AN ASSESSMENT OF A HOSPICE AND PALLIATIVE CARE PARTNERSHIP PROGRAM

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This project attempts to describe how a hospice and palliative care partnership program works. Through the assessment of one such program, the researcher sought to find out the essential components of the partnership including how the two partner organizations interact and work together. Data was collected using various methods: document review of organization documents such as newsletters, annual or quarterly reports, brochures and other available literature e.g. materials on organizations’ website and on social media; in-depth interviews with stakeholders of both organizations that included staff and board members; observation of staff working; and participant observation during organization events.

The findings of the research shows that in order for organizations to have an effective partnership program in place, both partners need to have strong leadership in place, possess a willingness to learn from each other, maintain regular communication, and visit each other regularly. With this in place, several outcomes of the program are likely such as: increasing advocacy for hospice and palliative care, increasing visibility of the organizations both nationally and internationally, and provides an opportunity for organizations to network with other organizations in their locality in order to achieve partnership objectives.

The study further reveals that global collaborations in the field of hospice and palliative care began with the advent of the international hospice movement. The assessment of this hospice partnership demonstrates how organizations can establish working relationships and the results likely to come out of such an initiative.
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INTRODUCTION

Statement of the Problem

With the increase in the number of cases of people living with HIV and AIDS as well as new cancer cases in Africa there is a rising disease burden. As of 2011 Sub-Saharan Africa was bearing 69% of the global disease burden of HIV and AIDS (UNAIDS, 2012). This statistic was up by 2% when compared to 2009. In addition to this, in 2007, there were over 700,000 new cancer cases and nearly 600,000 cancer related deaths in Africa (Africa Health, 2011). It is predicted that by 2020, in Africa, there will be more than one million deaths per year from cancer (Merriman, 2010). Further, research has shown that in order to provide early treatment of cancer, and be able to manage complications that may arise, early diagnosis is needed. However, in much of Africa, early diagnosis of cancer rarely happens due to a combination of various factors such as: inaccessibility to screening services due to geographical distance and costs involved, and a health infrastructure lacking necessary equipment and personnel to deal with the disease (Ddungu, 2011). The illness pattern in HIV and AIDS is also changing as a result of the availability of anti-retroviral therapy due donors such as the President’s Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund (Merriman, 2010).

In Uganda, a country with a population of 32.9 million people, the health system is at the moment highly burdened by preventable diseases such as malaria, acute respiratory infections, and diarrhea. The situation is further exacerbated by the presence of non-communicable diseases such as cancer, though there is a lack of data at the national level for these diseases (Uganda Ministry of Health, 2012). For those suffering from HIV and AIDS, only about 50% of people who are eligible for anti-retroviral therapy (ARV) in Uganda are receiving it
(Uganda Ministry of Health, 2012). For those who are on ARVs, there is ongoing risk of developing opportunistic infections, a situation that demands therapies to relieve suffering and improve the quality of life (Merriman, 2010).

With this rise in disease burden, there emerges a need to recognize the value of palliative care and integrate the service within the public health system not only in Uganda but in the rest of Africa. Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. It focuses on the prevention of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms-physical, psychosocial and spiritual (World Health Organization, 2002). Palliative care is appropriate at any stage in a serious illness and can be provided together with curative treatment (Beresford L. and Kerr K. 2012).

According to the World Health Organization (WHO), there are six essential building blocks of a health system that include: service delivery, health human resource, information, medical products, vaccines and technologies, financing, and leadership and governance (Africa Health, 2011). With an intent of including these essential building blocks within the health system, some hospice and palliative care programs in Africa have partnered with similar programs outside the continent. These partnership programs aim at: fostering idea-sharing, educational opportunities, professional exchanges, improving quality hospice and palliative care across the world, and generating financial support (Foundation for Hospices in Sub-Saharan Africa, 2010).

Global Partners in Care (GPIC, was formerly known as Foundation for Hospices in Sub-Saharan Africa (FHSSA) is the US hospice movement response in Sub Saharan Africa and other
parts of the world in addressing the global challenge posed by HIV and AIDS, cancer and other life threatening illnesses. GPIC enables, enhances and encourages the development of quality hospice and palliative care programs throughout Sub Saharan Africa through partnerships between US and Africa hospice programs (FHHSA, 2010). As one staff of GPIC explained, “The goal was to partner those organizations in the US and in Africa with a goal of having them to really build the capacity of the organizations in Africa and to have an opportunity for both the US and the African organizations to learn from one another.” Although well-articulated, there is little evidence of these partnership programs tracking and documenting their partnership working.

In addition to this, it is important to note that while the hospice movement is global in nature, end of life care is always provided in a culturally acceptable manner. For instance, in Uganda it is acceptable to move a dying person from the hospital to their homes while in the US it is acceptable to move a dying person from home to a health care facility such as a nursing home. In a later section of this document, I discuss more on the background of the hospice movement in the world today including how it came to be in the US and in Uganda. It is from this background that I chose to explore how a collaboration between two hospice institutions from different cultural backgrounds, works. I used anthropological skills such as observation, participation, and interviewing, to collect data to identify patterns of behavior that enable these organizations to work together.

Most importantly, this project builds on other work conducted by anthropologists in the past some of whom have challenged their colleagues to get involved in health issues at an international level. For example Craig et al. (2009) discuss the role of anthropologists in studying health inequities, and analyzing and critiquing international health programs and policies. They
argue that such work has led to various shifts in focus on the causality of a disease e.g. in HIV/AIDS whereby rather than looking at individual behavior only, epidemiologists now focus on the impact of poverty. Other scholars for instance, Walshe et al. (2007), argue that while partnerships are encouraged in hospice and palliative due to World Health Organization definition of palliative care that encourages multi-disciplinary approach to care, ineffective partnerships could be expensive and difficult to administer. They discuss some potential barriers to partnership working that include: differences in geographical location, size of the organization, different organization cultures, different statutory frameworks and policy agendas. This calls for a discussion among the partner organizations to come up with shared values, roles, responsibilities, objectives and outcomes (Walshe et al. 2007). Although their discussion has focused on palliative care in UK and the rest of Europe, it generates important aspects for consideration in other parts of the world. This research project explores how the participating organizations have been able to overcome and deal with some of these barriers.

Purpose of the Study

It has been five years since the Center for Hospice Care (CHC)/Hospice Foundation (HF) in Indiana and Palliative Care Association of Uganda (PCAU) entered into a partnership. This partnership was facilitated by Global Partners in Care (formerly known as FHSSA) an organization whose main objective is to partner US hospice and healthcare organizations with likeminded groups around the world. The partnership aims at supporting PCAU achieve its mission of ensuring that everyone in need of hospice and palliative care services in Uganda receives the service. More specifically, the collaboration aims at supporting PCAU achieve its
objectives that include: capacity building, advocacy, information gathering and dissemination, and sustainability (CHC/PCAU/HF, 2014).

For the time that this collaboration has been in place, both organizations have experienced tremendous success by seizing various opportunities to further strengthen their relationship. As the two partner organizations look at what lies ahead for them, they would like to use their experiences in the past to inform their plans for the future. Also, they would like to share their experiences and lessons learnt with other organizations. Thus, this research project was carried out to fulfil this aim. More specifically, this study sought to find out the following:

- The strategies and approaches used in the partnership
- The achievements of the partnership
- Identify opportunities for growth
- Identify measures in place to ensure sustainability of the collaboration
- Identifying what other similar partnerships are doing/have done with an aim of transferring lessons learnt

It was anticipated that by investigating how partnerships are developed and organized, some insights will be generated that will enhance the management and operations of palliative care programs that will eventually contribute towards increasing access to palliative care services in the world.
RELATED LITERATURE

Definitions

Over the years, several terminologies have been recognized as referring to the care for the dying. For example, Payne et al. (2004) discuss the following terms as some of the words associated with caring for dying people: hospice care, terminal care, continuing care, palliative care, care of the dying, end-of-life care, and supportive care. In the UK, where the international hospice movement emerged under the leadership of Dame Cicely Saunders, these terms have gone through various changes as a result of debate between who provides which services and the activities involved. Another possible explanation for multiple terms results from extending care beyond cancer patients, as was the case when the hospice movement begun in the 19th century, to other non-curable ailments. “Hospice” was in the past a kind of building that travelers would check in to get some rest. It is a term that signifies the relationship between a guest and a host (Merriman, 2010). In a similar fashion, the term is used in palliative care to define the relationship between a patient and a caregiver. In some countries like in Canada, in the 1970s the word “hospice” was associated with a “death house” (Merriman, 2010). Consequently, there have been several explanations given to differentiate between hospice care and palliative care.

The term palliative was introduced in the 1970s to represent the comfort care that is provided during long term illness care (Merriman, 2010). This type of care is introduced to a patient during early stages of disease trajectory and continues after death through bereavement service to the family members. It is care that must include pain and symptom control including psychosocial, cultural and spiritual aspects of the patients and families.
Merriman, 2010). In this case, the term ‘hospice’ is used to represent a philosophy of holistic care that is given to a patient at their preferred place and their families. It is a term that has changed with time to include patients in multiple stages of illness and not just those who are in the final days or weeks of life (Kabel, 2013). Moreover, it has been observed that in Africa, the words “hospice” and “palliative care” mean the same type of care i.e. holistic, quality care for those with chronic illnesses (Di Sorbo, 2011). Thus, the two terms are used interchangeably. Perhaps this is because unlike in the US where there is a demand to distinguish the two terms due to administrative models and sources of payments, such demand is non-existent in Africa (Di Sorbo, 2011). Also, since hospice and palliative care share similar aspects, often times the two terms are used together.

To this end, this project refers to the World Health Organization (WHO) definition of palliative care: “An approach that improves the quality of life of patients and their families facing 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” (WHO, 2002). Since in Uganda and other countries in Africa the terms “hospice” and “palliative care” are used together, I have made an attempt to use the terms hospice and palliative care together.

**Historical Background**

During the 19th century an epidemiological shift started to take place in some parts of the world- mainly in Europe, North America and Australia. There was a reduction in deaths due to infectious diseases and instead people were dying as a result of chronic illnesses. With this
shift, a new term emerged that was used to describe this new population. The terms was “the
dying.” Also, people were no longer dying in their homes but in specially built institutions where
they would receive care. These institutions that emerged during the late 19th century to early
20th century came to be referred to as hospices or “homes for the dying” (Clark, 2004). As these
changes were taking place, people involved in the care of “the dying” started to think critically
of this new type of care and how best to provide it. As a result, the ‘modern movement’ of
hospice care begun to emerge. By the last quarter of the 20th century, the movement had taken
shape in most parts of the world. New terms such as quality of life, pain and symptom
management and psychosocial care were being emphasized. New ideas such as specialized
training for doctors, nurses, and professionals in disciplines such as social work started to take
place. Care was recognized as something provided by a multidisciplinary team. It was also
during this time that people started to recognize palliative medicine as a specialty. In the early
21st century in some countries, especially the affluent countries, hospice and palliative care was
seen to have reached a mature stage owing to the recognition it had gained from the public,
policy makers and the professions (Clark, 2004). However, in other parts of the world, countries
were struggling to provide this new type of care due to limited resources. Given that their
health budgets were already strained, hospice and palliative care was given less priority.
Nevertheless, the modern day hospice and palliative care movement traces its way back to the
19th century to those religious organizations and philanthropists that initiated institutions to
care for the dying.

The international hospice movement is attributed to Dame Cicely Saunders in the mid-
20th century who founded St. Christopher’s Hospice in London in 1967. Through her writings
about issues of dying that were published in journals and in some cases in the newspapers, she was able to gain global recognition and in the process stir a global conversation about how to best care for patients who were dying from chronic illnesses. Initially, her audience was mostly nurses as these were the people who were left to care for the dying. This was during an era where cure was heavily emphasized and thus, people who were dying were seen as an indication of a failure of the medical practice and consequently received less attention from medical doctors (Clark, 2004). It is from this discourse that huge developments in hospice care emerged. For instance, professionals from various disciplines such as doctors, nurses, social workers and other social scientists became interested in conducting research about care for the dying; more attention was being paid to upholding the dignity of the dying; and the term “total pain” came into being with an emphasis of defining pain according to what the patient says it is. St. Christopher’s hospice was designed as a place for clinical care, education and research, marking a difference from previous institutions for the dying. This new design became an inspiration for modern hospice development in other parts of the world (Clark, 2004).

However, while the hospice movement was taking hold in most affluent countries, in poorer countries it was taking much more time. Therefore, as a means to foster development in poorer countries, an arrangement of mentorship and “twinning” (establishing working relationships that enable for example sharing of ideas and knowledge between organizations) from more established hospices in the west was utilized (Clark, 2004). To further this development of hospice care throughout the world, the first generation of pioneers built on their international network and support. It was during this time that various international collaborating organizations were born such as: International Study of Pain Washington, USA;
International Congress on the Care of the Terminally Ill, Montreal, Canada; Foundation for Hospices in Palliative Care - now known as Global Partners in Care; Latin America Association of Palliative Care; and Asia Pacific Hospice Palliative Care Network (Clark, 2004).

The United States

In colonial US society, health care was provided within social networks and was characterized by oral traditions that were passed down through friends and families (Sobo, 2009). The fact that communities were more isolated than they are in the present day, called for self-reliance. People could provide for themselves what they needed with little or no support from medical doctors. Physicians faced competition from lay practitioners of all kinds of treatments (Sobo, 2009). With regards to care for patients with chronic illnesses, the first hospice unit is traced back to the late 19th century when Rose Hawthorne established a home for free care for ‘incurable and impoverished victims of cancer’ on New York’s Lower East Side (Clark, 2004). Rose worked together with a group of women known as servants of relief of incurable cancer in order to get this home started. Following this establishment, other homes began to open up in other parts of the US like in Philadelphia, Atlanta and Cleveland, as a result of efforts of other groups of women. Although these first homes were seen as more of institution establishment, there were also other individuals such as doctors and nurses who were providing this kind of care in their own small way across the country.

As the modern hospice movement was inspired by a nurse-Cicely Saunders from the UK, another nurse in the US- Florence Wald - influenced the establishment of structured care for people with chronic illnesses in the country. This occurred after a visit to the Yale University
Hospital by Dr. Saunders and Dr. Kubler-Ross from the UK who were advocates for the death with dignity movement (Kohler, 1974). Following this meeting a two year study to explore existing facilities in the US to care for the dying was conducted, led by Wald. This led to a landmark meeting that was attended by health professionals, leaders of religious fraternity as well as not-for-profit representatives. The agenda of the meeting was to discuss how chronic ill patients were cared for. It emerged that these patients were aggressively treated until they died. However, with the newly acquired knowledge on how to better care for these patients, the participants of this meeting saw a better approach in hospice care (Kohler, 1974). With a small grant from various foundations, Wald and her colleagues established Hospice Inc. in 1974 that was modeled after St. Christopher’s hospice in London. The Hospice was located in Branford, Connecticut and provided outpatient and physical care to the residents of Connecticut (Kohler, 1974). Following this achievement, Wald became involved in advocating for hospice care in the US and was largely supportive in the establishment of similar facilities in the country. She made a plea for home care instead of treatment at an institution. Specifically giving families more help with home care and visiting nurses, and giving the families and patients the spiritual, emotional and financial help to support end of life care at home (NHPCO, 2014). In 1978, an umbrella organization for hospice organizations in the US was formed known as the National Hospice Organization (today known as National Hospice and Palliative Care Organization –NHPCO).

Unlike the previous home cares that were used to provide care for patients with chronic illnesses in the US, the establishment of the hospice movement brought some new developments in the US. This included for example embracing the medical establishment for
providing care to patients with chronic illnesses, and receiving approval for insurance reimbursement. Today hospice care services qualify for reimbursement by Medicare, Medicaid and private insurance agencies (Kohler, 1974). As of 2013, there were 5,500 hospice provider organizations in the US (NHPCO, 2013). Hospice care is provided in various locations such as private residences, nursing homes, residential facilities, hospice inpatient facility and acute care hospitals. While initially the primary recipients were patients suffering from cancer, today they account for less the number of admissions. Instead, other non-cancer conditions such as unspecified debility, dementia, heart disease and lung disease account for the majority of admissions (NHPCO, 2013).

The hospice movement in the US has made significant achievements since the establishment of the first hospice in the country. Literature review on the history of hospice care in the US shows that hospice providers have been involved in a lot of advocacy and lobbying with the government. This has led to various achievements such as: acceptance of hospice care as part of the health care continuum; development of guidelines for hospice industry; development of clinical guidelines on supportive and palliative care services; recognition of hospice and palliative medicine as a specialty; and accreditation of hospice and palliative medicine program (NHPCO, 2014). More importantly for my research project, an affiliate organization for NHPCO is the Global Partners in Care (GPIC) that facilitates partnership programs between US hospice and palliative care organizations with similar organizations in Africa and other parts of the world.
In Uganda, palliative care services were introduced in 1993 by Dr. Anne Merriman from Hospice Africa UK who was conducting a feasibility study in four African countries (Kenya, Uganda, Zimbabwe and Nigeria) to explore the possibility of setting up a model hospice program adapted to the African context (Uganda Ministry of Health, 2012). Previously, Dr. Merriman had supported the setting up of hospice and palliative care services in Singapore and Kenya and also had working experience in Nigeria. Despite this, she felt a strong desire to establish a program that would become a model for other African countries. It was during the visit to Uganda that Dr. Merriman met with the then Minister of Health who was very supportive of the initiative and provided the necessary and much needed support from the government level. This led to the setting up of the first palliative care service in Uganda in 1993 (Merriman, 2010). In a similar fashion to previous hospice initiatives in other parts of the world, services in Uganda began in a small way. They began in a room offered by Franciscan sisters at a regional hospital in Kampala, Uganda. The services provided were low scale and included seeing patients in the wards at the hospital and taking them home and continuing with the care at home (Uganda Ministry of Health, 2012). Since there was no other physician in the country qualified to provide palliative care services, Dr. Merriman found herself providing the new service alone. However, as of 1994, one of the Ugandan nurses joined her after having been inspired by the results she saw in patients receiving palliative care. She was intrigued to see how their pain had been controlled as well as the recovery they showed for other ailments such as wounds. Today she works for the palliative care association of Uganda - a national body that
helps to coordinate and facilitate the provision of palliative care services in the country- and one of the participating organizations for this research project.

Even before the introduction of hospice and palliative care services in Uganda, the people of Uganda were known to take care of their ailing loved ones to the last moment. In most cases, patients would receive care from either a hospital or a traditional healer and would later be discharged to be cared for by family members at home (Uganda Ministry of Health, 2012). With the increase of HIV cases in the 1980s, some local organizations were set up that provided supportive care services to these patients. These local organizations did not provide comprehensive pain control for the patients, but they did bring some respite for patients and their families. However, the introduction of hospice services in 1993 helped to bring about the much needed relief from pain especially for people suffering from cancer and HIV and AIDS (Uganda Ministry of Health, 2012). Pain is a common symptom experienced by both adults and pediatric patients with chronic illnesses. From what began as a small hospice program in a room at Nsambya hospital, grew to become today’s Hospice Africa Uganda that has two other branches in Uganda. Hospice Africa Uganda has also influenced the establishment of hospice and palliative care programs in other parts of Uganda, as well as in other parts of Africa by various individuals and institutions. Currently these organizations in Uganda provide services in various forms such as: outreach mobile clinics, roadside clinics, facility day care and community day care (Uganda Ministry of Health, 2012). Also, while the initial recipients of palliative care were cancer patients, other diseases were also taken into consideration, especially HIV and AIDS, sickle cell anemia, and other conditions such as organ failure, burns, cardiac problems.
Present day palliative care service provision in Uganda boasts significant achievements not only in the continent but also in the world. These achievements include: existence of national guidelines for the provision of palliative care; allowing nurses and clinical officers to prescribe liquid morphine - medicine that is affordable and manages severe pain very well in patients with chronic illnesses; inclusion of palliative care in the teaching curriculum of nurses and doctors at institutions of higher learning; the establishment of the Institute of Hospice and Palliative Care in Africa; and a joint public-private partnership that has seen Hospice Africa Uganda reconstitute liquid oral morphine for use by all public and private institutions in Uganda. Indeed, in 2007, Uganda was among one of the few countries in the world to have successfully implemented the World Health Organization (WHO) recommendation that states that ‘pain relief and palliative care programs are incorporated into existing health care systems’ (Stjernsward J, 2007). As of 2012, palliative care service provision in Uganda was in 61 districts of the 112 districts throughout the country (Uganda Ministry of Health, 2012).

Like other countries in Africa, Uganda is striving to avail and make accessible hospice and palliative care services in the country. In a similar way to other countries in Africa for example, Kenya, Tanzania, Ethiopia and Malawi, the models of delivery of care include home based care, day care services and in some instances inpatient care. However, Uganda has been hailed as an example of a hospice model for Africa. For example, it is the only country in Africa where nurses and clinical officers are allowed to prescribe morphine to help alleviate pain among chronically ill patients. This means that with the absence of a doctor or pharmacist, nurses and clinical officers are empowered to do something to make patients’ lives as comfortable as possible. This is quite an advantage for the country given that there is a high
ratio of doctor to patient which increases the likelihood of a patient being cared for by either a nurse or a clinical officer rather than by a doctor. The process to allow these cadres to be prescribers was not an easy one as it involved changing a statutory law which takes time. This called for a lot of lobbying with the Government of Uganda. This is an initiative that other countries such as Kenya, are working to achieve. Further, the establishment of an institute for higher learning in palliative care in Uganda, has over the years seen the county host health professionals from several African countries who come to learn and gain practical experience on how to deliver care tailored to an African context. This institute offers diplomas and degrees in palliative care (Uganda Ministry of Health, 2012).

As previously mentioned, the twinning of hospices in different parts of the world began as a way of supporting hospice and palliative care establishment in areas where it was taking longer for the services to take hold especially due to limited resources. The partnership program by Global Partners in Care (formerly known as FHSSA) is one of these initiatives that supports the partnering of hospices and palliative care organizations in the world. At the core of its formation was the growing need to respond to the HIV and AIDS pandemic that was taking a toll on hospice and palliative care providers in Africa. This became evident to US hospice leaders when they visited hospices in Zimbabwe and South Africa in the late 1990s. Following this visit, these leaders decided to form a non-profit organization that could mobilize American Hospices response to HIV and AIDS in Sub Saharan Africa. Thus, FHSSA was formed in 1999 (GPIC, 2014). This program has over the years developed into a proven partnership model to the extent that the organization has recently rebranded to Global Partners in Care (GPIC) with a view of expanding to other regions of the world, but still committed to partnerships in Africa.
(GPIC, 2014). There are currently more than 80 US partners in 30 states who are involved in a partnership program with hospice and palliative care organizations in 13 countries (GPIC, 2014).

Specifically in Africa, the partnership program by Global Partners in Care is described as a relationship between a US and African hospice/palliative care organization (FHSSA, 2010). The relationship involves: idea sharing; educational opportunities and professional exchanges; engage US hospices in improving quality hospice and palliative care internationally; and generate financial support for the African organizations through fundraising efforts of the US partners (FHSSA, 2009). Global Partners in Care also collaborates with regional organizations such as the African Palliative Care Association and national associations in the region for purposes of identifying and supporting hospice programs in the region. Further, Global Partners in Care is seen as promoting access to compassionate care especially for the poor in densely populated urban areas to the most remote rural areas across Africa. Compassionate care is defined as care that provides resources such as medicine, nutrition, medical supplies, bedding and school uniforms to orphans and vulnerable children, modes of transportation such as bicycles and vehicles, creating volunteer networks and youth care clubs to engage and empower the youth (FHSSA, 2009). Indeed, the three partnerships that participated in this research project provide evidence on how they have been able to access and provide these resources mentioned in this FHSSA report. Particularly, the CHC/HF and PCAU partnership illustrates how their collaboration has led to promoting educational opportunities especially for health care workers in Uganda, increasing access to pain relieving medication as well as promoting the exchange of ideas among stakeholders. Additionally, the two other participating partnerships, explained how as a result of their partnership, they have been able to access
modes of transport to help them reach patients in far to reach places; train health care workers and volunteers in palliative care, access medical supplies, and establish a bereavement program for children.

Organization Collaboration

There has been some research conducted on the topic of organization collaboration in the past to establish the successes and challenges of partnership working. Some of this previous research has focused on global partnership models - a theme that resonates with this research project. Also, some of this research has suggested future areas of investigation in partnership working, such as conducting assessments, and key principles to investigate (e.g. decision making processes, motives, values and beliefs). For instance Ball et al. (2005) note that there is a dearth of information to show the benefits when organizations collaborate with one another. It is the evidence that is lacking, not the collaborations. The findings of this project attempt to fill this gap of evidence. Similarly, Seitanidi et al. (2010), discuss the importance of partner organizations sharing the same scope of operation, industry sector and motives in order for a long term partnership to be possible. These factors are key indicators to partnership success. Evidence of this argument can be found in the findings of my research whereby participants discussed retrospectively about how they came into a partnership. The motives and ideas mentioned by the participants that led to establishment of the partnership, correspond to the factors discussed by Seitanidi et al. (2010).

A review of literature on global partnerships among hospice and palliative care organizations shows how these collaborations are contributing to an increase in palliative care
services in different parts of the world. Of importance to this project is Walshe et al. (2007) who discuss partnerships working in the field of hospice and palliative care and acknowledge the positive outcomes of such partnerships while at the same time calling attention to factors that can lead to ineffective partnerships. The authors suggest two ways of finding out if a partnership is successful: one, by assessing how a partnership works and two, by assessing the outcomes of a partnership. Assessing how a partnership works is described as finding out if the partner organizations acknowledge the need for the partnership; develop and maintain trust; having clear partnership arrangements; as well as monitoring, reviewing and experiencing organization learning. This research project sought to find out evidence of how a partnership works with an intent of laying a foundation for conducting an outcome assessment in the future. Another study that influenced this research project is by Vosit-Steller et al. (2011), who conducted a capstone project of a collaboration between two nursing groups- one in the US and one in Romania. This research shows the transformational changes that both groups went through in increasing their knowledge and skills in palliative and hospice patient care as a result of their collaboration. Through teleconference meetings, onsite conferences, research, publication and in-person visits; both organizations were able to learn from each other different nursing practices in the area of end of life nursing care.

Further literature review on hospice and palliative care in Africa yielded some more information that contributed to this project. For example, Di Sorbo (2011), compares hospice and palliative care in the US and in Africa. He argues that although often times, partnerships between American and African institutions are viewed as one way – Americans teaching Africans something- there are lessons that Americans too can learn from Africa to inform their
programs locally. For instance, while hospice care in the United States is primarily focused on prognosis that leads to care being provided during the last few days and weeks of life, in Africa focus is on providing quality care for those with life threatening illnesses. Certainly, the findings of this project illustrate Di Sorbo’s view on this learning process. On the same topic of hospice and palliative care in Africa, a special report written by palliative care service providers in the region asserts the importance of palliative care services given the disease burden of HIV and AIDS and rising cases of cancer. With complexities involved in predicting with certainty the progression from HIV infection to AIDS death, and with the advent of Anti-retroviral therapy (ART), people with HIV and AIDS are living longer. Given this scenario there is a need for effective monitoring of anti-retroviral (ARV) therapy, managing any toxicity and side effects arising from these medications, including addressing the new co-morbidities that come about as a result of the prolongation of life. This is where palliative care comes in (Africa Health, 2011).

Contribution to Anthropology

In addition to the research on palliative care in Africa and collaborative partnerships, this research project makes contributions to the discipline of Anthropology by addressing some areas that have been raised by other anthropologists in the past. For instance, Erickson (2003) asserts that there is a need for medical anthropologists to get involved in the state of the world’s population by offering their critical analysis and opinion. She explains that there is an important and desperate need for medical anthropologists to get involved in various global health related topics such as changes in population growth structure, health transition and
health inequities. Some of the predictions that she makes in this article (that was published in 2003) are already happening in the world today. She discusses the likelihood of an increase in chronic illnesses, the effect of war and violence in the world’s health population in various parts of the world, as well as a shift in the population structure. Her view reiterates the aim of my research study which is to offer an anthropological analysis to a global response to chronic illnesses.

Additionally, other scholars discuss how there is a need for anthropologists to focus on the global arena given the increased human interaction across borders. For instance Craig et al. (2009) describe how medical anthropology has been characterized by applied ethnographic research that includes studying social and cultural factors linked to improving community health in developing countries. Through the findings of my research study, we see how links between organizations in two separate geographical locations are facilitating availability and accessibility of hospice and palliative care services.

Further research indicates that over the last decade there has been a continued flow of financial aid from wealthier to poorer countries attributable to efforts from health activists and other professionals including medical anthropologists who have been vocal concerning the realities of health inequalities and disparities in the world. At the same time, these health activists remain alert and thoughtful to concerns on issues such as governance, oversight and public health efforts on health care systems. While questions still linger in discussions as to whether this aid should be channeled to government agencies or to non-governmental organizations (NGOs), some maintain that progress on specific diseases will only be met if aid is channeled through special efforts that are often led by NGOs, universities and other
international actors (Pfeiffer and Nichter, 2008). In this study I examine how NGOs are leading efforts in addressing the problems that arise with the increase in chronic illnesses.

Other scholars whose anthropological works influenced this research project are Elisa Sobo and Paul Farmer. Elisa Sobo has conducted several studies within health services. In her book, *Culture and Meaning in Health Services Research* (2009), she discusses her desire to see more anthropologists involved in conducting research with an aim of improving health care. She contends that health services research (HSR) is not focused on treatment standards as is the case in clinical trials. Instead HSR aims at optimizing the delivery of care through studying various elements such as staffing issues, patients’ experiences and health care workers’ experience in providing care (Sobo, 2009). To this end, my research study focusses on how collaboration between palliative care organizations leads to increase in access to palliative care services. In other words, finding out the experiences of stakeholders involved in partnership working. Paul Farmer’s experience of working in parts of the world where the disease burden is huge but resources are few has also been instrumental in this research study. Specifically, I use his work on how collaborations are key in facilitating access to health services. Interventions from such collaborations have been seen to be more successful when they are led by a local organization (Farmer, 2005).
RESEARCH METHODS

The project began with consultative meetings held between my academic advisor, representatives from Center for Hospice Care / Hospice Foundation (CHC/HF) and I. During this time, approval was received from both CHC/HF and Palliative Care Association of Uganda (PCAU) to conduct the study. Following the consultative meeting, I developed guides in consultation with CHC/HF and PCAU that listed several areas of interest about the partnership. These guides consisted of semi-structured questions so as to facilitate eliciting information from the different stakeholders while allowing me to ask for additional elaboration when needed. Ethical approval was sought and received from UNT Institution Review Board. The study design called for purposive sampling. Participants selected for the research had to be affiliated to either CHC/HF or PCAU, i.e. either involved in the day to day running of the partnership or have participated in partnership activities. Data was collected for a duration of four months - March to June 2014. I approached potential participants and explained the nature of the study. Informed consent was sought verbally from each participant prior to conducting an interview. When a participant agreed to participate in the study, both the participant and I signed a copy of the consent form. Some of the participants requested to keep a copy of the signed form while others did not. The interviews lasted between fifteen and thirty-five minutes. Of the thirty-four potential participants contacted, only one of them was unresponsive. Thus, a total of thirty-three interviews were conducted. All interviews were conducted in English and all were digitally recorded.
Data Collection

Data were collected in five phases: Phase 1 consisted of a document review of CHC/HF organization documents such as newsletters, quarterly reports, brochures and other available literature, e.g. materials on organizations’ website and on social media. Data obtained from this review showed the history and mission of the organization, how the organization is structured in terms of leadership and staff, the key areas of operation of the organization, and description of their partnership with PCAU.

In Phase 2, I reviewed Global Partners in Care (GPIC) organization documents that included: annual reports, strategic plan, ten year report, newsletters and content available on the organization’s website. This data revealed the history and mission of the organization, the programs that the organization is involved in especially the partnership program, and a description of the PCAU/CHC/HF partnership.

Phase 3 consisted of three parts: (1) I reviewed PCAU’s organization documents such as newsletters, annual reports, brochures, strategic plan and other available literature, e.g. materials on organizations’ website and on social media. This data showed the history and mission of the organization, how the organization is structured from the leadership level to the operational level, programs of operation, and a description of their partnership with CHC/HF. The review was conducted at PCAU office in Uganda. When I started the review I was shown by a staff member of PCAU where to work from. This was in another staff member’s office. The staff member was out in the field conducting mentorship visits of trained health professionals. Upon their return, I moved to the reception area where there was an available desk; (2) I conducted observation of PCAU staff working as well as participated in organization events that
included a staff update meeting and a farewell meeting for one of their visitors. These activities revealed the attitude and nature of interactions of the staff; (3) I conducted qualitative interviews with stakeholders of PCAU in Uganda. This involved either face to face or over the phone interviews. Face to face interviews with staff were conducted during office hours at PCAU office. The interview setting ranged from individual staff offices to the kitchen. Since some staff members shared an office, I had to look for an available room and at one time the kitchen was the only available space. For some of the board members, I interviewed them at their places of work. There were also three interviews conducted at the interviewee’s homes. These people lived within the suburbs of Kampala and it was possible for me to get to them. Phone interviews were done with health professionals since they are located in different parts of Uganda and it was not possible for me to visit each one of them. Sometimes the connection was poor and I had to redial the number again. On two occasions, I had to call back because the health professional was in the middle of conducting ward rounds while the other was on a break having a cup of tea.

For staff, I asked them questions such as how important the partnership was to them, what role they played in the partnership, some of the successes they have experienced as a result of the partnership, what challenges they may have experienced in working with CHC/HF and what benefits they thought PCAU got out of the collaboration as well as what they thought CHC/HF benefitted from the partnership. I asked board members similar questions. For health professionals who have received palliative care training as a result of efforts from this partnership, I asked questions such as what they had learnt from the training, how useful the training was to them, if they were aware of an existing partnership between PCAU and CHC/HF
and what areas they would like PCAU and CHC/HF to get involved in promoting palliative care in Uganda.

During Phase 4, I conducted qualitative interviews with stakeholders of CHC/HF in Indiana. These were done through face to face interaction and were conducted at CHC office. The room that I was assigned to carry out the interviews was a conference room that had an African touch to it given the numerous art pieces from Uganda that were on display on the wall and on the desk. They included two small drums one with the word Uganda inscribed on it, a painting of a dance group, and a sculpture of a male figure who looks like he is playing a musical instrument. There was also a miniature flag of Uganda.

For staff, I asked them questions such as how important the partnership was to them, what role they played in the partnership, some of the successes they have experienced as a result of the partnership, what challenges they may have experienced in working with PCAU and what benefits they thought CHC/HF got out of the collaboration as well as what they thought PCAU benefitted from the partnership. I asked board members similar questions. At CHC/HF I had an opportunity to interview some students who had gone to Uganda for an internship program as well as a volunteer. Interviews with interns were conducted at their campus which is located close to CHC. The interview setting included a cafeteria and a lounge area. For the interns, I asked questions such as what they had learnt from the internship program, how they were using the knowledge they had acquired, and their feedback on their observation of how PCAU and CHC/HF work with each other. As for the volunteer, I was interested to find out if they had knowledge on the partnership between CHC/HF and PCAU, how the partnership benefits CHC/HF and how it benefits PCAU, and if they play any role in the
partnership. I also participated in some organization events where I did observation of staff working. The events included an advocacy meeting and a volunteer’s luncheon. These events revealed the attitude and motivation of the staff and the organization’s approach in working with people and institutions in the community.

Lastly, in Phase 5 I conducted qualitative interviews with representatives from three peer organizations located in the US and in Africa, as well as from Global Partners in Care. These interviews were conducted over the phone. Some of the participants were at home during the time of the call, in the office, while another one was driving. Further review of these peer organizations was done by assessing material found on these organizations websites and from publications by GPIC. For staff from peer organizations, I asked questions such as, the history of their partnership program, how they would describe their partnership program, what role they play in the partnership, and what successes and challenges they had experienced. For GPIC staff, I asked questions such as, the history of the partnership program, what they define as a successful partnership program, their view on the CHC/HF and PCAU partnership and what they would like these partnership programs to achieve in the future.

All interviews were transcribed verbatim in English. This happened in between interviews and as close as possible to when the interview took place. This allowed me to review how I was asking the questions and if I was seeking enough clarity. This information was useful for subsequent interviews. Content analysis was used to identify common themes from the transcriptions. All the data was entered into NVIVO 10 (software for analyzing qualitative data) which involved identifying, grouping and interpreting major themes from the interviewees’
responses. I reviewed these themes further and some of them were subdivided whereas others were merged.

**Deliverables**

The data from the research was presented to both partner organizations in two main formats. First, I submitted a report discussing the structure, components and design of the partnership. In addition, information on the structure of two other similar existing partnerships was discussed. Second, the findings and recommendations of the research were disseminated through a verbal presentation to staff at both CHC/HF and PCAU. This was done in the form of interactive meetings. Due to geographical distance, the presentation for PCAU was done via Skype.
RESULTS AND FINDINGS

Demographics

A total of thirty three interviews were conducted. These include staff and board members from CHC/HF and PCAU, staff from peer organizations, students who participated in an internship program, health professionals, volunteer and staff from GPIC. Figure 1 below shows the various stakeholders interviewed.

![Figure 1. Number and type of stakeholders interviewed.](image)

Staff members from CHC/HF and PCAU as well as from peer organizations cited various roles that they play in their individual organizations including communication, fundraising, finance and accounting, marketing, training, coordination and management.

A majority of the interviewees were female totaling 22 of the participants while male participants totaled 11. This did not come as a surprise as I noticed that in most of the offices I
visited, there were more women than men. Figure 2 below shows the distribution of all the participants by gender.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>22</td>
</tr>
<tr>
<td>Men</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
</tr>
</tbody>
</table>

*Figure 2. Gender of participants.*

**Findings and Recommendations**

Overall, the majority of the participants are aware of the partnership between CHC/HF and PCAU. Several of them were able to describe in detail the relationship that exists. When asked to describe the relationship between CHC/HF and PCAU, staff, board members and volunteers used words such as: positive, fruitful, supportive, productive, good, friend, very interesting, educational, an eye opener, very strong, and heartwarming. Other stakeholders used terms such as: best I have seen, excellent, model partnership, shining star. These views were observable in some of the participants’ faces whereby their faces light up indicating a sense of enthusiasm and excitement. Figure 3 below illustrates the views mentioned by the participants.
Figure 3. Participants’ description of CHC/HF and PCAU partnership.

For a majority of the staff from CHC and PCAU, their organization involvement in the partnership portrayed enthusiasm and excitement. Nine staff members from both organizations indicated how pleased they were to be a part of a team trying to make a difference. Some of them stated this explicitly for example, “I am just really proud of our agency that we are partnered with (organization x)” (S007_B).

The following section discusses the findings of the study that have been organized thematically into five major themes based on the data generated from the interviews. These themes provide evidence that relates to the objectives of the project. The identified themes include: Elements of CHC/HF and PCAU that lead to effective collaboration, major achievements of CHC/HF_PCAU partnership, benefits of the partnership to the organizations, how peer organizations have structured their partnerships, and opportunities for growth for
CHC/HF_PCAU. Based on these findings, there are eight specific recommendations for CHC/HF and PCAU. Additionally, there are three areas identified from peer organizations that are worth consideration by CHC/HF and PCAU.

Elements of CHC/HF and PCAU that Lead to Effective Collaboration

A cross section of stakeholders discussed some of the innovative ways that they believe have contributed to CHC/HF and PCAU working together effectively. These include: having partner visits, bringing on board other local organizations, staff and administration of both organizations getting involved, and having a person(s) who is seen as the driving force. These factors were mentioned as some of the key influencers to effective collaboration.

Finding: CHC/HF and PCAU share some similarities in relation to their scope of work, industry sector and motives. While this finding may appear obvious for any partnership arrangement, the findings of this research project further reinforce the importance of having two partner organizations being in agreement on program goals. Information received from participants as well as from review of both organizations documents, reveal that CHC/HF and PCAU share similar goals and objectives that include: serving the needs of chronic ill patients and their families and having a sense of no end to caring. This finding was further revealed during organization events. For example, during a volunteers’ luncheon organized by CHC/HF, while discussing some of the achievements of CHC/HF in the past year, a senior staff member of CHC/HF spoke about the value that their organization has had in supporting PCAU in extending care for people with chronic illnesses in Uganda. This can be translated to emphasize the mission of CHC/HF which advocates for no end to caring.
Finding: Partner visits help to strengthen the relationship. Having staff from CHC/HF visit PCAU and also having PCAU staff visit CHC/HF was described as a means of learning more about one another. Of critical importance is the fact that it was after staff from CHC visited PCAU in 2008 that the partnership really kicked off. The importance of these visits was acknowledged by participants from both CHC and PCAU. This finding provides evidence that for a partnership to work more effectively, organizations need to create time and visit their partner organization so as to get a feel and understanding of how the other organization operates. The remarks below explain this further.

CHC has taken this partnership as its own. It has embraced it right from the administration to the staff. They all understand this initiative and the work. As in their role to help out in making this partnership to work. This all comes back to the time when we had the initial meetings, conversations way back in 2008. This is when we had an exchange visit for staff in order to have a better understanding right from the administration to staff. So the strategy is…. It has been open to all staff. We normally have these updates from people like us -who are coordinating these initiatives on behalf of the organization- to the rest of the staff. They have this sense of appreciation that ‘oh, this is something that is actually working.’ I think the only strategy is that we have been open. It is not something that we have been working from say a section. It has been open to all staff and they basically know what is going on (S001_B).

Our partnership started in 2008 and the approach that we took was like communicating initially on mail, then we had Skype and after that we started exchange visits. Members of CHC visited Uganda and PCAU was also able to visit its partner in the US, the Center for Hospice Care. That kind of brought us together it strengthened the relationship (S005_A).

During my visit to PCAU, I encountered a visitor from CHC/HF who was in Uganda participating in some of PCAU’s activities. When the time came for her to leave Uganda, the staff at PCAU organized a small farewell meeting that was attended by the staff. During the meeting, the staff expressed their gratitude to their visitor for taking time to visit with them. The staff spoke each at a time. One of the staff mentioned their gratitude to CHC/HF staff for sacrificing a portion of their salaries to support the work of PCAU. This indicates an awareness
by PCAU staff on the mechanisms of the partnership. To further show their appreciation, PCAU staff gave the visitor some gifts to take back to the US and expressed their wish to see her visit them again. The visitor in her part, expressed gratitude for the hospitality given to her. She explained that during her stay she had time to see the country by travelling with some of the staff as they conducted various activities such as trainings, mentorship visits and advocacy meetings. She stated that she will be sharing her experiences with CHC/HF when she got back to Indiana.

**Finding:** working together with other local organizations contributes to achieving partnership objectives. Participants from both CHC/HF and PCAU explained that working with each other had led them to involve other organizations in each of their communities in order to fulfil partnership activities. This finding illustrates that organizations involved in a partnership program will in most cases have to bring other organizations on board in order to fulfil the goals of their primary partnership. One of the board members explained how collaboration between PCAU and service providers in Uganda facilitates the internship program (one of the partnership’s program). They explained that since their organization is a health care provider, they “are working with PCAU” especially in taking in students for internship as well as welcoming visitors that want to experience the delivery of palliative care in Uganda. Another staff member appreciated how the partnership activities had led their organization to form important connections in their local community.

You know, it is actually one of the things.......and it may sound a little selfish but I don’t think any of us views it as being selfish. But without PCAU we would not have had some of the wonderful relationships with some of the universities like [institution y] that is right in our backyard. Without PCAU we would not have those relationships. PCAU has been like the key to that door and we benefit from having (institution’s y) alliance. Not necessarily
financially and not necessarily from status perception but it opens doors to relationships and resources that we would have had a much harder time making on our own (S004_B).

I am working with an organization that is doing health work. So PCAU is working with my organization and there are update meetings. Because PCAU promotes palliative care activities and the organization I am working with is doing palliative care, PCAU brings visitors and students to my organization for experience (B003_A).

I had an opportunity to attend an advocacy meeting between CHC/HF and an institution of higher learning located within their community. This meeting involved sharing the programs of CHC/HF and especially the opportunity they present for medical and global health students of this institution, to participate in an internship program in Uganda. This meeting shows that it is as a result of this partnership that CHC/HF has with PCAU, that CHC/HF is able to gain foot in these institutions and in the process also highlight their involvement in improving lives in their own community.

Finding: the involvement of staff and administration of both organizations has been a significant contributor to effective collaboration. While describing how the partnership works, a participant said of the partnership, “There are strengths at both ends and that strength can easily be blended. I think there is a good back and forth relationship. I think it’s an active partnership. It’s not a partnership that is just on paper. I think there is investment from both parties and there is also ability for both parties to be able to learn from each other as organizations” (V001_B). In fact, participants’ views and information obtained from organization documents show that the involvement of staff includes performing payroll deductions in order to fund partnership activities such as the training of health professionals in Uganda (CHC/PCAU/HF, 2014). This shows the level of commitment of staff to the partnership. The participation of staff and administration was also evident during organization events that I participated in and
observed. For instance, the presentation done by one of CHC/HF management staff during the volunteers’ luncheon included a highlight of their partnership with PCAU, a gesture that indicates that management is aware and involved in the collaboration.

In addition to this, it was pointed out that “the organization’s attitude” had been an important factor in making the partnership work. This suggests that another contributing factor to effective collaboration is staff having a positive outlook.

I think part of the success in overcoming the roadblocks has been that our organization has a can do attitude. “Yes we can do this. Maybe when we started out we went [ ] but let’s find a different route. It may take a little bit longer, we may need to raise a little bit more money, but we will eventually get there’. So I just think that we have a group of people that are not willing to take a no for an answer {laughs}. We can find a way to do it (S005_B).

Finding: organizational staff who assist in coordination of partnership activities and update other staff with news and events is a key ingredient to effective collaboration. Having an effective leadership network in place including clear roles, has been a great pointer towards partnership working. While at PCAU, I observed how the finance director facilitated the disbursement of funds to support various activities of the organization. This consisted of making sure funds intended to support for example, an upcoming training were released on time before the team went to the field. I observed her communicating with the programs manager to arrange this. She further explained to me how she had to also make sure that funds for children in their bereavement program were released on time to support any school purchases needed by the children. The bereavement program is one of the partnership initiatives in Uganda. All these was happening during a visit by auditors to the organization who would also call on her when they needed to access certain documents.
Still on the topic of coordination of partnership activities, one of the participants interviewed explained how she supports this coordination: “when we receive students or visitors who come, they are interested to see the work that we do. I am involved in helping them plan their time here. Once we have planned some activities, I may be with them or I send them to somebody. So that programming on the ground, I get so much involved” (S004_A). The idea of having clear roles for staff involved in the management of the partnership was further explained by one participant who stated that, “One of the things that has really helped us a lot in being able to orchestrate things more effectively from our end is having person y as our staff......has really helped us a lot in helping staff understand more of the challenges there and also bridging that communication gap that exists. It has worked very well” (S002_B). Another participant explained how “the goodwill of all the people that are involved in it has really helped in steering the partnership in the right direction.” They continued, “You know focusing on this global partnership or initiative or all of this is very important to us of the things that we do on the side with it. So this partnership is that important that people will take the time from other jobs that they are doing to make sure that this partnership flourishes” (S004_B). This leadership network was evident during organization activities that I observed and participated in whereby staff showed willingness to get involved in partnership activities in addition to their other organization roles. A case in point, the example of the finance officer at PCAU.

Finding: Fundraising from various sources supports partnership working. Review of literature on partnership programs facilitated by Global Partners in Care, indicate that partners involved in these collaborations need to come up with their own ways of identifying and securing resources to support their activities. In this case, CHC/HF and PCAU generate resources
from various sources. These include: holding events in the community that include for example auctioning handcrafted items from Uganda in the US, a soccer gala in Uganda; use of documentaries to show case the work of PCAU in the US; advocacy using mass media in Uganda; individual contributions from CHC/HF staff; and proceeds from PCAU’s biennial conference, membership meetings. The advocacy events not only lead to receiving contributions from organizations and individuals, they have also supported networking and building of relationships in the community that have been significant for the two organizations. The section on achievements includes more information on some of these connections.

In addition to this, it is important to note that other stakeholders besides those from CHC/HF and PCAU, pointed out some significant elements worth discussing here that they believe contribute to effective collaboration between CHC/HF and PCAU. Such factors include for example the willingness of both CHC/HF and PCAU to learn from each other. This was described as “openness.” One stakeholder pointed out,

When you look back at that partnership... not that the others are not successful.....it is truly a partnership. People treat each other with respect, there is a mutual respect, there is learning that occurs in the organizations that is rational. Because I think that the programs in the US and the programs in Africa have learnt a lot from one another but it’s that openness for learning to occur that I think it is really important (G_001).

This statement can be interpreted to mean that both organizations acknowledge the need of this partnership – a key pointer to effective collaboration. Further, two participants explained that other positive elements of CHC/HF and PCAU partnership are as a result of having strong leadership in place: “I say that they are a wonderful example of a partnership. They have as an organization embraced the partnership. They have one or two champions like (person x and
person y) you know from the leadership standpoint” (G_003). Another participant concurred with this view by stating that, 

The other thing that I just wanted to say is that, I think that I was surprised that both CHC and PCAU really have strong individuals that...... strong forces behind.... A lot of the changes that I was seeing....I think you can see that in (person x and person y at CHC) and (person z at PCAU)....those people are really excited and really motivated that it makes other people excited about palliative care and other people excited about their priorities (I_001).

![Figure 4](image.jpg)

**Figure 4.** Elements contributing to effective collaboration between CHC/HF and PCAU.

**CHC/HF_PCAU Partnership Achievements**

Achievements of the partnership between CHC/HF and PCAU were largely associated with the training of health professionals in Uganda, acquiring an office for PCAU, making a documentary showcasing the work of PCAU in Uganda, the internship program, and winning of the Global Partners Award in 2012. 66% of the participants stated one or more of the above factors when referring to the successes that this partnership has had. In addition to this, staff
from Global Partners in Care, described the CHC/HF and PCAU partnership as “a truly model partnership” and “a shining star.”

Finding: the training of nurses and clinical offices in Uganda in palliative care, was described as “a big thing” and “really satisfying.” Stakeholders from both organizations shared this view. As the remarks below show, this has to do with the added capability of these trainees to offer palliative care services in Uganda as well as the amount of funding necessary to fund health professionals to take the course.

I will tell you one of the things that there has been a lot of successes that we have been able to accomplish on the ground. Like funding the CPCC’s (Clinical Palliative Care Course) students. We have had 19 students so far; we have seven more so it will be a total of 26 students that we will have funded to go through that program that normally leads to significant outcomes. Because every time we do that it adds more districts in the code yellow (color that PCAU uses to illustrate districts on the map of Uganda that have palliative care services). So that is really satisfying (S002_B).

I think lots of successes. One, we’ve been able to train about nineteen students who have specialized in palliative care and these nineteen students have gone back to their own districts to implement palliative care services. Actually they are the leaders of palliative care in these districts. Which means we have added nineteen more districts on top of what was already existing. So you can see that is spreading our wings further in Uganda. So that has come about as a result of the partnership. Which is also important (S005_A).

Most importantly, the training of health professionals affects other factors of palliative care in Uganda that are of interest to PCAU. For example, some health professionals explained how (as a result of the training) they were able to bring about accreditation of their different health facilities in order to be able to procure and prescribe liquid morphine. Liquid morphine is an affordable and effective medication for pain relief especially in patients suffering from chronic illnesses. The health professionals explained how this accreditation would not have been possible without them having the knowledge and certification that they received as a result of the training.
Furthermore, it is important to note that these trained health professionals also reported other positive changes at a personal level. These changes include: a change in attitude towards patients experiencing pain; increase in career prospects; as well as a change in outlook towards palliative care. Some of these trained health professionals explained how they were looking forward to furthering their education by pursuing a degree in palliative care at the Institute of Hospice and Palliative Care in Africa that is located in Uganda. One health professional commented that “This training also opened my career because with this palliative care I can build my career. It can help me do planning for palliative care for patients in the country and those kinds of things” (HP_001). Another health professional described how she was able to see the transformation in a patient after controlling their pain:

> When I joined the training my expectation was to able to help alleviate pain in these suffering patients of which I have been able to do and I am still able to do. The patients come with pain and I prescribe morphine. I am very happy the next morning when I see the patient can smile. After I control the pain the patient is able to talk, I am able to communicate with them take their history which was a challenge to me before the training. I am now conversant with that. At least now the patients don’t die in pain. These opportunistic diseases, I am able to manage them (HP001_A).

This illustrates how the trained health workforce is becoming an important tool for advocacy for palliative care in their own communities. This reinforces the work of PCAU in Uganda.

Finding: PCAU’s recent acquisition of their own premises in 2012 was viewed as an achievement and described as “giving stability to PCAU.” This building not only gives PCAU a place to operate from but it is also a place where the organization can hold events such as membership meetings and other national events at a relatively low cost. Previously, the organization was renting an office and they were running out of space to hold membership
meetings. The new building is located off a highway that leads to the international airport in the country. It is a location that is easily accessible for individuals especially those using public means of transport. Like other countries in Africa, a majority of Ugandans rely on public means to move from place to place. Thus, the location of PCAU is a convenient place for their members and stakeholders. I used public means on several occasions to get to PCAU while I was in Uganda, and I found it very convenient. Even when it rained so heavily one morning, I was able to do a short run from the main road to the office and arrive barely wet. It is about 110 yards from the road to the office. Funding for the building was raised by both organizations with PCAU raising part of the amount required while CHC/HF supplemented this amount.

Stakeholders commented about this by stating the following:

I think that we’ve given PCAU stability that maybe they didn’t have. Uh... we helped PCAU secure a home (S005_B).

The other thing that is a benefit to us is that they have given us an office. The fact that they supported our existence. We have an address. If they had not given us the support we wouldn’t have an address. We wouldn’t have been recognized, we wouldn’t have a voice to reckon with as we have today (B005_A).

I think helping PCAU to get a building to operate from. I think it is very important (S006_B).

Yeah... plenty of success I should say because now we have a permanent ground. PCAU didn’t have its own permanent ground but now we have permanent offices because our partner came in and supported us with some funding. We added onto that funding that they have given us and we were able to obtain our own offices (S005_A).
Interestingly, CHC/HF also moved offices in 2012 and are now operating from their own premises.

Finding: the use of documentaries such as Okuyamba and Road to Hope to showcase the work of PCAU in Uganda was cited as a success. In fact, stakeholders’ responses and information obtained through document review showed that the documentary, Okuyamba, received both national and international recognition by winning several film awards as well as being used as an advocacy tool by other organizations across the world. These other organizations used the documentaries to sensitize their staff and stakeholders on the nature of their own partnership programs.

As a result of this success, CHC/HF and PCAU are currently working on a new documentary “the road to hope” that focusses on a bereavement program for child caregivers in Uganda. I witnessed the use of the documentary-Okuyamba- during an advocacy meeting by CHC/HF at an institution of higher learning in Indiana. The screening of the film stimulated discussion on the status of hospice and palliative care in Uganda. Participants posed questions such as, how do you train the workforce in the health sector? What are some of the conditions that patients present with? This led to a discussion on how CHC/HF was helping to contribute in scaling up palliative
care services in Uganda through PCAU. CHC/HF staff explained how they were for instance, supporting the education of health workers, supporting advocacy efforts with the government and the public in Uganda. At the end of the meeting some of the participants came forward to discuss with CHC/HF staff on how they can get involved. These participants included students and faculty who were particularly interested in the internship program.

Remarks from participants who I interviewed for this research project explain more on the use of these documentaries:

But the thing that I think that has been the most interesting, that has happened is getting into the movie making business. When we did the film Okuyamba in 2010 which really got into the public in 2012, it raised the profile of our organization nationally because our film was being used to educate people all across the country and ultimately around the world about the growing need for palliative care in developing countries. And shining a very bright spotlight on Uganda as being a model for palliative care. Helping people understand how that model can be used in other places. So for me that was a very significant thing for us to be involved with (S002_B).

Another participant shared a similar view: “Yes the Okuyamba. That video has been a huge success. It has been able to show the whole world what palliative care is all about. So that has been a major success” (B002_A).

While discussing a documentary in progress-, Road to Hope, one participant saw this as an opportunity to not only add value to the work of PCAU but also to indirectly impact the world in a positive way. They explained this observation by stating that:

Well, an indirect success from our relationship has been the Road to Hope. Uh.....I just think that it has developed into a wonderful project and had we not been given an opportunity to have a partnership with PCAU...... we save the world through our children. Or we make the world a better place through our children. I think there was a real need there that maybe everyone saw but was not able to do anything about it. I think that we have been given the opportunity. So I think that is an additional success (S005_B).
This observation suggests that stakeholders of CHC/HF and PCAU view their efforts through this partnership as having a long-term effect.

Finding: an internship program that involves giving both undergraduate and graduate students an opportunity to learn and participate in the delivery of hospice and palliative care services in Uganda is highly valued. A cross section of 9 participants were of the view that this program is important for the partnership. Some of them described it as something that “creates value” for both CHC/HF and PCAU and leads to “strengthening” the relationship of both organizations with other local organizations.

Specifically the internship program, I think, uh...I might be biased coming from (institution x) but it strengthens the relationship between CHC and (institution y). Because uh..... Like now just because I have those connections there, I know a lot about CHC/HF, I know a lot about hospice and palliative care. I think it gives them a space to kind of connect with the university and with students here too (I_001).

We’ve been able to establish internships which I think values both ends. Certainly it’s a value to PCAU but most times it’s a value to the students going over. But our hospice here has also been about education and extending into the community. That is part of what our mission is here but I think there are ways that PCAU can gain some value from the interns going over there (V001_B).

Having their students intern in Uganda to foster their classroom knowledge, that is also another success story because after these students have gone out there, they are able to get involved in so many activities like shadowing health care workers. These students have come with ideas on some research projects. We are working with some of them to go and work on their research interests which will be resourceful to us and to PCAU in our daily work (S001_B).

The success of this program was reinforced by feedback obtained from some of the students who had travelled for internship in Uganda. One of them described how the program had impacted her so much that she was preparing to go back to Uganda and conduct some research study with the help of the contacts she had made during her previous visit. Another
student discussed how her experience in Uganda had made her change her professional course from wanting to become a medical doctor to a public health practitioner instead.

While the internship program can currently be described as one directional, given the fact that no students from Uganda have been able to come for internship to the US, some participants explained their desire to see the program include students from Uganda. It is important to note that there have been attempts in this area to bring students from Uganda to intern in the US but issues beyond the two organizations such as visa processing and travel costs have hampered this attempt.

Finding: several stakeholders mentioned the winning of the Global Partners in Care Award as an indicator of success of the CHC/HF and PCAU partnership. This is more so because the award not only means that the partnership has been chosen from among 83 other existing partnerships, but also because it comes with a cash prize of $500. An initiative of GPIC, the Global Partnership Award presents an opportunity to recognize and appreciate the efforts of a US partner that demonstrate unique innovation and creativity in partnership activities. This could be in fundraising efforts, commitment from staff, and establishing networks in the community. The review process to determine the winner is done by a committee of individuals representing GPIC staff and board as well as the African Palliative Care Association. The award is given on an annual basis and it comes with a cash reward of $500 that goes to the African partner. (GPIC, 2014).

Participants of this research study expressed their appreciation for having received this award.

So there are others out there that are doing what we are doing. We were fortunate enough to have gotten an award a couple of years ago for the work that we did. So we as
a partnership – PCAU and us- we jointly received this award from the national organization which is now Global Partners in Care for recognition of the work we had done (S002_B).

Wow! There is quite so much that has been going on. We have a lot of success stories that we can talk about. One of them is that recently we won a global award. That means a lot to us. Especially with all the initiatives that we have done. By the time we win a global award, there are so many things that are looked at as success stories (S001_B).

A plaque that was given to CHC/HF and PCAU to symbolize this award can be seen hanging on the wall of CHC/HF offices. It is placed together with other awards that the organization has received in the past for different programs. This awards section is located towards the entrance of the building near the reception area. It is designed as a display section.

Figure 7. Summary of the most frequently mentioned achievements of CHC/HF_PCAU partnership.

Benefits of Partnership

Another area of interest for this research project was to find out what the different stakeholders thought of as benefits to each individual organization involved in this partnership. The goal here was to assess the areas that are of huge importance to each partner organization.

To this effect, some of the responses given by more than 20 participants who responded to this question included factors that can be described as tangible and intangible. Examples of tangible factors include: funding; while intangible factors include: making an organization known, learning from each other, as well as gaining personal satisfaction.
Finding: placements for US students in Uganda was regarded as a benefit for CHC/HF. Knowing and having a local contact in Uganda who could facilitate the internship program is quite beneficial and especially in relation to CHC/HF relationship with institutions of higher learning in their own community. One of the participant admitted that even though some of these institutions had already been doing some work in Uganda that was not related to CHC/HF and PCAU partnership, the importance of having CHC/HF as a facilitator cannot be underestimated. They described the role of CHC/HF as “pulling everybody together” and aligning their activities with the partnership.

Also the student exchange program where we have students coming from the US under the CHC partnership. They get a lot of experience by seeing how palliative care is done and I am sure they take a lot back home (B002_A).

R: I think for CHC may be the most important is placements. People come here for placements which is very good. So that exchange program bring various professionals from CHC to Uganda. Especially placements in the village. I have been with (person x), right deep in the village and even with some of the students we went to PROMETRA...so I think it is very good.

Q are those the traditional healers?

R: yes. We went there with some of the interns. So I think those placements give value to the collaboration (B001_A).

Finding: funding is a benefit to both CHC/HF and PCAU. For PCAU, funding directly from CHC/HF was seen to have led to most of the organization’s achievements such as training of health professionals, purchasing their office premises, supporting mentorship activities, supporting national events like membership meetings and conferences as well as capacity building of staff. For CHC/HF, it was suggested that as a result of showcasing their involvement in palliative care development in Uganda, this advocacy may have led to an increase in funding from their donors. However, in general, funding was in most cases seen as a greater benefit for PCAU
rather than for CHC/HF. Perhaps this is as a result of the structure of the Global Partners in Care partnership program whereby partners in the US are expected to make a financial contribution every year to their partner organization in Africa (FHSSA 2009).

I think that they possibly get… the advocacy that they do for PCAU in America, must bring them a lot of funding than if they didn’t do that (B004_A).

Q. what benefits does this partnership have for PCAU?

R: Of course the funding.

Q. okay, is there anything else apart from the funding?

R. I would say funding (S002_A).

For us to be able to do that I think it benefits on both ends because it opens our eyes to the world and it also allows us to share resources with PCAU and I just think it is very beneficial (S003_B).

Finding: for both CHC/HF and PCAU, being involved in a collaboration with each other leads to increasing visibility of their individual organization both nationally and globally. This was described as “being known” or “developing a reputation” by some participants. This is achieved when each organization is describing their work to different audiences for example at meetings, conferences, and even electronically. This was observable when CHC/HF discussed their involvement with PCAU during the volunteers’ luncheon. Following the meeting, some participants came forward to speak with the staff more about the partnership program and to congratulate the organization for the work they are doing in Uganda. Some of these participants were individuals that have travelled to other countries in Africa.

While discussing how the partnership had contributed to making the organizations known, participants of this research study commented the following:
That’s their name. The name of CHC. I don’t know if there is anything better than that……...
And so when we get out there, that’s their name. So a number of countries Zimbabwe, Mozambique, West Africa, French speaking countries are yearning for this now, like PCAU Uganda. But you see the expertise is with us. So when we say ‘ED send some of our advocacy people out there to help A, B, C and D,’ that’s their name. That’s their name going out and its spreading out (B005_A).

Good question. I keep asking myself how it benefits CHC. I mainly see it benefiting PCAU than CHC. I’m thinking…..uhm… which is this word? It’s like trying to create a name. I don’t know if you understand what I mean? {Laughs}. You know, recognition. Recognition in support for the vulnerable districts, for the vulnerable people (HP005_A).

I think that…the awareness, the fact that we are standing as one of the few organizations in the country that does this, puts us in a leadership position and probably enhances our image within the hospice community on a national basis (S006_B).
Finding: partners learning from one another was seen as a benefit of the collaboration.

Some participants explained this in terms of learning more about different means of palliative care delivery, learning new cultures and starting to see things differently.

The financial support, also the networking, the exchange of knowledge is very important. Of course in Africa we also need to see how palliative care is being provided in the first world and see what we can borrow. There is so much now in terms of organization development, things like communication, resource mobilization. All those are aspects that PCAU benefits from interacting with CHC (B002_A).

I think that something else that I would want them to know is that, uh…. How much there is also to learn about how Uganda provides palliative care because I think there is this perception that Africa always does it worse, they don’t know and whatever…. But having been there, there is like a whole lot of really good treatment methods and services that are provided that the US is kind of lacking and can learn from them…. One of the things that I was struck with was the way Ugandans approach and talk about death and sickness too. It was just really different from what I have experienced here in the US. Just the idea of all the family members providing the care. They are the home caregivers. It was a different system from what I had seen in the US. Where you have your own room and the nurses take care of you and the family sometimes comes to visit….. (I_001).

Some participants also saw the collaboration as helping them start to have a global perspective on issues. “I think it does provide them with an opportunity for a couple of different things. I think just more broadly, that it is good for organizations to have a global
mindset. For them to have a connection with people in Uganda is very important because it allows you to see a different culture and to see differences between people” (I_001). To another participant, the collaborations foster “intercultural learning.” “To be able learn.... Myself personally I am a very big proponent of intercultural learning and that kind of thing. I see a real benefit to it and I have enjoyed my participation in the partnership” (S003_B).

Finding: the thought of working with other people to deliver a service that is much needed by patients and families facing problems associated with chronic illnesses was described as “feeling good about ourselves”, “compassionate” and “rewarding” by a cross section of participants. One staff member showed me some portraits from Uganda that she has hanging on her office walls. She expressed her enthusiasm in supporting work in Uganda by purchasing these artefacts. The art pieces are part of the art and crafts objects that are obtained in Uganda and sold in Indiana as a way of fundraising for partnership activities. Additionally, one staff member explained how “having a friend from a far” was encouraging in carrying out their day to day work. They continued to explain that sometimes taking care of the sick with limited resources can be so challenging to the point of wanting to give up but by the sheer thought of knowing there are people supporting the work that they do, it keeps them going. The following statements explain the feelings of participants for this collaboration:

Well, the rewarding part, the fact that it is being done, the fact that we are helping it get done, the fact that we are seeing other hospices picking up in other parts of the world to help and support, the fact that it is helping spread.....it's a good thing. I just like everything about it (B002_B).

I think they are adding value to our activities by the support they are giving to us. It is one way of helping society I would imagine. By helping people who are not able to help.......I think in itself it’s rewarding. If you know that this money is going to help this person to become a prescriber and at the end of the day the patient will be able to access
medication, and have better pain relief. So it’s one way of knowing that you are helping somebody and at the end of the line helping the patient (S004_A).

Of course in terms of education and training in palliative care, exposing us, encouraging us; sometimes this work you can look around and think ah! Is there a way forward? Having a friend from a far is encouraging a lot (S001_A).

Finding: the partnership between CHC/HF and PCAU has led to the spread of palliative care services in Uganda. This is as a result of training nurses and clinical officers in Uganda in palliative care. At the PCAU office, there are two maps of Uganda hanging on the wall. One of these maps shows the districts of Uganda that were providing hospice and palliative care services by January 2012. The other map shows the districts of Uganda that were providing hospice and palliative care services by November 2013. To illuminate this effect, districts where the services are available are colored in yellow. A closer look at the two maps shows there is a gradual increase in the number of districts that are providing hospice and palliative care. This increase in the number of services was described by the participants as a benefit for both PCAU and CHC/HF. This is because both organizations share a vision of ensuring everyone who needs hospice and palliative care services is able to access the service. Therefore, even though the increase in services is happening in Uganda, it was argued that it benefits CHC/HF too.

I think it does. Because I am part of PCAU and CHC and I advocate for palliative care not only in my district but across the country. Because I know CHC wants palliative care to spread. Their mission is to have at least every [ ] to have access to pain management and treatment in all homes and villages. So I believe CHC can benefit in that way..... If I spread it, because that is my primary objective – to spread palliative care across, that is how CHC will benefit (HP004_A).

I think it mutually benefits both organizations. Uh..... We are assisting in a number of ways with PCAU. Mainly training nurses to go to the various districts in the country to provide palliative care. But also, I think it helps our organization because it heightens the awareness not only within our organization but also within other organizations- other hospice organizations in our country about what can be done to help other people in the world (S006_B).
Lastly, other benefits mentioned by participants included for example building relationships, friendships, becoming more attuned with what is happening in other parts of the world and sharing resources like computers. One participant concluded by stating, “No comment only that for us we only appreciate what CHC is doing for us. I came to PCAU when I didn’t know how to use computers but because now we have enough computers even a gateman knows how to use a computer {laughs}” (S003_A).

Peer Organizations

Given that there are other existing partnerships that are similar to the CHC/HF and PCAU collaboration, it was worthwhile to find out more about how these other partnerships work. This information would assist in learning more about some of the strategies that other partner organizations use that could be useful for CHC/HF and PCAU as well as for other organizations that would like to get into these kind of partnerships. To this end, two partnerships that have previously won the Global Partners in Care Award, were contacted during the research project. Although these interviews were conducted over the phone, I did share some informal conversations with the participants in between the interview which helped to build some rapport. For instance, one of the participants from an American organization shared with me about their family’s adventures in East Africa including learning one of my native languages. Another participant from Africa was keen to see me go and participate in hospice work in their country.

The findings obtained from these peer organizations indicate similar partnership structures to CHC/HF and PCAU. (1) They each have staff who are primarily responsible for
coordinating partnership activities from each end. (2) Staff from each organization visiting each other was described as an essential component for partnership working as it helps to build relationships and facilitates the sharing of knowledge among partners. (3) Communication through the exchange of emails and text messages was described as “special” by some of the partners and seen to be important in documenting the partnership. (4) One of the partner organizations reported that their staff make contributions to support partnership activities. (5) One of the partner organization has been involved in mentoring organizations that are in the process of starting off a similar partnership program.

In addition to this, when asked about some of the successes that their partnerships had experienced, their responses corresponded with those from stakeholders of CHC/HF and PCAU partnership. Some of the successes mentioned include:

- Facilitating the acquisition of office space for their African partner
- Supporting the spread of hospice and palliative care services in an African country through the training of health professionals in palliative care
- Capacity building of staff
- Supporting a bereavement program for children
- Staff exchanges
- Mentoring other organizations planning to get into such a collaboration
- Being previous winners of the Global Partners in Care Award

A participant explained how their partnership was a success to the extent of mentoring other organizations interested in getting into a similar partnership program.

I think that we are probably stronger than most of them in terms of the level of commitment throughout the organization. And probably in the amount of fundraising that we do. But I think that every partnership is unique, every hospice is unique, and so I don’t spend a lot of time comparing. I try to act as a resource to other partnerships. When there is a new partner and they are struggling or having trouble, FHSSA will ask them to call me and I will talk them through. There are a lot of partnerships that have contacted me and said ‘I have a question’ or if they have a new partnership sometimes they have me to be their mentor (S_001 P1_A).
There was also a similarity in terms of the benefits that these other partner organizations offer one another. Most mentioned is the funding, followed by education and training, and staffing in that order. Funding is seen as a benefit for the African partner as it helps to support various activities such as staff salaries, training of health professionals, and supporting other local programs. One of the partners explained how they raise funds in collaboration with other hospices in their region and with other global donors:

I think that raising money for the office, you know, working with these other hospices in (region x), is one of the successes because that way they have a training center that they can use. Clinical training for other people going into hospice and palliative care. ....I also think the X grant was another success of being involved in it because not only was it in hospice Y but it also kicked in hospice care through out (country A). So, those have been the biggest ones (S_001 P1_A).

However, there were some notable differences between these partnerships and the CHC/HF and PCAU partnership. This has to do with the nature of the collaboration. While CHC/HF is partnered with a national association whose main role is coordination of hospice and palliative care activities of a country, the other two partners in the US who were contacted for this research project are partnered with individual hospices in Africa. In fact, one of the US partners is in collaboration with three hospices in Africa. “I think everybody has the same mission. But instead of one hospice, we support three and do as much as we can. I think that is the difference. The similarity is that we are all trying to do the same work to reach many people as possible” (S_001 P2_A).

Some noteworthy differences between the partnerships included for example:

- Using online resources to supplement training of health professionals
- Increasing connections between partner organizations
- Working with other donors to raise funds
- Staff from Africa coming to the US for education and training
• Providing input in service delivery documents such as patient assessment tools
• Providing medical supplies
• Providing a means of transport in form of a vehicle or motorbike
• As well as supporting local community programs such as in agriculture

The following section discusses these differences further.

Finding: training of health professionals can be supplemented with online resources. A representative from one of the organizations in a similar partnership program to that of CHC and PCAU explained how they receive online education from their partner in the US. This came about as a result of their US partner organization visiting them in Africa, and while there they were able to collaboratively identify areas that the African partner would need additional support in terms of supplementing knowledge in the management and care of patients with chronic illnesses such as HIV and AIDS and cancer.

We also do online education, we exchange ideas online. We have Skype calls where we discuss difficult clients, we have got CME’s (Continuous Medical Education) where physicians at organization y prepare lectures on power point and they send them to us and we are able to sit down and review them as a team with a purpose to improve on our skills in providing palliative care..... We send them problem questions (B002_A).

Finding: increasing the number of connections between partner organizations strengthens the relationship and offers an opportunity for sustainability. Increasing the connections between partner organizations was described by one of the peer organizations as not only involving staff from the organization, but also other organizations within their locality. These organizations may include for example churches that have some affiliation in their partner country. In such cases, a peer organization would participate in their activities and get to know more about their work and in the process establish relationships. Another way of increasing these connections is by encouraging staff to visit their partner country on their own,
for example, take a vacation to country x and while there, they get an opportunity to visit their partner organization. The idea of increasing connections was also emphasized by other stakeholders who stated that:

One person can be the champion, can drive it, but, they can’t be the only person who is doing that. So I think that is also something else that we are very careful to talk with partners about planning for the future. We always talk about how they can work to get as many people within the organization to get involved in that partnership as possible. Such that when that person does leave, the partnership doesn’t sort of fade away (G_001).

A staff member from one of the peer organizations explained more on this topic by saying:

I think we have some of the strongest relationships….in terms of staff of hospice Y and their families and the staff of hospice x and their families. We have had so much back and forth….there are just so many connections. A social worker here in hospice x spent some time with a nurse from hospice y. She went back on her own to do some extra work. And a nurse here spent some time with a nurse over there, a chaplain here spent sometime over there……it’s those unique connections back and forth. A church here is leading a group to country z and we are sending gifts with them and they will bring some things back from hospice Y. The email and text messages back and forth. That is what has been special for me. If something happened to me or to the CEO, the partnership would continue. There are so many relationships’ (S_001 P1_A).

Finding: communication between partners both in person and via technology was described as “a critical piece” of keeping the partnership moving. While some participants acknowledged that there might be challenges involved in using technology to keep in touch especially on the African side due to lack of reliable infrastructure, partner organizations are encouraged to be creative in keeping in touch with one another in order to build on their relationship. As one participant explained, “the technology may not always be there so you have to get creative to establish that relationship and really maintain it and keep it sustained. It really takes time and you have to be willing to put time into it because you know, again it won’t be successful” (G_002). Where there was no communication between partners, challenges are
imminent and this could potentially lead to the breakaway of the partnership. The point here is not that there is no communication taking place, but the frequency of partners keeping in touch one another. Some participants explained more on this issue as illustrated by the remarks below.

I think that collaboration starts with a good communication plan and I think that .....That communication plan is really based on the ability of these programs to be able to come together, meet with one another, and really understand - a certain mutual understanding of who they are and build on that relationship (G_001).

I would give you the same....the partnerships fail because there is no communication. And the few that we have seen that have walked away from their partner was always out of frustration for not being able to get in touch with their international partner. It’s a matter of international phone service, internet service, you know, it can be difficult to get in touch. And sometimes you don’t have that champion on the ground who is advocating for the partnership. On either side- the US as well as the international side. We have had some...uh...some partnerships change partners. They haven’t walked from the concept of it but they have asked to change to a different partner because they were never able to get in touch with their original partner (G_003).

Opportunities for Growth for CHC/HF and PCAU Partnership

While attempting to determine the opportunities that exist for this partnership, I enquired from the participants if there were challenges that the partnership has faced in the past. The aim here was to find out if the participants had some suggestions on how to make the collaboration better. Responses to this question from a majority of the participants were directed at what the partnership has not yet accomplished and which they would like to see get done. In some instances, some participants would state that they do not see challenges but rather opportunities.

Interviewer: okay, are there some challenges that the partnership has had? Respondent: well, in my view as a person, I will say there are some challenges. One, hospice and palliative care services have not reached everyone who needs it. For me that’s a big challenge. Two, the coordination role of PCAU needs to put PCAU as a center for coordination for both government and non-state partners. I think that one is going there, but we have not reached (B001_A).
That’s difficult to say because I don’t look at them as challenges. I look at them as opportunities. There has really not been anything of significance that we could not overcome or put together. I think the biggest one now is going to be the funding for some of the programs that person x wants to do. I mean funding is always a challenge whether you are in Uganda or in Indiana (S003_B). However, four participants stated that communication, different time zones, and travel distance were some of the challenges they had faced. While these presented as challenges for the US side, the Uganda side seems aware of some of them especially the communication process. This was attributed to a lack of reliable information technology infrastructure. Thus, while the will is there, the absence of the necessary tools makes it difficult.

Well, there are always challenges especially when there is so much distance between the two groups. So I think the logistics of just traveling back and forth is a challenge. I think the time zone is a challenge because when we would do our communication... most of our real time communication with Uganda, I’m thinking that is probably their sleep time over there. Uh... and I think cultural differences are always a challenge. You know in the US we expect so much {chuckles}. We are so spoilt (S005_B).

The challenges have really been in the area of communication. Information getting out of Uganda to us so that we are aware of what is going on. A lot of this has to do with that there are not enough people, enough resources to be able to proactively keep us updated on what’s happening (S002_B).

In addition to this, there were some suggestions and recommendations provided by the different stakeholders interviewed in this study that offer some opportunities that CHC/HF and PCAU should consider exploring in the future in order to strengthen their relationship and continue to be a model program. Other opportunities can be found by examining what some of the peer organizations have done that has worked well for them. I have also included some recommendations based on my observations and analysis of the participating partnership programs.

Recommendation: continued training of health professionals in Uganda is and will be highly appreciated. More than 10 interviewees expressed a need for the partnership to
continue supporting palliative care training for health professionals particularly in Uganda. During the research study, I learnt that there were some health professionals that had not yet completed the training program and others were about to start. This indicates that training is an ongoing activity. While on the topic of training health professionals, some of the already trained health professionals explained that with more of their colleagues receiving a similar training, they would be able to share certain duties. For example, if there is only one trained health professional at a facility and they take a day off, patients who present on that day needing their services may not be able to receive them. One of the health professional explained:

And also if they would train more people or train me further, I would be very happy. If they could train more health workers. Like now here, I am the only one at the district hospital in charge of palliative care, in charge of requisition of palliative care, and sometimes when I am not there I find that [ ] this is not what they should get. I am the only prescriber. If it were possible to have other people trained.... That would be great work. And also even for advocacy for our politicians to know what is happening on the ground so that they consider palliative care, I would be happy (HP001_A).

The issue of shortage of staffing is something that was discussed during some of the events that I attended. I learnt that generally in Uganda the ratio of doctor to patients is 1:50,000. Thus, the shortage in staffing is not just being experienced in palliative care services but the overall health sector.

Recommendation: Strengthen PCAU in the area of research and data management. As a national association, some stakeholders were of the view that PCAU should be a hub of information of all matters related to hospice and palliative care in Uganda.

We need to strengthen research. Research is not good. An advocacy institution like PCAU must have a strong research base. An advocacy institution like PCAU must be supported to build a very strong database. In other words, PCAU in Uganda should be the hub of information regarding palliative care. Hospice and Palliative care organizations in Uganda
should get information from PCAU. So if there is anything that is needed to help PCAU in the future we should think about building a strong research base and a strong information base (B005_A).

Although, it is not the lack of data that exists but rather a lack of a functioning data system. While at PCAU, I observed some staff working to enter data on a computer. I learnt that this was one of the attempts that the organization is working on to develop an electronic database that can be easily accessed and used by her member organizations in the country.

Recommendation: exchange program for students needs to be bi-directional. Having an exchange program involving students affiliated with both organizations is another issue raised by the stakeholders. The findings show that there is something to learn from both ends. It would therefore be important for the two organizations to look into this program further to see how they can make it bi-directional. Some participants mentioned some of the areas that they believe would be of benefit to American students who intern in Uganda.

But I think they have also got good experience in terms of exposure to people who are living with HIV and AIDS. Most of their clients have got cancer and other life limiting illnesses like liver failure, heart disease or chronic obstruction pulmonary disease. So when they come here they get to see AIDS, the challenges of AIDS patients (B002_A).

We have also been given the opportunity to learn from everyone involved in PCAU. Uh...that you can do so much more with less (S005_B).

Uh.....I think it has changed how I look at being a doctor. Because I intend to be a medical doctor. Uh....but definitely working with some of the doctors in the health care, like the nurses and the clinicians definitely changed how I view what a doctor does. Especially like how long they would take with a patient and how much effort they would put in. everything they would look at like “did you have enough to eat this morning? Do you need the comfort fund?” so that’s day to day (I_002).

In addition to this, the students would also get to see how care is provided by a group of professionals at the same time rather than by one professional at their own time. One participant from Africa who had travelled to the US and witnessed the delivery of care, explained this
difference, “for example, I saw that every registered nurse is allocated a specific area to attend to a patient. For them, everyone goes at their own time during the day. But here at our hospice, when we go for a home visit, we go as a team” (S_001 P1_B).

Recommendation: increase awareness of palliative care, particularly in Uganda. When participants were asked to name some of the key things that they would want to see the partnership accomplish, at least 11 interviewees wished to see an increase in awareness of palliative care. The use of the mass media especially television and radio, has in the past proven to be a good resource in Uganda in raising awareness on palliative care issues. This is an avenue that should continually be emphasized by PCAU.

Recommendation: strengthen PCAU in the area of resource mobilization. The area of resource mobilization for PCAU was regarded by some participants as being vital in ensuring sustainability of the organization. To this end some participants explained their belief in PCAU as a national organization being capable of mobilizing resources not only for itself but also for its member organizations in Uganda. It was further noted that in order to fulfil this role, PCAU would need to take the initiative to reach out to other organizations to support them in this capacity such that it does not come across like something that is being imposed on PCAU. The suggestion of coming up with a model to ensure sustainability is very crucial for any organization.

PCAU as the mother organization, I believe will one day take a lead in mobilizing resources to support other organizations to build their capacity in terms of palliative care service provision. Resources not only financial but also training in management, communication and small things like helping to develop websites, develop strategic plans. All those are important things that organizations can benefit from PCAU. As we go on, I am sure it will happen (B002_A).
But to be able to be a resource and sounding board and a facilitator for PCAU to say, “this is how we become sustainable,” “this is our model and this is what we need to do in order to make it happen” and then we help bring those pieces together (S004_B).

While some of the opportunities are directed to both organizations—CHC/HF and PCAU—others rest on particular individuals especially those who for instance stated an interest of visiting their partner organization. In this case, it would be great if CHC/HF or PCAU helped to facilitate their travels through making the necessary local connections and orienting the individuals on what to expect.

Well, on a personal level like I explained to you, I want to go over to Uganda (B002_B).

I think personally I would like to learn more about and may be see the country of Uganda (S005_B).

Based on the above findings and from information gathered from literature review, I would also like to highlight a few recommendations for CHC/HF and PCAU. The following section explains this further.

Recommendation: working with other donor organizations can help strengthen the partnership. Other possibilities noted from the findings reveal that working with other donor organizations leads to strengthening a partnership. For example, one of the peer organizations described how they worked with other donor agencies to obtain a grant that helped support hospice and palliative care work in a country in Africa. Similarly, CHC/HF can help liaise hospices in Indiana or at least Northern Indiana with hospices in Uganda. As one of the peer organization explained, they worked with other hospices in their area to raise funds to benefit their partner in Africa. Such an effort if replicated by CHC/HF and PCAU would have a wider effect in Uganda given the strategic positioning of PCAU as a national organization. Additionally, CHC/HF could
establish relationship with other Global Partners in Care partners in the US who are working in Uganda and get to know each other with the view of strengthening resources.

Additionally, there are some existing organizations in the field of palliative care that are known to support palliative care leaders especially from developing countries. The International Association of Hospice and Palliative Care (IAHPC) has a travel scholarship program that has supported individuals to travel to various parts of the world and participate in events such as conferences and training programs. Perhaps this is an area that CHC/HF and PCAU can look into especially for purposes of providing further mentorship and training to the already trained health professionals in Uganda. The program could also be a means for supporting staff exchanges.

Recommendation: assess the impact of the partnership at the patient level. The findings of this research provide evidence on the goals and objectives of the partnership, parties involved, and activities done. In the future it would be of benefit to both organizations and their stakeholders to assess and provide evidence of the outcome of their efforts especially at the patient level. While this may be a complex exercise given that the assessment will be covering an entire country – Uganda, the data will be very beneficial for the partnership. Possibly this is an area that can be looked into in collaboration with some of the institutions of higher learning that CHC/HF and PCAU are already involved with.

Recommendation: keep internal stakeholders engaged and motivated. It can been argued that organizations need to keep external stakeholders fully engaged in partnership activities in order to win their support. While this is true, it is also true that in most cases the engagement of external stakeholders is determined by the level of engagement of internal
stakeholders. In order to keep the momentum of the partnership going, and to be able to take
the message out to external stakeholders, there is a need for each partner organization to
continually keep all staff aware if not involved in the partnership. This can be done through for
example: one, each staff taking responsibility to learn about their partner organization. It was
evident that each partner organization has available documentation about the collaboration.
Two, whenever possible ask staff for their feedback and opinion about the partnership; and
three, share updates about the partnership regularly with staff.
CONCLUSION

Global collaborations in the field of hospice and palliative care is not a new phenomenon. It is an arrangement that began with the advent of the international hospice movement. Such collaborations have/are supporting the development of hospice and palliative care in different parts of the world. The assessment of this hospice partnership program demonstrates how organizations can establish working relationships and the results likely to come out of such an initiative. Further, the data shows that there are existing organizations that facilitate the establishment of these initiatives. There are also existing programs that we can learn from.

The data shows that collaborations can take many forms. There is no one structure that can be termed as the correct one. Some partnerships involve two organizations while others involve one organization partnered with several other organizations. However there are some cross cutting elements such as having a buy in from management, having individuals who spearhead partnership activities in an organization, as well as coming up with ways of raising funds to support their activities; that are seen to be effective of these initiatives.

Although such collaborations are not without challenges, the evidence from the participating organizations for this project illustrate how organizations can overcome some potential challenges. Partner organizations should maintain openness and a willingness to learn from one another. They should view each other as colleagues interested in achieving the same goal. And they should regularly visit each other in order to build on their relationship.

My research outlines some methods that can be used to collect data to assess how a partnership works. Since it was the first kind of assessment being done for CHC/HF and PCAU
partnership, I believe it has elicited some data that will be useful for future assessments of this particular collaboration and other partnerships.

Discussion and Personal Reflection on Applied Thesis

When joining the anthropology graduate program at UNT, I had some knowledge of anthropological research methods given my undergraduate background that was also in anthropology. However, during my graduate studies I was exposed to more in depth anthropological research methods such as observation, participant observation; including theories such as symbolism, functionalism, post-modernism, political economy, globalization, and studying up. The knowledge and experience that I gained from this process contributed immensely to the design of my project.

For example, the theory of studying up challenged me a lot. I was encouraged to pursue a project that would consist of studying the “powerful”- in my case organization leaders and managers. Additionally, the theory of globalization instigated a feeling of wanting to do a project assessing issues at a global level. In my project I assessed how organizations are creating linkages with one another to solve similar problems in different parts of the world.

While conducting my interviews, I was aware of the need to deal with my personal biases and see issues from the participants’ view - a skill that is emphasized in conducting anthropological research. However, I was also aware that (at least from the post modernist’s perspective), I may not be able to entirely distinguish my biases from the participant’s view.

Also, by reflecting on the nature of the communication I had with the different participants, I noticed some differences in my methods of approach. For example, while I was
keen to wear dresses and skirts while in Uganda, in Indiana, it did not really matter although I would mostly wear trousers- probably because of the late Winter/early Spring weather. I tried to dress as close as possible to the way my participants were dressed. The use of the English language was sometimes also slightly different so as to keep up with the different pronunciation that participants are used to. Also, while interviewing participants in Uganda, I would use a lot of “mmm” as a sign to show I was listening while the use of the same sound in Indiana, seemed like an interruption and I had to refrain from using it. Instead I would wait to make sure the participant had said all they wanted to say.

I also noted that participants who shared a lot on different aspects of the partnership are those who had been actively involved in the planning and implementation of partnership activities. Some of them even requested to see a copy of the report of the findings. For those who were not as actively involved in partnership activities, as one of them explained, they could only base their responses from what they had seen take place such as during exchange visits.

Further, the field experience brought to my attention the various roles that a researcher plays while on the field. For some participants, I was an outsider and to others an insider - perhaps a factor reinforced by my nationality. To others I was a colleague – perhaps because of showing an interest in the field of hospice and palliative care. And to others, a confidant - someone they could sometimes express their personal opinion to. Having been (and still is) a volunteer for CHC/HF helped me a lot in making contact with the organization and building relationships with some of the people I worked with. Also, having lived and worked in Uganda in the past, was useful for me as it helped in knowing my way around including understanding the local language of the people. While this could have worked in my favor, it could also be a
limitation especially when participants think that what I am asking about is something I already "know" and they therefore see no need to explain further.

In conclusion, I was particularly intrigued by Elisa Sobo’s discussion on the potential of research using anthropological methods can have in improving health care. Her views on issues such as field entry, data ownership, and research deliverables were worthwhile for me to consider during this project. I hope that from my research I have been able to illustrate the role of anthropology in the field of health care and specifically in hospice and palliative care.
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