Dreams Can Come True:
Fighting the Stigma of Cancer and Facilitating Access to Safe, Appropriate Care in Belize

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This article describes a national effort to open access to cancer services and treatment for persons living with cancer in the developing, low-income country of Belize. The journey to establish the Belize Cancer Center Dangriga, located in the depressed southern region of the country, that provides affordable, culturally sensitive care primarily to low-income patients and families is explained. The challenges of establishing this center, the only multisectorial, multidisciplinary cancer center in the country to date, given the stigma associated with cancer, are discussed.

In late 2007, I met Alicia, a patient of Dr. Ellsworth Grant, a hematologist-oncologist in private practice in Los Angeles. Her story was heart wrenching and yet a typical example of the plight of patients and families in Belize after a diagnosis of cancer was made. Persons with cancer were not often told by their physician about their diagnosis, and many times were advised to seek care outside Belize; few had the financial support needed to follow the doctor's recommendation. Most of the patients diagnosed with cancer were women. Breast and cervical cancer were the most common diagnoses. Cancer's association with loss of life decreased this population's willingness to discuss cancer. Women were afraid other members saw them as deserving of the disease, whereas others feared lessened personal support. For the diagnosed cancer patient, life stopped, and even family members emotionally withdrew to insulate themselves from the impending loss. One patient summed it up best in saying, "People who I thought were my friends avoid talking to me. I go to school, and I feel everyone is watching me. My mother was talking on the phone about who would raise my kids when I'm gone. I don't need anybody to feel sorry for me; I want to live, and I want help and support to survive my disease."

According to Knapp et al,[1] when a person had a disease such as cancer, it set them apart, reducing their social worth in the eyes of others, threatening their sense of identity because of cancer's association with death. This manifested in ways that decreased people's willingness to discuss cancer. They perceived the diagnosis as a threat to personal identity, and communities raised questions about the person's moral worth. In Belizean culture, the stigma of a cancer diagnosis was extremely burdensome and emotionally distressing. Women would come to the center for "information" but on further questioning would reveal fumigating breast lesions that they kept secret and self-treated for months. One patient asked to be treated alone because she did not want anyone to recognize her. Fear of personal stigmatization has lessened throughout the years. It is now more appropriate to examine cancer and the stigmatization of cancer as complex and homogeneous, varying by type of cancer across factors such as treatment, cause, and outcomes.[2–4] Scientific knowledge about the disease has also increased. Survivors are also steadily increasing as new targeted therapies become more available and the public is better informed about cancer treatment options. Despite this, stigmatization will continue to be a very real impediment to timely treatment in smaller villages and close-knit communities.

Most diagnosed patients could not afford to travel outside the country for treatment, and inside-country options were suboptimal, including delays in lab results leading to significant delays in diagnosis. This was compounded by having only 1 anatomic pathologist for the entire country of approximately 375,000 people, working in suboptimal conditions. For some patients, not knowing the results was less frightening than hearing them, especially when no readily accessible treatment options were available prior to 2008. With no medical oncology, hematology, pediatric oncology, or radiation oncology services in-country, medical oncology and hematology care was provided by Dr. Ellsworth Grant, who traveled every 6 to 8 weeks from Los Angeles, California, to see patients in Belize. He managed patients in between visits using tele-oncology technology.

While serving as Chief Nursing Officer at Los Angeles County, Olive View-University College of Los

Angeles Medical Center (OV-UCLA-MC), Alicia's care-seeking journey came to my attention. Although by no means financially disadvantaged, her delayed access to appropriate care resulted from a six-month delay of her biopsy result. As a nurse leader who kept a watchful eye on Belize's nursing practice and patient care standards, the numerous negative experiences encountered by cancer patients within the public healthcare system was sufficiently compelling to forge a partnership with the Belize Cancer Society, in a countrywide effort to alleviate fear, pain, and suffering of cancer patients. Our strategy was to engage key stakeholders from the Ministry of Health (MOH) with the intent of changing the existing "no access, no hope" paradigm. Our goal was to establish basic oncology services, using a "shared responsibility" care delivery model that would open access to cancer treatment for poor patients and families across the country.

METHOD

February 2008 was a defining year for cancer care and services in Belize. Dr. Ellsworth Grant engaged in partnership with the Ministry of Health (MOH) to establish basic outpatient medical oncology services. A core group of stakeholders interested in improving access to care and quality of life for cancer patients were selected by the MOH chief executive officer (CEO). Included were representatives from surgery, medicine, administration, anesthesiology, palliative service, nursing, Dr. Grant, and myself. The challenges to cancer services access and availability were outlined, namely, extreme financial burden to patients with limited or no income, sociocultural barriers, disease stigma, cross-border transportation, family disruption, fragmentation of care, and crippling fear of the unknown with limited mental health support. As one patient said to a member of the team on learning his diagnosis, "I just got my death sentence, what am I supposed to do?" It was not an isolated comment; however, we had no real data to comprehensively gauge the scope of need as only mortality data was accurately reported and stored. Incomplete data limited the team's ability to determine what size footprint was needed to deliver cancer care in Belize. Nevertheless, the team adopted the following recommendations:

1. The outpatient Cancer Center would be a private–public partnership between the MOH and the Belizean Women's Wellness Foundation (BWWF), a charitable nonprofit organization in California. It would be apolitical and serve anyone with a cancer diagnosis who required treatment or other related services. Any source of referral for diagnosed patients would be accepted.
2. The US team proposed locating Belize Cancer Center in the southern town of Dangriga because there was an existing building for providing services. Dr. Grant converted his family home to a cancer center at no cost to the government or collaborating partners.
3. Human resourcing included access to physician services eight hours a day, five days a week along with the services of an experienced RN, Sister Carolyn Obi, who understood the existing gap in cancer care delivery both in the ambulatory and inpatient settings.

ADVOCACY AND NURSING

Advocacy can be understood as standing up and speaking out for moral good, voicing concerns of disadvantaged people, and collaborating with individuals or who need support in exerting their rights and preferences. Hofmeyer et al[5] contend that influence involves advocacy, and to be effective in advocating for change and better outcomes, for individuals, communities, and society at large, we need to be engaged. As a nurse leader, Sister Obi was the new face of hope for patients. She advocated for them through her leadership, creativity, and vision. She developed criteria for in-home chemotherapy administration and pain management when patients were not able to keep their appointments. Sister Obi participated in broad, transdisciplinary discussions about the National Cancer Plan, and gave input into its preparation for presentation to the Ministry of Health by the Belize (national) Cancer Society. A major leadership contribution was the establishment of an effective communications network to facilitate patient throughput that included all members of the interdisciplinary team. As the clinical manager she advocated for hospitalized patients and their families, focusing on life and survival with a realistic view of end-of life issues. As a mentor of other nurses, caregivers, and treating physicians, she increased sensitivity to end-of-life needs. Cross-border services delivered by care partners in Mexico and Guatemala were monitored for quality safety when referrals were made for pediatric oncology and radiation therapy. Patient concerns were investigated and resolved quickly. Patient advocacy has been a long tradition in nursing and continues through global health initiatives.[6]

Stakeholder and community collaboration was essential for forging meaningful, respectful, professional relationships for which cancer patients were the primary beneficiary.

Clinical team members actively engaged with physicians to ensure appropriate plan of care. As an advocate, it was not uncommon for Sister Obi to travel by bus for 108 miles to the Karl Heusner Memorial Hospital (KHMH) in Belize City to ensure patients navigated the complex Ministry of Health network. The role of an RN as expert clinician was needed for raising the right questions and clarifying clinical information until the patient understood. The nursing team gained respect for their knowledge and expertise in oncology nursing and, more significantly, for their caring, empathetic, sensitive relationship shared with patients and families every day.

Early involvement of local businesses and the healthcare community was essential when decisions were made to transform a donated residential building into an

outpatient cancer center, given the potential impact on the town's business infrastructure and the local hospital. Initially, the nursing leadership at Southern Regional Hospital (SRH) did not embrace the idea of the cancer center in the community due to a national nursing shortage, in part caused by a debilitating loss of professional nursing talent to US recruiters. To add a new practice for care of hospitalized oncology patients was an unwelcomed change in their already resource-poor clinical environment. The prevailing attitude toward cancer patients was reflected in the strong concerns voiced by physicians and nurses about providing care to hospitalized cancer patients. Cancer was taboo. Talking about it was unpleasant enough, but taking care of a friend, neighbor, or young adult served to remind many of the nurses about their own mortality and vulnerability. Questions of knowledge and skill surfaced. Many nurses at the regional hospitals were not trained in subspecialty care. Regional hospitals had no intensive care or telemetry units, and the only "higher level of care" facility was 108 miles away. Cancer patients admitted to SRH tended to be very ill, often needing blood or blood products, which were always in short supply. SHR nurses seemed emotionally unprepared to deal with the complexity of oncology nursing care, including prolong suffering. New nurses, in particular, were uncertain about how to address the need for emotional, psychosocial, spiritual, and symptom management support for the terminally ill. Given a large contracted workforce from Cuba, Latin America, and Nigeria, clinical skills and competency levels varied as did attitudes and behaviors toward specific groups of patients, based on their own cultural values and beliefs. A key strategy involved working with the hospital's nursing leadership about targeted education for nurses and increasing visibility of the cancer center's nursing staff on hospital units, an important resource real-time support. Establishing collegial relationships with hospital leadership and staff, as well as local community leaders, was key to ensuring lasting support for cancer patients and oncology nursing education. There were similar concerns from physicians, regarding lack of preparation and confidence in managing complications of cancer, due to limited exposure and clinical competence. Concerns also included working in resource-challenged hospitals with limited access to critical supplies, equipment and medication such as blood, blood products, rescue drugs, and appropriate antibiotics. These concerns were shared with the hospital's chief of staff and the CEO, Belize Health Ministry.

In light of stated nursing and physician concerns, decisions were made to temporarily engage Dr. Grant as a co-manager for hospitalized patients at the local hospital using electronic or phone consultations. This arrangement allowed time for the development and presentation of clinical guidelines on the management of cancer patients. For Belizean nurses, the first Oncology Nursing Society approved Chemotherapy Certification Course was presented by Robin Herman, Clinical Nurse Specialist (CNS) from Los Angeles County-University of Southern California Medical Center (LAC-USC MC). This 3-day course was well attended and included physicians and pharmacists. Unfortunately, time, distance, and work schedules were significant barriers to completion of the hands-on clinical competency validation, and the reality is that 10 years later, Sister Obi still remains the only chemotherapy-certified nurse in the country of Belize.

RESULTS

On October 1, 2008, the very first patient accompanied by her physician arrived for treatment at the Belize Cancer Center Dangriga (BCCD). As of December 2018, she is a 10-year breast cancer survivor. Referrals started slowly as physician referral to Mexico or Guatemala continued. Tensions surfaced between the KHMH physicians and BCCD staff when patients were referred to the tertiary hospital for a higher level of care. Like the local hospital, nurses and physicians expressed discomfort in taking care of cancer patients. Strengthening existing and building new relationships with the clinical and administrative leadership at the tertiary center was vital.

Through donated live media time from local outlets, the public was informed that the Center was an alternative option to the current practice of sending patients to fee-for-service providers across the borders. BCCD adopted an open access care delivery model with trained, experienced team enabling anyone to refer a person with a cancer diagnosis. The addition of in-home consultations by an RN expanded awareness, gradually increasing patient referrals.

In November 2010, a multisectorial meeting was convened to discuss the status of pediatric oncology care in Belize. Participants included the MOH; Casa de Amistad, a charitable nonprofit organization supporting children receiving cancer treatment in Merida (Mexico); the Belize Cancer Society (BCS); the Pediatric Oncologist (Mexico), the National Director of Palliative Services and BCCD staff. Discussions included challenges and barriers encountered when referring children with cancer for cross-border care, and explored how the cancer center could help ease the social and financial burden of Belizean pediatric oncology patients and families. The Center's focus was adults, not children, and they had little experience caring for children, which left them feeling vulnerable as pressure to provide services mounted. We needed to lean into our vulnerabilities, described by Brown as:[7] "discussion, conversation or meeting defined by a commitment to lean into vulnerabilities, to stay curious and generous, to stick with the messy middle of problem identification and solving, to take a break and circle back when necessary, to be fearless in owning our parts and, to listen with the same passion with which we want to be heard." After much discussion, the BCCD scope of service was expanded to enable comanagement of pediatric cancer patients with the Hospital O'Horan del Cuidad de Merida, Merida, Yucatan, Mexico.

DISCUSSION

During its 10-year journey, the Center has had a single mission: to provide care and services to persons living with cancer in Belize and to do so with compassion, irrespective of race, culture, gender, religion, political preference, or lifestyle choice. The center is especially sensitive to the poor, underserved, and socially disadvantaged. Often, selected phases of cancer treatment are provided free of cost. In some cases, arrangements are made for contribution to offset cost based on patients' ability to pay. The majority of funding for sustaining patient care and treatment comes for the Medical Director's and CEO's personal funds. Other generous donations are provided by Social Security Belize, the Government of Belize CEO Caucus, the MOH, individual donors, businesses, and groups. The MOH also provides consistent, in-kind support by funding the salaries of the Clinical Nurse Manager, Sister Obi, and oncology RN Pauline Okolo, enabling the center to remain opened 5 days a week and be available to new referrals seeking care, treatment, or related services. Stigma, education, and lack of resources are never-ending issues that we continue to address. All means of communication including social media, local press, television, printed media, health fairs, and text messaging are used to encourage patients and families not to be afraid to reach out to the cancer center staff. Our philosophy of care is that no one will be turned away, and anyone who comes to the center seeking care will be either provided care or be directed to the appropriate place where care can be provided. This message was also echoed by the Belize Cancer Society countrywide. The most powerful message of encouragement came from Belize's First Lady who shared her personal journey and experience with breast cancer. She reinforced the importance of early detection and intervention, and urged women to come out of the shadows. One patient put it this way: "Nurse, the First Lady has me looking at myself differently. I was ashamed to look at my body in the mirror, I use to change my clothes in the dark and never in front of my husband. Now, I look at me so I don't miss anything." The First Lady is a strong supporting pillar for access, quality, affordability, and safety in cancer care delivery.

The cancer center's current success lies in its connection with a network of multisectorial partners built over a 10-year period, and extending beyond the borders of Belize. Through professional networking, more patients are being appropriately referred to BCCD for oncology care. In April 2018, Belize welcomed Dr. Ramon Yacab, its first medical oncologist permanently residing in the country. As of October 1, 2018, BCCD is still the only public-private cancer treatment facility that provides oncology care nationwide.

Key accomplishments include the following:

- Provided oncology services, including chemotherapy, immunotherapy and biotherapy to over 1,100 patients
- Established:
  - Pediatric oncology partnership with O'Horan Hospital in Merida, Yucatan, resulting in an increase in survival of children with acute lymphocytic leukemia from 38% in 2008 to 78% in 2018
  - Cross-border, radiation oncology partnership with Centro de Radiotherapia y Oncologia in Guatemala City to facilitate radiation treatment
  - US-based pathology partnership to provide second opinion, and special studies, required to diagnose and manage complex oncology cases
  - Sickle cell disease program with point-of-care testing and results available in 10 minutes rather than 2 weeks
  - Partnership with Olive View Medical Center and the University College of Los Angeles, Department of Internal Medicine to launch the department's Global Health elective in Belize. In the first quarter, 2019, the Global Health initiative will launch a comprehensive diabetes program to address health conditions associated with management of this chronic disease.

The BCCD leadership led by example. Challenges encountered from both the private and public sector strengthened our resolve to be leaders of courage. Knowing the price of failure would cause so many to lose hope and return to the shadows, we worked tirelessly to gain public and collegial trust. The Center focused on improving interprofessional relationships, rethinking paradigms, inspiring innovative thinking, making tough decisions, and finding common ground for beneficial collaboration to improve the quality of life for any and all persons living with a cancer diagnosis. We were equally committed to internalizing the importance of empathy and relationship building in a changing environment, crowded with technology, where the attention to machines often took precedence over the human patient.

As of the end of 2018, the BCCD is the only oncology medical home for both adult and pediatric cancer patients, with 4 to 6 new referrals weekly.

CONCLUSION

Positive results of the quarterly patient satisfaction surveys as well as feedback from members of the community continue. Patients found the BCCD to be a place where dreams of care and cure could come true. The journey was long and winding, but well worth the effort. The Belize Ministry of Health acknowledged our leadership efforts to reduce the social, economic, and disease burden of cancer for low-income Belizean patients and families. Continuing to find ways to ensure access to care for resource-limited families remains the center's main priority. As nurse leaders, we play a pivot-

al role by actively participating in effective partnerships within and outside our respective organizations. In Belize, we focus on ensuring access to health care for our most vulnerable populations where early detection and preventative services can save lives.

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