FHSSA
Compassion has no borders

Quarter 3 – 2011

FOCUS ON COMPASSION

a quarterly newsletter

Marangu Hospital palliative care team stands with a local family receiving palliative care and OVC services.

CHAT Project Ends but Palliative Care Continues in Tanzania

The USAID-funded project leaves a lasting legacy within the ELCT health care system.

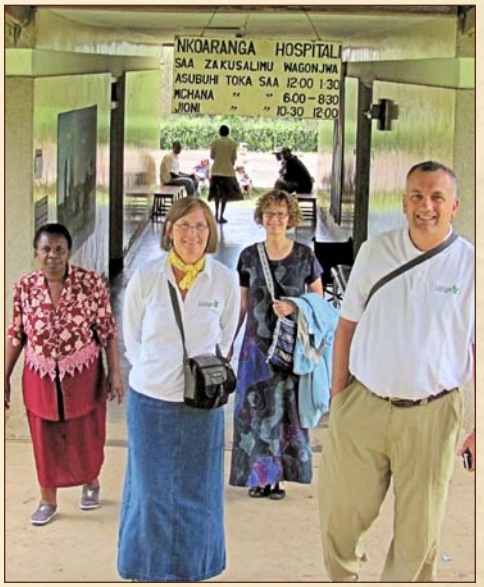
The success of the Continuum of Care for People Living with HIV/AIDS (CHAT) project in Tanzania cannot be overstated. CHAT set the stage for the Evangelical Lutheran Church of Tanzania (ELCT) to enhance the provision of quality palliative care and support through its system of health care. It is a successful story of change. Prior to CHAT, the ELCT health care system did not consider palliative care as part of its service provision. It now views it as essential. At the final stakeholders meeting, the leadership of ELCT health services proclaimed that regardless of continued funding from donors, their system of health care now actively provides palliative care.

Background

In 2007 FHSSA, in partnership with the ELCT and the African Palliative Care Association (APCA), started a $5 million project with funding from PEPFAR/USAID under the New Partner Initiative (NPI). The intent of the CHAT project was to expand palliative care services to 13 Lutheran Hospital sites in rural Tanzania. The concept was based on the successful work conducted at Selian Hospital where an interdisciplinary team at the hospital supported a network of home-based care (HBC) volunteers to provide quality palliative care to people living with HIV/AIDS in the surrounding community.

Successes of the CHAT project

- Palliative care was fully established as part of the health structure in 13 rural hospitals. As a result, 11,532 patients living with AIDS and their families were cared for with home based palliative care. An additional 2,695 individuals living with other life threatening diseases, such as cancer, heart disease, and diabetes, have received access to palliative care. With 14,227 patients and families served so far, these palliative care programs will continue to serve their communities into the future.
- A working Palliative Care (PC) Team at each site was trained and mentored in palliative care, including a palliative care coordinator, assistant, chaplain, social worker, and clinical officer. All PC teams received a three-week training in palliative care and extensive supervision at their sites. Additionally, teams attended bi-annual management meetings with the other ELCT PC teams in Arusha, Tanzania. Eight PC staff members received a diploma in palliative care in either Kampala,Uganda or Nairobi, Kenya.



A team from Gilchrist Hospice Care visits the palliative care program at Nkoaranga Hospice.

Husband and wife with their palliative care coordinator and volunteer from Gonja Hospital.

- At 12 of the sites, home-based care (HBC) volunteers received the government certified 3-week training on home-based care. Through CHAT, 517 HBC volunteers now visit patients with clinical back-up and supervision being provided by the Palliative Care Team.
- Nearly 15,000 orphans and vulnerable children (OVC) received one or more services through CHAT including educational, medical, nutritional, psychosocial, and bedding support. As families and individuals noticed that children were getting support and follow up was being made, more families were willing to disclose their HIV/AIDS status and ask for assistance. The OVC services were important to both helping the children who received them, but also for reducing stigma, opening doors, and supporting families.
- "Prevention with Positives" was a very important part of the program and allowed the PC teams and volunteers to talk with patients about a host of issues that affected both their health and the health of other members of the family. This included open discussions about condom use in serodiscordant couples (couples in which one person is HIV positive and the other is not), the use of soap and disinfectants for hygiene, and bed nets for malaria prevention.
- Morphine availability was a major breakthrough of the program and took many years of continued advocacy and support to achieve. The CHAT team worked at both the hospital level and the policy level to achieve success. At the hospitals, the capacity to subscribe and manage morphine was built. The CHAT team worked with the Tanzania Palliative Care Association (TPCA), APCA, and Ocean Road Cancer Institute (ORCI) to advocate for a more efficient and effective government approval process for morphine permits. All 13 sites received their permits and are trained in the use and storage of oral morphine by ORCI. This has greatly increased the availability of oral morphine in rural Tanzania.
- The FHSSA partnership program is a growing source of support for the 13 CHAT sites. All 13 sites are partnered with a US hospice organization and are receiving financial, in-kind, and moral support.

USAID funding has ended but the amazing work that was accomplished will continue. FHSSA, ELCT, and APCA would like to thank PEPFAR and USAID for their support for the CHAT project. It has made and will continue to make a significant impact on the lives of countless Tanzanians.

A Glimpse into FHSSA's Partnerships

The yearly Partnership Report provides valuable details about FHSSA partners

FHSSA's partnership program experienced its eleventh successful year in 2010, reaching 91 partnerships that connected 182 US and African hospice and palliative care organizations. Partnerships utilize the expertise and passion of individuals across continents to collaborate on the common goal of providing compassionate care to patients and families facing life-threatening illness. The 2010 Partnership Report, completed by 60% of US and African hospice partners, allows FHSSA to understand how partners work together. It also helps FHSSA identify what else is needed to assist partners in having even more successful partnerships.

Diversity of Challenges

FHSSA's African partners serve patients in diverse locations and with varying health conditions. Of the African partner programs, 57% serve urban/rural mixed areas, 36% are in completely rural areas, while 7% are work with completely urban populations. The challenges partners face due to the location of their patients has an impact on program needs. For example, in rural areas, challenges include very limited access to electricity and clean water. In many areas, there is a huge need for bicycles for volunteers to cover long distances between patients. And in urban settings, patients and families have limited ability to raise and cultivate food, which can be a hardship to families with no or low wages.

Additionally, African partners are faced with caring for individuals with a vast array of diseases, many of which have treatments that are not readily available. In 2010, 60% of African partners listed HIV as the primary diagnosis for their patients, 30% served primarily cancer patients, and another 10% served patients with other diseases such as diabetes, tuberculosis, and heart disease.

Needs Addressed

In the survey, US and African partners identified the needs that they wanted to address together. The most common goals in 2010 included financial support for a wide range of needs, including the acquisition of patient supplies and medication, home based care visits, nutrition and support of patients, transportation, training, and the general operations of the African program. Additional goals not related to fundraising included educational programs, partnership visits, building relationships, and building capacity through technical assistance.

continued on page 3

Staff members from Seke Rural Hospice in Zimbabwe and Arkansas Hospice work together to care for a patient

Staff of Hospice of the Western Reserve in Ohio visited Helderberg Hospice in South Africa.

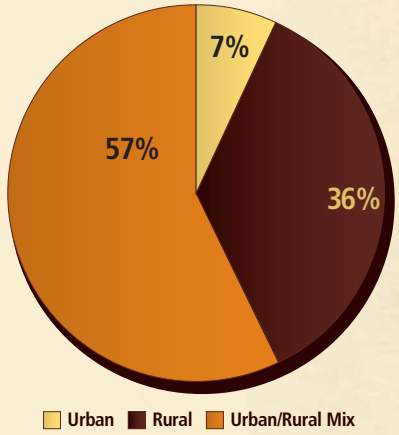
Carers with Ripples Healthcare in Ghana

Impact by the Numbers

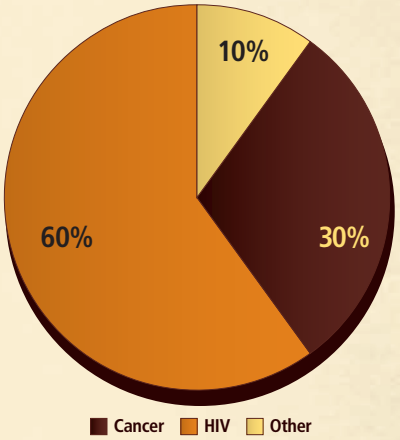
Through these collaborative efforts, more than $450,000 was sent directly to African partner programs in 2010, with an additional $122,000 in in-kind donations provided to support the African partner programs. As a result, 2,328 full-time employees, 631 part-time employees, and 3,826 volunteers were able to improve the quality of life for more than 60,000 patients and approximately 300,000 family members in 2010.

FHSSA would like to thank all of our US and African partners for the incredible impact they have on so many communities and so many lives. To see a full list of FHSSA partners, visit www.fhssa.org/partnerlist.

Service Area Type for African Partners in 2010



Primary Diagnosis for Patients Seen at African Programs in 2010



Sharing the Work of CHAT with the Global Health Community

FHSSA staff make the case for palliative care.

Public health professionals from across the globe gathered in Washington, DC in June for the Global Health Council's conference, "Securing a Healthier Future in a Changing World." In preparation for the upcoming United Nations high-level meeting focused on non-communicable diseases, representatives of successful health programs shared how they have used creativity and innovation to address infectious and non-communicable diseases in their communities and at a policy level.

Throughout the conference, FHSSA staff had the opportunity to learn from ministry of health officials, international health leaders, and outstanding public health colleagues. Staff also took part in important discussions regarding the role of palliative care in addressing the changing distribution of diseases in Africa.

FHSSA was also given the opportunity to present the collaborative work with the Evangelical Lutheran Church in Tanzania (ELCT) and the successes that were achieved in making pain assessment and treatment a routine part of care. That roundtable discussion titled "Improving the Quality of Life for Those with Life-Threatening Illness in Rural Tanzania" led by Erinn Nanney, gave participants the opportunity to discuss the challenges of palliative care provision in rural, resource-poor settings. They also talked about how quality of life can still be positively affected in the absence of oral morphine to control pain.

Non-communicable diseases are no longer solely the worry of wealthy countries. As the world changes, the burden of diseases such as cancer, diabetes, and heart disease continue to increase. Hospice and palliative care provide a wonderful opportunity to address the affects of these diseases in patients as well as providing a means for prevention and early detection for family members of those cared for in Africa.

Children Caregivers in Uganda

By Roberta Reynolds Spence, Volunteer, Center For Hospice Care, South Bend, Indiana and Rose Kiwanuka, Country Coordinator for the Palliative Care Association of Uganda

The prevalence of young children as long-term care providers for their sick or terminally ill parents and family members is a common occurrence throughout Africa. Children assume this role in other areas of the world, but the number serving as caregivers in Africa is much higher and the age much younger. In the United States, United Kingdom, and Australia an estimated 2% of children take on this responsibility while in Africa it is well over 4%. In some regions of the continent the percentage is even higher.

What is the impact on the quality of comfort care when children serve as caregivers? When children assume such a role, what effect does it have on their own health and quality of life? These are two vital questions facing those involved in palliative and hospice care in Africa.

First-Hand View

I (Roberta) had the opportunity to experience first-hand the significant role children play in care giving on a recent three-month visit to Uganda. Three years ago, The Center for Hospice Care in South Bend, Indiana partnered with the Palliative Care Association of Uganda in an effort to help expand and improve palliative care throughout the country. My visit was part of the Center for Hospice's ongoing commitment to offer assistance and resources through the FHSSA partnership program. I worked closely with Rose Kiwanuka, country director of the Palliative Care Association in Uganda, to establish training sessions, educational in-services, and plan strategies and objectives to improve palliative care in Uganda. Our journeys throughout the country highlighted more than ever the role children are playing in palliative care especially in remote villages where resources are more limited.

On one visit to such a village, two children, ages 9 and 11 were caring for their mother who was terminally ill with just days to live. Since their father left them, they had been performing the role of caregiver for some time. Other families in the village supported the children as best they could and the children appeared to be healthy. It was also apparent that the children did not perceive what they were doing as anything exceptional. Throughout Africa children who care for parents and loved ones often assume a protective role.

What is the Impact on the Children?

What was not so easily determined was the long term impact on the children's well-being. The sacrifices the children make regarding their own health, education, and day-to-day growth and development are not always easily identified. In most instances children who serve as caregivers are not in school or receiving formal education. Even if they were in school, at times, the circumstance in their home forces them to drop out. The failure to achieve an adequate education significantly lessens the child's chance to avoid a life of poverty. More importantly, their future after their parent dies is even less certain. In this particular instance the best that could be hoped for would be that the boys would be looked after by families in the village following their mother's anticipated death.

On another visit we met a five-year-old child who was caring for his father who was suffering from a gangrenous leg, the result of complications from tuberculosis. The father could not walk and the child was responsible for the father's toileting and hygiene needs as well as all other aspects of his daily care including the procuring and dispensing of medication. The child would walk approximately two to three miles to the nearest health clinic to procure necessary medication and receive instructions on how to dispense the medicine. He performed that role for his father on a daily basis. Since their home was not close to other families their primary support was visits from the hospice nurse.

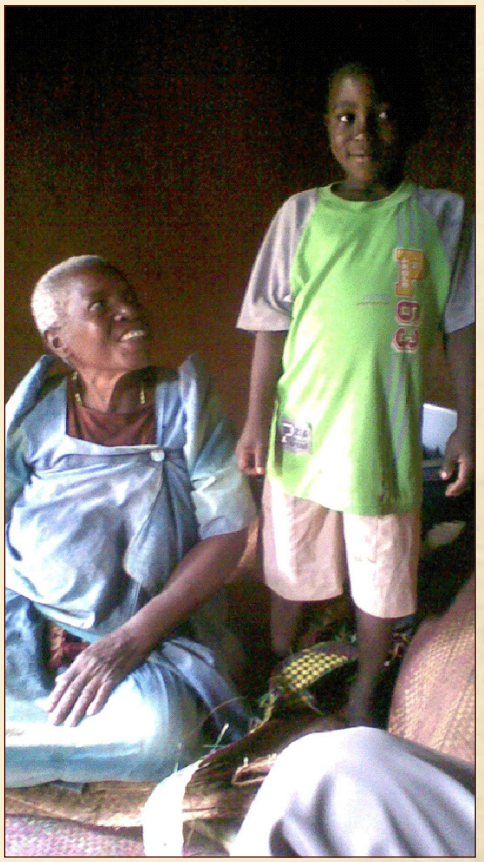
The issue of children as caregivers raises important questions regarding the future of palliative care in Uganda and other countries in Africa. With a lack of resources and personnel to administer to the overwhelming health care needs of the people children are likely to continue in the role of caregivers for the foreseeable future.

How to Respond

We could stop right here, acknowledge the situation and our helplessness. We could say that it is an overwhelming problem and we do not have the resources to adequately deal with it or know where to begin. However, we have begun! We have begun through partnerships and the openness to learn from one another. We have raised questions that require answers. We have worked to spread palliative care throughout Africa. With this comes the responsibility to struggle together and to take one step at a time no matter how small that step may be. We have to value the importance of one person, one relationship, and one opportunity in creating the beginning of meaningful change.

Amazing people have entrusted us with their stories, their hopes, and their desires for something different for their children. The power of their stories must be not only heard,

continued on page 5



This young boy cares for his grandmother. Both his parents have died.

Two child caregivers, 11 and 9 years old (seated to the left) outside their hut receiving instructions from the hospice nurse (kneeling) for care of their mother. Neighbors are present to support the two boys.

but felt so as to leave us with an unexpected vulnerability. We have been moved to tears for these children, but they cannot be just tears of pity, but tears of love, compassion, gratitude, and action. They have gifted us with their honesty, generosity, hospitality, presence, and strength. Something must emerge from all of this if it is only just one small step that we take together to begin to make a change for our children.

One way to help FHSSA continue to help African programs support child caregivers is to make a donation today:

www.fhssa.org/give

FHSSA invites you to celebrate

From San Diego to Africa...

www.nhpco.org/CTC2011FHSSAevent

Friday, October 7th, 2011
6:00 pm – 9:00 pm

Town and Country Resort
San Diego, California

Hors d'oeuvres, beer and wine, live entertainment, silent auction featuring items from Africa and much more… to attend the event or to make a donation please visit

www.nhpco.org/CTC2011FHSSAevent

FHSSA
Compassion has no borders

FHSSA is a 501(c)(3) organization (#16-1590512).
Contributions are tax deductible to the extent allowed by law.

The Foundation for Hospices in Sub-Saharan Africa is now doing business as FHSSA.

FHSSA
Compassion has no borders

1731 King Street, Alexandria, VA 22314
CFC# 11018 • (703) 647-5176
www.fhssa.org • info@fhssa.org

www.facebook.com/FHSSA
www.twitter.com/FHSSA_news
www.youtube.com/FHSSA