

# Translating a US Early Palliative Care Model for Turkey and Singapore

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## ABSTRACT

The field of palliative care is growing in acceptance and sophistication globally. No longer considered just for patients at end-of-life, palliative care is now being incorporated early in the disease trajectory. Despite professional guidelines supporting early palliative care, there are few models that have been created that can be translated into practice cross-culturally. In the United States, the Educate, Nurture, Advise, Before, Life Ends (ENABLE) early palliative care telehealth model has demonstrated effectiveness in improving quality of life, mood, symptom relief, and survival for patients with cancer and is now being tested in patients with heart failure. Family caregivers of patients who have received ENABLE concurrent with their care recipients have also demonstrated positive outcomes in quality of life and caregiver burden. Internationally, a number of investigators are culturally adapting ENABLE for patients and family

caregivers. While some elements of ENABLE, such as symptom management and self-care, and the caregiving role are relevant cross-culturally, others have been built on Western principles of self-determination or represent concepts such as advance care planning which will require more cultural adaptation. In addition, ENABLE was initially an in-person approach that was converted to telehealth to accommodate a rural population-it will be important to understand cultural norms related to receiving care by phone or if an in-person approach will be more culturally acceptable. This paper describes efforts in Turkey and Singapore to culturally adapt the ENABLE early palliative care principles for their countries.

**Keywords:** Educate, Nurture, Advise, Before Life Ends, oncology patients, palliative care

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## Introduction

Globally, there is a growing need and interest among healthcare professionals and policy-makers to improve the care of patients with serious, complex, and potentially life-threatening or life-limiting medical conditions.<sup>[1]</sup> Palliative care has emerged as one solution to meet the needs of this population and to influence global policies.<sup>[2-4]</sup> Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.<sup>[5]</sup> As described by the World Health Organization (WHO), palliative care focuses on meeting the needs of patients and families for symptom management, emotional support, information and decision-making guidance, and planning and coordinating needed resources throughout the illness trajectory.<sup>[6]</sup>

Palliative care needs to be available to patients and families in all settings where they receive care including home, outpatient clinics, acute care facilities, palliative care units, inpatient hospices, and nursing homes.<sup>[7]</sup> However, the current situation for availability and delivery of palliative care challenges widespread implementation problems.<sup>[8-10]</sup> There is a need for new care delivery models, one that will integrate the different components of care. Educate, Nurture, Advise, Before Life Ends (ENABLE) is one example of a palliative care delivery models that can be offered early in the disease trajectory. Developed in the US by nurse scientists, ENABLE has proven to successfully deliver the essential components of palliative care in a structured manner. The countries of Turkey and Singapore have adapted ENABLE according to their own culture and environmental requirements and are now in the early stages of using the program to effectively deliver palliative care.<sup>[7,11]</sup>

This paper will discuss the “ENABLE” concurrent early palliative care model which seeks to deliver the essential components of palliative care in a structured way and its adaptation for Turkey and Singapore-regions in which palliative care has begun to evolve through nursing research, education, and practice.

## The Development of Educate, Nurture, Advise, Before, Life Ends in the US

The ENABLE early palliative care intervention was based on Wagner’s Chronic Illness Care model and WHO continuum of care concepts to introduce supportive care to adults early in the course of a new diagnosis of an advanced

illness.<sup>[5,12,13]</sup> ENABLE is a collaborative approach to care of patients and caregiver, focusing on self-care management and skills training to empower patients to actively participate and make informed choices about treatment issues.<sup>[14,15]</sup>

Figure 1 illustrates the development of ENABLE, which was first introduced in 1999 as a 3-year study providing the conceptual basis, evidence, and modeling the process and outcomes. In 1999, Project ENABLE, a nurse-led, psychoeducational intervention, were conceived through the Robert Wood Johnson Foundation Promoting Excellence in End-of-Life Care program with a major goal “to enable patients with advanced cancer and their families to take full advantage of palliative care services from the time of diagnosis.”<sup>[14]</sup> Project ENABLE or ENABLE I provided an integrated approach to the management of life-limiting cancer aimed at alleviating the symptoms of disease and treatment, enhancing clinician and patient/family communication, offering support for families, friends and other caregivers, addressing emotional and spiritual needs of dying people and providing conceptual and administrative infrastructure for achieving end-of-life care consistent with patients’ values and preferences. Project ENABLE encompassed three main goals as follows: (1) to provide a palliative care nurse or nurse practitioner to coordinate care of patients and their families across clinical specialties and community agencies, especially emphasizing symptom and quality-of-life assessment and management; (2) to offer a workshop series for patients and families focused on living with life-limiting illness; and (3) to integrate palliative and hospice care into routine oncology care.

In ENABLE I although initially planned to be delivered in person, a significant amount of the intervention was done through telephone because patients were not able to come due to long travel distances and illness. As a result,

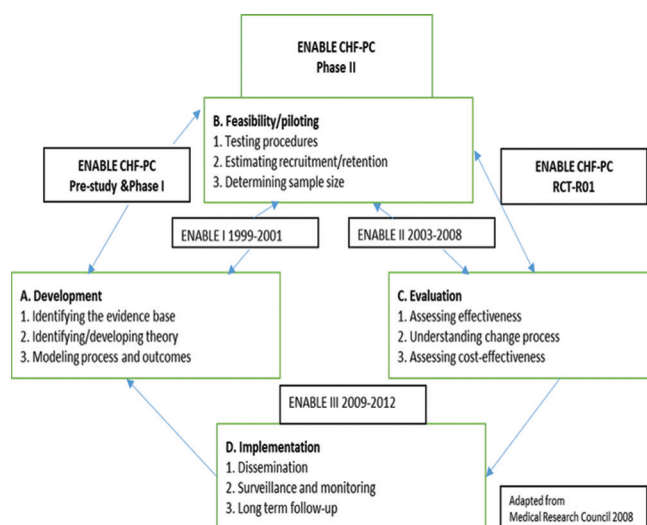


Figure 1: The development of Educate, Nurture, Advise, Before, Life Ends

for the subsequent study, intervention was converted to be delivered primarily by phone following an in-person comprehensive assessment. ENABLE II, included an advanced practice nurse-administered, telephone-based, intensive curriculum, and ongoing assessment and coaching in problem-solving, advance care planning, family, and healthcare team communication strategies, symptom management and crisis prevention, and timely referral to palliative care and hospice resources. Patients received a guidebook, called “Charting Your Course” which the nurse coach used to guide the patient through four structured sessions, each of which focused on a different topic.<sup>[16]</sup> ENABLE II tested intervention effectiveness on patient-reported outcomes and resource utilization using a randomized controlled trial randomized controlled trial (RCT) design. The positive results of this study, and seven others, served as a basis for the recommendation of the American Society of Clinical Oncology provisional statement, and a later update recommending early palliative care for all patients with metastatic cancer or high symptom burden.<sup>[17,18]</sup> Notably, ENABLE II did not include a specific intervention component for family caregivers although data on burden were collected. There were no differences between intervention and usual care group caregiver participants, suggesting that a more robust intervention component would need to be developed if caregivers were going to experience improved outcomes.<sup>[19]</sup>

From 2010 to 2013, the ENABLE III randomized controlled “fast-track” trial was conducted. The overall aims of this trial were to evaluate the optimal timing of early palliative care, to test the intervention in community centers and patients with hematological malignancies and to examine intervention mechanisms. The ENABLE III intervention was designed with three primary modifications: (1) a three-session life review component was added to the patient Charting Your Course curriculum; (2) a separate but parallel 3-session plus monthly follow-up intervention was developed for family caregivers; and (3) a “fast-track” study design was employed whereby patients and caregivers were randomized to receive the intervention immediately after randomization or 12 weeks later. For family caregivers, session content over the 3 weekly sessions covered taking on the caregiving role, introduced problem-solving coping, self-care, partnering in patient symptom management, building a support team, and decision-making, and advance care planning. ENABLE III showed an improvement in patient survival 1-year after enrollment, and improvement in caregiver depressive symptom and stress burden outcomes.<sup>[20-22]</sup>

Currently, ENABLE IV, the continuum of dissemination and long-term follow-up of intervention is being implemented

in four sites. This study empowering the centers to use the scientific evidence in their daily practicum with its three components: intervention program, implementation process, and practical progress measures.<sup>[8]</sup> In addition, the ENABLE intervention for caregivers is currently being adapted for minority and rural family caregivers using lay healthcare navigators.<sup>[22,23]</sup>

ENABLE has now also been adapted through a formative evaluation process to be tested in patients with heart failure and their family caregivers. In ENABLE comprehensive heartcare for patients and caregivers pilot study, ENABLE was tailored to be responsive to heart failure disease trajectory, and culturally adapted to be appropriate for minority and underserved populations in the Southeastern US rural population.<sup>[24,25]</sup>

## Palliative Care in Turkey

Palliative care is relatively new area of concern in Turkey. According to the Global Atlas of Palliative Care, Turkey’s developmental level for palliative care is listed in group 3B, indicating “generalized palliative care provision.” Generalized provision is defined as “the development of palliative care activism in a number of locations with the growth of local support in those areas, multiple sources of funding, the availability of morphine, a number of hospice-palliative care services from a community of providers that are independent of the health care system, and the provision of some training and education initiatives by the hospice organizations.”<sup>[26]</sup>

Historically palliative care development milestones started in the late 2000s. In 2008, the Turkish Ministry of Health, Cancer Control Department, introduced the National Palliative Care Program. Together with members of several professional organizations and the World Health Organization, a palliative care committee was developed to integrate palliative care into existing Turkish healthcare systems and to prepare a national palliative care action plan. In 2009, the Turkish Ministry of Health announced a 5-year National Cancer Control Program, with palliative care as a major focus. The PalliaTurk Project, introduced in 2010 by the Turkish Ministry of Health, Cancer Control Department proposed implementation of community-based palliative care models and an increase in opioid availability throughout communities.<sup>[27-29]</sup>

The Pallia-Turk project has identified “palliative care” as a medical discipline and has designated palliative care to be offered at three levels of organization (primary, secondary, and tertiary). Primary/level one service palliative care unit, level two palliative care center, and third level comprehensive palliative care center.<sup>[29]</sup> In this project, primary level included family physicians, early diagnosis, and training

centers; secondary level early diagnosis and training centers, care for acute-subacute and chronic palliation cannot be managed by level one; and third level centers for excellence with multidisciplinary approach.<sup>[29,30]</sup> These improvements contributed to the launch of “Regulation on Procedures and Principles of Palliative Care Service” 2014 and 2015.<sup>[28]</sup> This regulation identified essentials of palliative care services in seven areas including physical environment, staff, roles and responsibilities, scope of service, admission process, training, and supervision. Parallel to these efforts, the Turkish Oncology Group created a working group for supportive treatments, which made significant contributions to the further development of palliative care, especially for oncology patients.<sup>[30,31]</sup> In addition, the Turkish Oncology Nursing Association has created a palliative care subgroup. In 2006, the Palliative Care Association was established with a focus on palliative care for cancer patients, including end-of-life care.<sup>[32]</sup>

These initiatives occurred simultaneously with the development of multiple training activities like the End-of-Life Nursing Education Consortium train-the-trainer course (2014), Middle East Cancer Consortium Foundational Course in Palliative Care for Nurses (2014), workshops by Ministry of Health (2016), training booklets for primary care physicians by Ministry of Health (2016).<sup>[28]</sup>

Turkey has palliative care units in university hospitals, public hospitals, and private hospitals. In 2016, the Ministry of Health reported the existence of 148 active palliative care centers, an increase from 87 in 2015.<sup>[32,33]</sup>

Research on palliative care is still in the developmental phase. A recent literature review aimed at providing an overview of Turkish palliative and supportive care research, identified only 32 papers. The first publication was a review paper on palliative care in 1996, thereafter, until 2005 there were no other Turkish publications focused on palliative care. Since that time momentum for palliative care research has been growing though studies are mostly limited to descriptive studies or general reviews of topics such as opinions on palliative care, end-of-life caring, symptom management, and cancer populations.<sup>[34]</sup>

Current policies, research, and service delivery highlight the importance and need for community action-based research. It also highlighted the importance of developing intervention and models of care delivery, broadening palliative care services to noncancer populations and using evidence-based, patient engaged knowledge to build a national infrastructure.

A particular need for palliative care services and delivery models results from the high incidence of cancer in older populations, and the accompanying caregiving issues. ENABLE was identified as a good beginning to develop an early palliative care model for Turkey.

Therefore, ENABLE-TR, was developed to adapt and test this evidence-based, telehealth supportive care coaching intervention to Turkish caregivers of older adults with advanced cancer. The specific focus of the study was to determine family caregiver needs and to design and tailor ENABLE to be culturally-appropriate for the Turkish population using principles of problem solving, coping techniques, decision-making support, and optimal care coordination. To date, chart reviews and family caregiver interviews were held to culturally adapt ENABLE-TR. In this phase of project, caregivers tendency about model delivery was in person, face-to-face, were mostly in a need for educational material, and focus for sessions were more about emergency care, nutrition, information about disease, and supportive community services. Culturally oriented ENABLE implementation was proposed as a phone-based approach, weekly sessions including contents as tabled below [Table 1], will be tailored according to needs defined in first phase of study. In addition, ENABLE was planned to test in Turkish heart failure patients and caregivers with same perspective.

## Palliative Care in Singapore

In Singapore, the hospice movement began in the mid-1980s with hospice services being set up and funded by charity.<sup>[35]</sup> These hospice services subsequently came together to form the Singapore Hospice Council in 1995, when the first inpatient hospice was also built. Soon after, palliative care became available in mainstream hospitals, with the first hospital-based palliative care service setup in 1996 in Tan Tock Seng Hospital and the first department of palliative medicine set up in 1999 in National Cancer Centre Singapore. The undergraduate medical curriculum integrated palliative care in 2002 and palliative medicine was recognized as a subspecialty in 2006.<sup>[36]</sup>

Palliative care services are now well-developed in Singapore, and further advancements in palliative care are

**Table 1: Educate, Nurture, Advise, Before Life Ends-TR tentative family caregiver sessions and content**

Family caregiver sessions and content-tentative	
Session Number	Content
Session 1	Care and caregiver (the role of caregiver, care story, challenges faced by caregiver)
Session 2	Caring for yourself (self-care, nutrition, exercise, relaxation)
Session 3	Helping yourself (problem-solving and coping)
Session 4	Caring for patient (symptom management, care coordination, communication with family and healthcare providers)
Session 5	Looking for help and support (community resources, asking for help)
Follow-up	Follow-up calls (monthly) will be made to offer support and further assistance for caregivers
TR: Turkey	

now focused on the areas of education and research.<sup>[37]</sup> The Lien Center for Palliative Care was established in 2008 for this purpose and has been building capacity for palliative care training and research support to improve the quality of palliative care in Singapore.<sup>[38]</sup> An upcoming Palliative Care Centre for Excellence in Research and Education will further boost the existing research infrastructure.<sup>[39]</sup>

Research on the development and evaluation of palliative care services in Singapore is gaining momentum and small-scale pilot randomized controlled trials have been conducted for supportive and palliative care interventions in the outpatient setting.<sup>[40,41]</sup> These have shown that it is possible to conduct randomized controlled trials in Singapore, with good study completion rate and high acceptability of face-to-face sessions with a palliative care nurse or psychologist.<sup>[42-44]</sup> In a recently completed study of nurse education sessions with advanced lung cancer patients on how to cope with common symptoms, 69 patients were successfully recruited and 30 of 35 (85.7%) participants in the intervention group completed all four sessions. All patients were satisfied with the topics and felt they were useful [Table 2].<sup>[45]</sup> However, preliminary analyses did not demonstrate a strong effect on quality of life outcomes. As we looked more closely at our intervention, we noted that not all quality of life domains were addressed and that the content was highly focused on physical symptoms. Hence, we decided to expand and formally evaluate our intervention content, form, and delivery. We noted that the ENABLE intervention contained some of the missing content, and hence, this was an opportune time for collaboration with established researchers internationally to further develop our intervention and palliative care research in Singapore. The vast research experience of international collaborators will bring added rigor to study design and methodology of research projects conducted locally. To this end, we propose to translate, culturally adapt and pilot test the ENABLE intervention in Singapore. This will allow researchers in Singapore to build on the many years spent developing and refining the multicomponent ENABLE intervention.<sup>[45]</sup> Yet, cultural adaption is necessary because the effect of complex interventions such as ENABLE depends on the cultural context within which it is delivered.<sup>[46]</sup> For example, the process of advance

care planning cannot be adopted wholesale from Western societies, but needs to be tailored to family-centric societies in the Asian context.<sup>[46]</sup>

The adaptation phase of the proposed study will involve semi-structured interviews with a purposive sample of healthcare professionals and advanced cancer patients and their caregivers to explore their views on the relevance of content covered in the ENABLE intervention and useful topics that are not in the current version of ENABLE. Specifically, their perspectives on the tentative outline of topics for the ENABLE sessions, as well as the format of the ENABLE materials will be elicited. A multidisciplinary expert advisory group will then be convened to discuss the results of the semi-structured interviews and adapt the ENABLE content as needed. This expert advisory group will involve those with experience in caring for advanced cancer patients in the local Singapore context, including but not restricted to a palliative care doctor, a palliative care nurse, an oncology doctor, an oncology nurse, and a medical social worker. The principal investigators of the original ENABLE intervention, Dr Marie Bakitas and Dr Nicolas Dionne-Odom will also be invited to participate in this discussion.

## Summary

In conclusion, the need for palliative care is being recognized globally. The WHO originally proposed palliative care model to begin at the time of a new diagnosis and to continue through EOL and bereavement. However, similar to the US, many countries first adopted palliative care through hospice care or focused on inpatient acute care. One example of a scalable early palliative care model, ENABLE has been translated and adapted with the US and for other diseases. ENABLE is now being adapted and tested for efficacy in some areas of Eurasia. To improve the effectiveness and acceptance of model cultural differences are respected and planned in a culturally sensitive manner. Importantly, cultural adaptation is a key first step to determine which principles are appropriate in other populations and healthcare systems.

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**Table 2: Singapore Educate, Nurture, Advise, Before Life Ends feedback on nurse education sessions**

Feedbacks	Fatigue (n=34) (%)	Breathlessness (n=30) (%)	Anxiety (n=33) (%)	Recap (n=30) (%)
The length of the session is just right <sup>a</sup>	33 (97.06)	30 (100)	32 (96.97)	30 (100)
I feel the topics shared are useful <sup>a</sup>	34 (100)	30 (100)	33 (100)	30 (100)
I feel satisfied with the topics shared <sup>a</sup>	34 (100)	30 (100)	33 (100)	30 (100)
I feel comfortable discussing the topics <sup>a</sup>	32 (94.12)	30 (100)	33 (100%)	30 (100)
Mean duration, mean±SD (min)	30.88±8.92	24.30±6.87	29.70±11.79	19.5±9.13

<sup>a</sup>Data presented as n (percentage) of participants who agreed or strongly agreed with each statement. SD: Standard deviation

## Conflicts of interest

There are no conflicts of interest.

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