INTERDISCIPLINARY PRACTICE IN HOSPICE
& PALLIATIVE CARE DELEGATION TO
DURBAN/CAPE TOWN
SOUTH AFRICA

August 13 – 23, 2012

DELEGATION LEADERS
Elizabeth J. Clark, PhD, ACSW, MPH, Executive Director, NASW
John Mastrojohn III, RN, MSN, MBA, Executive Director, National Hospice Foundation and FHSSA
ARRIVAL IN DURBAN

Being part of a People to People delegation is always exciting, and arriving at the destination country is part of that excitement. We were a small interdisciplinary delegation (social workers, nurses, and an attorney). All but three of us had done the pre-delegation tour to Johannesburg, so we met at the Johannesburg Airport between our flight from the USA (about 17 hours) for our flight to Durban (only an hour). We had time to get a bite to eat before boarding. It was great to see returning delegates and to meet new colleagues. The group seemed immediately compatible.

When we arrived in Durban, it was already night time. All of our luggage arrived, but one delegate had missed her flight. She would join us the next day.

When we got through passport control (which was quite easy) our regional guide was waiting for us with a People to People sign. It is always a relief to find them. He had a van waiting for us and we had made good time in getting to the hotel.

Our check-in went smoothly, and our luggage was delivered to our rooms. It was after 10pm, and everyone was glad to call it a night.

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SOUTH AFRICA EXPANDS HIV/AIDS TREATMENTS.

John is the director of FHSSA (formerly called the Foundation for Hospices in Sub-Saharan Africa) an affiliate of the National Hospice and Palliative Care Organization (NHPCO) which is based in the USA. Enhancing compassionate care is the mission of FHSSA, and this is partially accomplished by having hospices in the USA partner with hospices in Africa. To date there are 95 such partnerships. We would visit three hospices which have US partnerships during the week. Only four African countries have integrated palliative care. These include South Africa, Uganda, Tanzania, and Kenya.

As the final part of our orientation, we had a presentation by Dr. Fakrooden. She is a medical doctor and she was representing the Hospice and Palliative Care Association (HPCA) of South Africa. She also works with the Palliative Care Association (HPCA) of Tanzania, and Kenya.

The delegates and Dr. Fakrooden had a discussion about workforce shortages. She said South African universities graduate 1000 physicians per year,
which is not nearly enough. She noted that many of their doctors are trained in Cuba, and that they lose health care professionals of all types to countries like Great Britain which pay higher salaries. She also mentioned the need for better work-life balance in health care, and how hard it is to maintain because the need is so great. It was nice to have a first-hand perspective from someone who had worked in hospice for so long.

CULTURAL PROGRAM

AFTERNOON – KA MULE MUSEUM, PHOENIX SETTLEMENT, AND OHLANGE INSTITUTE

After our briefing, we set off for lunch and a cultural afternoon. Lunch was at an art center called The Bat. The name of the restaurant was Apartheid Jazz Lounge. Our guide explained that they served what he would describe as urban soul food. Some of us were a bit challenged by the menu. Sisemba ordered sheep’s head. None of the delegates followed suit. When it came, it was actually one half of a sheep’s skull, a rather unusual presentation (see photo).

It was a beautiful day so we ate outside. We were close to the water and could watch boats going by. Service was rather unusual presentation (see photo).

The final visit of the day was to the Ohlange Institute, the first African-run and African-funded educational institution in South Africa. It was founded by Rev. John Dube, also a founder and first president of the ANC. In 1954, Nelson Mandela, the first democratically elected Prime Minister, met his vote there as a symbolic gesture to complete the work begun by Dube. The word “ohlange” means “place of refuge.” It is a moving historic site.

It had been a full day and we were happy to head back to our hotel, shower, and an early evening.

THURSDAY AUGUST 16, 2012

PROFESSIONAL PROGRAM

MORNING – BIG SHOES FOUNDATION

We departed early to travel to the Big Shoes Foundation, a non-governmental organization (NGO) that provides consultative services to hospitals in three provinces. Children who have been diagnosed by the hospitals as having a life-limiting illness are referred to the palliative care team. The team supports the child and family, focusing on quality of life.

Big Shoes was founded in 2003 for HIV testing for children in Johannesburg by a pediatrician named Michelle Moring. She found that children were being misdiagnosed and they started doing correct testing for children under 28 months. They also started a children’s home program. They chose the name “Big Shoes” because they want children to grow up and “fill big shoes.”

We met with Dr. Jula Ambler who had trained in children’s hospice care in Britain and who has been with Big Shoes for four years, and with a clinical social worker, Tracy Brand, who came to Big Shoes as the regional project manager and fundraiser four years ago. They are housed at Clairwood Hospital which is the venue we visited.

Clairwood is a state funded rehab hospital. It took several years for Big Shoes to grow up and “fill big shoes.”

There are 18 million children under 18 – 20 percent of them have a chronic illness, and five percent require palliative care. They have 57,100,000 deaths vs 8,100,000 in the USA.

Health care is focused on children with treatable diseases, not on dying children. Around 50 percent of children die outside of a health facility. These are waiting lists of 400 children needing cardiac surgery – some who could be cared. They only have one pediatrician per 39,000 children in Kwazulu-Natal (KZN). They estimate that KZN has 3,400 children who need palliative care. There are orphaned and vulnerable children programs at many hospices, but almost no true palliative care for terminally ill children.

Palliative care is not a recognized specialty in South Africa. Almost all training is done on a volunteer basis. There is a debate on whether palliative care should be under health or social service.

Tracy pointed out that there are only 724 social workers in KZN. She said that most social workers are glorified grants officers. They do the paperwork for civil social assistance support grants which provide 260 rand per month per child based on need. Case dependents grants for children with a serious illness are provided at 1000 rand per month.

To implement the Children’s Act for promotive services in South Africa they would need 66,300 social workers. “As of date, there are only 5400 trained in South Africa.

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Clairwood is a state funded rehab hospital. It took several years for Big Shoes (as an NGO) to get space at Clairwood; they opened the unit in 2010. Now they have a ten bed unit, and two full-time and three part-time staff. They take referrals from all over Durban. Last year they saw 145 children in their inpatient unit at Clairwood. They are just beginning interdisciplinary care.

The need for palliative care services for children is extremely great. Children’s palliative care is not very extensive in Durban and the rural problem is worse.

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To implement the Children’s Act for protective services in South Africa they need 66,300 social workers. To date, there are only 5600 trained in all of South Africa.

Ohlange Institute.

Big Shoes Foundation.

Children in Ghandi’s compound, called the Phoenix settlement. It was established by a 35-year-old Ghandi in 1908 as an experiment in communal living. It was quite a distance from Durban. It was an important site of resistance during apartheid. It seemed a peaceful place run mainly by volunteers who wish to keep Ghandi’s spirit alive.

The final visit of the day was to the Ohlange Institute, the first African-run institution in South Africa. It was founded by Rev. John Dube, also a founder and first president of the ANC. In 1994, Nelson Mandela, the first democratically elected President, cast his vote there as a symbolic gesture to the leader of the ANC.

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Ohlange Institute is a cultural afternoon. Lunch was at a small museum that gave a complete the work begun by Dube.

Our guide explained that they were close to the water and could see boats going by. Service was extremely slow. They seemed to be challenged by the menu. Sithembiso food. Some of us were a bit put off by an unusual presentation (see photo).

It had been a full day and we were happy to head back to our hotel, dinner, and an early evening.

Ohlange Institute.

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We were joined by Sue Boucher, a teacher who serves as the Information Officer for the International Children’s Palliative Care Network which started in 2003. They work with the World Health Organization and have received funding from the Open Society Institute as well as the Diana, Princess of Wales Memorial Fund.

They do offer a basic child health course, a five-day course for caring for dying children. There is also child abandonment training. They explained that there is only a 72-hour gap for post-exposure prophylaxis.

They expressed concern that they have no capacity for bereavement services or research. Bereavement services are a huge issue. There are frequently multiple deaths of children in one family. Many grandparents are struggling as they are often child caregivers. They try to get children back home with some community services and they had some success there. However, affording funerals for the children is a problem and some families simply can’t take the children back.

We toured the inpatient unit and the playroom, a colorful, happy place called “Sithandeni” which translates to “we love them.” That attitude was evident as it was located in a garden center that looked like a nursery. It was an African organic restaurant. The meal was good and the service excellent. We left at 2pm for our visit to Highway Hospice.

Our next stop was lunch at St. Clement’s restaurant. We had a little trouble finding an inspiring visit.

AFTERNOON – HIGHWAY HOSPICE

The Highway Hospice Association is one of South Africa’s first hospices. Its facility is situated in a heavily populated area (over 3.5 million people) called Sherwood. They are an accredited hospice and a member of both the Hospice and Palliative Care Associations of KZN and South Africa. They also have a training partner in the USA through FHISSA, it is VITAS Innovative Hospice Care of Chicagoland in Chicago, IL.

Many of the staff had gathered in the conference room to meet with us. They served us coffee, tea, and muffins that had just been baked there at the hospice.

In addition to Lesley Van Zyl, the CEO, we were pleased to meet with two social workers (Mary and Laticia), as well as the psychosocial manager (Roshnie), the nurse in charge of their home care team (named Mamusa), and the inpatient nursing manager (Michaële). Additionally we were joined by Karien, the nurse who does their quality management. She has been there for 30 years.

With regard to social work, Mary specializes in geriatrics; Laticia is their bereavement expert. There are three additional social workers on the psychosocial team. They have 11 nurses who go out into the community. They do assessments at community centers so people have easy access.

We were impressed by the breadth of their services. They offer Reiki, aromatherapy, music therapy, interactive play therapy, and pet therapy. They noted that the cat used in pet therapy is drawn to depressed patients.

The previous day at our briefing, Dr. Fakroodeen, who works with Highway Hospice, had noted that Highway Hospice had recently cut their patient caseload significantly – by almost half. They explained that this was due to the availability of ARVs which has allowed them to discharge over 200 patients this year. They refer the patients to other departments when discharged.

Funding is an issue. All care is provided without expectation of payment. They receive no government subsidy. They do receive some PEPFAR funds, but they have decreased recently. They have charity shops and a mini-lottery in the country and get some money from that, and they have special events – tree of life, golf, and auctions. They do have a trust. They said they have a “walking faith” with regard to funding, and that they “pray like hell.”

Another issue is that patients with HIV who go on the ARV program lose their disability grants. To help them, Highway Hospice has started a program called Ilambahle. For patients they give a bag of clothes. They sell the clothes in their communities. By doing so, they make about 10 rand per month. When established, they pay the Hospice 10 rand per bag. This gives them dignity and helps them earn a living.

They provide several activities for bereavement care. First of all, they explained that their country is enriched by rituals of their ethnic groups. These are prescribed for families when a loved one dies. Also they do memory work where they help clients build memory boxes to reinforce positive memories of their loved ones.

Friday August 17, 2012

Social Work Delegation – South Africa

Morning/Afternoon – ZULU VILLAGE VMFT

Friday was what is referred to as a cultural day. We were driving into the area of the Valley of 1000 Hills for what was listed as a “true to face of experience.” This would take place at an actual Zulu Village.

We got off to a late start due to the village guide (Alfred) being delayed because the van he was to use was carjacked the night before. It was a cool, overcast day. The trip took us over an hour. Along the way we stopped at a shopping center to get coffee and we purchased some homemade gifts for the village families we were going to visit. Our guide suggested we get some candy for the children who were going to perform a dance for us. On the way to the village, Sithembile, who was Zulu, gave us an overview of Zulu culture including wedding rituals.
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Many of the staff had gathered in the
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In addition to Lesley Van Zyl, the CEO,
the team and our social workers
(Mary and Laticia), as well as
the psychosocial manager (Robbie),
and the psychosocial manager (Robbie),
the nurse in charge of their home care team
(named Mamusa), and the home care
nurse manager (Michele). Additionally
we were joined by Karin, the nurse
who does their residential care. She
has been there for 30 years.

With regard to social work, many
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C U LT U R A L
P R O G R A M

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who was Zulu, gave us an overview of
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Delegates with Their Bracelets.
Delegates Learning to Make Bracelets from Reeds.

Zulu Village.

is the most important animal for whistle. All cows have names. The goat their cows with a certain kind of goats, dogs, and roosters. They call animals everywhere, especially cows, attempting to braid such bracelets. ritual of making bracelets from a certain reed. Delegates spent a few minutes learned, the Zulu village we visited was quite rural, and they all walked very long distances if they wanted to leave the village. There was a taxi stop the intersection of the highway and the village road, but it was quite a trek to get there.

At the village, we were met by a teenage guide named Jason. Jason spoke excellent English and was dressed like a modern teenager anywhere, down to his tennis shoes. His attire was unlike most of that we saw in the village.

The village was situated near a large reservoir, and we walked down to the reservoir, and we walked down to the edge of the water. The village does not have indoor plumbing, and they get their water from the reservoir. They are working on a water project to get clean water to their homes. While at the water, Jason explained the courting ritual of making bracelets from a certain reed. Delagates spent a few minutes attempting to braid such bracelets.

The village consisted of round yard-like houses with thatched roofs. There were animals everywhere, especially cows, goats, dogs, and roosters. They call their cows with a certain kind of whistles. Delegates were given names. The goat is the most important animal for ceremonies. They sacrifice goats for funerals and weddings.

They have psalm readers and healers. Healers are usually men, psalm readers women. However, Jason took us to meet a female healer. She was quite elderly, inside, the men sat on low benches. The women sat on the floor. Jason translated and told us that she healed people by calling on their ancestors. While were there, she lighted a small pile of herbs and performed a ritual.

From there, we went to the home where we would be served a vegetarian lunch. Again, the woman sat on floor mats. A large basin of water was passed around so we could wash our hands. The food was served on tin plates. They do not use any eating utensils. That was a new experience for many of us. We were served five different cooked vegetables including tomatoes, cabbage and spinach. They explained that they don't eat as a family. People just eat when they are hungry. One of the elderly men asked us about using silverware. He wanted to know if children have to be taught to use forks and spoons.

After lunch, a group of small children performed some ritual dances for us. In exchange, we gave them the candy she said were made in their village. Delegates purchased many items.

We returned to the van to begin our trip back to Durban. Sithembiso thanked the delegates for their generosity in buying the beads, providing candy and home gifts, and for tipping the healer and the local guide. He said it would go a long way toward helping the village financially.

Dinner that night was on our own. We would be flying to Cape Town the next morning, and we would be leaving the hotel at 7am, so delagates needed to pack and get ready for an early start.

Saturday August 18, 2012

All Day - Travel to Cape Town

The delegates were all ready on time and we arrived at King Shaka International Airport as planned. We had to do some shifting of luggage because of weight restrictions, but we finally got checked in. Very shortly after that, we found that our flight was delayed. It was eventually cancelled altogether. That began a chain of events that kept us there for many hours. We had an especially helpful customer service representative. She did manage to get us all on another flight in mid-afternoon.

Because of our delay, we called our guide in Cape Town. We had all been planning to visit Robben Island that afternoon, and we had purchased separate tickets for admission. Our guide, Linda van Doesburgh, tried to get us tickets for later in the week, but they were sold out. She did go to the area and sold our tickets to other tourists so we could get a refund on our purchase.

We arrived in Cape Town in late afternoon and Linda and her husband Johann were waiting for us. Johann had been our main guide on a previous People to People trip and it was so nice to see him again. Unlike Durban, Lin would be our driver as well as our guide. We were all impressed by his driving skills.

We didn't want the whole day to be wasted by travel issues, so Linda suggested we go to Signal Hill before heading to our hotel. The road up the mountain was exceptionally bumpy. It was the last day of Ramadan, and many people had come to Signal Hill to see the new moon rise. Despite very cold winds, they were having cookouts and picnics. It was a nice experience to be a small part of a cultural event.

From there we went to our hotel, the Protea Hotel President on Bantry Bay. Our check-in went smoothly, but there seemed to be a lot of confusion in the lobby as a large tour group was also checking in. It was actually another social work group from the USA - National Association of Black Social Workers. We knew many of them. It seemed like quite a coincidence.

We decided to eat in the hotel restaurant, but the two tour groups arriving at one time put great stress on the kitchen and wait staff. It took a long time to be served, and our food came at different times.

At the conclusion of dinner - around 10pm - we checked to see if some of our missing luggage had arrived. Just as we were checking, it was delivered. The day was a bit disappointing due to travel difficulties, but all of the delegates were flexible and we ended the day prepared for our cultural adventure the following day.
explained that there is a familial
ceremony for important occasions.
The king rules the land. Then
there is a head man, and next in line
authority are the police.

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SUNDAY AUGUST 19, 2012

Today was a day of tourist and cultural activities. It was a rather cold, grey day – a reminder that it was winter time there.

Linda picked us up as planned and we set off to see some of the major sights. We passed a large shantytown and she explained that the small dwellings we saw were recent immigrants, many from Somalia. The government keeps building small, concrete houses, but they can’t keep up with the need. She also mentioned that Habitat for Humanity helps build houses in the shantytowns. They are very organized there.

Our goal was a tour of the Cape Peninsula and Cape Point. Our first stop was Hout Bay, a beautiful spot for photographs. We next stopped briefly outside an ostrich farm. Raising ostriches is lucrative because of their eggs, meat and leather.

We passed through an area called Scarborough and Linda told us about a problem the community was having with baboon raids. The residents can’t agree on how to handle the situation. There are two groups of baboons and they have become quite sophisticated in entering houses and stealing food. The alpha baboon has even been named. They call him William.

We next drove into the Cape of Good Hope Reserve Park. It is in Table Mountain National Park. It is mostly a flora reserve, and botanists come from all over the world to see the various specimens found there. There are some animals there including five zebras. A zebra sighting was quite rare, but we did see several ostrich and one antelope.

At the Cape of Good Hope, we took a funicular up to the highest point where there is a lighthouse. They refer to it as the Beacon of Hope Lighthouse. Some of the delegates took the stairs to the top of the lighthouse. The views were spectacular.

One of the reasons we had come to this location was to see Cape Point, the place where the Atlantic and Indian Oceans merge. Our guide explained that we were not actually at the most southern tip of South Africa, but at the southernmost point of southwestern South Africa. It was quite windy and there were groups of tourists in line to have their photograph taken with the sign that indicates the latitude and longitude.

Our final stop before lunch was the African penguin reserve at Boulders Beach. Boulders gets its name from the huge rounded rocks found there. The penguin colony began with two pairs in 1984. There are now over 3000 there. It is unusual to see penguins on the mainland. In fact, there are only two mainland colonies in the world. African penguins are small penguins, but they provided ample photo opportunities.

We had lunch at Seaforth restaurant which is located fairly near the penguins. They were prepared for us and they were efficient in serving our food.

After lunch our destination was the Kirstenbosch Botanical Gardens. While driving through the village of Gansbaai, Linda spotted a pod of whales quite close to the shoreline. She explained that it is southern right whale season and they come to the area between July and October to have their calves.

Historically, their name derives from being the “right” whale to kill due to their high oil content and the fact that they float when dead. There were at least three of them in the pod. We were all thrilled to see them at such a close distance.

Our plan was to park at the top of the gardens and walk down to the main area. Linda wanted to show us some gardens of protea, the national flower. Protea flowers are ancient and are native to this part of the world, with 92 percent of the species occurring only in this region of South Africa. Interestingly, they have no scent. Just as we arrived, however, it started to rain, so we went to the indoor exhibits and the indoor amphitheater. We also allowed plenty of time to visit the wonderful gift shop which had many beautiful objects for sale.

Some of us wanted to do some shopping and we had enough time to visit the diamond factory before dinner. It is called Jewell Afrika. We were surprised they were open late on Sunday, but they were quite welcoming. They gave us a brief demonstration on cutting and selecting diamonds and then we had the opportunity to visit the sales floor.

Our dinner this evening was hosted by a local family – the Dixons. They lived in the suburbs and they had prepared a wonderful meal of chicken and mamal. Mr. and Mrs. Dixon had been joined by Mrs. Dixon’s sister and her husband. We divided into two tables and had delightful time talking with them. Be hosted by a local family gives us an additional perspective on the country.

MONDAY AUGUST 20, 2012

PROFESSIONAL PROGRAM

MORNING – STELLENBOSCH UNIVERSITY

Whenever possible, we like to meet with a university program to learn about their academic training. On this trip we had an appointment with the Stellenbosch University Nursing Division, Department of Interdisciplinary Health. They had added palliative oncology nursing in 2011.

Our main contacts at the university were Mrs. Dixon’s sister and her husband who live in a nearby suburb. They are a very friendly couple who invited us to their home for a wonderful meal of chicken and muttering.

We were also joined by Therese Crowley, a nurse lecturer who noted that she did curriculum design for the Hospice and Palliative Care Association.

We also joined by Theresa Crowley, a nurse lecturer who noted that she did curriculum design for the Hospice and Palliative Care Association.
DAY AUGUST 19, 2012

It was a day of touristic and cultural activities. It was a rather cold, gray day—under that it was winter time there. We picked us up as planned and we went to see some of the major sights.

The government keeps their small, concrete houses, but they keep up with the need. She also introduced that Habitat for Humanity build houses in the shantytowns. They are very organized there.

Our destination was a tour of the Cape Peninsula and Cape Point. Our first stop was Hout Bay, a beautiful spot for photographs. We next stopped briefly at a reserve, and we were efficient in serving our food.

After lunch our destination was the Kirstenbosch Botanical Gardens. While driving through the village of Glencarin, Linda spotted a pod of whales quite close to the shoreline. She explained that it is the southern right whale season and they come to the area between July and October to have their calves. Historically, their name derives from being the “right” whale to kill due to their high oil content and the fact that they float when dead. There were at least three of them in the pod. We were all thrilled to see them at such a close distance.

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Whenever possible, we like to meet with a university program to learn about their academic training. On this trip we had an appointment with the Stellenbosch University Nursing Division, Department of Interdisciplinary Health. They had added palliative and oncology nursing in 2011.

Our main contacts at the university were:

Ms. Lesley Patterson who is getting her doctorate in palliative care (lpatterson@sun.ac.za).

Dr. Jenny Morgan, a family medicine physician who is getting a master’s in palliative care.

Jenny Stidworthy, a nurse educator who does curriculum design for the Hospice and Palliative Care Association (jstidworthy@mighty.co.za). She was getting her master’s degree in health science.

We were also joined by Theresa Crowley, a nurse lecturer who received
that she was not yet fully supportive of palliative care as a specialty.

They all agreed that palliative care has not yet become a recognized specialty. The Nursing Council still doesn’t fully support it. Therefore, even though HPCA runs short courses, they aren’t registered as formal courses.

They described the health care system in South Africa as a decentralized system that relies on district medicine. Community based care is important and home based care is often provided by “caregivers” not nurses. Most care is non-profit. For every 50 cases, there is only one professional nurse. Access to social workers also is a major problem.

There is a dual delivery system of health care. You can get care if you have resources. The psychosocial needs are great, and some people don’t have food. Many people live on 500 Rand per month which is about $60 in the USA. Immigrants can’t access services at all.

They discussed how HIV/AIDS has restructured health care. They also emphasized that TB is a huge problem now. Palliative care is still mainly for patients who will die within six months. While palliative care is fragmented, they all felt that hospice did a good job in the community.

Interdisciplinary care includes social work. They are training all undergraduates in the basics of palliative care, but training is variable. Also, getting palliative care into clinical practice is a challenge. It needs to be integrated into routine care.

We also discussed pain control. Morphine is available but other pain medicines are harder to use due to unavailability. Also, many professionals still fear that patients will become addicted. There is a movement to have nurses be able to prescribe morphine.

They are very aware of cultural issues, and the HPCA has a program working with traditional healers. They have had several training sessions so far.

A major issue is a lack of shared language. As we had learned during our orientation, there are 11 national languages. Zulu and Xhosa are the most frequently spoken. Afrikaans is third. It is spoken by 15 percent of the population. English is only the fifth most common and is spoken by nine percent. This creates a cultural challenge for providing health care.

We had a rich exchange, and as a group, we were interested in the educational materials we had brought.

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The Cape’s original inhabitants named the mountain “Hoerikwaggo” which means “mountain of the sea.” It has an unforgettable profile – a flat-topped mountain. It overlooks the city center and is flanked by the distant formations of Lion’s Head and Signal Hill to the west and Devil’s Peak to the east. You can also see the series of formations called the “Twelve Apostles.” It was thrilling to be on top of the mountain and we were grateful to Linda for making that possible.

We were to have a free afternoon, but it was about 3pm when we got back to the hotel. Everyone was hungry so we decided to have a late lunch at the hotel restaurant. Due to such slow service the night we arrived, we had each received a coupon for another meal. It seemed like a good time to use them.

After lunch the delegates did a variety of things like visiting the Waterfront or doing some street shopping. There was also time to attend an important meeting. This was especially unfortunate since we were going to visit two hospices that have training partners through HPCA. One of the organizations that John met while in Cape Town is Hospice of Michigan in Detroit.

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After lunch the delegates did a variety of things like visiting the Waterfront or doing some street shopping. There was no group dinner planned for the evening.

The cars were wound so the floor could rotate allowing visitors a 360 degree view. The views were spectacular. There are several walks when you arrive on top. It was quite cold so Linda led us on a short walk that she enjoys. She and her family have hiked up Table Mountain.

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**Cultural Program**

**Afternoon – Table Mountain**

While at the University, Linda had checked the conditions at Table Mountain. We all had expressed a desire to go up the mountain, if at all possible. Since the conditions and visibility were good, we decided to go there instead of visiting the V & A Waterfront.

Table Mountain is one of the New Seven Wonders of the World. We bought tickets for the cable cars which have been in operation for 80 years.

The cars were round so the floor could rotate allowing visitors a 360 degree view. The views were spectacular. There are several walks when you arrive on top. It was quite cold so Linda led us on a short walk that she enjoys. She and her family have hiked up Table Mountain.

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After lunch the delegates did a variety of things like visiting the Waterfront or doing some street shopping. There was no group dinner planned for the evening.

**Tuesday August 21, 2012**

**Professional Program**

**Morning – St. Luke’s Hospice**

John Mastrojohn, one of the co-leaders, had to depart this morning for Rwanda to attend an important meeting. This was especially unfortunate since we were going to visit two hospices that have twinning partners through FHSSA, one of the organizations that John runs.

It was a pretty morning for our drive to our first venue – St. Luke’s Hospice. We arrived at 9 am and were greeted by Priscilla Nelson, the CEO of St. Luke’s who also happens to be a social worker. We had met Priscilla on a previous trip, so it was nice to see her again. In addition to several of her staff. We were also joined by Kathy Hemming, Chief Operating Officer from the HPCA.

In comparison to other hospices we visited, St. Luke’s is huge and well established. They have been in operation since 1980 and have 12 community hospices spread throughout Cape Town. They have 200 staff and over 650 volunteers. The facility we were visiting is one of two hospices with inpatient beds. Most patients are cared for in their own homes. Around 40 percent of their caseload have a diagnosis of AIDS. They offer services around the clock at no charge unless the patient has some sort of medical aid. There operating budget is 230 million (over $13 million US dollars) per year which seems incredibly low given the scope of their work. They have a FHSSA partner in the USA; it is Hospice of Michigan in Detroit.
They have a FHSSA partnership with Hospice of the Western Reserve (HWR) in Cleveland, Ohio. They had a quilt made by HWR hanging in their hallway. Shareefah Sabur, immediate past chair of the FHSSA Board of Directors, had visited there last year and had led a strategic planning group.

We spent a delightful 90 plus minutes discussing ethical and legal issues, staffing, and fundraising. We were pleased to be able to present them with a donation.

At the conclusion of the Helderberg visit, we returned to our hotel to prepare for our final banquet. It was held in Krugmann’s Grill which was located in the Waterfront Mall. Linda had reserved a separate room for us and it was quite lovely. The waiter was attentive, service was excellent, and the food was delicious. In all, it was a fitting conclusion to our visit.

WEDNESDAY AUGUST 22, 2013

DEPARTURE

All but three of us were going on to safari in Kruger. That group was leaving at 5:30am so we said our farewells at the banquet the night before.

Linda dealt with the early group and then came back to transport the rest of us to the Cape Town International Airport where we would retrace our steps first to Johannesburg, then a stop in Senegal, and on to Washington, DC.

When we arrived in DC, it was 6am and passport control and customs were just opening. Lines were short and we got through without difficulty. It seemed like we had just begun our journey a short while ago. I always think that how fast the time seems to pass is a measure of a good trip. This one was very good, indeed.
Afternoon - Helderberg Hospice

Our afternoon visit was also in Somerset West, not too far from our restaurant. Helderberg Hospice serves an urban and peri-urban area. It opened in 1996 and is the third oldest hospice in South Africa.

We met with the CEO, Ms. Gill Wasserfall, and two social workers. One social worker was named Lizette and the other was a social work associate from Uganda. They explained that the language in their area is predominantly Afrikaans, but English and Xhosa are also spoken.

They have 10 staff, including three social workers, and serve 350 patients annually. Like the other hospices we visited, they discharged 100 patients last year – mostly AIDS or TB patients who receive treatment with ARVs. Their annual operating budget is $1 million, and they only have a one year operating reserve budget.

They focus on palliative care – they don’t do other broad services but refer patients and families to other agencies as needed. They stick to their core services including respite care. They have a ten bed inpatient unit (there were only three inpatients when we visited). Social workers do the bereavement follow-up.

They have a FHSSA partnership with Hospice of the Western Reserve (HWR) in Cleveland, Ohio. They had a quilt made by HWR hanging in their hallway. Shareefah Sabur, immediate past chair of the FHSSA Board of Directors, had visited there last year and had led a strategic planning group.

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FINAL SUMMARY

Perhaps the most striking aspect of our visit were the similarities of hospice care in the USA and in South Africa and the similarities of the challenges they were facing.

SIMILARITIES WITH USA
The hospice concept and philosophy, the use of a multidisciplinary team, and providing bereavement care were quite similar. They also have similar workforce shortages with a great need for nurses, social workers, and physicians trained in palliative medicine. They mentioned that many of the nurses and physicians trained in South Africa go to places like England after they graduate because the pay is so much better.

The Hospice and Palliative Care Association (HPCA) is quite a force in South Africa. They have 70 staff and they have developed standards and an accreditation process. They also offer online and distant education in palliative care. They have had difficulty in getting their courses accepted in academic programs, so they offer a series of short courses.

Like in the USA, palliative care is not fully understood and is not integrated into primary care. In South Africa, it seems to apply only to end-of-life care and it is not common in hospitals or in serious illnesses that are not life-threatening.

At the same time, they discussed the way antiretroviral therapy has changed the focus of not only hospice care, but their entire health care system. They previously were overwhelmed with the number of people dying from AIDS. Now they are providing more care for people with cancer.

CHALLENGES
Unlike our country, there is no formal prayer source for hospice care. If someone has insurance they do charge for it, but that is not the norm. That means that funding is a continual challenge. They all used a large variety of fundraising initiatives, including grants, special events, bequests, in-kind donations, and various partnerships. PEPFAR funding has significantly diminished. This has had a huge impact.

Three of the hospices we visited, Helderberg, Highway and St. Luke's, have FHSSA partners in the USA.

Almost all the CEOs or Directors mentioned being optimistic that the funds will come in as needed. One said that “they walk on faith.” Another said that they did not have much in operating reserves, but that they had been in operation since 1986, and each year they manage.

One new challenge appears to be a significant increase in multi-drug resistant tuberculosis that is HIV-related. We had a fascinating conversation at Helderberg Hospice that detailed how they train their staff for dealing with tuberculosis – e.g., talking to clients in open spaces or outside, recognizing signs and symptoms, taking precautions regarding one’s own health.

Most of the hospices relied heavily on volunteers and on lay “cancer” at the homes. These reminded us of peer counselors or patient navigators in the USA. They did provide training for the lay staff and are in the process of evaluating the outcomes.

Two hospices remarked on how many patients were discharged from hospice in the previous year. Some noted that finances forced them to cut back on services. Highway Hospice in Durban had reduced their caseload by almost half this past year. Helderberg also mentioned a significant decrease. Mostly this was due to patients with AIDS receiving ARVs and having their TB treated.

Other challenges included insufficient time to conduct research and a lack of publication of best practices that would help to advance the field. Despite these, some innovative programming is underway. One program being developed is hospice care in prisons. In addition to working to provide direct end-of-life care for prisoners, HPCA has strong advocacy efforts underway to get the problem recognized by their legislature.

It is important to point out that we visited hospice programs in urban, or what they refer to as peri-urban, areas. While most of the hospices described have been in existence for over 20 years, hospice care in rural areas is in its well developed. Language and cultural differences of the indigenous groups create significant barriers. South Africa has 11 official languages and most of the staff we met speak only English Afrikaans. They all acknowledged this was a challenge.

With regard to cultural differences, many indigenous groups use healers from their own villages. We met a healer in the Zulu village we visited, used burning herbs to contact the ancestors of the people the she was helping. The hospice staff noted that they do try to supplant such healers and traditions, but that they try to work with them in a complementary fashion.

Pain control remains an issue. Morphine is readily available, but other pain medications are in scarce supply. Similar to the USA, some physicians are reluctant to use opioids because they fear the patient will become addicted.

The individuals we met were dedicated and passionate. Most of them had been working in end-of-life care for many years. They acknowledged the challenging aspects of their jobs and their programs, but they all appeared totally committed to advancing palliative care and hospice care in South Africa.
At the same time, they discussed the way antiretroviral therapy has changed the focus of not only hospice care, but their entire health care system. They previously were overwhelmed with the number of people dying from AIDS. Now they are providing more care for people with cancer.

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