### **Review Article**

### Cancer and Palliative Care in the United States, Turkey, and Malawi: Developing Global Collaborations

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Received: February 14, 2017, Accepted: April 25, 2017

#### ABSTRACT

As the global cancer burden grows, so too will global inequities in access to cancer and palliative care increase. This paper will describe the cancer and palliative care landscape relative to nursing practice, education, and research, and emerging global collaborations in the United States (U.S.), Turkey, and Malawi. It is imperative that nurses lead efforts to advance health and strengthen education in these high-need areas. Leaders within the University of Alabama at Birmingham School of Nursing, through a Pan American Health Organization/World Health

Organization Nursing Collaborating Center, have initiated collaborative projects in cancer and palliative care between the U.S., Turkey, and Malawi to strengthen initiatives that can ultimately transform practice. These collaborations will lay a foundation to empower nurses to lead efforts to reduce the global inequities for those with cancer and other serious and life-limiting illnesses.

**Key words:** Cancer, education, global partnerships, nursing, oncology, palliative care, research

### Introduction

The American Cancer Society reports that the global cancer burden is expected to double by 2030.<sup>[1]</sup> Economically developing countries are most disadvantaged and often have few qualified health-care workers to manage those

Access this article online

Quick Response Code:

Website: www.apjon.org

DOI:
10.4103/apjon.apjon\_31\_17

affected. Schools of Nursing have the opportunity to lead the way in educating and developing strong leaders to build capacity to manage this global problem. Since 1994, the University of Alabama at Birmingham

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Cite this article as: Walker DK, Edwards RL, Bagcivan G, Bakitas MA. Cancer and palliative care in the United States, Turkey, and Malawi: Developing global collaborations. Asia Pac J Oncol Nurs 2017;4:209-19.

School of Nursing (UABSON) has been designated as a Pan American Health Organization/World Health Organization (WHO)-collaborating Centre. The UABSON is one of the nine WHO-collaborating centers in nursing in the United States (US) and one of the 43 in the world. Since this designation, the school has participated in an international network that works toward realizing the United Nations' Millennium Development Goals and the WHO's major goal of "Health for All." The Centre has facilitated collaboration around the world to advance health in a variety of specialties. Cancer and palliative care are two such specialties where the authors have developed leadership and strengthened education in our own institution and abroad in Turkey and Malawi, Africa. This paper will describe the cancer and palliative care clinical, education, and regulatory contexts and how collaboration between the UABSON and institutions in Turkey and Malawi has begun to enhance cancer and palliative care nursing practice, research, and education.

## Cancer and Palliative Care in the United States

The U.S. is the third largest country in the world. Current estimates show a U.S. population of >325 billion with an average life expectancy of 78.8 years. [2,3] Cancer is second only to heart disease as a leading cause of death in the U.S., although the mortality burden of cancer has surpassed that of heart disease in many U.S. states.[4] It is estimated that there were approximately 1.69 million new cancers diagnosed and 595,690 cancer-related deaths in the U.S. in 2016. [5] Cancer risk increases with age and the expectation is for an escalating population of older individuals in the U.S. over the next several decades, many who will face serious illnesses such as cancer. [6,7] Although cancer death rates are trending down, by 2020, the number of new cancer cases is expected to increase to almost 2 million/ year.[8] With this, cancer will become the leading cause of death in the U.S.[8]

In the U.S., there is a critical need to improve health-care quality while reducing costs. The U.S. has the highest per capita spending on health care worldwide with a rate of growth that is unsustainable.<sup>[9]</sup> Given the unsustainable trend in the U.S. health-care expenditures, the public and private health-care markets are under pressure to deliver higher quality, coordinated care to the increasing number of patients with serious illnesses such as cancer. Since there is a growing understanding that palliative care improves patient outcomes and reduces costs,<sup>[9]</sup> there has been tremendous growth and acceptance of palliative care in the U.S. in the past several years.

## **Cancer Care Availability in the United States**

Based on the WHO's 2014 Cancer Country Profile, the U.S. offers advanced cancer services such as cancer-related policy, strategy, and action plans, a cancer registry, primary prevention policies and services, generally available screening and early detection programs, and advanced cancer treatment and palliative care.<sup>[10]</sup> In addition to the population aging, Western lifestyle choices such as tobacco and alcohol consumption, poor nutrition, excess weight, and an inactive lifestyle significantly influence the risk of cancer development.<sup>[5]</sup>

Disparities in cancer burden exist in the U.S. and are based on socioeconomic status, race and ethnicity, and geographic location. For instance, those of lower socioeconomic status, regardless of race, have higher cancer incidence and cancer death rates.<sup>[5]</sup> This is attributable to poor lifestyle choices as well as environmental and workplace exposures.<sup>[5]</sup> Individuals of lower socioeconomic status are less likely to have access to appropriate cancer care and often diagnosed with late-stage cancers, which adversely affect prognosis.<sup>[5]</sup>

## Palliative Care Availability in the United States

The Worldwide Palliative Care Alliance's Global Atlas of Palliative Care at End of Life uses a system of mapping palliative care development across the world. The U.S. falls into the highest category (category 4b) for both adult and pediatric palliative care. This indicates advanced integration including an array of locations of care, comprehensive palliative care provision by a variety of providers, a broad awareness of palliative care, unrestricted access to opioids, palliative care policy and education, and existence of a national palliative care association. [11] In fact, palliative care is the fastest growing medical specialty in the U.S. [9] Despite this, palliative care is not universally integrated into hospital and community settings and many barriers to palliative care access exist in the U.S. [9]

## **Regulatory Influences on Cancer and Palliative Care**

There are several key regulatory influences for cancer and palliative care in the U.S. The first, the 2010 Patient Protection and Affordable Care Act, was enacted to provide numerous rights and protections for health coverage, as well as subsidies for affordability. Whether these provisions have improved cancer care for patients in the U.S. is debatable. Examples of a few provisions affecting cancer care are listed in Table 1. Overall, data

on whether these suggested delivery systems and payment models have improved value for cancer patients are insufficient.[12]

In 2012, the American Society of Clinical Oncology (ASCO) released a provisional clinical opinion based on the review of the 2010 study by Temel et al.[13] that revealed early integration of palliative care for patients with advanced lung cancer led to improved quality of life (QOL), mood, and survival. The ASCO PCO was updated in 2016 to reflect more recent evidence with the overarching recommendation that inpatients and outpatients with advanced cancer should receive palliative care services starting early in the disease course and concurrent with active treatment.[14] The adoption of palliative care integration for advanced cancer patients and others has been slow despite the ASCO recommendations and similar recommendations from national palliative care organizations.

In 1983, the Centers for Medicare and Medicaid Services (CMS) established the Medicare Hospice Benefit to provide Medicare beneficiaries (those 65 years of age or more or with prequalifying conditions) with high-quality end-of-life care. The benefit offers coverage for various locations of care including acute care hospitals, hospice

Table 1: Regulatory influences on cancer and palliative care i

the U.S	nnuences on cancer and pamative care in
Provisions	Influences
2010 patient protection and ACA <sup>[12]</sup>	Access to health care has improved, but access to cancer care has been limited by narrowing of networks made available in the public and private insurance markets  Shift from fee-for-service models where reimbursement is based on the quantity of services to bundled payments and value-based purchasing, where reimbursement is based on the quality and value of services provided Alternate care delivery systems such as ACO and PCMH should be put into place by 2018  Measures to improve cancer screening and prevention, quality reporting, and clinical effectiveness research
ASCO clinical practice guideline <sup>[13]</sup>	Recommendations: Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement the existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services
CMS <sup>[14]</sup>	Released CPT codes for reimbursement of advance care planning discussions Medicare hospice benefit to provide Medicare beneficiaries (those 65 years of age or more or with prequalifying conditions) with high-quality end-of-life care
CMS: Centers for Medicare an	CO: American Society of Clinical Oncology, nd Medicaid Services, ACO: Accountable care organizations, lical homes, CPT: Common procedural terminology

inpatient units, nursing homes, residential facilities, or private residences. Evidence supports better patient outcomes (fewer hospital admissions, in-hospital deaths, and days spent in hospital and intensive care settings) and cost savings for patients who enroll on the Medicare Hospice Benefit.[15]

### **Cancer and Palliative Care Workforce**

In the U.S., there are impending cancer and palliative care workforce shortages. A 2007 Association of American Medical Colleges workforce study predicts a significant shortage from 2500 to 4500 medical and gynecologic oncologists by 2020.[16] This shortage is related to an aging and growing population, an increasing number of cancer survivors, and a slower growth in the supply of oncologists.[16] Information from this study prompted the creation of the ASCO Workforce Strategic Plan including formation of a Workforce Advisory Group, and more recently, a Workforce Information System (WIS). Information gathered from the WIS can be used to advocate for the needed health-care system and policy changes related to the impending workforce shortage.[17] For instance, a finding gleaned from the WIS is that there is low capacity for expansion in cancer fellowship programs warranting enhancement of fellowship training to better integrate collaboration with advanced practice providers such as nurse practitioners with specialty training in cancer. This may enable oncologists to be more productive at the outset of their careers.<sup>[17]</sup>

With the substantial growth and acceptance of palliative care in the U.S. over the past decade, there is a growing need for palliative care education and training for health-care professionals. A survey of palliative care clinicians by the American Academy of Hospice and Palliative Medicine revealed that almost half intend to leave the field by 2023 secondary to retirement, burnout, and dissatisfaction with organization/practice.[18] Current estimates reveal 6600 board-certified palliative care physicians in practice and fewer than 250 fellowship-trained physicians entering the field every year. [18] There is a cap on the number of CMS-funded graduate medical education positions, leaving programs to rely on philanthropy and other mechanisms to fund palliative care fellows. [19] The projected shortage of palliative care physicians to meet the current demands is substantial. Considering those leaving the field in the next two decades and a 20% growth in those needing palliative care services in that time, the ratio will be one physician to 26,000 patients by 2030. In addition, similar shortages in advanced practice providers, nurses, chaplains, and social workers trained in palliative care are predicted.[18]

## **Nursing Roles in Cancer and Palliative Care**

In the U.S., there is a variety of ways to enter and advance in the nursing workforce. Although there are large numbers of Licensed Practical Nurses (PN) and Licensed Vocational Nurses as well as associate degree and diploma nurses practicing in the U.S., there is mounting evidence that Bachelor of Nursing Science (BSN)-prepared nurses have unique skill and play an important role in the delivery of high-quality patient care. [20] BSN degrees take approximately 4 years to complete. Successful completion of the appropriate National Council Licensure Examinations (NCLEX-PN or NCLEX - registered nurse [RN]) is required to enter nursing practice.

Advanced nursing degrees include Master of Science in Nursing (MSN) and doctoral degrees including Doctor of Nursing Practice and Doctor or Philosophy. Although there is a national push to increase the number of doctoral-prepared nurses in the workforce, the majority of advanced nurses hold MSN degrees. Advanced nurses include nurse practitioners, clinical nurse specialists, nurse anesthetists, nurse midwives, informatics specialists, educators, administrators, and others. Those advanced nurses providing direct patient care (nurse practitioners, clinical nurse specialists, nurse anesthetists, and nurse midwives) require regulatory recognition beyond the RN license and fall under the umbrella of advanced practice RNs (APRNs).<sup>[21]</sup>

Licensure is granted by state boards of nursing and is contingent upon successful completion of the aligning certification examinations for the four distinct APRN groups within the population foci context. For instance, advanced nurses who have completed coursework in a family nurse practitioner program will take the corresponding certification examination offered through the American Association of Nurse Practitioners or the American Nurses Credentialing Center. Specialty preparation in areas such as cancer or palliative care is optional and must build on the APRN role/population foci competencies. Professional organizations rather than state boards of nursing assess competency at the specialty level and APRNs cannot be licensed solely based on certification in a specialty area. RNs and advanced nurses may choose to or be required (by workplace governance) to gain specialty certification through professional organizations in specialty areas such as cancer or palliative care. In the U.S., both cancer and palliative care nurses are widely integrated into the health-care system, and specialty certification through national cancer and palliative care nursing organizations is highly valued.

With the impending cancer and palliative care physician shortages, APRNs educated and trained to provide care for patients with cancer and other serious illnesses are well positioned to help fill these workforce gaps. APRNs are licensed to diagnose and treat diseases and manage symptoms in addition to many other high-level responsibilities. In addition, APRNs have prescriptive authority and can prescribe medications as part of their clinical practice. [22] Some universities offer elective graduate nursing specialty courses in cancer and/or palliative care.

# **University of Alabama at Birmingham School of Nursing Initiatives**

Recognizing the need to grow the cancer and palliative care workforce given the impending workforce shortages in these areas, subspecialty cancer and palliative care programs have been developed and made available to graduate-level nursing students at several U.S. nursing schools including the UABSON.

The vision for the Oncology (Cancer) Nurse Practitioner (ONP) subspecialty at the UABSON was to develop a track for APRNs that will enhance their expertise in cancer care and promote excellence in cancer nursing through positively influencing the care of patients with cancer and their family caregivers. The program development began in 2012 and the first cohort of students enrolled in 2014. The ONP program is offered to students enrolled in the Adult Gerontology Primary Care and Family Nurse Practitioner Master's-level programs. The ONP program involves courses [Table 2] that promote a strong advanced primary care base for caring patients with common health problems. The clinical experiences are in a variety of specialty clinic settings offering extensive preparation for the advanced practice role. Graduates of this program can work interdependently with other health

Table 2: Cancer and palliative care nurse subspecialty program courses

Courses	Credit hours
Oncology	
Advanced practice nursing for oncology care	3
Cancer assessment, diagnosis, and management	2
The effects of cancer and cancer therapies	3
Practicum I: Oncology nurse practitioner	2
Practicum II: Oncology nurse practitioner	2
Residency: Oncology nurse practitioner	2
Palliative care	
Advanced palliative care nursing I	3
Advanced palliative care nursing II	3
Practicum I: Advanced palliative care	2
Practicum II: Advanced palliative care	2

professionals to provide primary and cancer health care to adults of all ages with specialized knowledge of cancer. The program enables graduates to gain clinical expertise and knowledge specific to cancer.

The Advanced Palliative Care Subspecialty Program at the SON has a deeper history. In 2000, two individuals founded the Center for Palliative Care at the School of Medicine, which is now the University's Center for Palliative and Supportive Care. In 2003, the University received a Health Resources and Services Administration (HRSA) grant to begin the Palliative Care Nursing Subspecialty at the UABSON. This program was the first of its kind at a public institution to be funded by the Federal Government. Students enrolled in the program were dually enrolled in the Family Nurse Practitioner Program. A second HRSA award carried the program through 2012. In 2015, the Program re-opened to multiple population foci tracks to include Family, Adult-Gerontology Primary and Acute Care, Pediatric Primary and Acute Care, Psych-Mental Health, and Women's Health Nurse Practitioner tracks, and is inclusive of the didactic and practicum coursework. The Program involves courses over a period of two semesters [Table 2]. On completion of the program and the additional clinical hours needed, students are prepared to work collaboratively with palliative care teams to provide holistic interdisciplinary care to promote QOL and ameliorate stress for patients with serious illnesses and their family caregivers across the trajectory of the illness. Students may be employed in a variety of settings where palliative care services are offered to patients of all ages including hospitals, outpatient clinics, home health-care settings, long-term care facilities, and palliative care and hospice units.

### **Cancer and Palliative Care in Turkey**

Turkey is a transcontinental parliamentary republic in Eurasia, mainly on the Anatolian peninsula in Western Asia, with a smaller portion on the Balkan Peninsula in Southeast Europe. [23] According to the Turkish Statistical Institute, the population of Turkey is 78,741,053 as of December 31, 2015. The median age of the population in Turkey rose from 30.7 in 2014 to 31 in 2015. One-fourth of the population is aged 14 years and younger. [24]

As in most other countries, the burden of cancer is increasing in Turkey. Cancer is the second leading cause of death in adults with a rate of 20%, although still much lower than cardiovascular disease (39.9%). The incidence of cancer is 227 per 100,000, which means there are about 175,000 new cancer cases every year. [25,26]

# **Cancer and Palliative Care Availability in Turkey**

The Ministry of Health administers the Turkish health-care system. Government insurance covers all cancer screening activities and cancer treatments. [27] Privatization has been growing rapidly in all sectors, but private health-care systems have become particularly common in the recent decades. Most private health-care centers have total or partial agreements with the General Health Insurance Institute to provide some or all curative health-care services. Private insurance companies, mostly working internationally, provide some employees with private insurance, but employees are still required to pay a national insurance premium. If workers choose private insurance, they are responsible for paying the premiums. Many residents and foreigners prefer to have private insurance coverage. [28]

In 2009, the Turkish Ministry of Health launched a 5-year national cancer control program. The program includes five main initiatives: registry, prevention, screening and early diagnosis, treatment, and palliative care. Among these, palliative care is the weakest component of the current cancer control activities. The main reason for this seems to be the traditional Turkish family structure. Turkish families are extensive, and when a family member becomes ill, all family members gather around. This Turkish family culture therefore provides for an intrinsic palliation propensity, but this cultural norm was not well reflected in the professional public health system. Currently, there are few palliative care centers across the country with most functioning as pain units. In 2008, there were no palliative care centers in the country; by January 2016, there were 172 palliative care units at government and university hospitals.[26,29]

## Regulatory Influences on Cancer and Palliative Care

The Turkish Ministry of Health, Cancer Control Department, launched the Pallia-Turk project in 2010. The project focused on two main areas: opioid availability and implementation of a community-based palliative care model [Table 3]. Despite the fact that >20% of the raw material used in manufacturing opioid medications globally is produced in Turkey, the availability of morphine products within the country is lacking. However, following the 2010 project launch, the Turkish Council of Ministers passed a new law and created the opportunity for the Cancer Control Department (itself as a governmental agency) to import morphine tablets. Additional regulatory barriers include legislation that prohibits general practitioners and family physicians from prescribing morphine. Prescribing

Main topics	Primary-level organization	Secondary-level organization	Tertiary-level organization
What is service?	Simple acute measures (pain relief, constipation, and parenteral drug administration)	The patient who cannot be managed by family physicians will be admitted to a hospital to get necessary consultations	It takes care of complex patients who cannot be managed at the primary or secondary levels
Who are providers?	Family physicians Home care teams One general practitioner Three nurses	Physician (the head of the team educated and experienced in palliative care) Co-physicians Nurses Physiotherapists Dieticians Psychologists Social workers	Physicians (internal medicine physicians, medical oncologists, cardiologists, anesthesiologists/ algologists, general practitioners) Experienced oncology nurses (one for two patient Social workers Physiotherapists Dieticians Psychologists Chaplains
Where is the palliative care?	Home family physicians' office	Hospitals	Hospitals

opiates was limited to only a few licensed specialists and most clinicians did not know appropriate algorithms for managing pain and its side effects. As a result of the new legislation, all family physicians (more than 20,000) and their related home care teams will now be able to prescribe opioids. Providers will receive training with respect to pain management algorithms, use of morphine, and management of morphine-related side effects. The Turkish Ministry of Health in collaboration with a few professional national organizations (Turkish Society of Palliative Care, Turkish Society of Medical Oncology, and Turkish Society of Oncology Nursing) and international societies plan to implement nationwide training modules for all family physicians and nurses. Since the inception of Pallia-Turk project in 2014, Turkey started to produce its own morphine.[26,28]

Another influence on cancer and palliative care treatment is the "Regulation Amending the Nursing Regulation (2011)" that outlines duties, authorities, and responsibilities of cancer nurses providing palliative care services. [31] Table 4 lists these services. [30,32] Finally, in 2015, a directive entitled, "Directive for Palliative Care Services Implementation Procedures and Principles" was published to govern the minimal service standards of palliative care units established in hospitals. [33] This directive highlights the importance of interprofessional collaboration in the integrated provision of palliative care to patients and their families.

### **Cancer and Palliative Care Workforce**

Physician training in Turkey, as in the U.S., is a lengthy process with time in training related to the degree of specialization. Physicians receive a Medical Degree after completing 6 years of medical school and an additional 4 years of residency training to achieve recognition as a specialist in internal medicine or pediatrics. An additional 3-year fellowship is required for certification as a medical or pediatric oncologist, but there is no additional training

### Table 4: Palliative care services provided by oncology nurses in Turkey

Provide an ongoing emotional support to patients and their families
Evaluate and manage the patients' pain and other symptoms, and educate the
patients and their families to allow them to control symptoms at home
Inform patients and their families regarding their access to hospital and urgent
care services

Help patients to attain and maintain daily self-care and control, assist them in decision-making, and thereby increase their quality of life

Identify social support mechanisms available for patients and their families, and help them benefit from these support mechanisms

Inform patients and their families about the economic aspects of the disease, as well as the financial supports available for them

specific to palliative care. Cancer specialty and subspecialty training is offered by a limited number of university or government tertiary care medical centers.<sup>[25]</sup>

## **Nursing Education in Cancer and Palliative Care**

The traditional roots of modern nursing in Turkey date back to the efforts of Florence Nightingale, who cared for wounded English and Turkish soldiers in Selimiye Barracks in Istanbul during the Crimean War (1854–1856). Formal nursing education in Turkey first began in 1912 with the introduction of a 6-month course to train voluntary medical attendants because of the significant injuries and deaths during the Tripoli (1911) and Balkan (1912) wars. Carrying out their duties in battlefields and hospitals with great devotion, the first Turkish nurses played a significant role in promoting the nursing profession. Initially, nursing education was at the secondary and high school levels and in 1955 advanced to the bachelor's level. The first nursing master's program opened in 1968, and the first nursing Ph.D. program opened in 1972 [Table 5]. [34,35]

Although university graduates account for most Turkish nurses today, other levels of nursing education are still being offered. Graduates of high school and bachelor's program

Table 5: History of nursing education in Turkey		
Activities	Years	
Introduction of a 6-month course to train voluntary medical attendants, with Dr. Besim Ömer Pasha's advice to the Red Crescent Association	1912	
Admiral Bristol Nursing School introduced in Istanbul within an American hospital as caregiver course with private foreign school status	1920	
Kizilay Nursing School opened in the Republic period, as the first Turkish nursing school	1925	
The Ministry of Health founded the Nursing-Laboratory Schools, which offered a 3-year program to high school graduates	1946	
The Ege University School of Nursing was the first academy in Turkey that offered university-level education	1955	
The Nursing-Laboratory Schools, which had adopted a more hands-on approach, were extended to 4 years and were offered by vocational high schools as well	1958	
The University of Hacettepe initiated the Master of Science in Nursing Program	1968	
The Doctorate in Nursing Program was initiated at Hacettepe University	1972	
After the "re-constructing health training project" of the Ministry of Health, nursing and midwifery training requirements were required to be provided at the university level	1992	
The Supreme Council of Health decided that nursing, midwifery, and health official trainings should be given once again at the high school level	2000	

are also given a "nurse" diploma and work as "nursing personnel" in health institutions since 2014. According to a new government regulation, high school graduates now start work as a "nurse assistant." [36] Bachelor's or master's program graduates are preferred for nursing administrative positions, and doctorally prepared nurses are preferred for academic roles. [34,36]

There are two main problems for cancer nursing in Turkey. The first is the lack of training programs to graduate self-sufficient and confident nurses. The second is the lack of job definitions and professional standards for cancer nurses needed to increase the quality of care. The Association of Oncology Nurses has tried to develop standards in line with the 1998–2002 targets of the European Oncology Nursing Society (EONS). The target of EONS for 1998-2002 was to make cancer nursing an accepted specialty nursing branch in Europe and to standardize training programs for specialization. To this end, the EONS has aimed to determine the present status of cancer nursing, to organize research and evaluation activities in order to reach agreement on education and clinical experience, and to develop training programs awarding certificates based on these activities.[37]

Palliative care is mostly available to patients with cancer, but there are no certified palliative care/hospice care specialist nurses in Turkey. [25,32] Since there are no Higher Education Council (YOK)-approved palliative care education programs, curricula, graduate/postgraduate programs, or national certification programs for nurses on palliative care, palliative care is provided by nurse generalists who have completed their undergraduate or graduate

education. More recently, palliative care education has been developed as a 2-h course within the curriculum of some undergraduate and graduate nursing schools, and the Ministry of Health and Professional Cancer Congress has offered some palliative care education. Nurses providing palliative care, especially those caring for dying patients, face many physical, psychological, social, and spiritual concerns and are at a high risk for burnout. Despite a lack of specialty training, nurses who work on palliative care units, which are considered "intensive care units," receive higher wages for their work.<sup>[32]</sup>

# **University of Alabama at Birmingham School of Nursing Collaboration**

The UABSON has collaborated with Turkish nurses and researchers to develop a palliative care network and research. In 2013, these efforts at developing and sharing education and research materials were realized in Turkey through a partnership between the UABSON and Hacettepe University in Ankara, which educates many of the country's nursing leaders. To date, more than a dozen of successful faculty and doctoral student exchanges have occurred in which students and faculty have been matched based on the areas of interest to engage in scholarly research, and gain a perspective on cancer and palliative specialty nursing practice. Jointly conducted palliative care research and education has occurred with funding through the Scientific and Technological Research Council of Turkey. Table 6 lists the scholars and collaborative studies to date.

#### Cancer and Palliative Care in Malawi

Malawi is one of the smallest countries in sub-Saharan Africa. It is a landlocked country in the east of Zambia, west and north of Mozambique, and south of Tanzania with the beautiful Lake Malawi along its eastern border. It has a population of around 17–18 million. [38,39] It has three major regions (North, Central, and South) that comprise 28 districts. It is one of the world's least developed countries with around 85% of its population living in rural areas. Life expectancy in Malawi has increased dramatically from around 43 years in 2000 to 62/60 (women/men) years in 2014. [39,40]

### Cancer and Palliative Care Availability in Malawi

The Malawi Ministry of Health has focused on the improvement in the QOL for all people in Malawi by reducing the risk of ill health. [41] They have partnered in a variety of ways with governments and agencies around

Name of scholar	Aim/study area/project name	Time periods
Imatullah Akyar, PhD, RN (HU)	Develop knowledge and skills for research in palliative and geriatric care	December 2013 to April 2015
Zeliha Ozdemir, PhD, RN (HU)	Heart transplantation	June to August 2014
Fatma Uslu Sahan, PhD student, RN (HU)	Simulation for education in gynecologic oncology in palliative care	June to October 2015
Zehra Gok Metin, PhD, RN (HU)	Gaining knowledge in palliative care, gerontology, and pain management Complementary and alternative medicine in heart failure	June to March 2016
Gulcan Bagcivan, PhD, RN (TUBITAK - Gulhane Training and Research Hospital)	Developing research and practice, knowledge and skills in palliative care of hospitalized cancer patients Hematology/oncology palliative care study Looking back, moving forward: A retrospective review of care trends in an academic palliative and supportive care program from 2004 to 2015	November 2015 to July 2017
Senay Gul, PhD, RN (HU)	Investigation of the factors affecting the decision-making processes of caregivers at the end of life	May 2016 to March 2017

the world to help achieve their national health goals. The focus for a long period has been on communicable diseases such as HIV/AIDS.<sup>[39]</sup> Malawians have developed one of the most recognized HIV programs in the world, which has contributed to the increased life expectancy the country is now experiencing.<sup>[39]</sup> With this change, the incidence of noncommunicable diseases such as cardiovascular disease and cancer is increasing. These are the areas that the health-care system has neither prepared for nor do they currently have the infrastructure to handle.

Like many low- to middle-income countries (LMIC), Malawi faces many challenges within multiple aspects of their health-care system. First, the lack of available drugs and medical supplies is a major challenge. [38,41] Contributing to the shortage are things such as inconsistent funding or overspending, lengthy procurement processes, and weak information systems. Laboratory and radiology services have been a major challenge for several reasons including inappropriate or poorly maintained equipment or equipment. In addition, medical personnel are often hard to find, and once identified and trained, are hard to sustain. Finally, health financing remains a challenge for Malawi. [41] The government continues the slow and difficult process to create a health plan that is strategic and will help Malawians move toward universal health coverage. All these factors together with the complexity of cancer and palliative care set up LMIC such as Malawi for challenges that are not easily overcome.

Health-care system in Malawi consists of central hospitals, regional facilities, district community centers, and private facilities. [41] Of these facilities, six private and public medical cancer units have been established, spanning all three regions of the country. Three areas (Mzuzu, Lilongwe, and Blantyre) have pediatric capacity. [41,42] Palliative care programs have also been established throughout the country and are supported through foundations, hospitals, and privately.

## Regulatory Influences on Cancer and Palliative Care

Cancer and palliative care policy is lacking in Malawi. While the Ministry of Health does have a section on palliative care in its "Management of HIV-Related Diseases" manual, including sections of some symptom management, [42] there are few programs equipped to provide the care. A chapter has been included in the Ministry of Health "Malawi Standard Treatment Guidelines," and a director has been appointed to manage a noncommunicable diseases unit, but the country still lacks an overarching plan for palliative care. [43] Malawi does have a National Cancer Registry that receives external funding; however, collecting relevant information has been challenging due to lack of personnel and absence of required reporting. [43]

### Cancer and Palliative Care Workforce

The lack of adequately trained health human resources also remains a challenge of both today and tomorrow. Despite efforts to increase the health-care workforce, it has been difficult to sustain the increase and keep up with the increased heavy burden of disease. Despite the many different roles [Table 7] that contribute to patient care in the health-care system of Malawi, the workforce remains sparse. The WHO recommends 230 health-care workers per 100,000 people for Malawi. The reality is around 32/100,000. One author describes the human resources for cancer care in Malawi is limited [Table 8] and reports upcoming training graduates will improve the current shortage situation.

# Nursing Education and Training in Cancer and Palliative Care

Improving education at all levels and building capacity is the second biggest challenge for Malawi. [41] The Ministry of Health has requested the major health training institutions

Role	ning in the Malawian health-care system  Training
Doctors	One medical school in country Mostly trained outside the country
Nurses	Numerous programs Trained for 1-4 years in various programs and then posted to different locations throughout the country
Clinical officers	Have at least 3-4 years of training in internal medicine, pediatrics, obstetrics and gynecology, and surgery
Medical assistants	Provide basic primary care in clinics
Community health worker	Trained to provide health promotion to the community and intervene in emergencies

#### Table 8: Malawian health-care workforce for cancer

Five Malawian hematologist/oncologists in full-time cancer care Four Malawian pathologists

Two radiologists

Surgical oncology deficient in some areas

Pathology technicians are few

No cancer social workers

Three oncology-certified nurses - not yet registered with council

to rapidly increase student numbers. However, many barriers need to be overcome to meet this goal including inadequate resources and faculty. In 2015, the Nursing Education Partnership Initiative (NEPI) program noted that Malawi had a high vacancy rate for nursing and midwifery positions. The report also concluded that an additional 50-100 nursing educators and 227 clinical instructors were needed to meet the demand. [45] To help address this need, the NEPI program offered countries unique opportunities for sustainable innovative nursing education models and strategies to increase enrollment, graduation, and retention. These interventions were guided by school needs, system needs, and available resources.[45] In addition, the Center for Disease and Control in Malawi supported the training of health-care professionals through scholarships, resulting in more than 500 new health-care workers trained, the majority being from the nursing discipline.[39]

Training nurses in Malawi requires from 1 to 4 years depending on the position level. There are four main categories for education including nursing officers, nurse midwife technicians, community health nurses, and psychiatric nurses. The Ministry of Health, Ministry of Education and Nurses, and Midwives Council of Malawi all play an important role in the training and employment of nurses/midwives in Malawi. [46]

There are no cancer and palliative care specialties in the nursing schools in Malawi. Information provided is taught throughout the curricula, with the majority of information focusing on palliative care because of the health-care landscape. Those who wish to specialize in these areas typically leave the country for training in clinics or in other universities. Palliative care organizations also offer training in neighboring countries, but this remains economically challenging.

# **University of Alabama at Birmingham School of Nursing Collaboration**

With the support from the Fulbright Specialist Program, collaboration between the UABSON and the Kamuzu College of Nursing (CON) in Malawi focused on strengthening the capacity of faculty and students in evidence-based practice as it relates to cancer. The project involved assessing and strengthening the current curricula through mapping cancer content in the adult and community departments. In addition, development of new curricula and modules for cancer nursing was started. The project also consisted of cancer seminars and workshops for faculty and student development. Future workshop plans were developed in partnership through frequent communication between faculties at both institutions. As content was identified for the workshops, teams visiting from the U.S. were developed. Delivery of content was done in partnership with Malawi health professionals, thus enhancing the exchange of knowledge from both teams. In addition, emerging partnerships between students and faculty at the UABSON and CON nursing programs were also created during visits. Ongoing collaborations have been interdisciplinary, including providers from the CON, College of Medicine, and have incorporated both cancer and palliative care professionals.

### **Conclusion**

Given the global inequities in cancer care that will only be amplified by the anticipated increase in cancer burden, it is imperative that nurses lead efforts to advance health and strengthen education in those areas most in need. Leaders at the UABSON have successfully integrated collaborative projects in cancer and palliative care at home and in Turkey and Malawi, Africa. At home, the UAB faculty have collaborated to prepare the next generation of nurses through the development of cancer and palliative care courses for our graduate students. This curriculum has been used as a guide to help lead projects abroad including the integration of cancer content into curricula and the development of knowledge and skills-based research projects in palliative care. Our efforts are ongoing as we strive to create new and innovative evidence-based cancer and palliative care curricula and research projects. Through these efforts, we will continue to empower nurses to lead efforts to reduce global inequities for those affected by cancer and other serious and life-limiting illnesses.

### Financial support and sponsorship

Dr. Walker was funded by Fulbright Specialist Grant for work in Malawi. Dr. Bagcivan was funded by The Scientific and Technological Research Council of Turkey (TUBITAK) (1059B191500575), and University of Alabama at Birmingham, Marie L. O'Koren Endowment for work in US.

### **Conflicts of interest**

There are no conflicts of interest.

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