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Integrating palliative care for older adults:

A needs assessment for Hamad Medical Corporation's geriatric services

A report commissioned by
the World Innovation Summit for Health

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Integrating palliative care for older adults: A needs assessment for Hamad Medical Corporation’s geriatric services

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LIST OF ABBREVIATIONS

ACP	Advance Care Planning
ADI	Alzheimer's Disease International
CPR	Cardiopulmonary Resuscitation
DNAR	Do Not Attempt Resuscitation
DNR	Do Not Resuscitate
EAPC	European Association for Palliative Care
FATCOD	Frommelt Attitudes Toward Care of Dying
HLE	Healthy Life Expectancy
HMC	Hamad Medical Corporation
JCI	Joint Commission International
LMIC	Low- and Middle-Income Country
MENA	Middle East and North Africa
MoPH	Ministry of Public Health
NCCCR	National Center for Cancer Care and Research
PCKT	Palliative Care Knowledge Assessment Tool
PEG	Percutaneous Endoscopic Gastrostomy
PHCC	Primary Health Care Corporation
WHO	World Health Organization
WHPCA	Worldwide Hospice Palliative Care Alliance
WISH	World Innovation Summit for Health

FOREWORD: WISH

A key responsibility of society is to ensure that everyone is able to live well, and die a good death. Palliative care does just that, yet worldwide it remains underfunded and underutilized.

Access to palliative care is a human right that is recognized by the World Health Organization as an integral element to achieving universal health coverage. As such, we consider the provision of palliative care as one of the core ethical responsibilities of all health systems. Given the ageing population and the increasing prevalence of dementia worldwide, the need for palliative care services is expected to continue to rise.

WISH published its first report addressing palliative care and end-of-life care during its very first global summit in 2013. This report discussed the perceived challenges with service delivery, as well as the importance of utilizing science and data to drive innovative solutions to these issues.

We then decided to revisit the topic in 2018 with the launch of our report on palliative care and Islamic ethics, where we addressed some of the key ethical questions raised around palliative care, this time from an Islamic perspective. Given the lack of attention contemporary Islamic bioethics has paid to this topic, we found ourselves in some ways starting from scratch and offering new ideas for discourse as well as recommendations for future practice. Some of the main topics we discussed in this report were around pain relief, advance directives, and communicating bad news.

Coinciding with the launch of the report in 2018, "enhanced end-of-life-services" was also identified as a strategic goal within the Healthy Ageing pillar of Qatar's National Health Strategy 2018-2022. Since then, significant efforts have been made to build better palliative care services into the national healthcare system. We also began our journey here, with the help of our partners, to implement some the evidence-based policy recommendations from our reports with a particular focus on raising awareness and capacity building.

In collaboration with Hamad Medical Corporation and with the invaluable support from our colleagues at Alzheimer's Disease International, Worldwide Hospice Palliative Care Alliance and SANAD, the Home Hospice Organization of Lebanon, together we are undertaking a national development project to expand palliative care services to people with non-oncologic palliative care needs, particularly targeting the elderly population in Qatar.

From the outset, the aim of this study was to gain a better understanding and more insight into the specific needs of the Qatari population for palliative care, both from the perspective of the provider as well as the patient and their caregiver. In this report, in addition to sharing our findings we also provide a number of policy recommendations for improving the quality and accessibility of palliative care services in the country.

We are immensely proud of this work and look forward to this exciting new chapter where we continue to support the Ministry of Public Health in Qatar, as well as Hamad Medical Corporation in the years to come to implement and develop a high-quality, robust, and accessible national palliative care service.

N Sultana Afdhal
Chief Executive Officer
World Innovation Summit
for Health (WISH)

FOREWORD: ADI

Alzheimer's Disease International (ADI) congratulates the World Innovation Summit for Health (WISH), the Ministry of Public Health (MoPH) of Qatar, and Hamad Medical Corporation (HMC) on their initiative to develop a project for the implementation of palliative care services for older people in Qatar. ADI was delighted to be invited to take the lead in bringing together an expert group to advise on the way ahead. It has been a pleasure to work with SANAD, and Dr Stephen Connor.

ADI is primarily an advocacy organization for people living with dementia and their care partners. We know from the feedback we have from family caregivers and the development of dementia plans in response to the World Health Organization (WHO) Global action plan on dementia, that end-of-life issues are extremely challenging for people living with dementia, and their families.

We recognize that medical conditions pose challenges at the end of life, and across age groups. ADI strongly advocates for more attention and priority to people with dementia in access to palliative care. There are already 55 million people living with dementia worldwide, a figure that is expected to rise to 139 million by 2050. Dementia is a leading cause of death globally. The WHO Global action plan on dementia, unanimously adopted by all member states, requires countries to develop national dementia plans but, in five years only some 40 countries, including Qatar, have done so.

It is evident though that palliative care services, whether community or institutional, are all too often not available for people with dementia or are of variable quality. This is because of a lack of resources within health systems for palliative care and the lack of trained staff with the skills to deal with the complexity of end-of-life care for people with dementia, the majority of whom will have comorbidities.

Health systems need to be more sensitive to the needs of people with dementia for access to palliative care services and to the challenges it brings. These challenges include communication issues, the failure to recognize dementia as a terminal issue and the clinical challenges of care delivery, including knowing when to intervene. Those committed to good dementia care will be familiar with person centered care, namely putting the person with dementia first. In practice, good palliative care will also go beyond a biomedical approach to address the many cognitive, psychological needs and functional changes experienced by the person with dementia as the disease progresses. A holistic view is needed that aims to respect the person's autonomy of choice about their care, treatment, and place of death, and to support the person's quality of life to the end.

The challenge for the policy maker is to plan and design health systems that improve access to palliative care while ensuring that unique needs and views can be accommodated. There needs to be flexibility to accommodate the complex interplay between the physical systems of dying (which may or may not caused by dementia), the longer periods that people with dementia require care and support, and the involvement of family members and caregivers.

We know that older people prefer to remain at home for as long as possible. The challenge in Qatar, as worldwide, is to make it happen through innovations in nurse led assessment and care. The conclusion I draw from the needs assessment is that the time is right to implement palliative care services for older people including those with dementia. Longer term resources are needed to develop a National Palliative Care Plan for Qatar. These two actions are what makes the start of this journey in Qatar so exciting.

ADI looks forward to Qatar continuing to take the lead in improving the quality of life of people with dementia, including through the 2018 National Dementia Plan.

Glenn Rees

Chair, Palliative Care Project, Qatar

ADI Honorary Vice President

FOREWORD: HMC

Qatar's health system has undergone a momentous journey of transformation in recent decades via the vision set in Qatar's National Vision (QNV) 2030.

In Qatar, our first palliative care efforts commenced out of a desire to ease the suffering of patients living with cancer. Our vision recognizes the good work in this field and focuses on the equally important task of upskilling specialized healthcare professional teams to enable them to work effectively in what is a very difficult field, both medically and emotionally.

Over the years we have seen a growing need from patients over the age of 60 who do not have cancer but whose very real life-limiting conditions have severely impacted their lives and that of their families. We have understood this gap and had set the vision in the National Health Strategy 2018-2022 which identifies a strategic goal of its Healthy Ageing pillar as 'enhanced end-of-life services', and this has been the impetus for us to undertake a comprehensive review of the gaps in our healthcare provisions for this vulnerable cohort of patients.

The quantitative and qualitative aspects of the identified gap have been ascertained by the findings we have had with the valuable assistance of a consultancy (SANAD). In-depth surveys were conducted with patients and healthcare staff to ascertain the gaps, needs, and expectations for palliative care in Qatar.

This national initiative derived will enable the development of a new culturally and clinically appropriate care plan as well as enhanced focused services via community and acute care to support the 60+ age group, and their loved ones who need palliative care services. We will also create greater caregiver support programs to reduce the risk of caregiver burnout.

Our goal is to establish a seamless continuum of care that prevents repeat hospitalization to reduce the burden of cost on patients, families, and caregivers as well as on the health service. We can only deliver on this goal by all services and stakeholders working together.

I am immensely pleased that we have the invaluable support from Qatar's Ministry of Public Health, which endorsed the WHO notion that palliative care is a crucial part of integrated, people-centered health services. Particularly our minister of health, HE Dr. Hanan Mohamed Al Kuwari, who has been a staunch advocate for providing more targeted healthcare services for our older population.

Over the years we have developed strategic partnerships with experts who have supported us on our journey; partners such as Alzheimer's Disease International bring a wealth of expertise and unique experiences to our endeavors.

The team at WISH has been hugely supportive, particularly in their willingness and ability to engage stakeholders in important and constructive discourse. This report is immensely valuable in generating more awareness in the community about this important topic.

Dr. Hanadi Al-Hamad

National Lead for Healthy Ageing

Chair of the Geriatrics & Long-Term Department,

Medical Director of Rumailah Hospital and Qatar Rehabilitation Institute at HMC

EXECUTIVE SUMMARY

Palliative care is recognized as an essential component of universal health coverage under goal three of the UN Sustainable Development Goals for 2030, yet only 12 percent of the 57 million patients and families in need of palliative care worldwide, receive services. Qatar has long been providing palliative care services for adult oncology patients where around 100 patients receive it annually, yet palliative care is not integrated into the care of patients with other diagnoses. In 2019, a total of 2200 deaths were registered in Qatar, most of whom would have benefited from palliative care.

The global population is growing proportionately older. Qatar is no exception to this dramatic demographic shift. Data indicates that an ageing population faces increasing complications of chronic illness, cognitive decline and functional dependency. The expansion of palliative care services to a more diverse group of patients, including especially the elderly with dementia, has emerged as a national priority in Qatar.

The public healthcare system in Qatar is robust and modern. HMC is the largest governmental provider, with 14 hospitals which include integrative geriatric services, led by the geriatric department at Rumailah Hospital. There are no current hospital or home-based palliative care or end-of-life services that target older patients with non-cancer diagnoses.

This needs assessment was conducted to support the process of establishing a palliative care service model at the geriatric department tailored to the needs of older patients and their caregivers. The assessment explored the perceptions of patients and caregivers, healthcare providers and healthcare management about palliative care, truth telling and healthcare decision making, and death and dying to identify readiness, barriers, and opportunities to the development of geriatric palliative care and recommend the best palliative care models. The assessment included literature review, review of program data, key informant interviews, patient and caregiver surveys, nurse and physician surveys.

The results are divided into the following themes:

- **Knowledge and beliefs about palliative care:** Most patients and caregivers had never heard of palliative care or advance directives and did not know such services existed in Qatar. Yet when explained, both believed that palliative care could make patients feel better and help the family cope with serious illness. Most nurses displayed either poor or good knowledge of palliative care while physicians displayed good to very good levels of knowledge.

- **Patient and caregiver needs:** Fear of pain was the patients' most common concern followed by fear of being a burden on the family, fear of losing functionality and fear of loneliness. Both patients and caregivers described psychological support as the most common patient need followed by around the clock access to healthcare professionals, pain and symptom management and spiritual support. Around the clock access to healthcare professionals was the most common need reported by caregivers followed by the need for psychological support, access to medical supplies and equipment at home, and social support.

- **Truth telling and healthcare decision making:** Most older patients wanted to know about their diagnosis and prognosis and have the final say in their treatment and medical management. Similarly, most caregivers, physicians and nurses shared similar beliefs. However, patients and caregivers were less accepting of decisions regarding withholding resuscitation measures. Positive attitudes did not always translate into practice, as practice was often influenced by various religio-cultural factors.

- **Death and dying:** Most key informants, patients, caregivers, nurses, and physicians consider home the preferred place of death, yet due to the burdensome and complicated post-death processes, overmedicalization and absence of home-based palliative care services most patients die at the hospital. Both physicians and nurses portrayed a positive attitude toward aspects related to the care of dying patients and their families, yet some viewed the family's close proximity to the patient as interfering with their job.

- **Access to and utilization of opioids:** All forms of opioids are available in Qatar. However, prescription and administration of parenteral opioids is not permitted in home care settings. Physicians voiced concerns about being held responsible for any misuse or abuse of opioids by patients or family members when prescribing oral opioids in outpatient care settings. Some patients and caregivers thought opioids could hasten death. Physicians, more than nurses, believed that addiction to pain-relieving medication should not be a concern when dealing with a dying person.

- **Need for geriatric palliative care services:** Key informants viewed geriatric palliative care services as a basic right and fundamental for achieving healthy ageing in line with the national health strategy. Support from the current leadership was viewed as fundamental for the success of such services.

- **Palliative care models, skills and success factors:** A home-based palliative care model and a hospital-based palliative care unit were reported as the most common needed models for geriatric palliative care. Adequate staffing, integrating spiritual support via spiritual counselors and training are crucial to ensure the provision of high-quality palliative care. Communication skills including breaking bad news, conducting advance care planning, and providing psychological, emotional and bereavement support are important training needs to provide high quality palliative care.

- **Role of civil society and research:** Key informants noted that the palliative care research in Qatar was limited and emphasised the need to build on the available evidence. They also explained the need for the allocation of separate budgets that are specific to palliative care.

Recommendations

Providing high quality palliative care to older patients and their families in Qatar will necessitate adopting a whole-system approach which includes interventions at various levels. Based on the findings of the needs assessment, we draw recommendations on the policy, service provision, education, advocacy and awareness and caregivers, families and communities' levels.

- **Policy:** The assessment recommends the development of a national palliative care strategy that sets a framework and an action plan for palliative care for people of all ages and diagnoses, including minorities and vulnerable populations. Immediate policy changes are crucial to facilitate the integration of palliative care. These involve (1) facilitating the prescription of oral and parenteral opioids in outpatient settings and allowing the prescription and administration of the various forms of opioids in home care settings, and (2) facilitating post-death procedures especially for home deaths and (3) including palliative care for citizens and residents under the national health care coverage scheme.

- **Service provision:** The assessment recommends adopting a generalist palliative care approach and developing specialized palliative care services at hospital and home care settings under the geriatric department at HMC. Specialized palliative care service models recommended in sequence include a mobile consultation palliative care team, a home-based palliative care service, a palliative care unit, and an outpatient clinic.

- **Education:** The assessment emphasizes the importance of building the capacity of healthcare professionals to provide generalist and/or specialist palliative care services through training and integration of palliative care into the undergraduate cirriculum of various healthcare professions.

- **Advocacy and awareness raising:** The assessment highlights the need for advocating and raising the awareness of the public about palliative care, including advance care planning, truth telling, talking about death and dying, and end-of-life matters. Going beyond awareness raising to building compassionate communities is crucial to changing and reversing the over-medicalized culture that has dominated practice around death and dying. Hence, caring for the sick and dying can be better handled by community members supported by healthcare professionals.

- **Caregivers, families and communities:** The assessment sheds light on the preference of older patients to die at home with the people they love and the surroundings they are familiar with. This, in addition to ensuring high quality of life and care are equally dependent on strong family support and commitment. As such, caregiver and family support should be an essential component. This includes 24/7 access to healthcare professionals, psychological and social support, education and training for family caregivers, options for respite care, caregivers support groups and grief and bereavement support. Going beyond family support, interventions that adopt a public health approach to palliative care, and support building compassionate communities are highly warranted to improve people's experiences of death, dying and bereavement.

INTRODUCTION

The WHO first defined palliative care in 1990 and revised its definition in 2002. Palliative care is “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illnesses. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.” (1).

In 2018, the International Association for Hospice and Palliative Care conducted a study to develop a consensus-based definition of palliative care that focuses on the relief of serious health-related suffering, a concept that was put forward by the Lancet Commission Global Access to Palliative Care and Pain Relief (2). Palliative care was defined as “the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers” (2). The new definition emphasizes the importance of suffering in identifying palliative care needs, thus shifting from a disease centered to a person-centered approach (2).

An ageing population is a global phenomenon that was recognized by the United Nations as a macroeconomic and geostrategic force that shapes the world and impacts the future. With the advancement of medicine and public health, the proportion of the world’s population aged 60 years and above is expected to increase from 12 to 22 percent between 2015 and 2050. Global life expectancy in 2015 was 70.87 years and is expected to increase by 8.3 percent to reach 76.76 years by 2050 (4). Longer lives introduce more opportunities, yet more challenges which require complicated decision-making to address sensitive issues taking into consideration the physical, psychosocial, and spiritual needs of patients. Thus, there is a growing need for palliative care services to meet these demands, improve quality of life and ease suffering through the prevention and treatment of symptoms (5).

While geriatric medicine is defined by the patients’ age and palliative medicine by goals of care, an interdisciplinary collaboration between these two fields will result in a new approach of care known as geriatric palliative care. This collaboration not only improves patient quality of life in later years by providing patient and family centered care, but also facilitates the process of shifting goals of care from functional recovery and curative therapies to purely comfort-oriented goals (5).

Project rationale

The project is driven by the need to address quality of life issues for an ageing population in Qatar. In 2019 the 65 years and above population in Qatar represented 1.5 percent of the total population, a number which is expected to increase to 14.2 percent by 2050 (6).

In 2018, Qatar became the first Arab country to launch a National Dementia Plan with the aim of setting a vision for future services for people with dementia, their families, and caregivers (7). In the same year, published the five-year National Health Strategy 2018-2022, highlighting the elderly population, defined as citizens and residents older than 60 years, as one of their seven priority population groups (8). The strategy emphasizes the importance of healthy ageing by creating and promoting the right conditions to allow Elderly people to live actively for longer, stay well and within the sanctuary of their homes (8). One of the healthy ageing objectives is to ensure the provision of enhanced end-of-life care services to the elderly population of Qatar (8).

Oncology palliative care services have been available in Qatar since 2008. Currently, there are no hospital or home-based palliative care or end-of-life services that target the older population, other than those with cancer diagnoses. As such, inpatient and community palliative care services for older patients are being planned and budgeted for by Hamad Medical Corporation (HMC), the main public healthcare provider in Qatar (8). Palliative care research and policy has long been a focus area for the World Innovation Summit for Health (WISH). In 2013, WISH published its first report on innovative practices for end-of-life care, while the second, in 2018, addressed the ethical discourse surrounding palliative care, particularly through the lens of Islam. The 2018 report focused on the analysis, design, and recommendations for healthcare decision making in a way that is compatible with Islamic teachings and scholarship.

This assessment explores the perceptions of patients, caregivers, healthcare providers and healthcare management about palliative care, truth telling and healthcare decision making, and death and dying. The goal of the assessment is to identify barriers to, and opportunities for developing palliative care, and recommend the best palliative care models for older patients and their families.

This report is divided into five main sections: literature review, methodology, results, discussion and recommendations.

Context

The state of Qatar, on the eastern coast of the Arabian Peninsula, extends over an area of 11627.8 square kilometers, and is divided into eight municipalities, with Doha being the capital (9). Islam is the official religion, but significant populations of followers of various religions live in Qatar. While Arabic is the official language of the country English is widely spoken as a second language (10). The population is culturally diverse, comprising of more than 80 nationalities (11,12,9). Qatar's estimated population is 2.75 million (August 2021); it is expected to temporarily increase to 4 million during the FIFA World Cup games in the Fall of 2022 (11, 12, 9). In 2019, people above 65 years represented 1.5 percent (43,000) of the total population; this number is expected to increase to 14.2 percent (546,000) by 2050 (6). In 2019, Qatar had a total of 2,200 deaths of which 912 were persons over 60 years of age (9). Non-communicable diseases including cardiovascular diseases (310 deaths), cancer (143 deaths), diabetes mellitus (94 deaths) and respiratory related diseases (60 deaths) were the leading causes of death among Qatar's older population (13). Life expectancy at birth is 77.2; at 60 years, the figure is 19.2 years (14). However, Healthy Life Expectancy (HLE) at 60 is 14.2 years, indicating that the ageing population in Qatar will experience the burden and complications of chronic illness, as well as functional dependency and cognitive decline for an average of five years (14).

Healthcare services: Healthcare in Qatar is provided by a mix of public, private and semi-governmental services, with public providers delivering the bulk of services (15). All healthcare services are overseen by the MoPH which is also responsible for the formulation of healthcare policies and the national health strategies that guide the healthcare sector (16). Private healthcare services are provided by six hospitals across Qatar, with a total of 356 inpatient beds. Public healthcare services are provided by 19 entities accounting for more than 2,700 inpatient beds. The Public Health Care Corporation (PHCC), which runs 27 regional primary care centers across Qatar, and HMC, the primary state-owned organization and main provider of secondary and tertiary care, are the two main public healthcare providers in Qatar. HMC runs 14 Joint Commission International (JCI) accredited hospitals, community clinics and the national home care services and ambulance services. Qatar is integrating a unified electronic health record system across all HMC facilities and the PHCC.

Healthcare coverage: The entire population of Qatar benefits from universal health coverage (UHC) through the services of public hospitals and dedicated pathways for specific patients and age groups (17). In parallel, some employers provide health insurance for private hospital coverage for their employees (15). Emergency services are provided free of charge to the entire population (17). Since 2012, the Qatari government was the main source of funding for healthcare services in the country. According to the WHO, 93.4 percent of health expenditures in 2020 were covered by the government and private entities through private health insurance, while the remaining 6.6 percent was covered through out-of-pocket expenses (17).

Healthcare workforce: There are more than 7,000 physicians, 2,000 pharmacists, 9,000 allied health professionals, and 22,000 nurses in Qatar (9). The vast majority of these professionals are university graduates, and most nurses and midwives' leaders have advanced academic qualifications (11). According to the Planning and Statistics Authority of Qatar, the country has 2.7 physicians and 8.1 nurses per 1,000 people (9).

Palliative care services: Specialized oncology palliative care services were first established at the National Center for Cancer Care and Research (NCCCR) in 2008. Currently these services consist of an inpatient unit, outpatient services, and a mobile consultation service. There are no home-based hospice or stand-alone hospice facility models in Qatar (18), but such models are being planned and piloted. An early integration approach has been implemented in which all patients with metastatic cancer are automatically referred to the palliative care clinical nurse specialists who introduce the service and follow up with patients in an outpatient setting as needed. Palliative care is provided by an interdisciplinary team following a patient and family centered holistic approach.

Palliative care has gained acceptance as evident in the significant rise in the total yearly admissions of cancer patients to the palliative care unit since 2011, serving a total of 96 patients in 2016 (19). However, the need for palliative care services among cancer patients remains high especially during the end-of-life phase. In 2020, a total of 1,482 new cancer cases and 704 cancer deaths were registered in Qatar (20).

On a policy level, there are national palliative care standards and norms (policies and procedures). There is no national palliative care strategic plan in Qatar, nevertheless a national cancer plan with a section on palliative care is available (21).

Home health care services: Home care in Qatar has been provided mainly through the Home Health Care Services under HMC since 1998. This service covers around 2,600 patients per year, most of them Qatari. Home care services have gained wider acceptance by the community, and the number of patients has increased over time. Home care services provide 24/7 phone support to patients and their families, as well as care for short-term and long-term patients of various ages, nationalities and conditions. The majority are elderly and frail, bed bound or home bound, with a caregiver at home but do not require around-the-clock care. Such services promote earlier hospital discharge and faster turn-over of patients. The home care team consists of nurses and physicians; they have access to multidisciplinary referral services such as physiotherapy, social work, mental health, among others.

Although a portion of the patients cared for under the home care services are terminally ill, there are no specific home-based end-of-life or palliative care programs. Healthcare providers face challenges in delivering care for dying patients at home. These challenges are primarily centered around pain management and opioid administration. Although most pain medications are available in Qatar, such as codeine, morphine, oxycodone, methadone, and transdermal fentanyl (18), only oral forms of opioids can be prescribed for use at home. Consequently, patients need to be hospitalized if intravenous or subcutaneous morphine is required for pain management (22).

Geriatric Services: Geriatric care services at HMC are provided via a geriatric service network including Rumailah Hospital and long-term care, Hamad General Hospital (HGH), Heart Hospital, Qatar Rehabilitation Institute, Al Wakrah Hospital, and community integrated services. The geriatric department was established in 1992, and provides long-term care services, acute care services, outpatient services, urgent care services and residential care services at Rumailah Hospital. In addition, geriatric mobile teams support older patients at various HMC facilities through an array of service models such as acute care services, emergency services and orthogeriatric services at HGH and Al Wakrah Hospital, and cardio-geriatric consultation services at the Heart Hospital. The demand for these services is high. Phone support services via helpline and WhatsApp are also available for older patients including those diagnosed with Alzehimer's at Rumailah Hospital. Geriatric services are provided via a patient centered multidisciplinary approach, in which healthcare providers from different specialties (medical, nursing, social work, rehabilitation, mental health, pharmacy, etc.) collaborate to provide high quality care.

The need to further integrate palliative care into Qatar's healthcare system and beyond oncology diagnoses is crucial to ensure the provision of high-quality compassionate end-of-life care to all, specifically to Qatar's geriatric population.

LITERATURE REVIEW

This section provides a global perspective on the need and availability of palliative care and aims to define the different pillars of palliative care, levels and models of care.

Global need and availability of palliative care

Palliative care is considered an essential component of UHC, however, it remains largely inaccessible for most people. The Worldwide Hospice Palliative Care Alliance (WHPCA) estimated that 56.8 million people globally, needed palliative care, the majority of whom (76 percent) are over fifty years of age, and live in low- and middle-income countries (LMICs) (23).

Despite most of the needs being in LMICs, almost 70 percent of palliative care services are available in high income countries (HICs). There is a global shift toward more palliative care service integration and provision. Providers increased from 16,000 in 2011 caring for 3 million patients, to 25,000 in 2017 caring for 7 million patients (24). Unfortunately, only about 12 percent of the global need for palliative care is being met. Availability and access by patients with non-malignant diseases to palliative care services is limited. In general, frail patients and those with organ failure are less likely to receive palliative or hospice care compared to patients with malignant diseases (23, 25).

Even as palliative care becomes more widely available, the need for such services is outpacing the availability of providers and services, as well as the accessibility and quality. The development of palliative care services across countries is classified into six levels, from least to most developed. Qatar is among those countries where there is generalized provision of palliative care, yet there is a lack of integration into the health care system.

Palliative care pillars, levels, and models

Palliative care has evolved according to the changing needs and demands of populations. It adopts a public health approach rather than an individual one. Care no longer focuses largely on patients with terminal cancer during the end-of-life phase but includes all patients with life-limiting or serious conditions through all stages of illness (26). Palliative care services should adopt a needs-based, patient and family centered approach whereby palliative care is provided to patients who would benefit the most from such services, regardless of prognosis. These services should extend to family members as well. Palliative care should be provided by an interdisciplinary team (27).[1]

The European Association for Palliative Care (EAPC) has adopted geriatrics palliative care as sub-specialization and specified that geriatric palliative care should be part of the responsibility of both palliative and geriatric care specialties (28). It has also attained consensus on dementia palliative care as a sub-specialization, highlighting the challenge in caring for patients with dementia and indicating the need for specialist dementia care. The EAPC also reached consensus on 11 components to provide optimal palliative care in older patients with dementia (28,29), outlined below as follows:

- applicability of palliative care
- person-centered care, communication and shared decision-making
- optimal treatment of symptoms and providing comfort
- setting care goals and advance care planning (ACP)[2]
- continuity of care
- psychosocial and spiritual support
- family care and involvement
- social and ethical issues
- prognostication and timely recognition of dying
- avoiding overly aggressive, burdensome or futile treatment (including hospitalization, use of medications for chronic conditions, restraints, nutrition and use of antibiotics)
- bereavement support
- education of the health care team

There are three levels of palliative care which reflect the scope of palliative care providers (30). The first level, the *palliative care approach*, integrates palliative care methods and procedures in settings not specialized in palliative care. It is available to general practitioners, nurses, and staff throughout the hospital as well as in nursing homes. The second level is *generalist palliative care,* which is provided by primary care professionals and specialists mostly treating patients with life-threatening and limiting illnesses, such as oncologists and geriatricians. Lastly, *specialist palliative care* is provided as the main service by trained interdisciplinary palliative care specialist teams to patients with complex needs.

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[1] Non-hierarchical interdisciplinary teams are composed of professionals from various disciplines. The team features greater interaction, shared leadership and the full input and commitment of each member. There may be a designated administrative coordinator, but the position does not hold greater authority than others. The coordinator cannot make decisions without consulting with other members of the team. While in multidisciplinary teams, each member has specific roles and responsibilities, and independently performs his/her interventions, members work together toward achieving a common goal without having a common plan. These teams are organized hierarchically; usually leadership is attributed to the most important profession (Zeiss & Steffen, 1998).

[2] ACP is defined as a "process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" (Sudore et al., 2017).

Among the specialist palliative care services, and within the hospital setting, the specialist palliative care consultation team is the most common palliative care service model worldwide, involving a collaborative effort between the primary care team and the palliative care team. Palliative care units support patients with complex palliative needs, aiming to support patients to be discharged home, where their care can be continued by outpatient and home-based palliative care services. Home-based palliative care and hospice care models provide 24/7 support within the home setting through a dedicated interdisciplinary team. Care coordination and collaboration with the hospital palliative care teams is crucial to maintain continuity of care and avoid unnecessary admissions and interventions. Palliative care outpatient services offer consultations in stand-alone and embedded clinics or through telehealth-based palliative care (31). These services play a major role in the early integration of palliative care, and help the primary team save time otherwise spent on symptoms management, advanced care planning and coordination of care (32).

The most comprehensive model of palliative care practice integrates both generalist and specialized palliative care, in parallel with curative and life-prolonging treatment throughout the course of illness, not only at the end of life. (30). Current worldwide trends are moving toward a palliative care generalist approach, in which primary care staff are sensitized and trained to provide basic palliative care to patients with such needs (30). As the generalist palliative care approach is more structured and solid, the specialized palliative care consultation team will mainly focus on supporting patients with complex needs. Coordination and collaboration between generalists and specialists in palliative care is critical (30). Benefits to the patient include increased likelihood of death at a preferred location, and better symptom management. Benefits at the healthcare provider level include increased confidence in providing palliative care and more positive attitudes toward specialist palliative care (30). Research studies conducted on models of care have focused mainly on specialist models and have fallen short on studying the effectiveness of care models that combine specialist and generalist palliative care (30).

Barriers facing palliative care

There are many challenges facing palliative care services around the world. A key factor is the need for government policies that support palliative care services. National laws and regulations should define palliative care as part of the healthcare system, support it with standards and clinical guidelines, and recognize it as a medical specialty. Most countries do not have a national strategy that supports palliative care, and many of these rely on charitable palliative care services (23).

Lack of knowledge about palliative care is also a key barrier. Knowledge starts from the very basic, generalist training of all healthcare professionals, to intermediate level training of professionals who care for patients with life-limiting diseases, to more specialized palliative care training and research. People in the community should also be educated to raise their awareness and enable them to be efficient caregivers for their loved ones (23).

The WHPCA estimates that at least 2 million healthcare professionals worldwide are needed to meet the global demand for palliative care services. The shortage of professionals is a global challenge in healthcare services; the current number of professionals working in palliative care is estimated to be only around 400,000, with approximately 1.2 million volunteers from the community (23).

The absence of certain treatments can also be a barrier to palliative care as there are many essential medicines without which palliative care cannot be properly delivered. Opioids, for example, are essential for pain control. However, the use of opioids in LMICs accounts for only ten percent of the world's opioid consumption reflecting a global issue in the disparity of access to these medicines (23).

Human factors may challenge the implementation of palliative care services. These may be psychological, such as fear of death and a tendency to link palliative care with the end of life, and a consequent resistance to these services in the community. In addition, for some cultural and psychological reasons, people may avoid informing patients about their diagnosis and prognosis; this may be a barrier to palliative care. Access to quality palliative care can also be restricted due to financial limitations; hence the importance of government support (23).

Geriatric palliative care is facing several challenges. Ensuring the provision of timely and patient-centered care is complicated by limitations in decisional capacity, communication and behavioral problems, prolonged disease trajectories and complex social factors. Furthermore, additional challenges include ensuring coordinated continuous care amid a highly fragmented and specialized healthcare system (5).

Knowledge and beliefs toward palliative care

In Qatar, palliative care education has been integrated into the undergraduate medical curriculum only as an elective course, and as a fellowship sub-specialty medical program. It is similarly an elective course in the postgraduate nursing curriculum. At the medical level, a palliative care training program is integrated into the residency or fellowship curriculum of the oncology and hematology specialty at HMC (33). The nursing school of the University of Calgary in Qatar used to offer palliative care as a post-graduate program, allowing nurses to obtain a master's degree in nursing, with a focus on palliative care (18). Currently, only an elective course is available as part of the postgraduate curriculum.

Awareness and attitudes of oncologists toward palliative care in Qatar was assessed using a cross-sectional study conducted at the NCCCR, Doha, in 2013 (34). This study revealed relatively good awareness and knowledge among oncologists despite not receiving any previous formal training. However, researchers highlighted the need to raise awareness among oncologists to encourage their use of palliative care services, optimizing patient access (34). The lack of formal training discussed in this study was also elucidated in another descriptive study conducted at HMC which assessed the knowledge, perception and needs of oncology nurses with regards to palliative and spiritual care. Lack of formal palliative care training, experience and knowledge in the field among nurses was also indicated in a study published in 2014 (35). A cross-sectional survey, conducted in the emergency departments of all general hospitals in Kuwait, showed that physicians recognized palliative care as an important competence, however most had uncertain attitudes and poor knowledge toward palliative care, especially in opioid handling, management of dyspnea, and severe bleeding (36).

Awareness and beliefs among the general public are crucial for acceptance of such services. No studies have been conducted in Qatar about these aspects of palliative care. A study from Saudi Arabia, where palliative care has been available for the past 20 years, reflected limited general awareness among the public about, and less favorable attitudes toward, palliative care (37, 38). Better knowledge and awareness and more positive attitudes among the public regarding the role of palliative care have been reported in studies conducted in Western countries such as Ireland and United States (39, 40).

Patient and caregiver needs

Older patients and their caregivers have various needs for physical, social and psychological, spiritual care however latest evidence; despite limited, suggests that these needs are not met (41, 42). A recent systematic review published in 2022 on the needs of older patients with multimorbidity and non-malignant diseases, family caregivers and professionals highlighted a great variety of unmet needs (41). Emotional and mental health needs (social isolation, depression, anxiety, feeling like a burden on families), information needs (information about palliative care, disease severity and progression, and communication with healthcare providers), spiritual and cultural needs were all common needs reported by older patients. Physical needs were less of a concern to patients, where such needs were being met by the healthcare team. Similarly, caregivers' needs included emotional and mental health needs (sleep issues, stress, confinement, anxiety), informational needs (on how to handle emergencies, on disease progression and what to expect in the future), social and financial issues (isolation, employment loss/termination due to caregiving demands, costs of healthcare care and medications, among others).

Unmet needs can be attributed to underreporting by patients, underassessment and undertreatment of problems by healthcare providers (42). In the systematic review conducted by Llop et al., various reasons for limitations in meeting the needs of older patients were cited, as follows (41):

- complexity in determining these needs in older non-oncology patients
- lack of palliative care referral criteria or pathways
- lack of systematic processes
- lack of skills, defined roles
- lack of time and adequate staffing
- lack of specialist palliative care services for older, non-oncology patients

No studies were found on the palliative care needs of older patients with multiple morbidities and their family caregivers in Qatar or the Arab world.

Truth telling and healthcare decision making

To achieve ethically sound end-of-life decisions, provision of good information and communication is essential. Truth telling, shared decision-making and advance care planning are important concepts (43).

Truth telling: Truth telling refers to the act of disclosing accurate information to the patient or families about the patient's diagnosis. This could be communicating the futility of curative treatment, the reality of imminent death, possible clinical pathways to death, and the possible impacts of end-of-life decisions (44, 45). Patients should be informed about their condition and prognosis, so they have the opportunity to take end-of-life medical decisions aligned with their wishes and preferences. Truth telling embodies respect for patient autonomy and shared decision-making. In palliative care, breaking bad news is considered sharing any information that negatively changes the patient's view of the future (46). Truth telling, in some scenarios, can have a negative impact on patients (47).

In Qatar, as in many other collectivist societies – where people are tightly integrated into strong cohesive interconnected and interdependent groups whose members feel a strong sense of belonging and being cared for in exchange for loyalty, (48, 49)–truth telling and breaking bad news by physicians is mainly conducted with families rather than patients. The family is usually the main decision maker. Patients are usually involved in such discussions only upon family approval. This is also seen among Middle East and North Africa (MENA) countries such as Lebanon, Bahrain, and Saudi Arabia (50), and Asian countries such as India and China (51, 52). In contrast to the Eastern collectivist cultures, most Western cultures, such as in the United States, place more emphasis on patient consultation, and diminish the family role. Some 80 to 90 percent of patients in Western countries are fully informed about their diagnosis (53). No studies have been conducted about attitudes of the general public toward truth telling in Qatar. One study, conducted in UAE in 1997, showed that 71 percent of the Emirati community and 88 percent of physicians thought that it was justified for the physician to give the family full information, rather than the patient (54).

More recently, positive attitudes toward truth telling have been noticed among healthcare professionals practicing in the MENA region. In a cross-sectional study conducted at HMC Qatar, a sample of 131 physicians were polled; almost 90 percent of them believed that patients have the right to and should be informed about their diagnosis (55). Other studies done in Lebanon and Iran showed similar beliefs among healthcare professionals (47, 56).

However, healthcare professionals agreeing that the patients have the right to know, does not always translate into practice. A recent study in Bahrain found that physicians preferred to know their own diagnosis if they were patients themselves (50). When asked about actually giving a full diagnosis to their patients, around 49 percent of physicians had an “always tell” policy, whereas 34.8 percent implemented an “often tell” policy; five percent and three percent reported a “rarely tell” or “never tell” policy, respectively (50). The study concluded that there is a disparity between physician practice and personal attitude (50).

Challenges with truth telling are further complicated by ageing, as the last two decades of life are characterized by an increased burden of chronic non-malignant multimorbidity, potentially functional dependency, frailty, and often cognitive decline (28). The latter specially highlights the challenges to patient autonomy and shared decision-making (44). Timely discussion of the terminal nature of dementia helps prepare patients and families for the trajectory of the disease. It allows for proactive shared decision making by the patient, family, and healthcare professionals (44). In late diagnoses, prognostication and communication mostly occur solely with the family or caregiver who are tasked with decision-making on behalf of the patient (29).

Healthcare decision making and aggressive treatment: Healthcare decision making is a process that includes following definable steps in a desirable sequence (57). Shared decision-making is the optimal approach, where there is an ongoing process of open discussions between patient, family, physician and care team. Clinicians provide recommendations based on their expertise while patients utilize this information to make informed decisions that are aligned with their values and goals taking into account the perspective of their families (43). Toward the end of life, many patients lose their competencies and capacities to communicate and make informed decisions about their treatment goals (43). Aggressive treatment nearing end-of-life can result in patient suffering, poor experience of end-of-life care etc. by family caregivers and negative mental health outcomes of bereaved family caregivers (58, 59). Aggressive treatment or care include life sustaining treatment and aggressive health care utilization in the last month of life. Life sustaining treatment serves to prolong life without reversing the underlying medical condition and includes but is not limited to cardiopulmonary resuscitation (CPR), mechanical ventilation, hemodialysis, left ventricular assist devices, blood transfusion, antibiotics, artificial nutrition and hydration, insertion of feeding tube, radiation and non-palliative chemotherapy and hemodynamic support (intravenous inotropic medications or volume expanders) (60). Aggressive healthcare includes having more than one emergency room visit and hospitalization and an intensive care unit admission in the last month of life and death in an acute care hospital (61, 62).

As such, Advance Care Planning (ACP) is a vital process in palliative care. It includes conversations with patients and families, identification of, and participation of, surrogate decision makers who can represent patient interests and values and documentation of patient wishes. ACP includes decisions about aggressive treatments nearing end of life including, place of death, by completing an advanced directive, which may or may not be a legally binding document (58) depending on local laws. For patients suffering from cognitive decline, such as in dementia-like diagnoses, the patient's early preferences should be documented and honored as principle. Anticipating the progression of the disease and ACP should start as soon as the diagnosis is made, when patients may still be involved in sharing their preferences, values, needs and beliefs. Otherwise, family members will be the principal individuals responsible for end-of-life decision making in proxy (29).

Code status is a formally indicated status of patient with respect to the desire for resuscitative measures. Any adult patient who is legally and cognitively competent is eligible to agree to a Do Not Attempt Resuscitation (DNAR) order which refers to allowing natural death to occur as a consequence of a disease or injury (64). At HMC-Qatar a DNAR policy and order are available and practiced. In most cases, DNAR orders are decided by the treating physician upon discussions with the family in the event of a patient's deterioration in the case of terminal or non-treatable disease with no hope of survival (18). However, the practice of withholding aggressive treatment, particularly life sustaining treatment, is not commonly accepted by families in Qatar, as is the case in other Arab countries. Although a retrospective study conducted on the trend of aggressiveness in end-of-life cancer care at NCCCR in Qatar showed significant decrease in aggressive treatments, occurrence of such treatments was higher than similar studies reported internationally. This study recommended the integration of palliative care services in Qatar for further reduction of aggressive end-of-life interventions for cancer patients (65). Another study attributed a prolonged length of stay (average 30.5 days) of oncology patients at the palliative care unit at NCCCR (a higher average compared to other countries) to the cultural belief that hospital settings are the best providers of end-of-life care, as well as a lack of home hospice or palliative care models (65).

Challenges to allowing a natural dying process and reducing aggressive treatments have been attributed to socio-cultural and religious issues around ethics that can arise from such decisions. In 2018, a report published by WISH about palliative care and Islamic ethics, stated that beyond life-saving interventions whose efficacy is certain (and therefore mandatory from an Islamic perspective) curative treatments are generally categorized as an ethically neutral act and are thus optional. That is why forgoing certain treatments such as mechanical ventilation and CPR are acceptable under certain conditions (18). Despite the presence of DNAR policies and fatwas (authoritative opinions on Islamic law) that support the withdrawal of life-prolonging treatments, neither is legally binding, raising issues of medicolegal liability (18). These ethical and legal issues might help explain the orientation of medical staff in Qatar toward curative and acute care. Accordingly, ACP and completing advance directives are not yet a routine practice in Qatar (66).

No studies have been identified regarding DNAR awareness among the general public in Qatar. One study conducted in Saudi Arabia reported that almost half of patient and caregiver participants did not accept the concept of DNAR, and the majority were unaware about the presence of the DNAR policy or fatwa (67). Similarly, a study conducted in an oncology hospital in Iran, revealed an overall negative attitude among patients and family members toward DNAR orders (68).

Death and dying

A core component of palliative care is assessing preferred and actual place of death. In 2013, a systematic review of 210 studies from 33 middle- and high-income countries showed that most of the public and patients prefer to die at home. Moreover, preference for home death was consistent among patients, as only 20 percent changed their preferences as disease progressed (69). Another systematic review of 23 articles conducted by Nilsson (70), showed that an average of 60 percent of patients prefer home death while only 40 percent died there, highlighting the incongruence between the actual and preferred place of death. Compared to the rest of the world, the preferred place of death is still being explored in the Eastern Mediterranean region (71). Only one Arab country, Egypt, explored the preferred place of death among patients with incurable cancer diagnosis and their family caregivers. The study demonstrated that home was the preferred place of death among 93 percent of the patients and 90.1 percent of caregivers (71, 72).

Dying at the hospital is very common in Qatar. A retrospective, population-based study titled "Patterns in Place of Cancer Death in the State of Qatar: A Population-Based Study", showed that 99 percent of cancer patients die in hospitals. The researchers highlighted the importance of improving and developing home hospice care programs to support patients in dying at home (73). Studies conducted in several Arab countries on the attitudes of healthcare professionals toward the care of the dying revealed more positive attitudes with years of experience and frequent exposure to dying patients (74-76). This highlights the importance of training and capacity building interventions.

Access to and utilization of opioids

Absence or restricted access to certain treatments, specifically opioids, acts as a barrier for palliative care provision. In 2013, a study conducted by Cleary et al., found that opioid availability is low in most of the MENA countries. Formulary deficiencies are severe in several countries, in particular, Afghanistan, Iraq, Lebanon, Libya, Palestine, and Tunisia (77). Access is also significantly affected by widespread over-regulation that is pervasive across the region (77). In Qatar, opioid analgesics for palliative care pain management are available, including codeine, transdermal fentanyl, different forms of morphine and oxycodone (18, 78). Yet several factors act as barriers for pain management for palliative care patients including restrictive policies for opioid prescription where only oncologists, anesthesiologists and palliative care specialists are authorized to prescribe them (21), restrictions on prescription of non-oral forms of morphine in home care settings (22) and inadequate qualification to prescribe opioids . The National Health Strategy calls for plans to educate healthcare professionals on best practices in opioid prescription (22).

In Qatar, a study conducted by Al Masri in 2018 explored the perceptions of healthcare professionals on opioid use among cancer patients in order to understand potential barriers and facilitators to optimal prescribing (79). Most participants believed opioids had a major role in cancer pain management, and described the law as an overwhelming barrier, restricting who could prescribe, when, to whom, in what setting and in what modalities (79). Family involvement and fear of opioids were commonly mentioned. Physicians perceived cultural beliefs as a potential barrier, and believed that specialized pain management programs, and timely referrals to these teams, and patient counseling would facilitate the efficiency of the prescribing process. This study concluded that opioid use is a process that is affected by a multifaceted complex system. As such, any intervention aiming to optimize the use of opioids in any setting must be well researched and grounded in the local context (79).

In our study, we explore the perceptions, attitudes and practices toward these themes in Qatar. In following sections, we will delineate the methodology and results of our assessment, discuss implications of our results and provide recommendations to integrate palliative care into older adult care.

METHODOLOGY

Purpose

The purpose of our quality improvement study was to better understand the needs of Qatar's older patients facing serious illness toward designing quality palliative care services to meet those needs. This included exploring the perceptions of older patients, caregivers, healthcare providers and healthcare management about palliative care, truth telling and healthcare decision making, and death and dying, to identify barriers and opportunities to the development of palliative care and recommend the best palliative care models for older patients and their families.

Study design and population

In this cross-sectional study, a needs assessment approach was adopted. It is a systematic process used to identify gaps between what is currently available and what is desired to be achieved by obtaining qualitative and quantitative data from various sources (80). A needs assessment for the geriatric services at HMC was conducted to support the process of establishing a palliative care service model tailored to the needs of older patients and their caregivers. The needs assessment is intended to align with the hospital's priorities and resources, by using the hospital's strengths to address its weaknesses.

The study population primarily included older patients and caregivers, key informants and healthcare professionals. The study involved conducting key informant interviews, patient and caregiver surveys, nurse and physician surveys and analysis of program data.

Key informant interviews: Key informants were identified by the research team and the administration of the geriatric services. Key informants were also asked to recommend other staff whose input could be of added value to the assessment. Key informants included professionals from the geriatric, home healthcare, rehabilitation, oncology palliative care, emergency medicine, internal medicine, mental health, and quality services in addition to the nursing, medical and continuing of care administration at HMC, and key informants from research and academic entities. The list included frontline staff, managers, and senior leadership. Semi-structured, one-on-one interviews were mainly conducted. Focus group discussions were conducted with frontline staff, such as physicians and nurses whenever applicable and feasible. An interview guide was developed and tailored to the position of each key informant. A sample of the interview guide is presented in Appendix 1.*

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* All appendices are included in the soft copy that can be accessed on the WISH website www.wish.org.qa

Patient and caregiver survey: A cross-sectional survey was used to understand the views of older patients and their primary caregivers about concerns and needs related to the patient's severe illness, their views and attitudes toward truth telling, healthcare decision making, death and dying, and their knowledge and attitudes toward palliative care. Two surveys were constructed, one for patients, another for caregivers, based on tools and questions used in other research studies (40, 72, 81, 82). The patient and caregiver surveys included a total of 34 and 38 closed-ended questions, respectively, including multiple choice and Likert scale responses. Surveys were translated to Arabic and administered by trained research assistants. Surveys were piloted in English and Arabic.

Eligible patients were aged 60 years and above who were cognitively competent (as determined by the patient's primary care team), and who presented to the geriatric outpatient clinics or the urgent day care unit at the geriatric services at Rumailah Hospital. Eligible caregivers included primary caregivers of at least 18 years who were either family members or friends of patients (i.e., who were not hired to care for the patient), and who presented with their patients at the geriatric outpatient clinics or urgent day care unit at Rumailah Hospital. The patient and caregiver surveys are detailed in Appendix 2 and Appendix 3.

Nurse and physician survey: A cross-sectional survey was used to assess the palliative care knowledge, attitudes and practices of nurses and physicians working at the geriatric services. Two self-administered, paper-based surveys were constructed, a nursing and a medical survey, based on tools and questions used in other research studies. The surveys were divided into four main sections: background information, knowledge, attitudes, and practices. We used the Palliative Care Knowledge Assessment Tool (PCKT), adapted from a study conducted in Vietnam with older patients for assessing knowledge (83). We used the shortened version of the Frommelt Attitude Toward the Care of the Dying (FATCOD) tools (84). We used six multiple choice questions to assess the practice of holistic assessment, discussion of diagnosis and prognosis, cultural assessment, emotional support, and pain management obtained from similar studies (85,86).

Nurses and physicians working in geriatric services at Rumailah Hospital and/ or physicians working in home healthcare services were eligible to complete the survey. There was no need to translate the surveys into Arabic as English is the main language used at work. The nurse/physician survey is detailed in Appendix 4.

Review of program data: To better understand the context, operational data for the geriatric and home healthcare services was obtained from the system for the previous three years (2019, 2020 and 2021). This included data about volume of admissions, discharges, referral sources, length of stay, occupancy rates and deaths.

Ethical considerations, data confidentiality and protection

This needs assessment was evaluated as a quality improvement initiative, and thus did not require an institutional review board approval. Nonetheless, the research team followed ethical principles of participant voluntary oral consent, confidentiality, privacy, and anonymity. Following recruitment and prior to the administration of the survey, all participants were briefed about the study, informed that their participation was entirely voluntary, that they could stop the survey before completing it, or decline to partake, without repercussion. This conversation happened in a private setting. The participants were also clearly informed that no identifying information would be shared, the results would be presented in aggregate form, maintaining their confidentiality and anonymity. Overall, the study was deemed to pose zero to minimal risk to the participants.

Procedures and data analysis

Data collection took place between September and October 2021.

1. Key informant interviews

A total of 33 key informant interviews were conducted including 28 semi-structured one-on-one interviews and five focus group discussions. Key informants were invited to participate by email. Meetings were scheduled based on the availability of the key informants. An information sheet, consent form and interview guide were emailed to key informants. Consent to participate, to record the interview, and take quotes was taken at the start of the interview. Interviews were conducted online, either in Arabic or in English, according to the preference of the key informant, by two members of the research team who are experts in palliative care. The average duration of interviews was 77 minutes; the shortest and the longest interviews were 45 minutes and 127 minutes, respectively. All interviews were transcribed verbatim. Demographic data were not collected from interviewees. Table 1 includes a list of key informant interviews by profession.

Table 1: List of key informant interviews

Number of interviews		
Type	One-to-one interview	Focus group discussion
Medical	8	1
Nursing	-	4
Allied healthcare	5	-
Administration (nursing/medical/others)	12	-
Research/Academia	3	-
Total	28	5

Interviews were analyzed using deductive thematic analysis. An analysis framework was developed including codes, sub-themes and themes based on the interview guides and literature review and agreed upon among the research team. The analysis process consisted of familiarization with interviews by reading the transcripts, coding (giving labels/codes to main ideas in the transcripts), indexing the transcripts, and charting data into the matrix. The first four transcripts were coded using the predefined codes. No new codes emerged; only the phrasing of the codes was modified. Data collection and analysis were conducted iteratively. Coding was conducted by two team members, one of whom conducted the interviews. Data saturation was achieved.

2. Patient and caregiver survey

Older patients and family caregivers were approached through the geriatric outpatient clinics and the urgent care unit. The surveys were administered by trained research assistants or nurses who could speak the first language of the patient. The surveys were administered to patients and their caregivers separately to avoid being influenced by each other's views.

Data was analyzed to produce descriptive statistical measures. Percentages and frequencies were used for categorical and ordinal variables (all survey questions) and median and range or mean were used for continuous variables. Data were stratified by gender, age, nationality, and education using percentages and frequencies. Variables were grouped by gender, patient age groups (60 to 69 years, 70 to 79 years, and 80 years and older), caregiver age groups (below 40, 40 to 59, and 60 and older), nationality (Qatari or non-Qatari), and education level [no formal education, primary education (to Grade 6), secondary education (to Grade 12), tertiary education (university and postgraduate)].

3. Nurse and physician survey

Hard copy surveys were distributed to nurses and physicians who work in geriatric services at Rumailah Hospital, and to physicians who work at the home healthcare services. Completed surveys were returned to the research assistants.

The responses were analyzed descriptively. Percentages, frequencies, median and range were used to present demographics. Means and percentages were used to analyze palliative care knowledge across its sub-domains (philosophy of palliative care, pain, dyspnea, psychiatric and psychological and gastrointestinal problems). Percentages and frequencies were used to analyze attitudes toward death and dying and current practices.

Data was analyzed using Excel and EPI INFO Windows Version developed by the US Centers for Disease Control and Prevention (CDC).

RESULTS

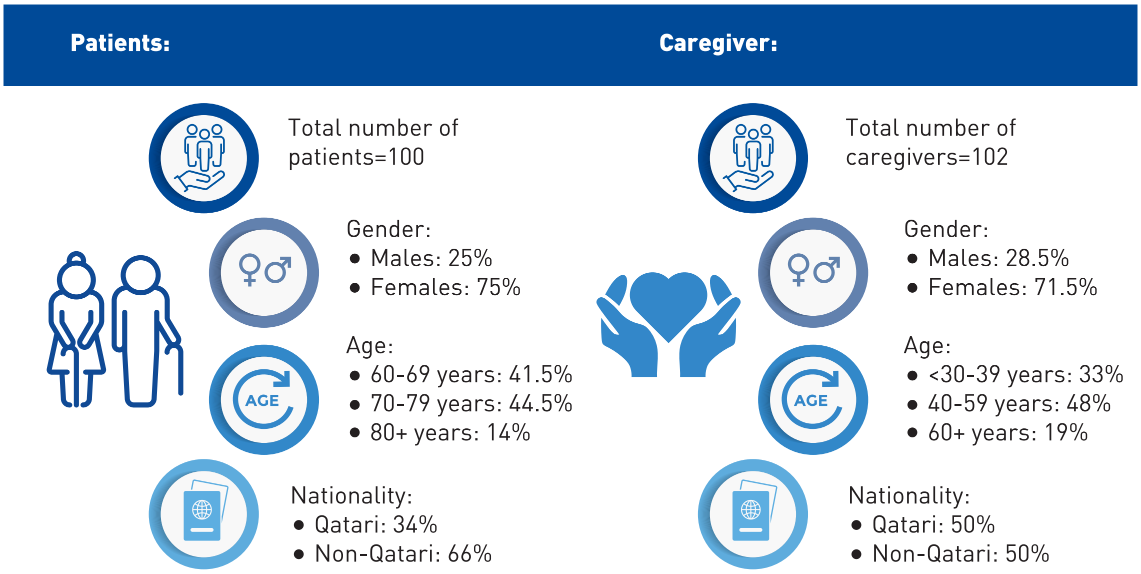
Demographics and background information

1. Patient and caregiver survey

Patients: A total of 100 patients participated in the survey; most were recruited from the outpatient clinics. The mean age was 70 with the majority being female, non-Qatari and literate. Patients' most common medical conditions were hypertension followed by diabetes and coronary artery disease.

Family caregivers: A total of 102 caregivers participated in the survey; most were recruited from the urgent care unit. The mean age of caregivers was 46 with the majority being female. Half of the caregivers were Qatari, and the majority were literate. Table 1 in Appendix 5 includes detailed responses about patient and caregiver demographics and background information.

Figure 1: Patient and caregiver demographics



Patients:

Total number of patients=100

Gender:
- Males: 25%
- Females: 75%

Age:
- 60-69 years: 41.5%
- 70-79 years: 44.5%
- 80+ years: 14%

Nationality:
- Qatari: 34%
- Non-Qatari: 66%

Caregiver:

Total number of caregivers=102

Gender:
- Males: 28.5%
- Females: 71.5%

Age:
- <30-39 years: 33%
- 40-59 years: 48%
- 60+ years: 19%

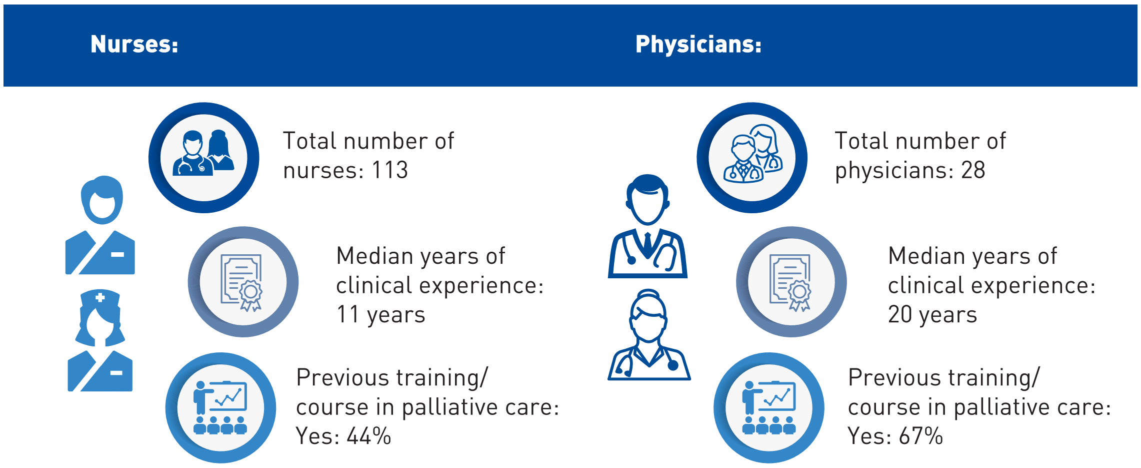
Nationality:
- Qatari: 50%
- Non-Qatari: 50%

2. Nurse and physician survey

Nurses: A total of 113 nurses completed the survey, with a response rate of 96 percent. Nurses had a median age of 34, most were females, and had a bachelor's degree in nursing. Fewer than half of the nurses took care of severely ill patients during the latest stage of disease on a daily basis, with more than half reporting having never received a course or training in palliative care.

Physicians: A total of 28 physicians completed the survey, with a response rate of 39 percent. Physicians had a median age of 42; more than half were males and most were attending physicians. Almost one third of the physicians took care of severely ill patients during the latest stage of disease on a daily basis, and 33 percent reported never receiving a course or training in palliative care. Table 2 in Appendix 5 includes detailed responses about the demographics and background information of nurses and physicians.

Figure 2: Nurse and physician demographics



Nurses:

Total number of nurses: 113

Median years of clinical experience: 11 years

Previous training/ course in palliative care: Yes: 44%

Physicians:

Total number of physicians: 28

Median years of clinical experience: 20 years

Previous training/ course in palliative care: Yes: 67%

Knowledge and beliefs toward palliative care

1. Key informants

When asked about education and knowledge of healthcare professionals on palliative care, key informants described the available resources and training offered to healthcare professionals, identified main gaps, and underscored the need for additional training.

Key informants highlighted the need for theoretical and practical training in palliative and end-of-life care, where the current demand exceeds available resources. To be able to provide geriatric palliative care services, key informants underscored the need for:

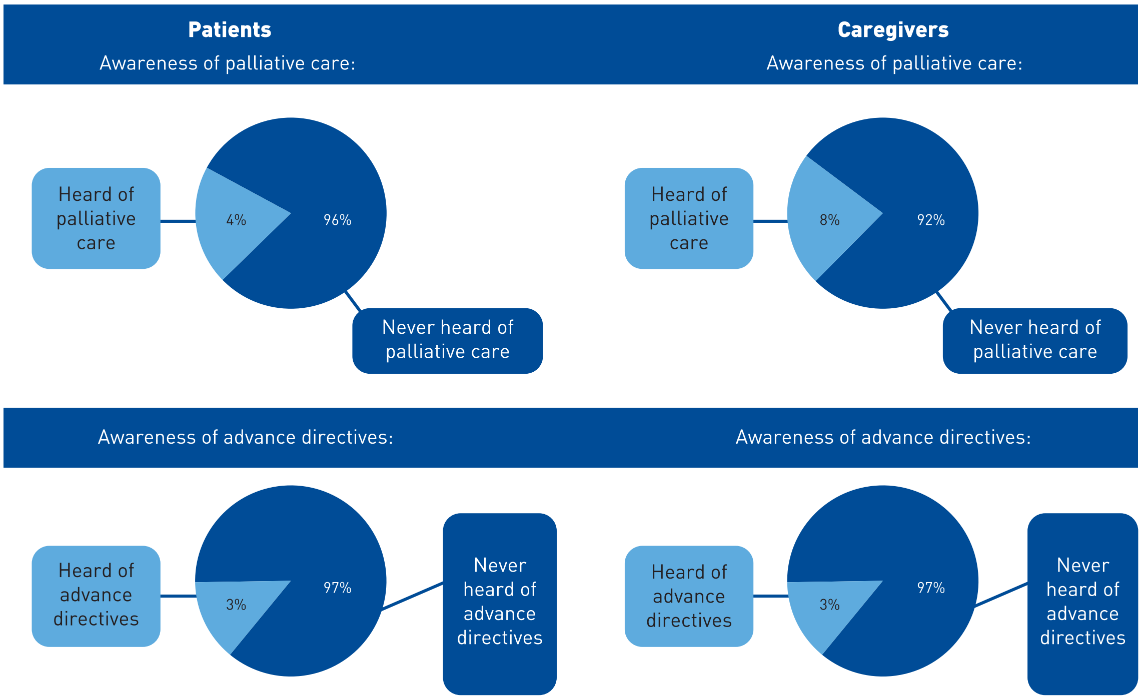
- Palliative care training targeting healthcare professionals in geriatric and home care services to be able to provide specialist palliative care
- Training on the proper identification of palliative care patients for accurate and timely referrals
- Training on effective communication including breaking bad news, providing psychological support, and management of physical symptoms

- Training religious figures on palliative care, given the great influence of religion and spirituality in decision-making toward the end of life.

2. Patient and caregiver survey

Patients and caregivers were asked about their awareness and beliefs toward various aspects of palliative care. Ninety six percent of patients and 92 percent of caregivers had never heard of palliative care, and did not know that these services existed in Qatar; none reported receiving palliative care services in the past. Similarly, most patients and caregivers had never heard of advance directives, and none reported completing one. Only a few patients and caregivers linked palliative care to cancer diagnosis, to death or to a physician giving up on the patient. Furthermore, most patients and caregivers thought palliative care can make the patient feel better, and that it can help the whole family cope better with severe illness. Table 3 in Appendix 5 includes detailed responses of patient and caregiver knowledge and beliefs about palliative care.

Figure 3: Patient and caregiver awareness of palliative care and advance directives



3. Nurse and physician survey

Nurses' knowledge scores mostly ranged between poor (36 percent) and good (61 percent), while physicians' scores ranged between good (34.5 percent) and very good (59 percent). Nurses displayed good knowledge of the philosophy of palliative care and psychiatric and psychological domains, and poor knowledge in the pain, dyspnea, and gastrointestinal domains; they scored lowest in the dyspnea domain. In contrast, physicians displayed very good knowledge of the philosophy of palliative care and dyspnea domains, and good knowledge of psychiatric and psychological, gastrointestinal and pain domains; they scored lowest in the latter. Table 2 below shows the distribution of nurse and physician knowledge scores. Table 4 in Appendix 5 details the responses of nurses and physicians to the knowledge section of the survey.

Table 2: Nurse and physician level of knowledge in palliative care

Participants	Nurses % (N)	Physicians % (N)
Very Poor	1% (1)	0% (0)
Poor	36%% (41)	7% (1)
Good	61%% (69)	34.5% (8)
Very good	2% (2)	59% (20)

Patient and caregiver needs

1. Key informant interviews

Patient needs: Most older patients who sought geriatric services have multiple morbidities. Many are bed ridden, cognitively impaired, and may have various physical, psychosocial, and spiritual needs. According to key informants, however, psychological and spiritual needs are much more prominent than physical and social needs. Key informants perceived religious/spiritual support as crucial, especially in end-of-life discussions, and highlighted the need to have religious/spiritual advisors as part of the interdisciplinary team. Key informants also emphasized the need to integrate palliative care assessment tools for systematic assessment of palliative care needs of older patients.

Caregiver needs: Generally, patient caregivers are family members, hired personnel or a mix of both. Hired caregivers may or may not have a nursing background and are mostly involved in the day-to-day care of the patients such as bathing, feeding, administering medications, etc. Assessment of caregivers' needs, and education is conducted systematically and continuously at the geriatric services. Key informants described several challenges with caregivers. Most older patients have hired caregivers, resulting in family members being less involved in the care of the patient. Healthcare professionals face challenges as families become more resistant to the palliative care approach. Other challenges include turnover of caregivers, lapses in the care of patients at home due to the lack of time, fear of not being able to provide proper care, and neglect of patient needs.

All key informants reported the absence of formal bereavement services that provide mental health support to families after a death.

2. Patient and caregiver survey

Patient concerns and needs: Patients and caregiver were asked about the patients' possible fears, concerns and needs during severe illness in the last year of life. According to patients and caregivers, fear of pain was the most common concern followed by fear of being a burden on the family, fear of losing functionality and fear of loneliness. According to both patients and caregivers, psychological support was the most common patient need, followed by around the clock access to healthcare professionals (by phone or home visits), pain and symptom management, and spiritual support.

Caregiver concerns and needs: Patients and caregivers were also asked about possible caregiver needs during a patient's severe illness in the last year of life. According to caregivers and patients, around the clock access to healthcare professionals was the most common caregiver need, followed by the need for psychological support, access to medical supplies and equipment at home, and social support. It is worth highlighting that only one caregiver reported bereavement support as a need during the patient's last year of life. Tables 5, 6 and 7 in Appendix 5 include information about patient and caregiver priority concerns and needs.

Figure 4: Patient concerns and needs

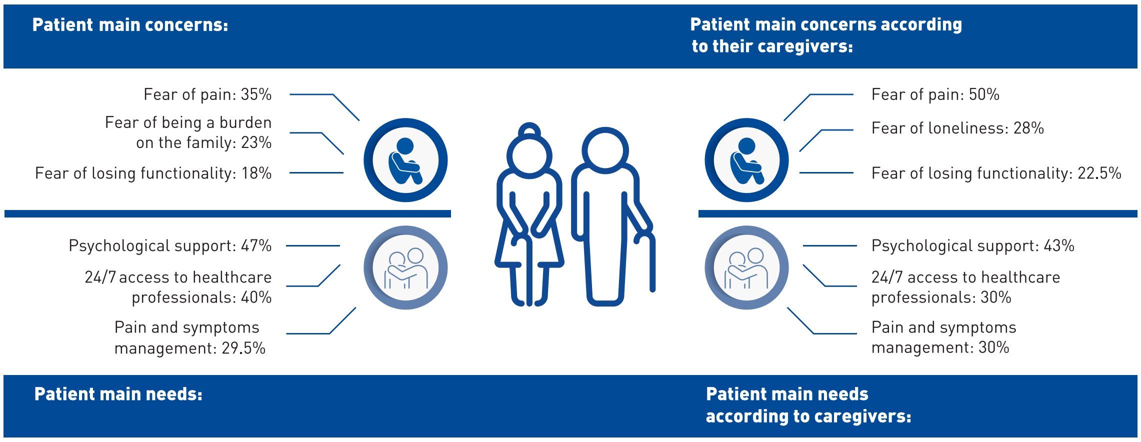
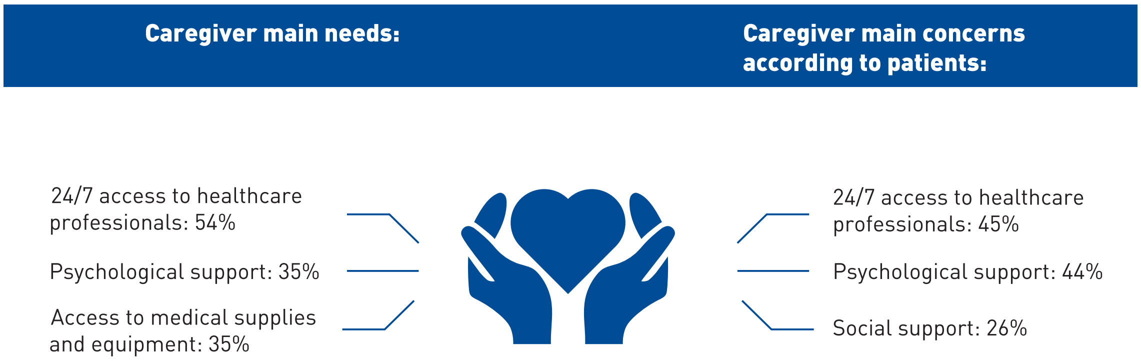


Figure 5: Caregivers' needs



Truth telling and healthcare decision making

1. Key informant interviews

Description and process: Truth telling and supporting patients in making informed healthcare decisions in advance was reported as a challenging and culturally sensitive process further complicated by language barriers. According to key informants, truth telling and discussions of disease prognosis and goals of care including code status, patient preferences and wishes, etc. are conducted during a family meeting with the primary family caregiver and the interdisciplinary team. Such discussions are mainly conducted as the patient's condition deteriorates. Decisions are made on whether to pursue aggressive treatments, or to provide comfort measures. Patients are involved in this process when they have the mental capacity and when their families permit. Hospital DNAR orders are applicable and valid at all HMC facilities but not for home care services where home care physicians need to initiate end-of-life discussions with the patient and/or family and set their own DNAR orders. Despite having a DNAR policy, DNAR orders are not legally binding, hence any family member can reverse or overturn the DNAR decision.

Challenges: All key informants strongly highlighted the ethical principle of confidentiality and the duty of sharing health information with patients solely, and empowering them to make informed healthcare decisions about their care. However, all key informants described the process and dynamics of truth telling and conducting end-of-life discussions as challenging and influenced by many disease-related and cultural factors. First, several key informants highlighted the challenge in identifying prognosis of dementia-like diagnoses and involving the patient in these discussions given their reduced mental capacities in advanced stages of the disease. Second, most key informants described that families in the Arab world tend to be emotional and believe that the patient's awareness of the diagnosis and prognosis and talking about death would negatively influence the patient's emotional state. Thus, they tend to be overprotective and request that the physician refrain from discussing such matters with the patient directly.

The taboo around dementia diagnosis in the community was also highlighted as intensifying the sensitivity and complexity of these discussions. Furthermore, many key informants emphasized the challenges they face with family members who tend to opt for aggressive treatments, and seek any intervention possible for fear of guilt and social shaming. Others pointed out that some family members may perceive these discussions as the physician's and/or hospital's unwillingness to treat and care for their patient. On the other hand, several key informants noted that even when families agree to the DNAR status, many of them overturn this decision and request full, aggressive treatment as the patient's condition deteriorates.

> "…sometimes we do find patients who are towards the late stages and the medical interventions are not in the best interest of the patient. But families insist on having all the medical interventions, which sadly may be putting more distress for the patient." *[Physician, interview 19]*

> "A large number believe in doing everything possible. That's really, uh, having a large number of patients that are full code to get everything to be done to the last moment. I think there is a culture element of… shame if this is not done." *[Administration/management, interview 29]*

> “Sometimes the family chooses “Do not resuscitate”. But when they go out and talk to people, they will convince them that their decision is wrong. That is religiously not allowed and culturally not allowed. So, they come back and change their mind and we have to respect their wishes. If they don’t agree, we will cancel the first consent.“ *[Administration/management, interview 33]*

Language was described by several key informants as a challenge to effective end-of-life discussions. Non-Arabic speaking healthcare professionals find it challenging to communicate with Arabic speaking patients and families even with the support of translators. These discussions were described as deep and extensive and required several meetings to reach informed decisions.

> “The conversations I have had most of them went very well. The ones that didn’t go out well were where I was relying on a translator to provide the information to the patient.“ *[Physician, interview 25]*

Some key informants described other factors that may influence the process of truth telling and conducting end of life discussions, such as the patient’s type of disease or condition. Non-oncological diagnoses, mainly common geriatric conditions, are less likely to be perceived by patients or families as terminal. Moreover, the difficulty in identifying the prognosis of dementia-like conditions adds to the perception that these may not be terminal. Other challenging factors included lack of knowledge and awareness within the medical community about the palliative care approach, being cared for by several physicians, and being unaware of the patient’s code status upon transition to a home care setting.

Opportunities: Despite challenges, various supporting factors and opportunities can help facilitate the acceptance of the palliative care approach by the community. Several key informants described a positive shift in patient and family attitudes toward accepting the DNAR status, especially among cancer patients receiving palliative care. They also noted an increase in the knowledge and skills of healthcare professionals in approaching and addressing these discussions. Nevertheless, key informants emphasized the fundamental need for healthcare professional training and raising community awareness on palliative care. Most key informants highlighted the importance of addressing spiritual and religious challenges, building on the Islamic Ethics and Palliative Care report whose results delineate the similarities and alignment between Islamic and palliative care principles.

> “We have a basic value in Islam, which is truthfulness (sudk). I have to tell the truth to everybody...not to mention if I’m a physician. So I cannot lie. So if someone has a disease, I have to tell the truth. This is in principle. So let’s agree this is one of the principles to agree on that.“ *[Researcher/Academic, interview 31]*

> “The adab al-tabib (etiquette of the physician) speaks about how physicians should treat the patient and… about these issues. They are always inclined to tell the truth because this is a basic value.“ *[Researcher/Academic, interview 31]*

> “The only thing that we say here is… the question how to communicate the bad news? So it’s not to communicate or not to communicate. The Islamic tradition is clearly in the direction of communication. But the question is how? They always say in the literature “bi lotfin min al-qul”…“kalam latif” (in gentle language… gentle words), not harsh.“ *[Researcher/Academic, interview 31]*

> “Creating more culturally appropriate and sensitive materials, and giving people clear policies from Islamic perspectives, help shape the narrative. People take comfort in guidance if you give them that guidance. Known, authentic source material helps in shaping the decision they made.“ *[Researcher/Academic, interview 7]*

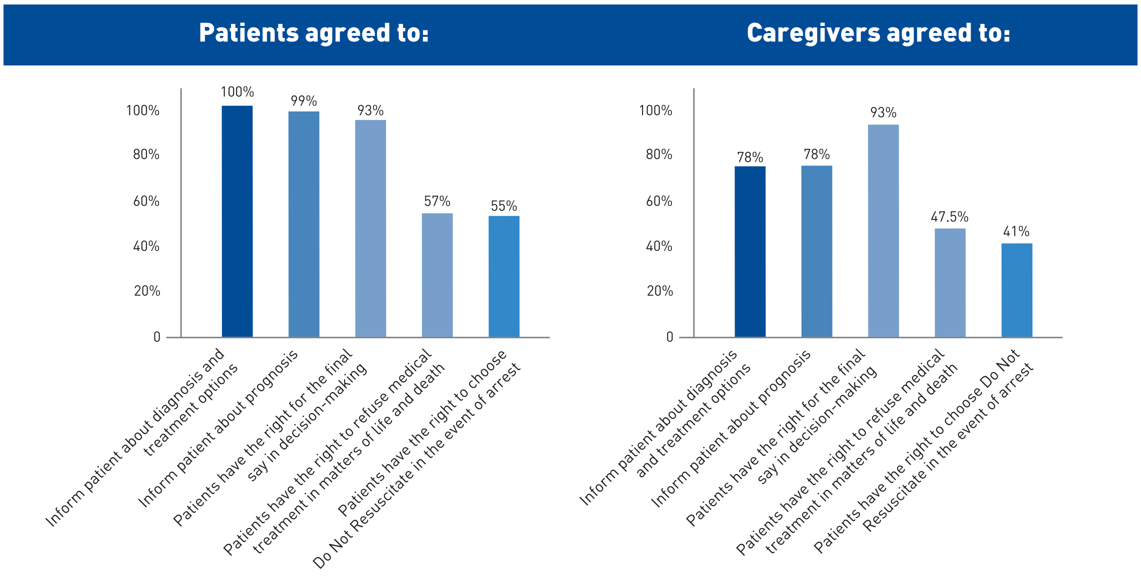
Other facilitating factors suggested included starting ACP discussions at an earlier stage, having policies that legally support healthcare professionals to do what is best for patients when family members have conflicting opinions or are indecisive regarding end-of-life decisions, and having more Arabic speaking professionals and a private room to conduct end-of-life discussions.

> “It’s always easier to talk to the patient or the family with their first language. So, I could use more sensitive terms and more sensitive words and that makes it easier.“ *[Physician, interview 25].*

3. Patient and caregiver survey

Arab culture and Islamic religion were the most reported influencers of patients’ healthcare decisions. Most patients and caregivers reported that patients prefer to share healthcare information with family members. All patients, and the majority of caregivers, agreed that patients should be informed about their diagnosis, treatment options and prognosis. Almost 93 percent of patients and 65 percent of caregivers believed that patients had the right to have the final say in decision making. Yet a lower percentage of patients and caregivers believed that patients had the right to refuse medical treatment in matters of life and death, and the right to choose “do not resuscitate” in the event of respiratory or cardiac arrest. Table 8 in Appendix 5 provides details of patient and caregiver responses in relation to truth telling and healthcare decision making.

Figure 6: Patient and caregiver beliefs toward truth telling and healthcare decision making



4. Nurse and physician survey

Most nurses and physicians agreed that patients should be informed of their diagnosis and prognosis, based on the patient's wishes followed by the family's wishes. Physicians conducted end-of-life discussions mainly "when the patient's disease progresses" (53.5 percent), or "throughout the diagnosis" (28.5 percent). Table 9 in Appendix 5 includes nurse and physician responses to aspects related to truth telling and decision making.

Death and dying

1. Key informant interviews

Key informants from various backgrounds talked about death and dying, including preferred and actual place of death of older patients, and related challenges and approaches for dying patients and their families.

Perceptions and views about actual and preferred place of death

Most key informants related that most older patients die in hospital, although they preferred to die at home surrounded by their family –as long as the needed medical, nursing, and psychological support was provided.

> “As per experience, we came to know that the majority of the patients and families wish to stay at home peacefully… based on my experience for the last few years here in Qatar.“ *[Nurse, interview 4]*

> “She [the patient] desperately wanted to be in her own home with kids around her, that would allow her to die close to her family and not to be laying at the hospital.“ *[Psychologist, interview 30]*

Key informants described several factors that influence where older patients die, including (1) families opting for aggressive treatments, (2) families feeling guilty, unprepared, and afraid to keep their patients at home, (3) families unable to meet their patients’ care needs, especially when older patients are bedridden, (4) financial and time constraints involved with caring for patients at home, (5) patients felt they would burden the family, (6) lack of home-based palliative care services, and (7) complex and burdensome post death legal procedures for the family when the patient dies at home. All these elements play a role in favoring the hospital as the actual place of death rather than the home.

> “If he (caregiver) stayed with him (patient) at home, the cost would be higher. He needs to ensure having a person to care for the patient. This is one of the challenges, and the lack of support from the families. Sometimes the families… don’t prefer to take care of their patients, so if there is an option that the patient stays at the hospital then the family will keep him at the hospital.“ *[Administration, Rehabilitation, interview 10]*

> “If we have the right structure and the right system and easy access to the patient and family, I can guarantee for you a lot a lot a lot of our patients will be willing to die at home.“ *[Administration/management, interview 32]*

Most older patients in Qatar are Qatari; a smaller number are expatriates who are mainly from other Arab nations. Key informants related that those expatriates who have been residing in Qatar for a long time and have their families with them mainly would prefer to die in Qatar. However, those who have been in Qatar for a short time and do not have family with them, would prefer to die in their home country. Among expatriates who die in Qatar, a portion would prefer to be buried in their home country.

> “Oncology patients, even if they have a do-not-resuscitate order (DNR) order in place, end up in hospital for the last 48 to 72 hours of their lives, just because symptom management is not manageable at home. And so the plan is often for those patients to end up back on the palliative ward, where they will die…. but they’re not for resuscitation.“ *[Physician, interview 25]*

> "When we first started (palliative oncology service), 99.9 percent of cancer patients died in the hospital. A third of the cases died in the ICU, a third died in other NCCCR units, and the rest died in other facilities. Now, patients prefer to die at home with the support of a team of healthcare professionals." *[Administration/management, interview 5]*

> "We don't want them to die in the hospital; it is painful place to die…. They all want to be at home, in their comfort. It will be very few elderly patients who want to go to the hospital." *[Physician, interview 12]*

Practices and policies related to death and dying

Key informants described practices and policies related to end-of-life care, death and dying and post death procedures.

An end-of-life care policy is available at HMC and focuses on symptom control aiming to optimize comfort and maintain dignity. Emotional and spiritual support are core elements of end-of-life care. Although spiritual counselors or advisors are unavailable, spiritual support is provided by allowing and supporting religious practices (Quran recital, prayers, etc.). Families are encouraged to consult their religious or spiritual advisor for support, and to spend as much time as possible with the patient in their last days of life. Some patients are surrounded by their families and others, especially patients who are on ventilators, are often left alone. Unfortunately, assessing the patient's preferred place of death is not a routine practice due to the lack of home-based palliative care services.

Repatriation services are available to support patients who wish to return to their country to spend their last days at home.

Challenges

Key informants highlighted challenges related to the death and dying phase. Several described the difficulty in determining when a patient is near end of life especially those with dementia. This emphasizes the importance and the need for clear identification criteria in addition to the need for end of life clinical management guidelines. Additionally, the need for a culturally and religiously sensitive end-of-life model that considers the diverse nature of the population in Qatar was underscored, as well as the need for communication skills training for healthcare professionals.

> "Europeans and North Americans don't mind dying at home; they stay at home and take the treatment there. Here, Arabs say they don't want to take the blame, they say, oh, I did my best. I took him to hospital, and he died there, not in my home, so it's not my fault. Some prefer to go to private [hospital] because they think, well, if

> you die in a private hospital at least I showed my family and my close relatives that I did my best. Others say, Okay if he dies, let him die abroad.“ (KI interview # 34)
>
> “Doctors and nurses come with different educational and training backgrounds. They don’t deal with dying patients and their families the same; palliative care specialists deal with death and dying differently than acute care physicians.“ *[Physician, interview 34]*

In Qatar, death certificates are provided only by the HMC mortuary. When patients die at home, an ambulance escorted by police will transport the deceased to the hospital where natural death is confirmed, and death is declared. Many key informants described these procedures as complex and burdensome for families. Sometimes families transfer their patients to the hospital during the end-of-life phase to avoid going through these procedures.

Opportunities

Key informants highlighted several practices that if implemented could improve patient and family experience with death: (1) modifying post death policies and procedures, such as allowing home care physicians to issue death certificates for home palliative care patients, (2) providing spiritual/religious support by integrating spiritual/religious counselors into the healthcare system and the multidisciplinary team, (3) training healthcare professionals and providing them with the needed guidelines and protocols to support dying patients, (4) establishing home palliative care services to support patients at home at the end of life, (5) raising awareness in the community about issues and ideas around death and dying, and (6) sharing the experiences of families whose patients died at home and were supported by the future home palliative care services.

2. Patient and caregiver surveys

Patients and caregivers were asked about various topics related to death and dying, including the meaning of the end-of-life phase, preferred place of death, attitudes toward suffering, and talking about death. When asked about the meaning of end-of-life, most patients (62 percent) and caregivers (51.5 percent) believed that they cannot answer such a question and that “only Allah (God) would know” the answer. Most patients (95 percent) and caregivers (94 percent) believed that if the patient is very ill, receiving spiritual or religious support would be important.

Thirty nine percent of patients and 41 percent of caregivers believed that suffering is part of dying. Forty one percent of patients and 39 percent of caregivers believed that talking about death can make people lose hope.

Most patients and caregivers believed that it would be better to die at home than in hospital. When asked where they (their relatives) would prefer to spend the last days of life, 87 percent of patients and 85 percent of caregivers chose to stay at home surrounded by their family. Table 10 in Appendix 5 includes detailed information about patient and caregiver responses regarding death and dying.

Figure 7: Patient and caregiver preferences and beliefs toward death and dying

Patients agreed with:	**Caregivers agreed with:**
Suffering is part of dying: 39%	Suffering is part of dying: 41%
Talking about death can make people lose hope: 41%	Talking about death can make people lose hope: 39%
If the patient is very ill, spiritual or religious support would be important: 95%	If the patient is very ill, spiritual or religious support would be important: 94%
It is better to die at home than in a hospital: 84%	It is better to die at home than in a hospital: 76%

3. Nurse and physician surveys

Nurses and physicians were asked about their perceptions and attitudes toward topics and issues related to the care of dying patients and their families. Both groups mostly **disagreed** with the following statements:

- It is difficult to form a close relationship with the family of a dying person.
- When a patient asks, “am I dying?” it is best to change the subject.
- They would hope the person they are caring for dies when they are not present.
- They are afraid to become friends with a dying person.
- Educating families about death and dying is not a healthcare provider responsibility.

Their responses indicate a positive attitude toward topics related to dying patients and their families. Both nurses and physicians agreed that having the same religious beliefs as their patients enhances the caring process. Comparing nurses' and physicians' responses, the latter displayed higher percentages of positive responses.

Nevertheless, most nurses (61 percent) and half of physicians (50 percent) agreed that family members who stay close to a dying person often interfere with the healthcare professional's job with the patient. Furthermore, most nurses (66 percent) agreed that they would be upset when the dying person they were caring for gave up hope of getting better. In contrast, physicians (64 percent) indicated they would not be upset.

The majority of nurses (81 percent) and physicians (79 percent) agreed that patients would prefer to die at home with their families supported by healthcare professionals. Table 11 in Appendix 5 includes detailed information about nurse and physician responses to aspects related to death and dying.

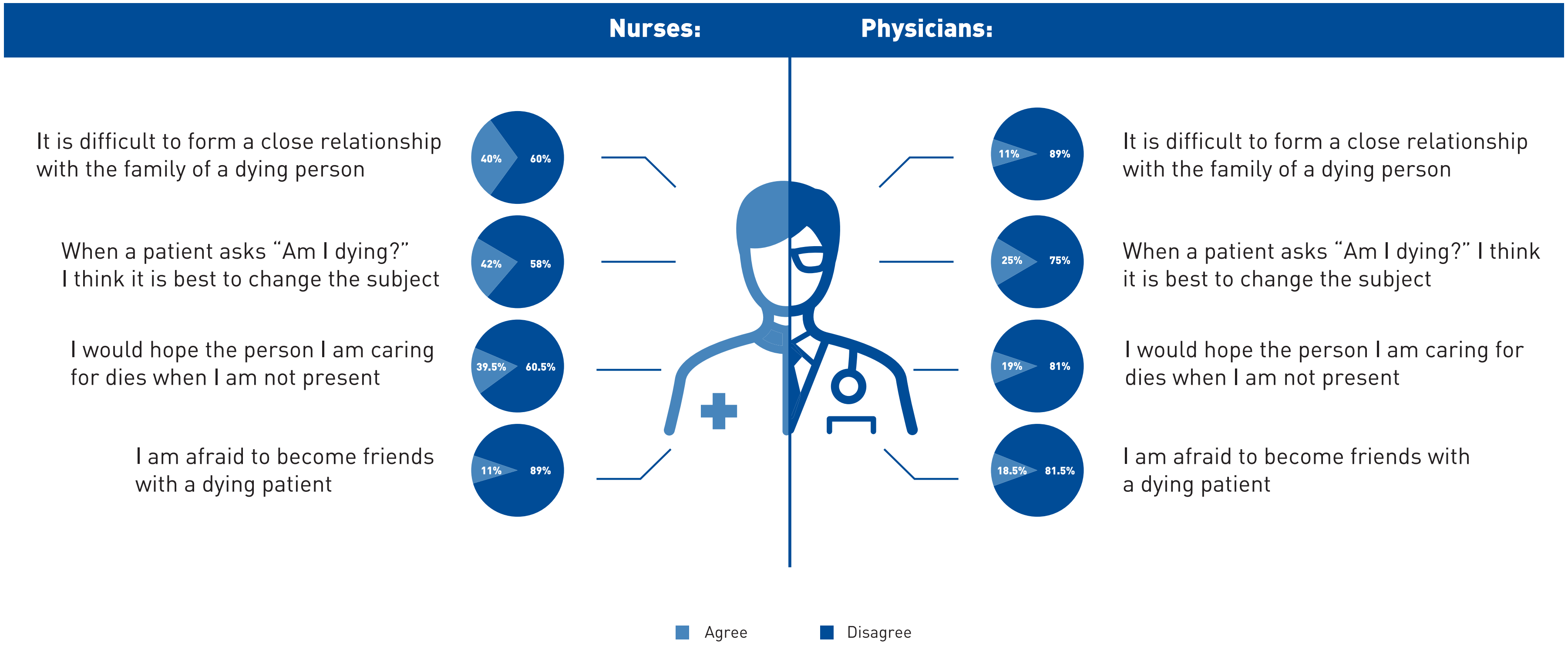
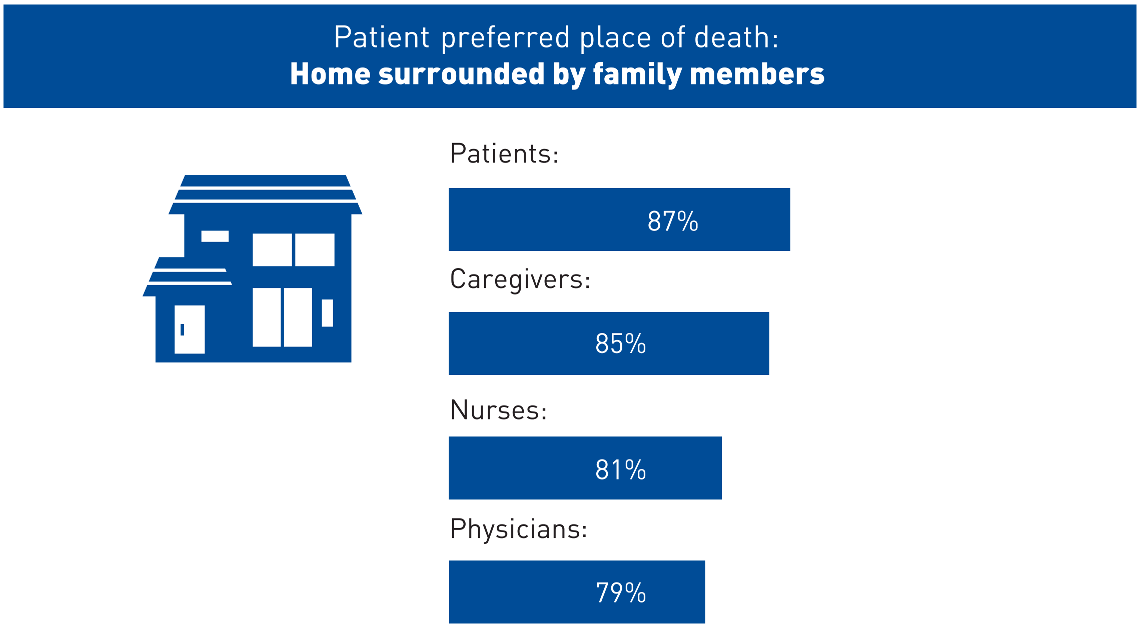


Figure 8: Nurse and physician attitudes toward death and dying

Figure 9: Patient preferred place of death according to patients, caregivers and healthcare professionals



Access to and utilization of opioids

1. Key informants

According to key informants, opioid outpatient prescribing privileges are only granted to oncologists, internal medicine specialists and geriatricians. Only oral forms of opioids are prescribed and administered in home care settings. Most challenges are related to opioid prescription in outpatient settings. Physicians reported various concerns that could lead to their hesitancy in prescribing opioids. These concerns were fear of legal repercussions, of losing papers from the narcotic book, and fear of being held legally responsible for misuse or abuse of orally prescribed opioids in home settings.

> “I think I used it [the opioid booklet] only twice so far for the last two years.“ *[Physician, interview 18]*

> “I haven’t written any [opioid prescriptions for home use] in the last seven years.“ *[Physician, interview 12]*

These restrictions were not regarded as major issues for some key informants; they explained that in the management of geriatric patients, opioids are not frequently needed as they could cause more adverse drug reactions for older persons.

Key informants mentioned that favorable change in policies is possible (even likely) toward allowing prescription of various forms of opioids in home care settings, especially in making the case for reducing the need for hospital admissions and supporting patients who prefer to remain at home.

> ''I think once you bring a lot of evidence, once you show what's practiced abroad, because we know, we will gradually change''. *[Administration/management, interview 34].*

Key informants reported facing no major challenges related to patient and family attitudes toward opioid use and fear of addiction.

2. Patient and caregiver surveys

Patient and caregiver knowledge about opioid use was assessed by asking whether strong painkillers such as morphine could make death occur sooner; 37 percent of patients and 41 percent of caregivers did not know whether this statement was true or false. Thirty-four percent of patients and 39 percent of caregivers disagreed with the statement that morphine could hasten death.

3. Nurse and physician surveys

Nurses and physicians were asked about their knowledge, attitudes, and practices in relation to opioid use. Physicians [89 percent] more than nurses [59 percent] believed that addiction to pain-relieving medication should not be a concern when dealing with a dying person. Most nurses and physicians knew that use of opioids did not influence survival time. When managing severe pain, nurses and physicians commonly reported administering paracetamol (73 percent, 76 percent, respectively), morphine (60 percent, 72 percent, respectively) and tramadol (52 percent, 62 percent, respectively). Physicians more than nurses reported using non-steroidal anti-inflammatory medications and codeine.

Need for geriatric palliative care services

1. Key informants

There was unanimous agreement that palliative care for older adults is highly warranted. Key informants underscored the important role of the National Health Strategy of Qatar in highlighting the need for developing palliative and end-of-life services for older populations in Qatar. Key informants viewed geriatric palliative care services as fundamental for reducing suffering and improving the quality of life of older patients, and for optimizing use of resources and supporting value-based healthcare. Key informants believed that a large number of older patients can benefit from palliative care; it was mentioned that around 60 percent of patients under home health care services could benefit from home palliative care.

> “If we don’t do it [provide palliative care], we’ll be really late. We will be very old fashioned“. *[Administration/management, interview 34]*

> “We see those (older) patients going through painful procedures and processes, long hospital stays during their admissions. So we want to reduce that, and we want to improve the quality of life for our elderly population.“ *[Physician, interview 14]*

> “We medicalize everything in our life, which is not always good. So palliative care shows us all, as physicians, as patients, as families, that there are limits for the role of medicine.“ *[Research/Academia, interview 31]*

Furthermore, key informants highlighted the need for palliative care services to support family members facing spiritual, social and emotional challenges in the care of their loved ones.

> “Palliative care is needed not only for the people who are in a dying process, but also for the people who will remain living afterwards.“ *[Research/Academia, interview 31]*

Geriatric palliative care models, skills, and success factors

1. Key informants

Key informants shed light on the impactful role of HMC leadership in setting palliative care as a high priority.

When asked about two priority palliative care models, a home palliative care model, and a hospital-based palliative care unit were the most frequently suggested models.

Table 3: Models of palliative care suggested by key informants

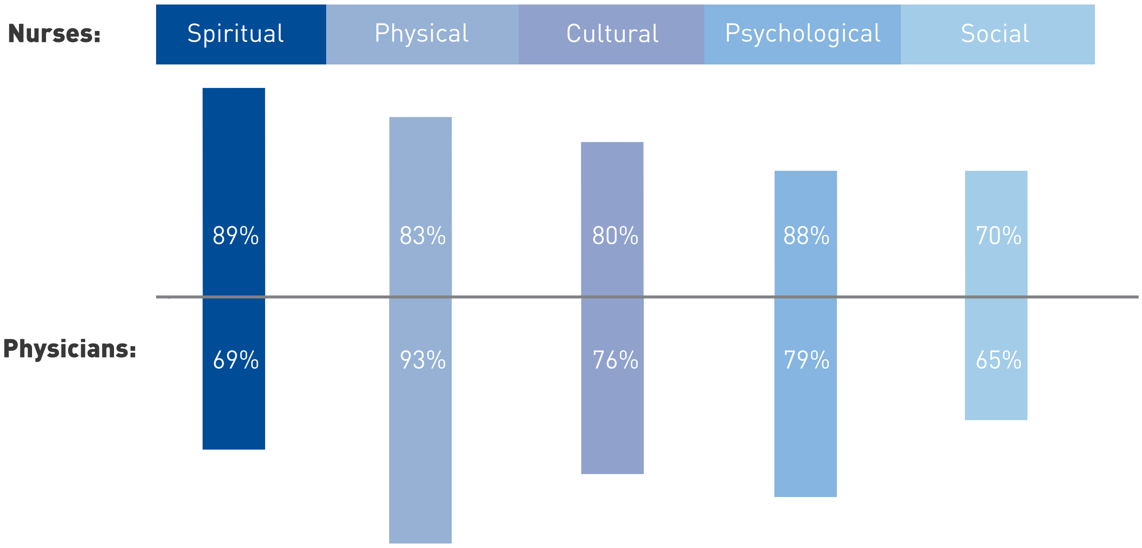
Model	Total suggestions
Home-based palliative care	24
Palliative care unit	22
Hospital consultation team	11
Swing beds	1
Stand-alone hospice facility	7
Outpatient services	1

Key informants also highlighted the need for the following to ensure the success of geriatric palliative care service: (1) providing palliative care as an alternative to aggressive treatments, so as to reduce suffering and pain and maintain human dignity at the end of life, (2) enhancing communication skills and competencies of healthcare professionals to facilitate truth telling and end-of-life discussions, (3) enhancing the psychosocial support skills of healthcare professionals (nurses), (4) including a clinical psychologist as part of the interdisciplinary team to support patients, families and staff to avoid burnout, (5) integrating the role of the spiritual advisor or counselor into the healthcare system, including the palliative care interdisciplinary team, (6) raising awareness in the community about palliative care, (7) adopting a community participatory approach to palliative care service models, and (8) ensuring adequate staffing.

2. Nurse and physician surveys

Results showed that the approach to care of older patients is holistic when physicians and nurses work to address the physical, psychological, social, cultural, and spiritual concerns of patients. They approach spiritual and religious issues through empathetic listening and connecting patients with spiritual/religious counselors. Cultural issues mainly related to patient preference on who should be involved in health-related decision-making, and their preference to know their diagnosis and prognosis. Most nurses and physicians would address psychological concerns through the provision of emotional support, and by referral to a psychologist and/or counseling. Table 12 in Appendix 5 includes detailed information about nurse and physician responses to practices related to palliative care.

Figure 10: Nurses and physicians' considerations with severely ill patients



Role of civil society and research

The role of civil society organizations in the care of older patients and palliative care seems to be limited in Qatar, where only one organization, the Ehsan Center for Empowerment and Elderly Care, provides a variety of social services such as daycare services, psychological care services, and social welfare services.

Several research studies have been conducted on palliative care and published in reputable journals by the palliative care department at the NCCCR. Research on palliative care nursing is limited (due mostly to lack of funding) to a few current studies. For one key informant, this indicates an urgent need for including palliative care in the research agenda and for dedicated funding to support the role of nursing in palliative care in Qatar.

The WISH report on palliative care and Islamic ethics played a significant role in improving understanding of Islamic perspectives on palliative care, countering myths and providing a framework for healthcare professionals in conducting end-of-life discussions with patients and families (18). The report can serve as a valuable, authoritative foundation for future national strategies.

DISCUSSION

The aim of this project was to explore and assess the needs and readiness for integrative palliative care for older adults as part of the geriatric services at HMC, Qatar. The project explored the full range of issues and topics around patient and caregiver needs, knowledge and beliefs toward palliative care, truth telling and healthcare decision-making, death and dying, access to and use of opioids, and palliative care skills and practices.

Our findings reveal an overall readiness and unanimous agreement among key informants on the need for geriatric palliative care. There is good knowledge and preparedness among healthcare professionals to provide such care, yet a lack of knowledge and awareness of palliative care among patients and caregivers persists. Patients and caregivers are mainly concerned about patient pain and symptoms, loss of functional ability, and feeling burdensome. Subsequently, psychological support and around the clock access to healthcare providers were viewed as priority needs. Despite a preference for home death, most patients continue to spend their last days in hospital because of a lack of palliative care resources in the home care setting.

Although physicians and nurses display positive attitudes toward truth telling, forgoing aggressive treatments, and death and dying, key informants describe significant socio-cultural and religious challenges for implementing these practices. The biggest challenges to truth telling and ACP are perceived to be the overprotectiveness of families, religious misconceptions about withholding aggressive treatment and families' fear of guilt and social judgment.

Patient and caregiver needs

Our patients and caregivers fear pain, loneliness, and loss of functional ability during severe illness in the end-of-life phase. They indicated the need for psychological support, around the clock access to healthcare professionals (through phone or home visits), pain and symptom management and spiritual support. Our results resonate with the conclusions of a recent systematic review conducted about the needs of older patients with multimorbidities and caregivers when emotional/mental, spiritual and social needs were commonly reported (41).

The provision of 24/7 support in home hospice or palliative care has been an essential component of care to patients and their caregivers, and is a standard of palliative care delivery. In 2017, a systematic review of the current qualitative research on the experiences of patients and family caregivers with home palliative care services, found evidence that the availability of the hospice team to vist patients and caregivers at home around the clock, was important to feeling secure at home (87). Another systematic review done in Qatar revealed a similar conclusion and recommended that 24/7 care should be part of palliative care services provided in Qatar (88). During the end-of-life phase, meeting the preferences and wishes of older patients is dependent on the role of the family in caring for the patient. Family and caregiver support is foundational to ensure that older patients live in dignity and are surrounded by their loved ones during their last phase of life. As such, family and caregiver support interventions should be a core element of palliative care service models and awareness raising campaigns.

The absence of the need for bereavement support among our caregivers may be due to lack of knowledge about the presence of such services in the first place, and to negative stigma associated with mental health issues in Qatar as in the Arab world. As such, ensuring the availability of bereavement services coupled with increasing awareness about grief and bereavement support is crucial to ensure acceptability and utilization of these services by the community.

Knowledge and beliefs about palliative care

Given that palliative care is only available currently to oncology patients in Qatar, most patients and caregivers are understandably unaware of the concept of palliative care and advance directives, and have no prior exposure to palliative care services. When these practices are explained, patients and caregivers perceive certain elements of palliative care correctly or positively. They can understand such care is not restricted to cancer patients and can help patients feel better and families better manage illness. In addition, they can also better understand that this type of care is not exclusively linked to death. Such positive perceptions might also be a result of a social desirability bias in which respondents tend to provide socially desirable responses and underreport socially undesirable ones.

In the Arab world, Saudi Arabia was the first country to introduce palliative care; it has been integrated into the healthcare system for the past 20 years. Despite this fact, a study conducted in 2019 showed limited awareness among the general public about palliative care (37). This study showed that more than half of the participants believed that palliative care improved quality of life of patients, yet a third linked palliative care to the end of life. (38).

Misconceptions that palliative care is specifically for cancer patients, or that people who receive it must give up their doctors were evident in a study conducted in Ireland (39). However, this same study and another in the United States revealed positive attitudes toward palliative care in that it helps the patient feel better and more able to cope with serious illness (39, 40). Lack of knowledge and awareness about palliative care among the public remains one of the main barriers for the development and uptake of palliative care services worldwide.

Lack of knowledge among healthcare professionals is also a key barrier to palliative care. In our study, the higher knowledge scores among physicians in comparison to nurses may be due to the variety and quality of their exposure to palliative care experience, education and training. Almost three-quarters of the physicians, but fewer than half of the nurses had received some training and had previous experience in palliative care. Our findings are in line with studies conducted in Iran, Vietnam, and Japan where the nurses' knowledge in the philosophy of palliative care was good, but insufficient in all other domains (89, 83, 90). Comparatively, physicians' knowledge ranged between good and very good, with physicians in Qatar scoring higher in most domains (90).

Our results and similar studies highlight the need for palliative care education and training. The World Health Assembly Resolution 67.19 urges member states to include palliative care as an integral component of the ongoing education and training provided to healthcare professionals (91). This resolution emphasizes the importance of ensuring that (1) basic training and continuing education should be integrated in all undergraduate medical and nursing professional education, and as part of in-service training at the primary care level, including health care workers, caregivers addressing patients' spiritual needs and social workers, (2) intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, pediatrics, geriatrics and internal medicine, and (3) specialist palliative care training should be available to prepare health care professionals who will provide integrated care for patients with complex needs (91).

In Qatar, palliative care is integrated as an elective course as part of the fourth medical year at Weill Cornell Medicine- Qatar, as a separate medical fellowship program under HMC for those interested in pursuing a subspecialty in palliative care and as an elective postgraduate course as part of postgraduate nursing curricula (33, 92). Further efforts are warranted to include palliative care education and clinical rotation as a mandatory requirement for all undergraduate medical and nursing students. Integrating palliative care courses as part of continuing education programs and requirements is also vital to ensure continuous knowledge update especially in settings where healthcare professionals come from various countries and educational systems like Qatar and the Gulf region.

Truth telling and healthcare decision making

In Qatar, as in other MENA nations, religion, culture, and deeply held social norms have a strong influence on healthcare decision-making and truth telling. Most older patients want to know about their diagnosis and prognosis and want to have the final say in their treatment and medical management. Interestingly, caregivers, physicians and nurses share similar beliefs. But these preferences and attitudes are not always followed in practice. Conversations breaking bad news take place between the physician and family members and exclude the patient. These practices are also highlighted in a previous study conducted in Qatar in 2012 (55). Patients and caregivers from other collectivist societies, such as UAE and China, displayed similar attitudes and/or practices. Nurses and physicians from Lebanon and Iran also showed these attitudes (54, 51, 56, 93).

Although our patients and caregivers' attitudes generally favor truth-telling and patient-centered decision making, they are less accepting of the DNAR alternative, or the right of a patient to refuse medical treatment in case of severe irreversible illness. Other studies in Saudi Arabia and Iran displayed similar findings (67, 94). These may be explained by the common beliefs and misconceptions among the community that withholding life sustaining measures are prohibited in Islam, even when these measures are aggressive, invasive and often severely taxing for a frail patient.

Truth telling is a crucial prerequisite for shared decision making. Despite the dramatic shift from paternalistic societies in which physicians are the main decision makers, to individualistic societies in which patients are more proactive in the decision-making process, cultural differences still exist across countries (53). In certain collectivist societies in Eastern cultures, families make decisions on behalf of patients including deciding whether to tell the patient their diagnosis/ prognosis and treatment plans, or whether to pursue aggressive treatments (53). This is usually attributed to factors including protecting patients from the perceived harm of knowing the truth, fear of guilt and societal shaming, and a lack of knowledge and understanding of alternative, holistic approaches to the end of life. Patients, families, and healthcare professionals are often victims of an overmedicalized healthcare system. Adopting an open-minded, culturally sensitive approach in further explorations will lead to better understanding of the importance of truth telling in healthcare decision-making in Qatar.

An approach that balances the moral obligation of truth telling with culturally sensitive, patient-centered care is highly warranted (53). This includes respect for patient preferences and wishes, including when patients request not to know the truth, and involving family members in patient-related decisions. It is recommended that healthcare professionals avoid one-size-fits-all approaches and decide on the best approach based on several discussions among healthcare provider, patient, and the family (53). This emphasizes the important role of ACP in which such discussions with patients and families start earlier in the disease process, happen in a gradual manner, and facilitate collaborative decision making among all stakeholders. ACP is especially important for geriatric patients whose mental capacity declines over time, in order to avoid a situation in which family members become the main decision makers without having prior knowledge of the patient's wishes and preferences regarding their care.

Death and dying

Most of our patients and caregivers, as well as healthcare professionals, consider home as the preferred place of death. However, the large majority of people in Qatar continue to die in hospitals due to complicated and burdensome post-death procedures and lack of home-based palliative care services. Similar outcomes were observed in other studies conducted across Europe and another in Egypt, suggesting that on this matter, practical barriers for preferably dying at home, are cross-cultural (95,71).

In our assessment, many patients and caregivers link dying to suffering and believe that talking about death can make people lose hope. Such beliefs are common among collectivist societies where the predominant value of non-maleficence ("do no harm" to the patient) leads people to avoid talking about death and related topics (53). Our numbers are higher than results from similar studies conducted in the United States, suggesting differences in cultural backgrounds and perceptions of dying, as well as general lack of awareness about palliative care and the newness of the concept and its practice in Qatar and the Arab World (72, 96).

Our nurses' and physicians' general acceptance and positive attitudes toward dealing with dying patients and families are similar to those found in studies conducted in various countries in the region (85). Several factors influence healthcare professionals' attitudes and practices including age, gender, educational level, previous exposures with dying patients, years of clinical experience and training about end-of-life care (97). As such, periodic capacity building and training in end-of-life care are crucial to support healthcare professionals in better caring for dying patients and their families.

Access to and utilization of opioids

Recent research in Arab countries reveals a discrepancy between the need and utilization of opioid resources (98). Estimates of annual opioid consumption in the Arab region are among the lowest in the world, suggesting that lack of patient access to opioids is a source of concern (98). Our results shed light on restrictive policies, lack of knowledge and negative attitudes as barriers to access and use of opioids. Restrictive opioid prescription policies in the home, and fear of penalties and legal repercussions in case of lost prescription sheets or misuse or abuse of opioids prescribed at outpatient settings are most concerning. Misconceptions about fear of addiction and morphine hastening death seem to be common. Policy restrictions, lack of government support, knowledge deficits, inadequate assessments and misconceptions are common barriers reported internationally (99, 100). A multilevel approach including national and organizational policy development and implementation, continued education and training of healthcare professionals and systematic assessment for risk of opioid misuse should be adopted to help support safe opioid accessibility and prescription processes (100). Furthermore, rules and regulations should avoid unnecessary bureaucratic procedures and safeguard healthcare providers in case of misuse or abuse.

Limitations

We believe that our needs assessment has contributed significantly to understanding the needs and preferences of older patients, caregivers, and healthcare professionals regarding truth telling, healthcare decision-making, death and dying, and important aspects of palliative care. However, assessments of this kind inevitably have limitations. The assessment used non-probability convenience sampling of patients, caregivers, nurses and physicians from the geriatric services for survey administration. This method may not be representative of the entire population, and therefore the results cannot be applied broadly and generally across the population. Considering uneven participant demographics, the limitation of sampling to one care setting (geriatrics), and other issues, some results may be biased, or under or over reported.

Further qualitative research is needed to reveal deeper understandings of our survey results, particularly the sociocultural beliefs and perceptions toward truth telling and aggressive treatments among patients and caregivers.

Nonetheless, we are confident that our assessment and related international studies support the report's recommendation that Qatar is well positioned to proceed with the detailed work needed for implementing palliative care services for older people at the geriatric services at Rumailah Hospital and to expand it to home health services.

RECOMMENDATIONS

This assessment goes beyond recommending specific service models to develop a system and culture in which the palliative care approach is embedded into the routine delivery of care by all healthcare professionals, and to building the awareness in the community about palliative care and its importance, guided by a strategic national plan.

As such, we adopt the WHO's recommended whole-system approach to improve palliative care for older populations which includes combination of initiatives at various levels that are planned and integrated (101). The recommendations provided will cover policy, service provision, education, advocacy' and awareness raising and caregivers, families and communities.

Policy

On a national level, based on the results of our needs assessment we suggest the following policy recommendations:

- Formulation and formalization of a national palliative care strategy and action plan that includes several action areas covering policy, education, service provision, caregiver and family support, access to essential medicines, advocacy and awareness raising and research and that targets people of all age groups and diagnoses including minorities and vulnerable populations.
- Identification and mapping of key stakeholders in the country, from ministries to religious representatives, and academia and civil society groups.
- Policy actions to cover governance and legislation issues, such as the modification of current policies on opioid administration in home care settings, eligibility of clinicians from additional settings and specialties to prescribe opioids, integration of advance directives, reducing complex post death mortuary procedures, including palliative care for citizens and residents under the national health care coverage scheme.

Preliminary findings of this needs assessment were shared during a three-day national palliative care symposium organized by WISH under the patronage of the MoPH, November 28-30, 2021, in Qatar. The symposium was attended by policy makers, leadership, senior level management and healthcare professionals at HMC. A roundtable discussion focused on the integration of palliative care into the existing home care services under HMC, and a Doha Declaration was signed by all the partner organizations. It called for 1) providing technical training, 2) developing measures to improve care, 3) implementing robust counseling services, incorporating religious and spiritual care guidelines, 4) improving accessibility of pain medications, especially in outpatient and home care settings, and finally,

(5) developing a funded national strategy and action plan for implementation of expanded palliative care in Qatar. Days two and three included a generalist palliative care sensitization training, covering main areas in palliative care service provision for older patients and targeting health care professionals at HMC.

Following the symposium's closing ceremony, a meeting was convened to discuss the outcomes of the symposium, and to consider the next steps forward. The meeting led to an agreement to set up a national working group to act in an advisory capacity to oversee the implementation phase of the project, following the needs assessment activity. It was proposed that the national working group include representatives from all the relevant departments at HMC, as well as the education sector, religious authorities, civil society organizations, WISH, and key international stakeholders. Priority areas to be addressed included training and capacity building of healthcare providers, preparation for palliative care model building (home and hospital-based models) for older patients and referral pathways.

The implementation of palliative care services within the geriatric and the home healthcare care services for older patients will require leadership and coordination with multiple interests. A national group with oversight of both the implementation of services for older adults and the proposed National Palliative Care Strategy was suggested as an important way of ensuring palliative care services are integrated for people of all ages in Qatar over the longer term. A summary of the three-day symposium is available in the Appendix 6.

Service provision

At the service provision level, we recommend the following to be implemented at the geriatric department at HMC:

- Adopt an **integrated palliative care model** in which specialist and generalist palliative care are provided in parallel with curative or life-prolonging treatment and not only in the end-of-life phase.
- Adopt a ***generalist palliative care approach,*** where geriatricians, as primary physicians who are to be trained in basic palliative care skills, implement palliative approach as part of their day-to-day practice, hence meeting the basic palliative care needs of older patients and their families. This approach can be adopted by other health facilities at HMC, such as the Heart Hospital, assuming adequate training is provided.

- Develop ***specialized palliative care models*** that meet the complex palliative care needs of older patients and their families and in which specialized palliative care teams play an advisory role in supporting primary teams to develop their palliative care skills and expertise. We recommend four specialized palliative care models:

    1. **Palliative care consultation team:** The team is developed under the geriatric services and composed of a core team of a palliative care physician, nurse, social worker, and psychologist. This model will provide mobile consultation palliative care services upon the request of the primary team or physician-geriatrician. At the beginning, the consultation team will attend to patients with basic or complex palliative care needs.

    2. **Home-based palliative care model:** The home palliative care team shoud be developed under home healthcare services and should operate through a separate staffing model providing 24/7 support. The team should be interdisciplinary and receive specialist training. Care coordination with hospital care settings, including hospital-based palliative care models, should be at the core of this model to ensure continuity of care and reduce unnecessary admissions and interventions.

    3. **Palliative care unit:** This unit is developed under the geriatric services, in which patients with complex needs requiring continuous specialized palliative care are admitted to the unit. Patients are admitted to the palliative care unit after the patient's primary geriatrician consults the palliative care team who, in turn, decide on the need to admit the patient to the palliative care unit. The palliative care unit will also aim at supporting patients to be discharged home under the care of a home-based palliative care program.

    4. **Palliative care outpatient services:** These are developed under geriatric services and offer consultation services via a stand-alone clinic. Such a model will play a major role in the early integration of palliative care and provides the necessary support to the primary team to save time spent on symptoms management, advanced care planning and coordination of care. Patients who still have good functionality will be able to follow up with their palliative care team through these services.

It is also important that these specialized palliative care models provide spiritual support by spiritual counselors (sheikhs, chaplains, gurus, etc.), respite care for caregivers and bereavement support services.

Prior to the development of the palliative care models, it is recommended that the geriatric department:

- Conduct interviews with older patients and caregivers to further qualitatively explore concepts related to DNAR and religion, death and dying and other key survey results;
- Conduct an internal feasibility study to develop a clear business model;
- Ensure that the development of palliative care models is guided by operating standards/procedures for palliative care, clinical practice guidelines specific to the older population, program quality and operational indicators, and ensures the integration of spiritual care and counselors of various religions into the palliative care services.

In the long-term, integrating palliative care services into the care of older adults at other HMC facilities and other healthcare facilities in Qatar can benefit from this pilot. Future national efforts can focus on integrating palliative care at primary care settings.

Education

In the domain of education, we recommend the following to be implemented:

- Provide specialist palliative care training to nurses, physicians, allied healthcare professionals, and spiritual counselors who will be part of the specialized palliative care teams working as part of the palliative care recommended models. Specialist training should meet international standards and should cover theoretical and practical aspects;
- Provide generalist palliative care training to nurses, physicians, and allied healthcare professionals who are primary care providers of patients who have advanced and life-limiting illnesses at the geriatric services or other services at HMC. Trainings should cover all aspects of palliative care with a special focus on communication skills including breaking bad news and discussing goals of care, and ACP with older populations;
- Integrate palliative care education and training into undergraduate curricula and continuing education of healthcare professionals including allied healthcare professionals;
- Integrate spiritual counseling and consequently spiritual counselors trained in providing spiritual support during the end-of-life phase into the higher education system and the healthcare system respectively.

Advocacy and awareness raising

Our findings suggest that when services come on stream, there will be a need for national awareness raising initiatives. We recommend the following to be implemented:

- Conduct a national level public opinion survey to assess attitudes, beliefs, and general public knowledge of palliative care;
- Launch a national campaign on palliative care and its core concepts, such as ACP (with attention to specificities for older populations with dementia-like diagnoses), truth telling, symptom management and psychosocial support, value of death and bereavement support, and on the available palliative care services in the country;
- Launch awareness raising campaigns targeting healthcare professionals and addressing ethical concepts related to palliative care across various religions; we recommend using several academic and religious sources and fatwas as awareness tools to address pressing and challenging ethical issues including the locally produced WISH report on Islamic ethics and palliative care (18).

To kick-start the national efforts on raising awareness, WISH recently produced a simplified leaflet for patients and caregivers that serves as a culturally sensitive guide on how to deal with ethical dilemmas from an Islamic perspective. The leaflet covers important topics such as life sustaining treatments, analgesics and communicating bad news.

Caregivers, families and communities

Our assessment results show that introducing palliative care services into the health care system enables more older people to die at home with their loved ones, in familiar surroundings. It is critical to emphasize that the positive outcomes we seek in quality of life and care, and in meeting patients' preferences and wishes are equally dependent on strong family support and commitment. This requires active support for family caregivers that goes beyond awareness campaigns. In their responses to this assessment families and healthcare providers have identified certain requirements. These include:

- 24/7 access to healthcare professionals to provide pain and symptom management;
- psychological and social support;
- education and training for family caregivers;

- options for respite care;
- caregiver support groups for families to share experiences;
- ways to share issues with healthcare providers, in addition to grief and bereavement support.

The priorities and design of strategies to support families requires further ongoing consultation with families, and with those providing existing home and community-based services, as well as future home-based palliative care services. Good palliative care, like good aged care, requires partnership and good communication among family and the professional health care providers.

It has become clear with time that experiences with death, dying and bereavement are an integral part of a community's experience; people are best supported through their community. Improving such experiences requires returning to a social approach, rather than taking an exclusively medical approach to death. It suggests going beyond supporting families to adopting a public health approach to palliative care in which communities play a fundamental role in caring and supporting patients and their families (102). We recommend designing and implementing "compassionate community interventions". The latter concept emerged recently in Australia (102). The goal of building such communities is to extend the circle of care and support to include friends, workplace, schools and universities, faith communities, etc. The intended outcome is for people to explore and learn more about end-of-life issues to support their family members, friends and neighbors during their illness. These include attitudes toward death, dying and bereavement, and ways to support patients and their families (102). Revitalizing the practices of simpler, community-based times when people were supported by their relatives, neighbors and friends can play a powerful and positive role for those in their last days.

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Farah Demachkieh, a nurse and a public health professional, holds a Bachelor of Science in Nursing (2006) and a Master of Science in Public Health (2017) from the American University of Beirut. She has ten years of nursing clinical experience. Farah's work in palliative care dates to 2018, when she joined SANAD-the Home Hospice Organization of Lebanon as the head of quality, research, and development unit. Her work is focused on overseeing projects that include quality assurance and improvement, capacity building and training, service development, awareness raising and research in palliative care. She led several needs assessment projects in Lebanon and in the region. Her research interests include patient reported outcome measures, implementation research, and compassionate communities in palliative care. She recently completed a six month online palliative care fellowship course, a joint program among the UK, India and Bangladesh.

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Glenn Rees has worked at senior levels in the British and Australian Public Services. In Britain, he worked as private secretary to senior ministers, in the Cabinet Office and in economic departments. In Australia since 1976 he has worked in program and policy areas including the office of the prime minister and cabinet, employment and training, aged care, disabilities, housing and on the Aboriginal and Torres Strait Islander Commission. He was chair of the Nursing Homes and Hostels Review in 1986, and was involved in implementing the first wave of aged care reforms in Australia. He was CEO of Alzheimer›s Australia from 2000 to 2014, and chair of Alzheimer's Disease International from 2015 to 2021.

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