palliative care services at the hospital, a palliative care development team should create a strategic plan for progressing palliative care service provision, community partnerships, and international partnerships. All levels of St. Luke staff working with patients should be involved in these discussions.

The long-term goal for palliative care development in Haiti is to build a national health infrastructure through which resources are coordinated and provided equitably. However, a more feasible development model may begin at the community level. Hospitals such as St. Luke

simply do not have the necessary space or resources to provide inpatient care for every patient near the end of life in Haiti. Due to the limited space and staff resources in medical centers, family caregivers already provide critical care in the Haitian medical system. Palliative care service provision, especially outpatient or in-home services building on the family-based care model already prevalent in Haiti, may offer an approach for decreasing the burden this patient population places on Haitian health centers while improving patient quality of life before death. As illustrated by the palliative care model in India, community-level development may be possible through the collaboration and dedication of a palliative care champion, community health leaders, and national and international partners providing required specific expertise.

Although the hospital-level program St. Luke was initially considering may be successful, there is greater opportunity for infrastructure building and broader service provision if the Hospital were to progress as leaders of a community-level initiative. If St. Luke decides to become a palliative care champion, the Hospital's role in the development and implementation of palliative care services in Port-a-Prince will not be directly aimed at changing policy, government infrastructure, or public health services. However, the community leaders involved in this palliative care conversation must have a cohesive long-term vision for establishing a nationwide palliative care system and health network. This vision will help unite the efforts of various partner organizations toward a common goal. The St. Luke palliative care development team should begin conversations with government leaders, specifically the Ministry of Health, as early in the program development process as possible. Even if the government is not initially involved directly in model development, the team should notify and attempt to create a working partnership with the government early in the initiative to foster dialogue and communication on the national level. When future research data become available, this will facilitate easier

initiation of result dissemination and national discussion. This will hopefully also maintain the future possibility of developing an overarching national palliative care infrastructure.

However, national-level development will likely only occur after successful implementation of a community-level intervention. Thus, the palliative care development team should work together to design a strategic plan and implementation steps for a community-specific palliative care program. This program may then be used as an intra-country palliative care model, illustrating the efficacy of palliative care in Haiti via program evaluation and analysis. A committee should be assembled to discuss palliative care-specific symptom definitions, the burden of each symptom on patients in the considered community, existing resources available at the community level for symptom management, and standardization of symptom management procedures. In addition, the committee must create evaluation measures, quantitative and qualitative symptom management goals, procedures for identifying patient and family caregiver needs and values, and strategies for addressing individual patient quality of life planning. These efforts will provide an intra-country case study to facilitate Haiti's eventual progression toward fulfilling the WHO human right directive by moving the country from a capacity building status to a palliative care service provider status. If St. Luke decides to become a palliative care champion, the Hospital staff and overarching organization will spearhead advancement of Haiti's end of life care services and begin providing opportunities to improve the quality of life for thousands of patients and family caregivers.

Appendix A. Survey Research Tools – English Versions

Appendix A1 – Patient Critical Care Survey

Patient Demographic Form:

Gender: Male / Female Age: _____

Married / Divorced / Single / Living with a significant other / Widowed

Nationality: _____

Have you always lived in Haiti? Yes / No

If no, where else have you lived? _____

What level of school have you finished? _____

Do you identify with a religion? Yes / No

If yes, which religion? _____

Who in your family helps you make medical decisions? _____

How long have you been receiving care for your current illness? _____

How long have you been in the hospital? _____

a. 1 day
b. A few days
c. A week
d. More than a week

Patient Critical Care Survey

Instructions: Please listen and respond to the following questions.

Multiple Choice:

1. Where do you get health information about your illness? (Respond as a "Yes" or "No" to each of the following)
    a. Your medical team at the hospital Yes / No
    b. Community or mobile clinics Yes / No
    c. Physical or occupational therapists Yes / No
    d. Family members Yes / No
    e. Traditional healer Yes / No
    f. Internet and websites Yes / No
    g. Radio or television Yes / No
    h. Social services or worker Yes / No
    i. Other: _____

2. Do you get regular medical care from any of the following sources? (Respond as a "Yes" or "No" to each of the following)
    a. Hospital
    b. Community or mobile clinics Yes / No
    c. Physical or occupational therapists Yes / No
    d. Family members Yes / No
    e. Traditional healer Yes / No
    f. Other: _____

3. What is your diagnosis?
    a. _____
    b. I am not sure

4. Have you talked with your doctor or nurse in the past week about your goals and wishes for your health care?
    a. Yes
    b. No

5. Have you received the following types of care: (Respond as a "Yes" or "No" to each of the following)
    a. Physical: Yes / No
    b. Psychological: Yes / No
    c. Occupational: Yes / No
    d. Spiritual: Yes / No
    e. Social: Yes / No

6. Would you like to receive the following types of care: (Respond as a "Yes" or "No" to each of the following)
    a. Physical: Yes / No
    b. Psychological: Yes / No
    c. Occupational: Yes / No
    d. Spiritual: Yes / No
    e. Social: Yes / No

7. Have any of the following stopped you from getting medical care: (Respond as a "Yes" or "No" to each of the following)
    a. Difficulty traveling to or from the hospital or health clinic: Yes / No
    b. Difficulty getting medications: Yes / No
    c. Not understanding your doctor or nurse: Yes / No
    d. Financial difficulties: Yes / No
    e. In-home medical care is not available: Yes / No
    f. Lack of information: Yes / No

8. Have any of the following helped you access medical care: (Respond as a "Yes" or "No" to each of the following)
    a. Traveling to or from the hospital or health clinic: Yes / No
    b. Having good access to medications: Yes / No
    c. Understanding your doctor or nurse: Yes / No
    d. Financial support: Yes / No
    e. In-home medical care is available: Yes / No
    f. Adequate information: Yes / No

9. In addition to your current medical care, is there anything else that you would like the hospital to do or provide for you?
    a. Yes
    b. No

If yes, please explain what else you would like:

10. While you are being treated in the hospital, what are your main concerns?

11. Have any practical problems resulting from your illness been addressed (such as financial or personal)?
    a. Yes
    b. No
    c. Other: _____

12. With this illness, who do you trust the most to treat you?
    a. Medical doctor
    b. Traditional Healer
    c. Religious leader – pastor or priest
    d. Other: _____

13. How often do you experience pain?
    a. All the time
    b. Multiple times a day
    c. Once a day
    d. A couple times a week
    e. Once in a while
    f. Never

14. Would you prefer to live at home and receive medical care at home or live at the hospital and receive medical care at the hospital?
    a. At home
    b. At hospital

15. What do you expect your recovery will be?
    a. Full recovery without any disability
    b. Limited disability
    c. Severe disability
    d. Death

Appendix A2 – Family Member Critical Care Survey

Family Member Demographic Form:

Gender: Male / Female Age: _____

Married / Divorced / Single / Living with a significant other / Widowed

Nationality: _____

Have you always lived in Haiti? Yes / No

If no, where else have you lived? _____

What level of school have you finished? _____

Do you have a religion? Yes / No

If yes, which religion do you follow? _____

Do you help your family member with medical decisions? _____

How often are you in the hospital with your family member who is sick? _____
(Choose one response.)

a. Every visit
b. A few times per week
c. Once a week
d. Occasionally
e. Rarely

How are you related to the patient? _____

Family Member Critical Care Survey

Instructions: Please listen and respond to the following questions.

Prompt: The following questions are only about your family member currently in the hospital with an illness.

Multiple Choice:

1. Where do you get health information about your family member's illness? (Respond as a "Yes" or "No" to each of the following)
    a. Your medical team at the hospital Yes / No
    b. Community or mobile clinics Yes / No
    c. Physical or occupational therapists Yes / No
    d. Family members Yes / No
    e. Traditional healer Yes / No
    f. Internet and websites Yes / No
    g. Radio or television Yes / No
    h. Social worker Yes / No
    i. Other: _____

2. Does your family member get regular medical care from any of the following sources: (Respond as a "Yes" or "No" to each of the following)
    a. Hospital
    b. Community or mobile clinics Yes / No
    c. Physical or occupational therapists Yes / No
    d. Family members Yes / No
    e. Traditional healer Yes / No
    f. Other: _____

3. What is your family member's medical diagnosis?
    a. _____
    b. I am not sure

4. Have you talked with a doctor or nurse in the past week about your goals and wishes for your family member's health care?
    a. Yes
    b. No

5. Does your family member get these types of care? (Respond as a "Yes" or "No" to each of the following)
    a. Physical: Yes / No
    b. Psychological: Yes / No
    c. Occupational: Yes / No
    d. Spiritual: Yes / No
    e. Social: Yes / No

6. Do you think your family member would like to get these types of care in the hospital? (Respond as a "Yes" or "No" to each of the following)
    a. Physical: Yes / No
    b. Psychological: Yes / No
    c. Occupational: Yes / No
    d. Spiritual: Yes / No
    e. Social: Yes / No

7. Have any of the following stopped you from getting your family member medical care? (Respond as a "Yes" or "No" to each of the following)
    a. Difficulty traveling to or from the hospital or health clinic: Yes / No
    b. Difficulty getting medications: Yes / No
    c. Not understanding your doctor or nurse: Yes / No
    d. Financial difficulties: Yes / No
    e. In-home medical care is not available: Yes / No
    f. Lack of information: Yes / No

8. Have any of the following helped you get your family member medical care? (Respond as a "Yes" or "No" to each of the following)
    a. Traveling to or from the hospital or health clinic: Yes / No
    b. Having good access to medications: Yes / No
    c. Understanding your doctor or nurse: Yes / No
    d. Financial support: Yes / No
    e. In-home medical care is available: Yes / No
    f. Adequate information: Yes / No

9. Is there anything else that you would like the hospital to do or provide for you?
    a. Yes
    b. No

If yes, please explain what else you would like:

10. What are your main concerns given your family member's current condition?

11. Have any practical problems resulting from your family member's illness been addressed (such as financial or personal)?
    a. Yes
    b. No
    c. Other: _____

12. In the treatment of your family member's illness, whom do you trust the most?
    a. Doctor
    b. Traditional healers
    c. Religious leaders – pastor or priest
    d. Other: _____

13. Would you prefer to stay at your house and receive your family member's medical care in your house or stay at the hospital and receive their medical care there?
    a. In your house
    b. In the hospital

14. What do you expect your family member's recovery will be?
    a. Full recovery without any disability
    b. Limited disability
    c. Severe disability
    d. Death

Appendix A3 – Medical Staff Critical Care Survey

Staff Demographic Form:

Gender: Male / Female Age: _____

Medical Specialty: _____ Nationality: _____

Have you always lived in Haiti? Yes / No

If no, where else have you lived? _____

Where did you attend medical school? _____

How long have you been practicing medicine? _____

How long have you worked with your current Hospital? _____

What, if any, religion do you identify with? _____

How often do you work with patients with chronic, life-threatening conditions?

a. All the time
b. Often
c. Sometimes
d. Never

Staff Critical Care Survey

Instructions: Please read through the following questions and respond based on your individual experience and opinions. There are no "incorrect" responses.

Prompt: These questions relate only to your patients with a terminal prognosis that may be life threatening within next 6 months.

Multiple Choice:

1. Do you feel that you have the resources necessary to manage your patients' life-threatening condition?
    a. Yes
    b. No

Please explain why or why not:

2. Do you feel that you have sufficient medication to address the following symptoms at the end of life? (Circle either "Yes" or "No" for each symptom)
    a. Pain Yes / No
    b. Shortness of breath Yes / No
    c. Weakness or lack of energy Yes / No
    d. Nausea and vomiting Yes / No

3. Circle all of the following human resources that are necessary for managing a patient's end of life needs:
    a. Internal Medicine Physicians
    b. Spiritual care/clergy to visit patients in the hospital
    c. Social work/social services
    d. Trained palliative specialists
    e. Physical therapists
    f. Other: _____

4. Are you connected with any other community resources to help support terminally ill patients and their families? Please circle all that apply:
    a. International NGOs
    b. Hospitals
    c. Community health clinic
    d. Government programs
    e. Local organizations
    f. Other: _____

5. Do treatments available to terminally ill patients currently extend beyond the hospital setting (for example family training for home care, referral to further support, or home therapy regimen)?
    a. Yes
    b. No

Please explain why or why not:

6. In addition to physical needs, do you address any of the following needs for terminally ill patients or their family members: psychological, spiritual, occupational, social, or emotional?
    a. Yes
    b. No

If yes, please explain how you do so:

If no, is there anything that you could be given that would encourage you to incorporate these non-physical needs into your patient care? (i.e. time, training, private space, a specific professional trained to handle these needs, etc.)

7. Do you feel that you have adequate preventative care for your patients?
    a. Yes
    b. No

Please explain why or why not:

8. Do you feel that you have adequate diagnostic tools that allowed for early identification of treatable stages of your patients' terminal illnesses?
    a. Yes
    b. No

Please explain why or why not:

9. Are you satisfied with the care that you are able to provide your patients?
    a. Yes
    b. No

Please explain why or why not:

Short Response:

10. What do you wish you could do differently for your patients with terminal illnesses?

11. What are the main barriers keeping you from meeting all of the needs of your terminally ill patients?

12. In your words, what is palliative care? What role should it have in Haitian healthcare?

13. Does your hospital provide palliative care to patients? If yes, how? If not, why not?

Appendix A4 – Integrated Palliative Care Outcome Scale (iPOS) Staff Version (3 Day)

IPOS Staff Version

Patient name : .....

Patient number : .....

Date (dd/mm/yyyy) : .....

Q1. What have been the patient's main problems or concerns <u>over the past 3 days?</u>

1.
.....
2.
.....
3.
.....

Q2. Please tick <u>one box</u> that best describes how the patient has been <u>affected</u> by each of the following symptoms <u>over the past 3 days</u>?

	Not at all	Slightly	Moderately	Severely	Over-whelmingly	Cannot asses (e.g. unconscious
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Please list any <u>other</u> symptoms and tick <u>one box</u> to show how you feel each of these symptoms has <u>affected</u> the patient <u>over the past 3 days</u>.						
1.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
2.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
3.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Over the past 3 days:

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*	*Cannot assess (e.g. unconscious)*
Q3. Has s/he been feeling worried about his/her illness or treatment?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q4. Have any of his/her family or friends been anxious or worried about the patient?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q5. Do you think s/he felt depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
	Always	*Most of the time*	*Sometimes*	*Occasionally*	*Not at all*	*Cannot assess (e.g. unconscious)*
Q6. Do you think s/he has felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as much as s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Q8. Has the patient had as much information s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
	Problems addressed/ No problems	*Problems mostly addressed*	*Problems partly addressed*	*Problems hardly addressed*	*Problems not addressed*	*Cannot assess (e.g. unconscious)*
Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Appendix B. Survey Research Tools – Haitian Kreyol and French Versions

Appendix B1 – Patient Critical Care Survey (Kreyol)

Fòm Pasyan Demografik:

Sèx: Gason / Fam Laj: _____

Marye / Divose / Selibatè / Plase / Vèv

Nasyonalite: _____

Eske ou toujou ap viv an Ayiti? Wi / Non

Si non, ki lòt kote oute viv? _____

Nan ki nivo lekòl ou te rive? _____

Èske ou gen yon relijyon? _____

Si wi, ki relijyon? _____

Kiyes moun nan fanmi ou ki ede ou pran desizyon pou vin lopital? _____

Depi konbyen tan w ap pran swen pou maladi sa? _____

Depi konbyen tan ou nan lopital la? _____

a. 1 jou
b. Kelke jou
c. 1 semèn
d. Plis ke 1 semèn

Konbyen mwa w ap suiv tretman kansè nan program sa a? _____

a. Mwens ke 1 mwa
b. 1-3 mwa
c. Plis ke 3 mwa

Patient Critical Care Survey

Enstriksyon: Tanpri koute epi reponn a kesyon sa yo.

1. Ki kote ou jwenn enfòmasyon sou maladi ou a? (Reponn "Wi " oswa "Non" nan pou chak repons sa yo)
    a. Doktè yo avek enfimyè yo nan lopital ou Wi / Non
    b. Kominote oubyen klinik mobil Wi / Non
    c. Moun ki bay sèvis fizyoterapi Wi / Non
    d. Manm fanmi yo Wi / Non
    e. Bòkò oubyen ougan Wi / Non
    f. Intènèt ak sit wèb Wi / Non
    g. Radyo oubyen televizyon Wi / Non
    h. Lòt akonpayatè Wi / Non
    i. Lòt yo: _____
2. Èske ou jwenn swen medikal regilyèman nan men nenpòt nan sous sa yo: (Reponn "Wi " oswa "Non" nan pou chak repons sa yo)
    a. Lopital ou Wi / Non
    b. Kominote oubyen klinik mobil Wi / Non
    c. Moun ki bay sèvis fizyoterapi Wi / Non
    d. Manm Fanmi yo Wi / Non
    e. Bòkò oubyen ougan Wi / Non
    f. Lòt yo: _____
3. Ki sa rezilta akzamen ou te revele?
    a. _____
    b. Mwen pa konnen
4. Èske ou te pale ak doktè w oswa enfimyè nan semèn ki sot pase ya sou objektif ou ak volonte ou pou swen sante ou?
    a. Wi
    b. Non
5. Èske ou jwenn kalite swen sa yo: (Reponn "Wi " oswa "Non" nan pou chak repons sa yo)
    a. Swen doktè: Wi / Non
    b. Swen sikoloji: Wi / Non
    c. Eske yon moun te ede ou adapte maladi a ak travay ou: Wi / Non
    d. Sipò spirityel: Wi / Non
    e. Sipò sosyal: Wi / Non

6. Èske ou panse ou ta renmen jwenn kalite swen sa yo nan lopital la? (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Swen doktè: Wi / Non
    b. Swen sikoloji: Wi / Non
    c. Yon moun te ede ou adapte maladi a ak travay ou: Wi / Non
    d. Sipò spirityel: Wi / Non
    e. Sipò sosyal: Wi / Non

7. Ki repons nan lis la ki fe ou kapab jwenn swen medikal? (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Ale nan lopital oubyen klinik mobil defisil: Wi / Non
    b. Difikilte pou jwenn medikaman: Wi / Non
    c. Pa konprann lang doktè ak enfimyè pale: Wi / Non
    d. Pwoblèm finansyè: Wi / Non
    e. Ou pa jwenn swen medikal la kay ou: Wi / Non
    f. Mank enfòmasyon: Wi / Non

8. Ki repons nan lis la te ede ou jwenn swen medikal? (Reponn "Wi " oswa "Non" nan pou chak repons sa yo)
    a. Ale nan lopital oubyen klinik mobil: Wi / Non
    b. Jwenn bon medikaman: Wi / Non
    c. Konprann lang doktè ak enfimyè pale: Wi / Non
    d. Sipò finansye: Wi / Non
    e. Ou jwenn swen medikal la kay ou: Wi / Non
    f. Jwenn bon jan enfòmasyon: Wi / Non

9. Aprè swen medikal, èske gen lòt sipò ou ta renmen benefisye nan lopital la oubyen program kansè?
    a. Wi
    b. Non

Si wi, tanpri eksplike ki lòt bagay ou ta renmen:

10. Pandan ou te ap trete nan lopital la, ki sa ki enkyetid prensipal ou?

11. Èske nenpòt pwoblèm pratik te koze pa maladi ou te adrese (tankou finansyè oswa pèsonèl)?
    a. Wi
    b. Non
    c. Lòt yo: _____

12. Nan tretman maladi ou, ki moun ou fè pi plis konfyans?
    a. Doktè
    b. Bòkò oubyen ougan
    c. Lidè relijye - pastè oswa pè
    d. Lòt yo: _____

13. Konbyen fwa ou gen doulè pandan ou malad la?
    a. Tout tan
    b. Anpil fwa nan yon jounen
    c. 1 fwa nan yon jounen
    d. Kelke fwa yon semen
    e. Yon fwa nan yon ti tan
    f. Jamè

14. Èske ou ta renmen rete la kay ou pou pran swen medikal oswa entène nan lopital?
    a. La kay
    b. Nan lopital

15. Kijan ou pense w ap ye aprè tretman an?
    a. Trete net
    b. Pa gen trop andikap
    c. Gwo andikap
    d. Lanmò

Appendix B2 – Family Critical Care Survey (Kreyol)

Fòm Demografik Manm Fanmi:

Sèx: Gason / Fam Laj: _____

Marye / Divose / Selibatè / Plase / Vèv

Nasyonalite: _____

Eske ou toujou ap viv an Ayiti? Wi / Non

Si non, ki lòt kote oute viv? _____

Nan ki nivo lekòl ou te rive? _____

Èske ou gen yon relijyon? _____

Si wi, ki relijyon? _____

Èske ou ede manm fanmi ou pran desizyon medikal? _____

Konbyen fwa ou vini lopital ak fanmi ou ki malad? _____
(Chwazi yon nan repons sa yo.)

a. Tout vizit yo
b. Kèk fwa
c. 1 fwa nan semèn
d. Yon le konsa
e. Raman

Ki relasyon ou a pasyan an? _____

Family Member Critical Care Survey

Enstriksyon: Tanpri koute epi reponn a kesyon sa yo.

Èd memwa: Kesyon sa yo se sou manm fanmi ou kounye a nan lopital la ak yon maladi.

1. Ki kote ou jwenn enfòmasyon sou maladi manm fanmi ou a? (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Doktè yo avek enfimyè yo nan lopital ou Wi / Non
    b. Kominote oubyen klinik mobil Wi / Non
    c. Moun ki bay sèvis fizyoterapi Wi / Non
    d. Manm fanmi yo Wi / Non
    e. Bòkò oubyen ougan Wi / Non
    f. Intènèt ak sit wèb Wi / Non
    g. Radyo oubyen televizyon Wi / Non
    h. Lòt akonpayatè Wi / Non
    i. Lòt yo: _____

2. Èske manm fanmi ou jwenn swen medikal regilyèman nan men nenpòt nan sous sa yo: (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Lopital ou Wi / Non
    b. Kominote oubyen klinik mobil Wi / Non
    c. Moun ki bay sèvis fizyoterapi Wi / Non
    d. Manm Fanmi yo Wi / Non
    e. Bòkò oubyen ougan Wi / Non
    f. Lòt yo: _____

3. Ki sa rezilta akzamen manm fanmi ou te revele?
    a. _____
    b. Mwen pa konnen

4. Èske ou te pale ak doktè w oswa enfimyè nan semèn ki sot pase ya sou objektif ou ak volonte ou pou swen santé manm fanmi ou?
    a. Wi
    b. Non

5. Èske manm fanmi ou jwenn kalite swen sa yo? (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Swen doktè: Wi / Non
    b. Swen sikoloji: Wi / Non
    c. Eske yon moun te ede ou adapte maladi a ak travay ou: Wi / Non
    d. Sipò spirityel: Wi / Non
    e. Sipò sosyal: Wi / Non

6. Èske ou panse manm fanmi ou ta renmen jwenn kalite swen sa yo nan lopital la? (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Swen doktè: Wi / Non
    b. Swen sikoloji: Wi / Non
    c. Eske yon moun te ede ou adapte maladi a ak travay ou: Wi / Non
    d. Sipò spirityel: Wi / Non
    e. Sipò sosyal: Wi / Non

7. Ki repons nan lis la ki fe ou pa kapab jwenn swen medikal pou manm fanmi ou? (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Ale nan lopital oubyen klinik mobil defisil: Wi / Non
    b. Difikilte pou jwenn medikaman: Wi / Non
    c. Pa konprann lang doktè ak enfimyè pale: Wi / Non
    d. Pwoblèm finansyè: Wi / Non
    e. Ou pa jwenn swen medikal la kay ou: Wi / Non
    f. Mank enfòmasyon: Wi / Non

8. Ki repons nan lis la te ede ou jwenn swen medikal pou manm fanmi ou? (Reponn "Wi" oswa "Non" nan pou chak repons sa yo)
    a. Ale nan lopital oubyen klinik mobil: Wi / Non
    b. Jwenn bon medikaman: Wi / Non
    c. Konprann lang doktè ak enfimyè pale: Wi / Non
    d. Sipò finansye: Wi / Non
    e. Ou jwenn swen medikal la kay ou: Wi / Non
    f. Jwenn bon jan enfòmasyon: Wi / Non

9. Èske gen lòt sipò ou ta renmen benefisye nan lopital la oubyen program kansè?
    a. Wi
    b. Non

Si wi, tanpri eksplike ki lòt bagay ou ta renmen:

10. Bay manm fanmi ou maladi a, ki sa ki enkyetid prensipal ou?

11. Èske ou te jwen soultion pou tout pwoblèm pratik ke maladi manm fanmi ou te koze (tankou pwoblem finansyè oswa pèsonèl)?
    a. Wi
    b. Non
    c. Lòt yo: _____
12. Nan tretman maladi manm fanmi ou, ki moun ou fè pi plis konfyans?
    a. Doktè
    b. Bòkò oubyen ougan
    c. Lidè relijye - pastè oswa pè
    d. Lòt yo: _____
13. Èske ou ta renmen rete la kay ou pou pran swen medical pou manm fanmi ou oswa entène nan lopital?
    a. La kay
    b. Nan lopital
14. Kijan ou panse manm fanmi ou ap ye aprè tretman an?
    a. Trete net
    b. Pa gen trop andikap
    c. Gwo andikap
    d. Lanmò

Appendix B3 – Medical Staff Critical Care Survey (French)

Questions sur votre situation personnelle:

Sexe: Mâle / Femelle Âge: _____

Spécialité Médicale: _____ Nationalité: _____

Avez-vous toujours vécu en Haïti? Oui / Non

Si non, où d'autre avez-vous vécu? _____

Dans quelle pays avez-vous fréquenté l'école de médecine? _____

Combien de temps avez-vous pratiqué la médecine? _____

Depuis combien de temps travaillez-vous dans votre hôpital actuel? _____

Quelle est votre religion, si aucune, a laquelle vous identifiez-vous? _____

À quelle fréquence recevez-vous des patients atteints de maladies chroniques, ou dans des conditions de vie en danger?

a. Toujours
b. Souvent
c. Parfois
d. Jamais

Questionnaire sur votre pratique professionnelle

Instructions: S'il vous plait lisez les questions suivantes et répondez en fonction de votre expérience individuelle et de vos opinions. Il n'y a pas de réponses incorrectes.

A savoir: Ces questions ne concernent que vos patients avec un pronostic terminal qui peuvent décédés dans les 6 prochains mois.
Questions a choix multiples:

1. Pensez-vous que vous avez les ressources nécessaires pour gérer les conditions menaçant de manière urgente la vie de vos patients?
    a. Oui
    b. Non

S'il vous plait, expliquez pourquoi:

2. Pensez-vous que vous avez suffisamment de médicaments disponibles pour trater les symptômes suivants de maladie terminale? (Entourez “Oui” ou “Non” pour chaque symptôme)
    a. Douleur Oui / Non
    b. Essoufflement Oui / Non
    c. Faiblesse ou manque d'énergie Oui / Non
    d. Nausées et vomissements Oui / Non

3. Entourez toutes les ressources humaines qui selon vous sont nécessaires pour s’occuper d’un patient en fin de vie:
    a. Médecins
    b. Soutien spirituel - la visite à l'hôpital d’homme d’eglise
    c. Assistance sociale ou des services sociaux
    d. Spécialistes des soins palliatifs
    e. Physiothérapeutes
    f. Autre: _____

4. Êtes-vous connecté avec d'autres ressources communautaires pour vous aider à soutenir les patients en phase terminale et leurs familles? S'il vous plaît entourez les items necessaires:
    g. Les ONG internationaux
    h. Les hôpitaux
    i. Les cliniques de santé communautaire
    j. Les programmes gouvernementaux haïtiens
    k. Les programmes gouvernementaux internationaux
    l. Les organisations locales
    m. Autre: _____

5. Est-ce que les traitements disponibles pour les patients en phase terminale s'étendent actuellement au-delà du milieu hospitalier (par exemple la formation de la famille pour les soins à domicile, l'orientation vers un soutien supplémentaire, ou à la maison régime thérapeutique)?
    a. Oui
    b. Non

S'il vous plaît expliquez pourquoi:

6. En plus des besoins physiques, avez-vous déja adressé pour vos patients en phase terminale ou un membre de leur famille, l'un des soutiens suivants: psychologique, spirituel, professionnel, social ou émotionnel?
    a. Oui
    b. Non

Si oui, s'il vous plaît expliquez comment vous le faites:

Si non, est -il quelque chose que vous pourriez faire? Que vous envisageriez d'intégrer dans vos soins aux patients? (À savoir le temps, la formation, l'espace privé, un professionnel spécifique formés pour traiter ces besoins, etc.)

7. Pensez-vous que vous avez des soins préventifs adéquats pour vos patients?
    a. Oui
    b. Non

S'il vous plaît expliquez pourquoi:

8. Pensez-vous que vous avez les outils de diagnostic adéquats qui vous permettent l'identification précoce des stades traitables de maladies terminales de vos patients?
    a. Oui
    b. Non

S'il vous plaît expliquez pourquoi:

9. Êtes-vous satisfait des soins que vous êtes en mesure de fournir à vos patients?
    a. Oui
    b. Non

S'il vous plaît expliquez pourquoi:

Questions à réponses courtes:

10. Que voulez-vous, ou que vous pourriez faire différemment pour vos patients avec des maladies en phase terminale?

11. Quels sont les principaux obstacles qui vous empêche de répondre à tous les besoins de vos patients en phase terminale?

12. Dans vos mots, que sont les soins palliatifs? Quel rôle devraient-ils avoir dans les soins de santé Haïtien?

13. Est-ce que votre hôpital fournit des soins palliatifs aux patients? Si oui, de quelle maniere? Si non, pourquoi pas?

Appendix B4 – French Integrated Palliative Outcome Scale (iPOS) Staff Version (3 Day)

IPOS Version staff

www.pos-pal.org

Nom du Patient : ……

Diagnostic du Patient : ……

Date (dd/mm/yyyy) : ……

Q1. Qu'est-ce qui a été le problème principal du patient ces trios derniers jours?

1.
.....
2.
.....
3.
.....

Q2. Veuillez cochez le box qui decrit le mieux comment le patient a ete affecte par les symptomes suivants ces trios derniers jours?

	Pas du tout	Legerement	Moderement	Severement	De maniere exageree	Ne peut etre evalue (inconscience
Douleur	0☐	1☐	2☐	3☐	4☐	☐
Difficultes respiratoires	0☐	1☐	2☐	3☐	4☐	☐
Faiblesse et manque d'energie	0☐	1☐	2☐	3☐	4☐	☐
Nausee (sensation que vous allez etre malade)	0☐	1☐	2☐	3☐	4☐	☐
Vomissements	0☐	1☐	2☐	3☐	4☐	☐
Faible appetit	0☐	1☐	2☐	3☐	4☐	☐
Constipation	0☐	1☐	2☐	3☐	4☐	☐
Bouche amere ou seche	0☐	1☐	2☐	3☐	4☐	☐
Vertiges	0☐	1☐	2☐	3☐	4☐	☐
Mobilite reduite	0☐	1☐	2☐	3☐	4☐	☐

Veuillez noter tout autre symptomes non listes ici et cochez le box correspondant au mieux comment ils ont affecte le patient ces trios derniers jours						
1.	0☐	1☐	2☐	3☐	4☐	☐
2.	0☐	1☐	2☐	3☐	4☐	☐
3.	0☐	1☐	2☐	3☐	4☐	☐

Durant ces trios derniers jours:

	Pas du tout	***Occasionellement***	***Parfois***	***Le plus souvent***	***Toujours***	***Ne peut etre evalue (ex inconscience)***
Q3. S'est il ou elle inquite de sa maladie?	0☐	1☐	2☐	3☐	4☐	☐
Q4. Est-ce que des proches ou des amis sesont inquietes de sa maladie et de sa situation?	0☐	1☐	2☐	3☐	4☐	☐
Q5. Est-ce que vous pensez que le patient est deprime?	0☐	1☐	2☐	3☐	4☐	☐

	Toujours	*Le plus souvent*	*Parfois*	*Occasionellement*	*Pas du tout*	*Ne peut etre evalue (ex inconscience)*
Q6. Est-ce que vous pensez que	0☐	1☐	2☐	3☐	4☐	☐

le la patient (e) est en Paix?						
Q7. Est-ce que le patient a pu partager son etat d'ame avec ses proches et amis?	0☐	1☐	2☐	3☐	4☐	☐
Q8. Est-ce que le patient a pu obtenir toutes les informations desires?	0☐	1☐	2☐	3☐	4☐	☐

	Problemes addresses/ pas de problemes	*Problemes addresses en grande partie*	*Problems addresses en partie*	*Problemes htres peu addresses*	*Problemes non addresses*	*Ne peut etre evalue (ex inconscience)*
Q9. Est-ce que des problems pratiques resultatnt de la maladie du patient ont ete addresses? (ex finaces et personels)	0☐	1☐	2☐	3☐	4☐	☐

Appendix C. Consent Forms – English Versions

Appendix C1 – Patient and Family Member Consent Form

Consent Form

You are being asked to take part in a research study about caring for people with life-threatening conditions in Haiti. We are asking you to take part because you or your family member is currently getting care for a serious medical condition. Please listen to the following information carefully and ask any questions you may have before agreeing to take part in this study.

The purpose of this study is to learn what barriers exist to getting medical care for people with life-threatening conditions in Haiti and better understand how Haitian citizens feel about the provided medical care.

If you agree to be in this study, we will conduct an interview with you. The interview will include questions about your experience with the medical care provided at this hospital or program. The interview will take about 45 minutes to complete.

There is the risk that you may find some of the questions about your medical care experience to be sensitive. There are no benefits to you for participating. We hope to learn more about the experience of individuals receiving medical care in Haiti.

Participating in this study is completely voluntary. You may skip any questions that you do not want to answer. If you decide not to participate or to skip some of the questions, it will not affect your relationship with the hospital or doctors providing your care. If you decide to participate, you can stop at any time.

Please ask any questions that you have now. If you have questions later, you may ask at any point during the interview.

Statement of Consent:
I have listened to and understand the above information. I have received the answers to all of the questions that I asked. I consent to participate in this study.

Your Signature _____ Date _____

Your Name (printed) _____

Appendix C2 – Medical Staff Consent Form

Consent Form

You are being asked to take part in a research study about caring for people with life-threatening conditions in Haiti. We are asking you to take part because you have provided medical care to patients in Haiti experiencing life-threatening illnesses. Please read the following information carefully and ask any questions you may have before agreeing to take part in this study.

The purpose of this study is to learn what barriers exist to providing medical care for people with life-threatening conditions in Haiti and to collect data to help inform future palliative care programming.

If you agree to be in this study, you will be provided with a Staff Survey that you will read and complete. The survey will include questions about your experiences and perspectives on caring for individuals with life-threatening conditions. The survey should take you about 30 minutes to complete.

There is the risk that you may find some of the questions about caring for individuals with life-threatening illnesses to be sensitive. There are no benefits to you for participating.

Participating in this study is completely voluntary. You may skip any questions that you do not want to answer. If you decide not to participate or to skip some of the questions, it will not affect your relationship with the hospital. If you decide to participate, you can stop at any time.

Please ask any questions that you have now. If you have questions later, you may ask anytime while completing the survey.

Statement of Consent:
I have read and understand the above information. I have received the answers to all of the questions that I asked. I consent to participate in this study.

Your Signature _____ Date _____

Your Name (printed) _____

Appendix D. Consent Forms – Haitian Kreyol and French Versions

Appendix D1 – Patient and Family Member Consent Form (Kreyol)

Fòm Konsantman:

N ap mande ou pou w patisipe nan yon etid rechèch sou swen medikal pou moun ki gen kondisyon ki menase lavi an Ayiti. N ap mande ou pou w patisipe paske ou menm oswa yon manm nan fanmi ou ap jwenn swen pou yon kondisyon medikal grav. Tanpri koute enfòmasyon sa yo ak anpil atansyon epi poze nenpòt kesyon ou ka genyen anvan ou dakò patisipe nan etid sa a.

Rezon ki fè etid sa a se pou nou aprann obstak ki egziste pou moun nan Ayiti jwenn swen medikal pou kondisyon ki menase lavi ak pou nou byen konprann ki jan sitwayen ayisyen yo santi yo sou swen medikal ke yo jwenn.

Si ou dakò pouw nan etid sa a, nou pral fè yon entèvyou avèk ou. Entèvyou a ap gen ladan kesyon sou eksperyans ou avèk swen medikal yo bay nan lopital sa a oswa nan pwogram sa a. Entèvyou a ap pran apeprè 45 minit.

Gen risk ke ou kapab jwenn kèk nan kesyon sansib sou eksperyans swen medikal ou yo. Patisipasyon'w pa bawou dwa ak okenn privilèj. Nou espere aprann plis apwopo eksperyans moun kap resevwa medikal an Ayiti.

Patisipasoyn w nan etid sa se yon bagay ki volontè. Ou ka sote nenpòt kesyon ke ou pa vle reponn. Si ou deside pou w pa patisipe oswa sote kèk nan kesyon yo, li pa pral afekte relasyon w ak lopital la oswa doktè yo bay swen ou. Si ou deside patisipe, ou ka kanpe nenpòt lè.

Tanpri poze nenpòt kesyon ke ou genyen kounye a. Si w gen kesyon apre, ou ka pose li nan nenpòt pwen pandan entèvyou a.

Deklarasyon sou Konsantman:

Mwen te tande e konprann enfòmasyon ki anwo yo. Mwen te resevwa tout repons de tout kesyon ke mwen te pose yo. Mwen dakò pou patisipe nan etid sa a.

Siyati ou _____ Dat _____

Non ou (enprime) _____

Appendix D2 – Medical Staff Consent Form (French)

Formulaire de Consentement:

Vous êtes invité à prendre part à une étude de recherche sur les soins en Haïti, aux personnes ayant des conditions pathologiques létales, menaçant directement et de manière urgente leur vie. Nous vous demandons de prendre part à cette étude parce que vous avez de l'expérience dans les soins médicaux à ces patients, dans le traitement de maladies mortelles en Haïti. S'il vous plaît lisez attentivement les informations suivantes et posez-nous toutes les questions que vous pourriez avoir avant d'accepter de participer à cette étude.

Le but de cette étude est d'identifer les obstacles existants pour fournir des soins médicaux aux personnes ayant des conditions de vie en danger en Haïti; ainsi que de recueillir des données pour la formation de futurs programmes en soins palliatifs.

Si vous acceptez de participer à cette étude, il vous sera fourni un questionnaire que vous allez lire et compléter. Le questionnaire comprend des questions sur vos expériences et votre point de vue sur les soins aux personnes souffrant de maladies mettant leur vie en danger. Répondre aux questionnaire devrait vous prendre environ 20 minutes.

Des questions sur les soins aux personnes atteintes de maladies mortelles peuvent être sensibles. Aussi, vous ne tirerez aucun avantage direct (argent, avantage en nature, …) de votre participation.

La participation à cette étude est entièrement volontaire. Vous pouvez sauter les questions auxquelles vous ne voulez pas répondre. Si vous décidez de ne pas participer à cette étude ou si vous sauter quelques-unes des questions, ce ne sera pas notifié à votre l'hôpital et n'affectera en aucun cas vos relation professionnelles. Aussi, si vous décidez de participer, vous pouvez vous arrêter à tout moment.

S'il vous plaît posez-nous toutes les questions que vous avez maintenant. Si vous avez des questions plus tard, vous pourrez demander à tout moment tout en complétant l'enquête.

Déclaration de consentement:
Je l'ai lu et compris les informations ci-dessus. J'ai reçu les réponses à toutes les questions que j'ai demandé. Je consens à participer à cette étude.

Votre signature _____ Date _____

Votre nom (en lettres majuscules) _____

Appendix E. St. Luke Study – Results Data Summary Tables

Appendix E1 – Family Caregiver Interview Results Summary Table

Survey Statement		**% Yes**	**n/N**
Family caregiver help patient make medical decisions		93.3%	42/45
Frequency staying in hospital with patient	All the time	71.1%	32/45
	Sometimes	20.0%	9/45
	One time per week	4.4%	2/45
	Occasionally	0.0%	0/45
	Rarely	4.4%	2/45
Family caregiver receives health information from:	Your medical team at the hospital	80.0%	36/45
	Community or mobile clinics	55.6%	25/45
	Physical or occupational therapists	24.4%	11/45
	Family members	51.1%	23/45
	Traditional healer	0.0%	0/45
	Internet or websites	15.6%	7/45
	Radio or television	28.9%	13/45
	Social worker	28.9%	13/45
Patient receives regular medical care from:	Hospital	73.3%	33/45
	Community or mobile clinics	55.6%	25/45
	Physical or occupational therapists	28.9%	13/45
	Family members	77.8%	35/45
	Traditional healer	0.0%	0/45
Family caregiver understands patient diagnosis		51.1%	23/45
Family caregiver talked with medical provider in past week		40.0%	18/45
Family caregiver thinks patient currently receives:	Physical care	100.0%	45/45
	Psychological care	48.9%	22/45
	Occupational care	44.4%	20/45
	Spiritual care	62.2%	28/45
	Social care	13.3%	6/45
Family caregiver thinks patient would like to receive:	Physical care	100.0%	45/45
	Psychological care	95.6%	43/45

	Occupational care	97.8%	44/45
	Spiritual care	97.8%	44/45
	Social care	91.1%	41/45
Getting the patient medical care has been inhibited by:	Difficulty traveling to or from the hospital or health clinic	44.4%	20/45
	Difficulty getting medications	55.6%	25/45
	Not understanding your doctor or nurse	15.6%	7/45
	Financial difficulties	77.8%	35/45
	In-home medical care is not available	80.0%	36/45
	Lack of information	62.2%	28/45
Getting the patient medical care has been aided by:	Help traveling to or from the hospital or health clinic	58.1%	25/43
	Having good access to medications	48.8%	21/43
	Understanding your doctor or nurse	86.0%	37/43
	Financial support	20.9%	9/43
	In-home medical care is available	18.6%	8/43
	Adequate information	34.9%	15/43
Family caregiver want the hospital to provide additional support		93.3%	42/45
Practical problems resulting from the patient's illness have been addressed		22.2%	10/45
To treat the patient, you most trust:	Doctor	28.9%	13/45
	Traditional healers	0.0%	0/45
	Religious leaders (i.e. pastor or priest)	6.7%	3/45
	God	60.0%	27/45
	Other	4.4%	2/45
Family caregiver prefers the patient receive further treatment:	At home	64.4%	29/45
	At the hospital	35.6%	16/45
Family caregiver thinks patient recovery will be:	Full recovery without any disability	71.1%	32/45
	Limited disability	11.1%	5/45
	Severe disability	8.9%	4/45
	Death	8.9%	4/45

Appendix E2 – Medical Staff Survey Results Summary Table

Medical Staff Survey Statement		**% Yes**	**n/N**
Have necessary resources to manage life-threatening conditions		25.0%	3/12
Have sufficient medication to manage:	Pain	50.0%	6/12
	Shortness of breath	36.4%	4/11
	Weakness or lack of energy	50.0%	6/12
	Nausea and vomiting	83.3%	10/12
Managing patient end of life needs requires:	Internal Medicine Physicians	91.7%	11/12
	Spiritual care/clergy to visit patients in the hospital	83.3%	10/12
	Social work/social services	83.3%	10/12
	Trained palliative specialists	83.3%	10/12
	Physical therapists	75.0%	9/12
To support terminally ill patients, the hospital is currently connected with:	International NGOs	33.3%	4/12
	Other hospitals	33.3%	4/12
	Community health clinics	8.3%	1/12
	Government programs	8.3%	1/12
	Local organizations	8.3%	1/12
Terminal patient treatment extends beyond the hospital		25.0%	3/12
Psychological, spiritual, occupational, social, or emotional needs of terminally ill patients are addressed		83.3%	10/12
Adequate preventative care		41.7%	5/12
Adequate diagnostic tools		8.3%	1/12
Satisfied with the care you provide		36.4%	4/11

Appendix F. St. Luke Study – Qualitative Observational Field Notes

Observational Note #1 – Patient's confidence in and thankfulness for medical treatment

Throughout my stay in Haiti, there were multiple situations that emphasized that the community members visiting the hospital had an inherent gratitude and trust of the St. Luke physicians and nurses. Even after difficult procedures, that may or may not have been well explained by the physicians, involving significant pain, most patients and their family members were grateful for all provided care. It didn't seem to matter if the procedure were successful, painful, or necessary, the patients and their family members had an innate confidence in the medical staff providing care. Two cases stand out. Both were within my first month working at St. Luke's.

The first incident occurred near midday while I was assisting the wound care nurse. A patient had just shuffled out of the tiny open-air wound care cubicle when a small woman dragged her son past the dark green privacy screen. Although the patient was in his late twenties and towered over his mother, the woman easily pushed him to lie on the exam table while barraging him with a stream of Kreyol that was much too fast for my rudimentary training to be of any use in translating. He quickly dropped his pants, presenting large boils on his buttocks. With the efficiency of a medical professional that has seen and managed many similar situations, not even blinking an eye at his casual nudity, the wound care nurse handed me cleansing solutions and gestured that I should begin preparing the area. When the area was sanitized, she began draining the boils by squeezing out and wiping away the resulting pus, sanitizing the wound again, and finishing by adding a topical ointment.

Throughout the procedure, the patient was screaming and pleading the nurse to stop. Meanwhile, the patient's mother kept her hand on the patient's upper back, holding the patient in

place and scolding him about this pain being his fault because he let this happen. The nurse just kept squeezing. After she thought it was sufficiently drained, she motioned that I should complete the procedure by dressing the area. Pulling his pants back up and awkwardly ducking his head beneath his mother's glare, he thanked the wound care nurse and I as he limped out of the room. The nurse never talked directly with the patient. Even after enduring incredible pain with no sympathy or communication with the nurse regarding the procedure, the patient was thankful for the care provided and confident that it had been in his best interests.

The second incident happened in L'Urgence. A patient had been admitted the day prior with a suspected case of meningitis. To confirm the diagnosis and eliminate other potential illnesses, a visiting doctor suggested performing a lumbar puncture, a procedure in which the doctor inserts a needle between the patient's lumbar vertebrae into the spinal canal to collect cerebrospinal fluid (CSF). CSF is a clear fluid that surrounds and protects the central nervous system. This fluid can be tested to confirm meningitis. This procedure is rarely completed at St. Luke's because it is primarily a diagnostic tool, the family must be able to afford the costs of sample analysis, and it is a sterile procedure because a needle enters the spinal canal. However, this procedure is completed routinely in high-resource nations such as the United States and is not considered to be high risk in that setting.

After the patient's family stated that they could afford the testing fees and agreed to the procedure, a physician at St. Luke's prepped the patient for the procedure by establishing a sterile environment, properly positioning the patient, and preparing the numbing agent, Lidocaine. The physician was clearly nervous and had not performed the procedure since training years prior. A group of nurses and other medical staff had also gathered around the patient to observe and learn.

Beginning the procedure, the physician did not communicate with the patient regarding the necessity of the procedure, procedural steps, importance of remaining completely still while the procedure was performed, or degree of pain that the procedure would cause. Unfortunately, the patient kept screaming while trying to stand up and move away from the pressure of the needle. This action disrupted the sterile area that the physician had made, forcing the doctor to begin from the beginning while wasting resources and increasing the patient's pain. The visiting doctor was patient and calm, allowing the doctor try three times. After that, the visiting doctor took over, asking the St. Luke physicians to talk with the patient while he completed the procedure.

As the patient's back was bandaged and their clothing replaced, the patient looked at the medical team through diminishing tears and said, "thank you." Even after all the pain and lack of communication, the patient and the patient's family members shared their gratitude multiple times following the procedure, trusting that it had been in the patient's best interest. The visiting doctor asked that the CSF to be sent out for analysis. Unfortunately, it was discovered at noon the following day that the CSF still hadn't been sent to the analysis lab at the other hospital. The wait time had ruined certain markers that the analysis tested, but the visiting physician still ensured that the family took the vial to the necessary hospital. For all testing that cannot be completed in St. Luke's lab, the family is responsible for the transport of all test samples.

Observational Note #2 – Family member role in daily patient care

Given the low-resource care setting, family members provide the majority of daily care for patients admitted to the hospital. For days on end, family members will sit in plastic or metal folding chairs beside the patient's bedside, providing critical supportive care that is necessary to

running a successful hospital, including responsibilities typically held by trained nurses in high-resource care environments such as the United States. Family caregivers: 1) help the patient reorient or shift in their bed; 2) walk the patient to the restroom or assist them in using a shallow bed pan; 3) maintain sanitary conditions for the patient such as cleaning the bed, providing linens, and rinsing any used tubs or other materials; 4) manage periodic wound care or specific illness symptoms; 5) fan the patient to keep the flies away and provide a slight respite from the heat; 6) hold tubs for excess body fluids such as blood or sputum; 7) cook meals at home and bring them to the hospital for the patient to eat; 8) buy medications and medical supplies; and 9) travel to other hospitals, labs, and pharmacies to get required medical tests, blood for transfusions, or medications.

The nurses do not do any of this care, unless the patient has no family caregiver. In that circumstance, social services staff members will assist the patient with these basic care necessities a couple of times a day as well as bringing them meals and bed linens as available. For patients with a feeding tube, including many stroke patients, family caregivers will even prepare meals and feed their family member through the feeding tube. Social services hold daily sessions each afternoon to teach the family members the basics of how to care for their loved one while they are in the hospital.

Observational Note #3 – Family choosing not to explain the complete diagnosis to the patient.

After a physician suggested that I talk with a patient diagnosed with cancer, I approached the patient and his family members – a man and woman who had spent the past few days at the patient's bedside. Both family members were open to talking with me and one completed the research survey. However, when I mentioned talking directly with the patient, they looked at one

another, and the male caregiver quietly informed me that his family purposefully, “doesn’t tell [the patient] everything because it could hurt his psychology. He doesn't know how serious his illness is and believes that he will have a full recovery." The family caregivers allowed me to interview the patient after I explained that I was just there to listen, not tell the patient anything about his condition. However, the patient was under the impression that he was suffering from a severe case of malaria and had no knowledge of his medical diagnosis. As the summer progressed, similar situations arose with other patients. A clear trend was established: the doctors discussed diagnoses with the family before talking with the patient, often allowing the family members to decide what to tell the patient.

Observational Note #4 – Need for spiritual care

On a late Friday afternoon, I walked into L’Urgence to check-in with the head physician, noticing a patient hunched over in a wheelchair near the entrance with sunken skin around his forehead, in a late stage of starvation. The patient’s brother brought him in hours earlier, explaining to the medical staff that he was fasting and praying to God because their mother was dying. The patient’s brother had tried everything to get him to eat, but he wouldn’t. The patient’s brother was very worried because the patient was starting to sound “crazy,” talking incessantly about God and not understanding that if he didn’t eat he was going to die along with his mother.

Discussing the case with a sad expression, the doctor explained to me that it was a mental or behavioral problem, and thus, there was nothing that she could do to treat it medically. The doctor had asked one of the St. Luke Catholic priests to talk with the man. If they were unsuccessful in convincing the patient to eat, the patient’s brother would need to admit him to the public insane asylum. As with most of the publicly run medical facilities in Haiti, the asylum

has a horrible reputation. The physician asked the priest to talk with the patient as a last attempt to keep the man out of the asylum since the issue seemed to be religious in nature. Unfortunately, the Father was busy all day with other, non-medical duties and was unavailable to talk with the man until much later that night. By the time that the priest was available, the patient's brother had already taken the patient to the public asylum because he needed to spend time with his dying mother.

Observational Note #5 – Social Services: Patient abandonment

A significant portion of patients admitted to St. Luke's are abandoned, especially within the patient population of this study. In a discussion with social services, the lead nurse explained that some families bring in a patient but leave when the patient's condition worsens or takes too long to improve. Otherwise, family caregivers accompanying a patient may provide the hospital with an invalid cell phone number or contact address. The social services nurses stated, "It is because every day you are in the hospital you have to pay for care, and [the family] doesn't want to or can't pay anymore." Also, some patients are left in the street in front of the hospital, usually at night or in the early morning before the hospital opens, with no family to help admit them.

For these abandoned patients, social services staff members try to find them place at Sanfil, a local facility with limited resources and means for treatment which has special rooms specifically for abandoned patients. Although this is not an ideal setting for any patient, St. Luke's cannot admit patients indefinitely. The social services head nurse mentioned that they had one patient that was in the hospital for two and a half years that they transferred to Sanfil for end of life care. From my understanding of the nurse's comments, Sanfil does not provide medical care but will provide a bed and basic necessities for abandoned patients.

One example was a middle-aged man who was found in the street and left in front of the hospital. He was dying from an unknown ailment (suspected to be a repeat stroke), but he was still cognizant and trying to talk. In the hospital, he was lying on a crinkly, plastic, ripped hospital bed with no sheet – just a small cotton cloth covering the huge bedsore wounds on his back and buttocks. Twice a day, social services would turn him, clean him, and feed him. If not for them, he would have been dying alone.

Observational Note #6 – Need for family member caregiver self-care

Throughout my discussion with the medical care providers and social service staff members, there was a common theme about the importance of self-care for family members. Sometimes, family members become so engrossed in their grief and duty caring for the patient that they forget to take care of themselves. This then leads to the family caregiver becoming another patient for the hospital to treat. Family members often ended up sick or fainting.

Observational Note #7 – Gender roles within family dynamics

Throughout the interviewing process, it was often difficult to talk with female family caregivers alone. For example, one female family caregiver had been in the hospital almost a week caring for her husband. I approached her regarding participating in the research study, but she mentioned that she wanted to talk it over with her husband when he woke up. When I approached her again the following morning, a couple of men from her church were with her, "providing support." Although the female caregiver agreed to participate in the study and seemed exited to talk with me, the men from her church continued to hang around during the interview. Trying to answer questions for the woman, they would not allow her to respond or would talk

over her. After a few polite reminders that the questions were intended for the female caregiver, the men remained quiet. However, throughout the remainder of the interview, the female caregiver glanced at the men before answering each question. She seemed to be unused to responding to questions, so the interview proceeded at a very slow pace.

A similar situation occurred later in the summer when I was interviewing a female caregiver, and a man kept hanging around while we were talking. He kept trying to interject and speak for her whenever I asked her a question. The female caregiver later informed me that he was a member of their church and usually handled conversations with the hospital. He spent very limited time at the hospital but came whenever they were supposed to talk with a doctor. Throughout the interview, I needed to repeatedly remind him to allow the female caregiver to answer the questions because he would answer before she had the opportunity to respond, influencing her eventual response.

In many cases, when I approached the female caregiver most frequently in the hospital with the patient, she would try to direct me to a male in the family who knew very little about the patient's condition and hospital visit. Often, once I explained the study to the male family member and began asking questions, the man would tell me that he could not answer them and would refer me back to the female caregiver. The female caregiver would then seem happy to interview with me.

Observational Note #8 – Haitian expression of grief and international understanding

One morning after rounds, a short-term visiting doctor asked me if, "Haitians care less [than Americans] that their family members are sick?" Clarifying the question, I realized that the doctor was referring to how many Haitian family members would sit stoically beside the

patient's bed, some even smiling and joking with other family members or nearby patients and their family members. Throughout the three months that I was in Haiti, I saw Haitian family members show the depth of their caring through innumerous everyday gestures such as carefully and meticulously washing the patient's body, changing the patient's bed pan, helping the patient cough mucous into a bowl, gathering in a group around the patient's bed to pray for recovery, and feeding the patient an entire bowl of soup spoon by spoon three times a day. During some of the family interviews, the family caregiver needed to take a break to collect his or herself. Although some of the family members did cry, most collected themselves without tears.

A few days later, a woman died in the cholera ward. Watching her daughter grieve for the loss of her mother on her knees with wracking sobs and loud keening, the American doctor witnessed the full embodiment of grief that occurs in the wake of a Haitian family member passing. It is almost violent in outward emotion and absolutely heart wrenching to witness. Many women needed to be dragged out of the hospital by male family members after a loved one passed away. Unfortunately, these acts of grief were not rare throughout my summer at the hospital.

Observational Note #9 – Continual crisis mode conditions

St. Luke Hospital moves at a different pace than most hospitals in the United States. St. Luke only provides in-hospital care through its emergency wards. Due to the high demand for care services and the severity of most patients at St. Luke, there is a continuous influx of patients and family members in crisis. While working with the medical team, I began to realize that the hospital moves at, in general, a less rapid pace than US hospitals. Due to these challenging conditions, St. Luke medical staff need to cope with providing continuous emergency care and

maintain their many other, non-patient-related duties. While observing patient sessions, I noticed that St. Luke physicians would receive phone calls while in clinic with their patients, talking freely while gesturing for the patient to wait. There was no pretense of secrecy regarding the conversation, and the patient would always wait without complaint, even if they were in extreme pain or discomfort.

On my last day at the hospital, I experienced an example of emergent situations becoming the everyday reality for the St. Luke physicians. While walking back from the second emergency ward, I found a man lying unconscious on the ground bleeding from his head and mouth. Eight people, including multiple hospital cleaning staff, were standing around the man in a semi-circle and staring down at him. I was the first one to grab gloves, attempt to control the bleeding, send someone to tell a physician what had happened, and ask someone to grab something to help transport him to the emergency ward. The hospital did not have a backboard, so one of the staff members grabbed a wheelchair.

The hospital staff members and I positioned the man in the wheelchair and transported him to the emergency ward. Although the doctors were in the ward treating other patients with care regimens seemingly less urgent than the bleeding man, the doctor on the ward took a few minutes to begin assessing the man. Once the assessment began, it was much less hurried than any emergency assessment I have witnessed in a United States emergency room as an Emergency Medical Technician.

Another doctor later told me that the man had been on his way to get a CT scan but must have lost consciousness walking to the testing area, hitting his head on the concrete pathway. After the bleeding was controlled and his vitals were assessed, the man was sent back to the CT scanning area for the original testing, this time unconscious in a wheelchair. Given his continued

unconsciousness and medical history it was suspected that he was having a stroke. In a high-resource medical environment like the US, there are medications that can be given in the early stages of a stroke to lessen the lasting effects of the stroke, such as tissue plasminogen activator (TPA). However, St. Luke did not seem to have access to this medication. This lack of available treatment response seemed to lessen the immediacy of care.

Observational Note #10 – Limited triage admission process

Likewise, the triage process at St. Luke was much faster and seemed to be less thorough than the processes I have observed in US emergency rooms. Upon arrival, the nurses would check a patient's vitals twice, including temperature, blood pressure, pulse, blood oxygen levels, respiratory rate, and if applicable, blood glucose levels. The first triage was intended to identify patients with immediate need for care and begin the process of searching for patient medical records, while the second vital check was a more thorough assessment with some additional verbal questions. However, few questions were asked throughout the process, seeming to save that for the patient's interaction with the doctors. After the two vital checks were completed, the nurse handed the patient a physical card with their triage number written on it, gesturing for them to wait until a doctor to calls for them. The triage line is always extremely long at the beginning of the day because all the patients would come as early as possible. A triage nurse explained that they had attempted to schedule appointments with patients receiving out-patient care, but all the patients came as early in the morning as possible anyway. However, through midday the triage nurses would be done with their work.

Observational Note #11 – No priority for "untreatable" patients during morning medical rounds

The pace of the St. Luke emergency ward morning rounds is very rapid compared to the speed of rounds conducted at US hospitals. During the morning rounds, the physicians did not seem to spend any extra time on patients that were indicated to be near end of life. If anything, the physicians seemed to spend less time on patients that were deemed untreatable. There are a lot of patients for the doctors to discuss, so there isn't time to discuss many of the cases in depth, especially patients not treatable with traditional medical procedures.

Observational Note #12 – Hierarchy within hospital effecting information flow

St. Luke Hospital has a very strict hierarchy, also observed in most other organizations in Haiti. However, it is challenging to learn where all the staff are in the organizational hierarchy unless you are ingrained in the community. Unfortunately, this hierarchy creates miscommunication or complete lack of communication throughout various ranks of the hospital staff. For example, when the head physicians know something, the message will often not be passed down to newer doctors or nursing staff that should be aware of the problem or change.

Especially when working with international volunteers, these communication challenges may lead to misunderstandings in the beginning stages of hospital partnerships and collaborations. However, this also affects the Haitian medical team by making the medical center less efficient and fostering an environment where only a few staff members have input and power. This type of work and care environment does not help with clinician fatigue and quality of life or the patient medical experience.

Observational Note #13 – Medical staff have no outlet for their ideas

Every clinician, specialty staff, and social services staff member that I talked with, below the highest level, seemed hesitant to discuss anything indicating that St. Luke could make improvements. Although it was often clear that a staff member had ideas or suggestions for improvement, the staff member would insinuate an issue or challenge throughout our conversation without saying anything specific that could be acted on. The staff members always returned to discussing what the hospital was doing well.

In the beginning stage of the medical staff survey research, I asked one of the head St. Luke physicians if she could point me to a nurse or doctor that would be willing and able to complete the staff survey. The physician directed me to a nurse that I quickly learned had only been working at the hospital for two weeks. Although the nurse was initially willing to participate, after reading the survey questions, she said that didn't feel she knew enough about the hospital to complete the survey. I returned to the doctor for another suggestion, and she then directed me to an experienced St. Luke nurse manning the front l'Urgence 1 desk nurse.

When the doctor initially asked the nurse to complete the survey, she said yes and took the form. However, immediately following the doctor's exit, the nurse told me that she, "knows nothing about the hospital," and returned the form to me. She had worked at St. Luke for 4 years. It was clear that she did not feel comfortable answering the survey questions. Although she did not tell me why she was hesitant to complete the survey, I felt that she felt she could get in trouble for her responses. Even after reiterating that the survey responses would be anonymous and could be brief, she would not complete the survey. I suspected that she felt she should have no opinion or input regarding the hospital.

Possibly in response to the hierarchical environment of the hospital and perceived job insecurity, the doctors and nurses unfortunately have no place they feel they can freely discuss their opinions about the hospital or the care they provide. They also seemed to have little opportunity for involvement in the improvement of the overarching organizational aspect of the care environment. Many St. Luke medical staff did not provide specific responses in their surveys, even though it was always stated that all survey results would remain confidential.

Observational Note #14 – Current social services capacity

Although immediate care is provided by the St. Luke physicians and nurses working in the emergency ward, much of the holistic care associated with palliative care services are provided by the St. Luke social services unit. As of August 2016, the St. Luke social services unit was composed of three employees with similar team roles. The lead nurse began working at St. Luke as a nurse in 2011 and transitioned to become the first social services staff member. In 2013, she was selected to train at L'hopital St. Damien for two months with their existing pediatric social services team. She worked to adapt the pediatric social services model to create the first adult social services program at St. Luke. The second employee was a female nurse that had only begun working in social services earlier in the summer of 2016. She was still completing her training with the lead social services nurse. Finally, there was a recent male addition to the team that transferred from another organizational administration area and seemed to focus more on the fundraising aspect of social services.

During one of our many conversations, the lead social services nurse described their typical day. She and her colleague began by going to the clinic waiting area, immediately beside the patient triage area. In clinics from Monday through Friday, St. Luke physicians meet with

both walk-in triage patients and established patients receiving specific out-patient care (i.e. hypertensive patients). The social services nurse would talk with the patients and their family members while they waited, teaching them: 1) the location of the pharmacy, restrooms, and laboratories; 2) general information regarding Human Immunodeficiency Virus (HIV) and Tuberculosis (TB) and the resulting importance of sanitation while in the hospital; and 3) what foods specific patient populations should be given (i.e. diabetes, elderly, hypertension). She would also explain that patients could return to the hospital before their next scheduled appointment if they got worse or had an emergency.

Next, the social service nurses went through the emergency wards, identifying and providing support for the abandoned patients without family members to care for them. They provide abandoned patients with food and medicine, help navigating the hospital environment and procedures, and if required, they would try to provide them with suitable donated clothing and bed linens. To provide medications, the social services would fill the prescriptions at the pharmacy and then leave them with the emergency ward nurses to distribute to the patients.

After caring for the abandoned patients, the ward nurses would tell them if any of the patients with family members still did not have life-saving medications a day or more after being prescribed them. These family caregivers are identified as having significant financial need and social services approaches them about helping fill the prescription. Social services work directly with the patient and their family members to meet their needs as quickly as possible after the emergency nurse notifies them of the issue.

Finally, every weekday, the social service nurses hold an afternoon meeting for all the family caregivers remaining in the hospital with a patient. They: 1) present the hospital rules, visiting hours, and expectations for respecting people and things; 2) instruct the caregivers on the

importance of washing their hands every time they touch something in the hospital; 3) general patient hygiene and care techniques (i.e. brushing their teeth, how to wash and feed them, etc.), especially for patients that cannot care for themselves; and 4) explain the importance of self-care for the family caregivers, trying to prevent caregiver fainting and sickness. Each patient is allowed a set number of visitors in the hospital at one time. Two patient populations are allowed two family members inside the hospital: patients that cannot care for themselves and patients that are very large or morbidly obese. All other patients are only allowed one visitor at a time.

Social services also mentioned a lack of resources for trying to help patients. The lead social services nurse shared that they often ran out of things, but also said that it was not too bad because they usually were not "necessary" things. During this interview, the social services staff seemed very hesitant to provide any critique of the existing systems in place.

Observational Note #15 – Lessons learned from Norma at Kay Germaine (rehabilitation therapy)

Kay Germaine, the rehabilitation center affiliated with St. Luke's, also provides services closely related to palliative an end of life care. The rehabilitation center is for adults with neurological mobility deficit as well as children with developmental or neurological disabilities. All of patients must be referred through either St. Luke of its affiliated pediatric hospital, St. Damien. Kay Germaine is currently directed by its founder. For adult treatment, the center also employs two movement therapists and one speech therapist as well as highly qualified and skilled international volunteers providing a specific, needed expertise.

Referred patients can schedule two, forty-five minute visits per week for a small participation fee. However, the founder told me that many of the people that come to be treated are wealthy, Bourgeois. She explained that it is difficult because she is working in Tabarre, Port-

au-Prince to provide care for the poor, but the clinic's reputation attracts people who do not require the reduced cost care. However, ethically, all patients must pay the same amount for the care they provide. On average, the three adult therapists treat approximately twenty-five patients on a busy day and fifteen patients on a slower day. Most of their adult patients are admitted to St. Luke for stroke and written prescriptions upon discharge for Kay Germaine's rehabilitation and physical therapy.

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