

**PALLIATIVE CARE AND ONCOLOGY:
TIME FOR INCREASED COLLABORATION
AND INTEGRATION**

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INTRODUCTION

Guest Editor

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We have witnessed great progress in both Oncology (Onc) and Palliative Care (PC) in the last twenty years. In Onc we have witnessed the establishment of Multi-Disciplinary Teams and meetings, centralization of care, especially in relation to surgical oncology, the progress in Radiotherapy (RT) techniques from 2D to 3D conformal and then Intensity Modulated RT, Image Guided RT and stereotactic RT, to the revolution of molecular biology, with the understanding of oncogenic addiction and the emergence of targeted therapy and now immunotherapy with checkpoint inhibitors. In PC, essentially a new specialty was set up in many countries worldwide with major steps made in capacity building leading up to integration in a few countries (Lynch/Centeno). Furthermore, there has been recognition of the important role of PC in the palliation of patients with advanced illness, whilst more recently evidence for the earlier integration of PC in the disease trajectory has been produced (Smith, Temel).

However, despite the fact that the two disciplines often look after the same patients, i.e. patients with advanced incurable cancer, in most countries worldwide they have so far chosen to work independently with little collaboration between them. At best the collaboration between the two specialties is where one (Onc) refers to the other (PC), and often this is late in the disease trajectory sometimes as late as within the last three days prior to death (Earle).

One may ask why should the two specialties collaborate and why should patients be referred to PC? The answer simply is that PC can address issues often neglected by Onc, whilst the collaboration is likely to help with more resources becoming available to PC providers. The American Society of Clinical Oncology (ASCO) in a statement with the title 'Individualized Care for Patients with Advanced Cancer' gives recognizes deficiencies in the standard oncology care today [Peppercorn] and specifically recommends that beyond disease-directed therapy, there should be "attention to symptom management and attention to quality of life". Unfortunately a number of studies show that oncologists often lack the necessary skills and fail to manage adequately even the simplest of the physical symptoms, that of pain even in countries with developed healthcare systems [Fisch, breuer, cleeland, von roenn], never mind to address psychological, social and spiritual problems of cancer patients. Furthermore, the ASCO statement on Individualized Cancer Care recommends that "care for patients with advanced disease, should include an individualized assessment of the patient's needs, goals, and preferences throughout their illness", and highlights that "realistic conversations about prognosis, the potential benefits and limitations of disease-directed therapy, and the potential role of palliative care, occur late in the course of illness or not at all". It is vital therefore that care for patients with advanced cancer includes input from PC teams, as is also recommended by ASCO in another provisional clinical opinion, that early introduction of PC can improve patients' symptoms, quality of life and possibly even improve survival [Smith].

We have argued in the past for the need of clinical training in PC for oncologists to improve both patients' symptoms control and also to improve the referral problem to PC (HC/MS). Clearly this is not an easy undertaking, as it would require a major training initiative worldwide. As an alternative, we feel there is a need to look at ways of working and collaborating closely, and providing more physical presence of PC teams within Onc centres and hospitals. There are some obvious ways of doing this, and in a minority of countries with integrated PC services within the healthcare systems, e.g. UK, Canada and Australia, there is a physical presence of PC specialists and teams within hospitals, which facilitates referrals of patients to PC, and reviews of patients whilst they are in hospitals. This is however not the norm. In most countries, PC teams are underdeveloped, they work in the hospice and often are not part of the hospital services, resulting in little direct contact between the two specialties.

We shall provide you with the example of Cyprus, where similar problems existed, and the initiatives that have been undertaken in the last few years. Whilst PC teams existed in the community organized by two (2) Non-Governmental Organizations (NGOs), essentially independent non for profit organizations (like Marie Curie in the UK), there was little communication or col-

laboration between the PC and Onc teams. There were only two (2) PC physicians for a population of just around one million, and they both worked for one of the NGOs, being based at the hospice, with no presence in either the main hospitals or the main oncology centre in Cyprus. Furthermore, in Cyprus the predominant oncology practice used to be of disease directed therapy very much until the end-of-life, and then referral to the hospice or in fact patients would often die in hospital (as there was a stigma attached to going to the hospice, as the place “where you go to die”). HC/BP/SN chapter.

But things can change. About six years ago in 2010, following a number of PC training courses organized by the Middle East Cancer Consortium (MECC) (silbermann annals), it was realized that there was a need for more collaboration between the Onc and PC providers (HC/BP/SN chapter). As a result a number of initiatives were set up. Firstly a weekly specialist PC clinic is run at the oncology centre, allowing for the referral of patients with difficult to control symptoms. On the same day of the clinic, the PC physician attends the daily ward-round, helping both with symptom control issues and also facilitating the referral of patients to the hospice. Furthermore, joint training through lectures for both Onc and PC staff has been organized at the Onc Centre. Following the success of these initiatives, encouraging earlier introduction of PC in patients with advanced/metastatic cancer, in 2012 the Board of the Onc Centre decided to fund the training of two staff grade physicians from the Onc centre to receive post-graduate/specialist training in PC in the US. As a result, we have been able to form a PC team within the Onc centre and run daily a supportive/PC unit/drop in centre, to address urgent symptom control problems for cancer patients. Finally, since February 2013, a weekly Multi-Disciplinary Team meeting involving both Onc and PC professionals (oncologist, PC nurses, physicians training in PC, Onc nurses, pharmacists, psychologist and a Christian Orthodox priest), has been set up at the Onc Centre. This has resulted in a more comprehensive multidisciplinary care, by involving earlier the appropriate members of the multidisciplinary team to meet the complex needs of patients with advanced cancer, and to improve collaboration and communication between the Onc and PC community and hospice teams (Silbermann MDT). As a result of the various initiatives in Cyprus, there has been a gradual change in terms of attitudes of oncologists and their approach to PC, resulting in increased referrals from oncologists to PC and earlier involvement of PC teams in patients’ care in the community, evidenced by increased cancer patients receiving PC under the care of both NGOs in 2012 compared to 2010 (HC/BP/SN chapter).

If you were to replicate these initiatives where you work, you would need to form alliances with other healthcare professionals sharing the same values as you. It may be appropriate to start with common training initiatives as was done in Cyprus, and help from other PC organizations from other countries in setting these training initiatives may be needed (Pantilat). It would be worth considering also some obvious obstacles and prejudices that need to be taken into consideration. A review by Ahmed et al, looking at barriers to access and referral to PC, identified lack of knowledge and education amongst health and social care professionals, as a key factor. Even after the presentation of the Temel study, still a minority of Lung Cancer Specialists from Europe (22% of participants in a survey about Early PC), had overtly negative attitudes regarding PC (HC/Pallis), and this was similar to the ESMO survey carried out ten years earlier, where most of the responding medical oncologists expressed positive views regarding PC, however 15% of respondents had pervasively negative views (Cherny). In terms of patient attitudes, even in countries with established PC, surveys of oncologists show that the biggest barrier for referral related to negative attitudes of patients to PC (Ward/Wendtland), possibly due to “the misconception that PC is only for patients at the end-of-life and the death-defying mentality in our society” (Hui).

It is therefore important that both physicians and patients attitudes and misconceptions are addressed, whilst cultural norms in the individual countries are being respected (Silbermann new approaches), in setting up collaboration between Onc and PC. Let us all work towards this goal, in our respecting countries.

Dr. Michael Silbermann
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Palliative care is being practiced in every culture, and in every ethnic group, over the course of cancer care. What is new is our deeper understanding of the causes of suffering of people who face a terminal disease. This has served as the fuel for the promotion and recognition of this discipline in mainstream clinical practice. In recent years immense efforts have been invested in cancer awareness, early detection and diagnosis, which are well integrated in the overall outlook of palliative care practice. In the last 50 years we have advanced our understanding from wound dressing to emotional disturbances, from pains to spiritual care, and finally, in integrating palliative care into mainstream cancer care.

This Special Issue owes its origins, in large measure, to the collaborative work between the Middle East Cancer Consortium, the American Oncology Nursing Society, the American Society of Clinical Oncology, PRIME, The Ohio Health, and The European Society of Medical Oncology. The goal, in part, was to bridge the gap between societies and cultures in the Middle East and beyond it; while the guiding factor has been the compassion and love to the suffering human being. All of us shared an appreciation for the close relationship of cancer to hope, belief and mercy.

This Special Issue serves as an update on ideas that have brought palliative care over the radar in Middle Eastern countries, the US and the UK. My personal involvement in promoting this relatively new clinical discipline in the Middle East lends me the feeling of being one of the “midwives” of palliative care in this part of the world.

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Cultural Challenges in Implementing Palliative Programs in Emerging Countries

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Special Edition
"Palliative Care and Oncology:
Time for Increased Collaboration
and Integration"

Mini Review

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Cultural Challenges in Implementing Palliative Programs in Emerging Countries

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ABSTRACT

Clinical approach of palliative care is beneficial during an individual's journey with illness, and can be utilized through many care settings by all members of the health care team. Many complex cultural issues can affect the patient and the families during the course of a life-threatening illness. Palliative care services in all countries need to be delivered in a way that meets the cultural and spiritual needs of its people.

KEY WORDS: Palliative care; End-of-life; Challenges; Culture; Patient; Family.

Insuring the availability of palliative care has become an increasingly important global health priority in recent years. As population age and the prevalence of chronic illnesses increases in emerging countries, as in all other countries worldwide, the need for palliative care has risen significantly. The World Health Organization (WHO) estimates that more than 40 million people require palliative care annually at the end-of-life.

One of the challenges of palliative care is to honour the personal wishes of culturally diverse patients while meeting universal medical relief standards. Palliative care begins with the understanding that every patient has his/her own story, relationships and culture, and is worthy of respect as a unique individual.

Culture refers to common elements or characteristics within one's sociological grouping. Different values, beliefs, behaviours, languages, rituals, customs or traditions, and accepted practices for living and dying, partnering, marriage, childbearing, parenting, and family communal life creates cultural groupings. Culture can include elements such as developmental stage of life, profession, and educational level, geographic region of the country, religion, spirituality, sexual orientation, political affiliation, gender, socioeconomic status, and more.

Palliative care is a relatively new concept in many countries in the developing world. Health professionals and whole populations are unaware of palliative care. Health care is not only providing cures, also improving the quality of life of patients and patient's families. Palliative care is applicable during the onset of life-threatening illness. A common misconception is that only terminal ill cancer patients are in need of palliative care. By contrast, the hospice and palliative care movement has been providing increasing awareness of various end-of-life issues. End-of-life care means more than treating physical symptoms – it extends to the psychosocial, existential, and spiritual aspects of the patient's needs, including developing trust in the substantial care of the patient and the family during this time. Numerous studies aimed to understand the relevance of culture to death and dying and found that communication was the greatest barrier between the health-care provider and the patient and family during end-of-life care.¹⁻³

Early discussion of prognosis and end-of-life care options were found to help and facilitate an earlier acceptance of palliative care.⁴ The desire to tell or know the truth about illness or death is clearly a Western cultural value. Every patient has the right to know about his/her ill-

ness for decision-making in end-of-life care. In some societies, however, talking about diagnosis, prognosis and death and dying is a taboo subject because it causes loss of hope and concern about reduced compliance with treatment.⁵⁻⁷ Not knowing the fact of the patient’s illness is a major challenge for an effective relationship between physician and patient and the administration of palliative care.⁸⁻¹¹

The family may expect information to be given to them first, so that they can make the best health-care decisions. Although collective decision-making is the norm in some societies, it often clashes with the value of autonomy and an individual’s right to make one’s own decisions about health and dying. Still, many cultures actively protect dying patients from knowing their prognosis.¹² Additionally, family members often do not want to be the ultimate decision-makers when death is inevitable. They may have the expectation that it is the physician’s role to decide on all health care and end-of-life care. These values can cause a treatment dilemma for the health-care provider whose focus is on getting the patient involved in palliative care. Patient beliefs and values should be respected in the decision-making process and in the case of the end-of-life issue even if the decisions differ from the family’s or the health-care professional’s views. While respecting cultural norms by providing patient autonomy, independent decision-making rights are also recognized.¹³

The belief system that makes the disease meaningful, and its symptoms, should be evaluated when the patients themselves are evaluated in accordance to varied cultures. Pain is a universal phenomenon, but culture can affect a person’s response to pain, both in the meaning and the expression of pain.¹⁴ Total pain is more than a response to a physical/biological injury. The basic principle in palliative care is to assess and relieve suffering not only from physical pain, but also from psychological, social and spiritual distress. Concealing pain may result in under-medicating pain symptoms.¹⁵ In some cultures, pain must be experienced as evidence of the body fighting to overcome disease. In

other cultures, pain is viewed as punishment.¹⁶ In some cases, it may be necessary to make changes according to pain assessment scales.^{17,18} Patients may be reluctant to take medication and analgesics for a number of reasons. Lack of knowledge and skill in pain assessment and treatment, unavailability of morphine, and fear of opioid addiction are some of the complex barriers in emerging countries.

Cultural factors shape patient’s preferences regarding decision-making, receiving bad news, and end-of-life care.¹⁹ Death is an inevitable outcome of every person’s life but each individual’s experience of death is unique. Treating patients at the final stages of their life is often stressful and sad for everyone involved—a situation that may be worsened when the health care professionals do not fully comprehend the nature of the patient’s beliefs. Some cultures have different attitudes toward reducing or ceasing artificial nutrition and fluids. Discussions about resuscitation and approaches to providing symptom control may also be dictated by an individual’s belief systems. Some cultural and religious groups may choose to prolong life despite a medical assessment of futility. At the end-of-life, palliative sedation can engender a merciful death when treatment resistant and highly distressing symptoms (e.g., pain, dyspnea and delirium) are present. However, loss of consciousness by sedation is unacceptable for the control of resistant symptoms in some cultures (Table 1).²⁰⁻²²

There is no one best way to deal with a life-threatening illness, yet cultural, religious and interpersonal approaches strongly affect an individual’s feelings. Individualized care is based on the fact that human responses to a similar situation vary significantly, and the recognition that only part of these variations, are predictable.

In anthropology today, culture is not viewed as homogenous or static. Culture is inseparable from economic, political, religious, psychological and biological conditions. Moreover,

Table 1: The Attitudes Towards Truth Telling in Different Country and Religious Beliefs on End-of-Life Management.

Country	Attitudes towards truth telling	Religious beliefs on end-of-life
Italy	Trend of partial and non-disclosure persists. ⁵	Christianity - Key belief is repentance and life after death.
Spain	Tradition of partial and non-disclosure. ⁵	If wanting to confess, strong religious justification for high-technology medicine to maintain consciousness until final anointing Those who have repented may recognise no need for aggressive interventions to postpone death. ²⁰
Turkey	Tradition of non-disclosure. ⁵	Islam - Decisions about aggressive invasive treatment to extend life are jointly made by all associated with the patient including religious leaders. Withdrawal of life-sustaining treatments, when considered futile, is seen as allowing death to take its natural course. ²¹
China	When fatal diagnosis or prognosis, physician informs family and hides it from patient. ⁷	Buddhism - There is no need to go to extreme lengths to provide treatment if little or no prospect of recovery. Some may be unwilling to take strong analgesics or sedatives. ²²

the presence of palliative care awareness in a community will also affect culture. To effectively integrate palliative care in emerging countries, appropriate national policies must provide for adequate opioids availability; the education of health-care workers and the general public; and a culturally appropriate implementation of palliative-care services at all levels of society.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Implementation of Palliative Care in Palestine: Cultural and Religious Perspectives

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Special Edition
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Review

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Implementation of Palliative Care in Palestine: Cultural and Religious Perspectives

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INTRODUCTION

The care of terminally ill cancer patients poses a significant global public health problem.¹ Populations are growing older as healthcare interventions become increasingly more effective in the management of chronic diseases.² Care of the terminally ill patients has evolved significantly over the centuries in the developed countries from Hospice services to highly specialized palliative care programs and facilities. In the Middle East, the progress in this area has been very slow over the last two decades which could be attributed to several reasons including the lack of education, training, budgets and several other barriers.³ Although age projection for Palestinians does not indicate generational transition toward an older population,⁴ yet the increasing incidence of cancer cases and other chronic diseases that need palliation, alerts the policy makers to the crucial need of introducing and developing palliative care services. Thus, the aim of this paper is to: 1) Reflect on the need and access of the Palestinians living in the West Bank and Gaza Strip to palliative care; 2) Define the factors that might interfere with the proper introduction of palliative care; and 3) Focus on the positive compensatory effect of religion and culture on palliative care.

The Palestinian population in the West Bank and Gaza Strip at the end of 2016 was 4.88 million (61% and 39%, respectively).⁴ Palestinians live in refugee camps were about 41.9% distributed between the West Bank and Gaza strip, and 16.7% live in rural areas (2.7% in Gaza Strip compared to 25.6% in the West Bank).⁴ The Palestinian population is a young generation, though it has been gradually aging; birth, fertility, and death rates have been dropping. In fact, the median age of the Palestinians was 16.4 years in 2000 and increased to 20 years in 2016, with 39.1% of the population under 15 years old compared to 2.9% over 65 years of age. The life expectancy of the population was 73.7 years in 2016 compared to 72.4 years in 2011.^{4,5} The Palestinian population has low income, and the majority do not have health insurance and cannot afford to seek medical care.⁶

Palliative Care Definition

A wide range of brief and comprehensive definitions of palliative care have been published. World Health Organization (WHO) defined palliative care as "an approach that improves the quality of life of patients and their families".⁷ Three palliative care forms exist according to the need of the patient: palliative approach, specialized palliative services and end-of-life/terminal care. A palliative approach focuses on the improvement of the quality of life (QoL) for terminally ill patients and their families; specialized palliative care supports the initial palliative plan through a specialist individual or a team to provide advice and interventions; and the end-of-life (terminal) care focuses on patients in their final days or weeks of life including the patient's physical, emotional and spiritual comfort through medication management of symptoms and support for the patient's family.⁸

Palestinian Palliative Care Needs in Perspective

Although palliative care focuses on cancer patients, it recognizes and targets all groups experiencing serious pain, including patients with cardiovascular diseases (CVDs), chronic respiratory diseases, HIV, dementia, and diabetes.^{9,10} There are several approaches used to estimate the size of palliative care needs. One approach is to estimate 75% of deaths; another one relies on mortality rates for specific diseases like cancer, CVDs, diabetes, HIV, dementia, senility, renal diseases, and chronic respiratory diseases.¹¹ In the Palestinian community, CVDs were reported as the leading cause of death in 2015 with 3,484 deaths (27.5% of all deaths).⁶ Moreover, cerebrovascular diseases account for 9.9% of all deaths.⁶ As for cancer, it has become the second leading cause of death since 2011 comprising 13.8% of all deaths according to the last Ministry of Health (MOH) report in 2015. Mortality rates were 41.9 and 36 deaths per 100,000 people in the West Bank and Gaza Strip, respectively.^{6,10,12} As projected by the WHO, estimates of death in 2030 for CVDs world-wide and in Eastern Mediterranean Region were almost 24 million and 2.1 million compared to 19.4 million and 1.44 million in 2015, respectively. For cancer, world-wide deaths are estimated to be 12 million in 2030 (17.6% from worldwide expected deaths).¹³ In Eastern Mediterranean Region, 630,000 deaths are projected to occur in 2030 compared to 402,000 deaths reported in 2015.¹³

Globally, it is estimated that 20 million patients or more need palliative care at the end-of-life and this number doubles if taking into consideration those patients at earlier stages of illness that could also benefit from such care.¹ Nevertheless, only 3 million end-of-life patients receive palliative care, and although most global palliative services are provided in developed countries, 80% of needs are required by low- and middle-income countries.¹ Moreover, late diagnosis of cancer poses a significant problem in the Middle East. Most cases (68%) are diagnosed in stages III and IV of the disease when the individual is terminally ill, needs aggressive treatment strategies and have limited chances of survival.¹⁴ In Saudi Arabia and Egypt, more than 70% of breast cancer cases are diagnosed at advanced stages with or without metastasis.¹⁵ Upon assessment of QoL of cancer patients in the West Bank, poor scores in all QoL domains were revealed. Poorer QoL functioning was associated with sex, income, pain, fatigue and stage of cancer.¹⁴ In the Eastern Mediterranean Region, only 5% of patients who need palliative care receive it.¹⁵

Palestinian Palliative Care Facilities, Education, and Research

Despite the development in the advancements Palestinians have witnessed in the last few years, cancer care is still suffering from major deficiencies. Only seven hospitals provide cancer care for the Palestinians; two governmental hospitals located in the West Bank (Beit Jala and Al-Watani), and two non-governmental facilities (Augusta Victoria and An-Najah National University Hospitals). The other three hospitals are governmental organizations located in Gaza Strip (Al-Shifa, European, and Al-Rantisi Specialized Pediatric Hospitals). Palliative care services are not

provided in any of these hospitals, and specialized palliative care doctors or nurses are completely lacking.

The only registered non-governmental organization (NGO), Al-Sadeel Society, provides palliative care services in Bethlehem focusing on educating physicians, nurses, patients and their families about fundamental practices. The organization has two qualified palliative care workers (a nurse and a social worker). This NGO provides consultation for cancer patients and their families through its team along with occasional consultations from a trained oncologist who received six months of training in palliative care.¹⁶ Recently, Al-Sadeel started a recent program with the MOH and Augusta Victoria Hospital at Ibn-Sina College for Health Sciences to train undergraduate nursing students on palliative care.^{12,16} Hospice and end-of-life care services are not available for terminally ill Palestinian patients, and the teams working with cancer patients and geriatric departments lack knowledge and training in these areas.¹⁶ In the West Bank and Gaza, palliative care is not a requirement in medical and nursing curricula and training programs. Although, recently Bethlehem University in the Southern West Bank started a higher diploma program in oncology nursing.

Availability of research in a particular country reflects the size of attention directed toward developing palliative care. Few researches were conducted in West Bank and Gaza Strip to assess this need.^{16,17} A recent, small-scale study conducted in Gaza Strip reported low attitude toward caring for dying patients among nursing students at the Islamic University of Gaza, which was attributed to lack of knowledge and skills.¹⁷ Another cross-sectional study assessed the knowledge and attitude of nurses towards palliative care in the West Bank. The study included 120 nurses working in the three hospitals located in the Northern region, 45.8% of the subjects had a low-level of knowledge in palliative care, whereas 56.2% had a moderate score for attitude towards palliative care. The study also found a significant influence of the qualifications, years of experience and palliative care training, on knowledge scores among Palestinian nurses.¹⁸

Pain Assessment and Management

In terminally ill patients, pain is one of the most commonly experienced symptoms. Worldwide, about 80% of cancer patients and more than 60% of patients with advanced CVDs reported moderate to severe pains.⁹ Pain assessment and frequent reassessment using proper instruments with reported psychometrics is crucial,¹⁹ and the most comprehensive tools are the multidimensional ones. To achieve optimal treatment, pain intensity, severity, location, timing, relieving factors and interference with the daily activities should be essential components of a pain assessment tool. In developing countries like the Middle East, insufficient knowledge of healthcare providers on pain assessment and treatment, high cost and limited resources, strict policies and regulations regarding prescription of narcotic drugs contribute to the low utilization of palliative care pharmacological agents.^{20,21}

In 1986, the WHO developed global strategies to control cancer pain and the cornerstone was the permanent availability of opioid analgesics. Opioids are the most efficient narcotic drugs used for the relief of moderate to severe pain in cancer patients; examples are morphine, oxycodone, and fentanyl. Furthermore, as pain is documented to be associated with depression and anxiety, benzodiazepine anxiolytics and other psychotropic drugs have been used to treat neuroglial and mental cancer-related disorders.²²

In the developing countries, pain medications are still scarce. The WHO and the International Narcotics Control Board (INCB) use consumption of morphine as an indicator of access to palliative care.²¹ Despite the unavailability of statistics and accurate information on narcotics' consumption in the West Bank and Gaza, some crude information from the Palestinian MOH showed the distribution of consumption of narcotic drugs and psychotropic substances in governmental and private health sectors in 2015.⁶ The reported data reflected the amounts of narcotic use including pethidine, fentanyl, and morphine in their different concentrations and forms. However, the reported values did not differentiate between the use for the purpose of palliative care of terminally ill patients or post operation pain relief.⁶ The INCB reported the average consumption of narcotic drugs in several Middle Eastern countries between 2007-2009, but Palestine was not included.²² Fadhil and her colleagues reported a small level of opioids consumption (0.384 mg per person) in the Eastern Mediterranean Region compared to the rest of the world (6.24 mg per person).¹⁵ Regarding prescription of medications and especially pain medications and opioid drugs, Palestinian nurses have no privilege in ordering or modifying medications.¹⁶

Religious and Cultural Aspects: Islamic Perspective on Illness, Pain Management, Palliative Care and Euthanasia

Religious aspects: The majority of the Palestinians living in the West Bank and Gaza are Muslims, with less than 2% Christians. Religion and spirituality are related parts of the human personality, and a cornerstone of palliative care; they affect the way in which patients cope with their illness, and spiritual care is as important to the families as to the patients themselves.²³ Furthermore, they help the patients to find "inner strengths" and to "think positive" which consequently empower them to deal with the suffering resulting from their terminal illness.²⁴

Muslims believe in Allah (God) and in the inevitability of death, and that death and illness are God's will that cannot be avoided or stopped. Eternity is in the hereafter and whatever we do in this temporary life on earth will be either rewarded or punished for in the hereafter. This belief helps patients to cope with illness and die in peace looking forward to the reward in the hereafter. Furthermore, from an Islamic perspective, illness and suffering are accepted as a way of atonement of sins. It brings a Muslim closer to God, makes him more thankful and strengthens his belief. Also, it is considered as an evidence of accepting God's will, a reminder of the weakness of a human being and a

sign of how close death could be. It is received as a test from God for the strength of faith as prophets being the most tested "*In-deed, those who patiently persevere will truly receive a reward without measure*" (Zumar 39.10), and a reminder of the bounties of God such as the bounty of health. All of this does not conflict with the necessity of giving all efforts to relief suffering.²⁵ According to most Muslim scholars, seeking treatment for illness is permissible, and the duty of pursuing treatment increases with increasing the seriousness of the disease. Otherwise, the patient will commit a sin if he does not pursue treatment for serious illness.^{25,26} However, using opioids as pain killers to reduce the level of pain, and not as a medication, is permissible, but not mandatory. On the contrary, if a Muslim decides to tolerate the pain and not take pain killers, he will be rewarded more in the hereafter.

Euthanasia: According to Islamic teachings, the person is entrusted on his life, and it is not his choice or the choice of the family (passive euthanasia) or the doctor to end it (active euthanasia), but to protect it. Islam prohibits euthanasia or killing a patient as a mean of mercy. Allah (God) says in the Qur'an:

"... and do not cast yourselves into destruction with your own hands" (Al-Baqra 2:195)

"... and do not (commit suicide) kill yourselves [or one another]. Indeed, Allah is most Merciful to you" (An-Nisaa 4:29)

Islam encourages seeking medications and doctors should look for all means and work hard to treat the patient and make his life comfortable. Doctors should not listen to patients if they request their life to be ended even if it is a rational valid refusal (passive euthanasia). This is also in accordance with the Hippocratic Oath for medical doctors "I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan".²⁷ The doctor is considered a killer in Islam and will be punished as such if he applies euthanasia to any patient. In the hereafter, God also punishes those who commit suicide even if the reason is the intolerable pain. Most Muslim scholars consider the following cases as not being euthanasia (active or passive): first, when stopping medication by the supervising medical committee if proven ineffective including ending life supporting machines or any other interventions like resuscitation for patients diagnosed as "brain dead;" second, when the patient refuses to administer a medication that the medical committee firmly believes that it won't be effective; and third, increasing medication doses to reduce pain unless the medical committee is confident that increasing it will kill the patient.²⁸

Like Islam, the teachings of Christianity also prohibit euthanasia, and the culture of both Palestinian Muslims and Christians is nearly the same in respecting life as a gift from God, and suicide and euthanasia are considered sins and not practiced by the Palestinian society.

Cultural aspects: Palestinian set of cultural values are mainly derived from religion. Culture is an important determinant in

healthcare because of its influence on lifestyle, beliefs and values, the perception of individuals' QoL and palliative care, the interaction with healthcare system and decision making throughout illness and end-of-life.²⁹

Despite the undergoing changes in the social structure, the Palestinian family has an extended structure rather than nuclear. Children live with their parents until they are old enough to get married and build their families, and they maintain proximity to their parent even after marriage. Family members gather frequently and in different social and religious occasions. The respect for elderly and filial piety are integral parts of the social and religious values of the community. Similarly, other cultural values include the care and help to the weak and ill; decision making is collective and involves parents, spouses and older members (brothers, sisters, grandparents, etc); and family and familial bonds are sacred. Palestinian Christian families have the same values of extended families and respect for the elderly as Palestinian Muslims.

Spouses, friends, and neighbors stand by each other's side; it is the family's duty to take care of the ill members, to be there for them in weakness and pain, at the end-of-life and the moments of death. What constitute a "good death" in this population for the ill members are dying surrounded with family and at home and securing their families before they leave.³⁰ When someone is terminally ill, family members in most cases prefer to take the patient home to be around him to provide comfort and company, friends and relatives tend to go and visit the patient and stay with him for a while. One of the common practices of Muslims is reading verses from the Holy Qur'an for patients which might be a comfort.³

Among Arabs, the desire of appearing strong and to please others at all costs, bearing physical pains, hiding emotions, staying at the head of responsibility, performing duties and playing roles without admitting the need for help or showing signs of weakness are important factors in maintaining one's dignity.³¹ On the other hand, this factor may contribute to the high rates of late diagnosis and refusal of palliative care, and pain treatments and psychological interventions.^{32,33}

Barriers to Palliative Care

The Palestinians living in the West Bank and Gaza suffer from the same barriers reported by the neighboring Arab countries including the lack of support by health policies and education, little or no knowledge of the principles and practices of palliative care among healthcare providers and patients and their families. In addition to the weak healthcare system and the scarcity of resources and unavailability of medications especially opioids,^{1,15,22} the Palestinians have additional barriers due to the peculiar political situation since the West Bank and Gaza governed by the Palestinian authority (PA) are still under Israeli occupation.

Despite the lack of resources, the PA provides full coverage for cancer patients' diagnosis and treatment and to many people injured by wars and conflicts. In Gaza, more than 18,000 persons were injured because of three wars in the last ten years. Most of the injured require medications and in most cases opioids. This burden can't be tolerated by the PA government whose budget was about four billion U.S. dollars in 2016 and only 8.5% was allocated to health. Around 32% of the health allocated budget is usually used to cover referrals to Israeli and neighborhood hospitals due to the shortage or lack of advanced diagnostic tests and treatment for cancer and other diseases in the West Bank and Gaza. Thus, an additional budget should be allocated to improve the Palestinian Healthcare System (PHS). Moreover, tremendous efforts and support to the PHS are required to introduce palliative care at the level of training and education of the healthcare providers and the patients and their families. Further, financial support is required to the PA to implement a national palliative care policy including "a ready access of suffering patients to opioids" according to the recommendations of the WHO in 2002.³⁴

Interventions and Recommendations

Introducing and implementing palliative care for Palestinians in the West Bank and Gaza require integrated local and international efforts and support. At the local level, Palestinian ministries and stakeholders should place palliative care on their priority list. Additional budget should be allocated to the MOH to capacity build the human resources and the premises of the Palestinian healthcare system. The extra budget should be invested in improving cancer screening, early and proper diagnosis, and follow-up, which consequently will decrease the number of terminally ill patients who are in need of palliative care. Moreover, professional and well-structured training programs should be conducted especially in hospitals with oncology and geriatric departments to improve the qualifications of the healthcare providers and to train them to adopt the skills and the attitudes that are part of palliative care. The international community such as WHO, Middle East Cancer Consortium (MECC) and other cancer-related organizations could significantly contribute to this training. Furthermore, a national policy and legislation regarding palliative care provided at hospitals and homes should be implemented and integrated with the healthcare system and the health insurance to warrant the availability and access to opioids.

The Palestinian Ministry of Education and Higher Education should also take the initiative to integrate palliative care in the medical and the nursing curricula and encourage them to develop specialized tracks in this field. Master programs should also be offered by the Palestinian universities to improve the qualification of the healthcare professionals and to motivate research conduction in palliative care.

Finally, the Palestinian culture that stems mainly from religion compensates with increased psychological comfort and spirituality, especially for terminally ill patients. Improving pal-

lative care among Palestinians requires not only to implement the above interventions but also to strengthen the positive religious and cultural values in caring for the sick people particularly with the new generation where these values tend to weaken with time.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Cultural Challenges in Implementing Palliative Services in Turkey

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ABSTRACT

Palliative Care (PC) is a set of approaches that aims to improve physical, social and psychological well-being of both patient and the family. PC should begin at diagnosis and continue throughout treatment till the end of life. In Turkey, PC is at its infancy; the Pallia-Turk Project, to improve PC, has been implemented by the Ministry of Health since 2010. Turkish Ministry of Health has launched regulations on PC including both as a home care team and also hospitalization settlement in 2014. After these regulations, the number of PC units in Turkey has increased significantly. There is no certified PC specialization or resident program in Turkey for physicians and no certification programmes for nurses. However, PC education programs organized both by the Ministry of Health, Middle East Cancer Consortium and international and national cancer congresses by the oncology groups are encouraged in recent years. For most of the families, "palliative care" means end-of-life care. Hence, the health staff in PC, at first, should describe the mission and objective of PC both to the patients and to the families. The second most important point is that, the health care professionals should be sensitive and tolerable of various traditions or religious beliefs in order to meet the needs of patients and families and ensure a "good death" and healthy bereavement.

KEY WORDS: Palliative Care; Pallia-Turk Project; Well-being for patient and the family

ABBREVIATIONS: WPCA: World Palliative Care Alliance; PC: Palliative Care; MECC: Middle East Cancer Consortium; DNR: Do-not-resuscitate.

INTRODUCTION

The World Health Organization (WHO) defines palliative care (PC) as an approach that improves the quality-of-life (QoL) of patients and their families facing the problem associated with life-threatening illness, such as cancer, through the prevention and treatment of symptoms and side effects of the disease and its treatment, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.^{1,2} In a patient diagnosed with cancer, PC should begin at diagnosis and continue through treatment, follow-up care, and the end-of-life.^{1,2}

In developed countries, PC is well developed; but in the most resource limited settings, PC services are still uncommon. The Pallia-Turk Project, to improve PC in Turkey, has been implemented by the Ministry of Health since 2010.

CURRENT STATUS OF CANCER AND PALLIATIVE CARE IN TURKEY AND CULTURAL ISSUES AND CHALLENGES

Turkey has undertaken the Health Transformation Program from 2002 on, to transfer and improve the health system and its outcomes and the situation regarding public health, insurance of the patients, and the patient satisfaction has improved in the following decade. Turkey's health

care system has underwent radical changes since 2003 both in the provision and financing of health care services. The most important of these was the removal of different accessibility rules between social security schemes and applying the same rules to all of them.^{3,4} Under the General Health Insurance Scheme, all citizens are covered by the Social Security Institution. Health services are predominantly government-based managed through a social security scheme, by the Ministry of Health. When the patient has a chronic disease such as diabetes, hypertension or cancer, the patient receives full reimbursement.^{2,5}

World Palliative Care Alliance (WPCA) like WHO, is an organization that promotes activism, monitors progresses and provides resources on education and policy to countries developing PC. WPCA in 2011 updated a global inventory of hospice and palliative care development with multiple factors and assigned the countries to six categories.⁶ According to this inventory, Turkey was upgraded from group II (defined as, capacity building country) in 2006 to group 3b (defined as, there is generalized palliative care provisions) in 2011.⁶

Turkey is a member of the Middle East Cancer Consortium (MECC), which aims to promote health care and encourages cancer education and research. MECC has been supporting the improvement of PC in the region by conducting various education and training programs in PC in cancer since 2004 in various Middle East countries, including Turkey.^{2,7-9}

The Turkish Ministry of Health has launched a national cancer control programme in 2009.¹⁰ The programme includes five main headings: Registry, prevention, screening and early diagnosis, treatment and palliative care. The Pallia-Turk project in this respect has been implemented by the Ministry since 2010.¹⁰ This project, focuses on implementation of a PC model with family physicians, nurses and home care teams so that patients with chronic diseases can receive basic PC services. This project also integrates non-government organization (NGO)s and local municipals to cover the psychosocial, economic and religious needs of the patients. The project secondarily aims new legislations for morphine prescription to increase morphine availability and to train the medical staff against “opiophobia”. The project has three levels of organization: Primary, secondary and tertiary palliative care centres. In the primary level organization, family physicians and home care teams manage patients; patients who need higher level health care are referred to secondary or tertiary level centres.¹⁰ Home care teams are responsible for simple acute interventions such as pain relief, constipation, wound dressing and parenteral drug administration. In an evaluation done in 2011, the majority of almost 40,000 patients who received home care had neurological disease (45%), cardiovascular disease (21%) and other chronic diseases, only 4% had cancer.^{2,5,10} Thus, most patients with cancer have not received home care. The number of patients receiving home care has increased significantly to 760.645 in 2016. However, the number of cancer patients receiving home care is still inadequate. Currently, as of 2016, Turkey has 5495 physicians working in 954 home care

teams.¹⁵ The Turkish Ministry of Health has launched regulations on palliative care including both as a home care team and also hospitalization settlement in 2014.¹⁶ Secondary teams include at least one physician as the head of the team educated and experienced in PC and co-physicians, nurses, physiotherapist, nutrition expert, psychologist and social workers. Tertiary centers work in a multidisciplinary approach and include all physicians related with PC (internal medicine, surgery, medical oncology, radiation oncology, cardiology, thoracic diseases, psychiatry, physical treatment and rehabilitation, anesthesiology or algology, general practitioners), experienced oncology nurses, social workers, physiotherapists, nutrition experts, psychologists and religious people. The medical oncologist is usually the coordinator of the team. These centres also plan and take role in research and training activities of doctors, nurses and social workers and interact with NGOs and local governors.^{2,10,17,18} The number of PC units in Turkey has increased from 15 in 2014 to 197 in 2016; the number of beds for PC patients has increased from 179 in 2014 to 2020 in 2016.¹⁵

Although, formal PC units or team are not available in most oncology centers in Turkey, most medical and pediatric oncologists, internists, anesthesiologists and family physicians provide some form of PC in their inpatient or outpatient clinic by way of consultations with the related disciplines. Although there are some education programs on pain and other symptom control, formal comprehensive PC curriculum is not yet present.^{2,13} PC continuing education for residents and doctors are more satisfactorily done. During the fellowship programs of medical or pediatric oncology specialties, there is few formal PC lectures in the curriculum. However, residents and fellows mostly learn PC while caring for these oncology patients during their hospitalization. There is no certified PC specialization or resident program in Turkey.^{2,13}

Most nurses in medical/pediatric oncology get the experience while working in the oncology ward, from more experienced nurses and the pediatric oncologist/hematologists. In general, there are no certified PC/hospice care specialist nurses. PC in general has not been incorporated yet into the curriculum of nursing at both undergraduate and postgraduate level.¹⁹ However, PC training, for both physicians and nurses, is increasing via interdisciplinary care program in the inpatient clinics and via lectures and courses in national meetings and also in doctoral and postdoctoral curriculum.^{2,19} The Ministry of Health, has organized PC educations for nurses and doctors since 2010.^{2,5,15}

There are permanent psychologists and psychiatrists as a part of PC only in a few oncology centers. In most centers, psychology/psychiatry consultation is requested from the related department as needed. There are few social workers, almost no art therapists employed in the oncology centers. A liaison psychological support is very helpful in the centers that have the team to perform it. At pediatric setting, sometimes families do not control their feelings and may have unrealistic expectations or they may deny their children's diagnosis and/or the news of

end of life. The families also need psychological support. Thus every center should have a permanent psychological support team.² The medical/pediatric oncology doctors and nurses try to cover the role of the psychologist, social care worker in many centers. Although, oncologists advise and apply standard treatment protocols, they also respect patients' and their families' wishes. Mostly, it is the families rather than the patients' who participate in the decision. In pediatric cancer, the families are informed of the malignancy and the prognosis of the disease in detail, the child is informed of the malignancy in words that they may understand according to their age. Most parents do not want the doctor to tell the child that they have "cancer", and the doctor tries to convince the parents to at least use the term "tumor" in the first session. In adults, especially in the elderly, most families do not want the patient to know that he/she has cancer.⁴ Turkish patients suffering from cancer clearly express their desire of being told about cancer diagnosis and prognosis.^{20,21} However families believe that cancer is 'that is not to be named', since nothing can be done to treat it and it is always fatal.^{4,20,21} While this is dishonesty, it is also an expression of the individual's desire to protect a loved one from cancer – the bad news. However, the family members also deprive the patient of the right to make decisions about his or her life.⁴ Physicians tend to respect the patients' right to know the truth but is limited from the family pressure.^{4,20,21}

In a recent study, advances in technology, cancer treatment and supportive care; adequate family support and presence of governmental health insurance were reported as important factors for high levels of hope.²⁰ Financial problems were reported to negatively affect the psychological distress and thus adversely affect the level of hope.²² Contrary to the general attitude and belief of the families in developing countries, the total hope scores of patients were found to increase with their information level about the disease. Hence, at diagnosis, family members should be convinced that the patient himself/herself should also be informed of his/her disease.

In two surveys conducted among health care professionals in Turkey,² it was reported that the high number of patients, the limited number of staff in the healthcare team, the limited time that may be allocated to each patient, and the cultural and/or educational background of the patient are important barriers in providing PC. The patient at terminal stage may not be hospitalized due to lack of available hospital bed. The intensive care unit (ICU) beds are also very scarce and the oncologist is confronted with the hard decision of whether to use the oncology bed or an ICU bed either for a patient who has a high chance of cure or for a dying patient. Written PC policies or guidelines should be established in each center. There is a lack of community awareness about PC in Turkey, but surveys show that volunteers for psychosocial support, mostly in pediatric oncology are somewhat more active in big cities like Istanbul, Ankara and Izmir. Some NGO voluntary groups try to give psychosocial support especially to children by organizing parties, picnics, and celebrations which are very much appreciated by the patients

and the parents. They also sometimes make home visits to the patients.²

The right of dying patients has not yet been established by law in Turkey, and do-not-resuscitate (DNR) order or practice of euthanasia for patients suffering from refractory symptoms is not legal.^{2,23,24} End-of-life care is given mostly in the inpatient setting. Although, most of the patients or family members in rural areas prefer to stay at home at their end-of-life period, most patients in urban areas and most families of children with cancer prefer to stay in the hospital in the terminal stage, in contrary to many countries in the Middle East, where the patient or families prefer the patient to die at home where they are cared for by their family.^{2,25} Sending the patient home to die is frequently considered by the families as "giving up on us" and the hospital sometimes becomes more "home" for the patient than his/her own home. However, if hospice or home care were available, they could prefer it. Sometimes, families resist PC consultations because this may symbolize evidence of the patient's deterioration, which may be difficult to face. For most of the families, "palliative care" means end-of-life care; they think this kind of care will stop all the other medications about the cancer disease itself. Hence, the health staff in PC, at first, should describe the mission and objective of PC both to the patients and to the families. All cancer care must be provided respecting families' spiritual, cultural background to promote a sense of well-being and to ease suffering of the patients and the families. So health care professionals should be sensitive and tolerable of various traditions or religious beliefs in order to meet the unique spiritual needs of patients and families and ensure a "good death" and healthy bereavement.²

As a result, the patient and the family should be offered an integrated model of PC that continues throughout the course of the illness, regardless of the outcome.^{2,26} Both regulations and legislations done by the Ministry of Health to improve the health system including PC is promising.

There is always a need of funding for the organizations necessary in the PC setting. This funding issue should be supported by the government, also the support of NGOs may be incorporated. To increase the awareness of the importance of PC in the public, thus facilitate the support of the public and NGO's the media including TV, internet (facebook, twitter) newspapers may be used.

Regarding medication for pain relief in cancer, there are regulations for prescriptions and distribution of opioids in Turkey. These are controlled by the Ministry of Health. Thus illegal use of opioids is avoided. Opioids can be prescribed by all physicians including family physicians.^{2,5,10} The Ministry of Health has also planned to decrease the unnecessary legislation according to European Union guidelines by 2015 and e-prescriptions, like the prescriptions of other drugs, are also planned for opioids.^{2,5} Since the end of 2014, slow releasing morphine is being produced in Turkey.¹⁵

CANCER CARE TO FOREIGNERS IN TURKEY

Multidisciplinary cancer treatment in Turkey is quite advanced in comparison to most countries in the region. Some cancer patients come from Middle East countries, Balkan countries and Turkish origin or Turkish speaking countries. There are also refugees coming to Turkey from neighboring areas of conflict. Around 3 million and 500.000 Syrians have come to Turkey since 2011.²⁷ In addition to refugees' basic needs, the health care needs of refugees have been addressed. Refugees with cancer can be treated at tertiary government and university hospitals free of charge. In a recent study evaluating 212 refugee children with cancer, the survival outcome of these children was found to be similar to the Turkish children with cancer.²⁸

CONCLUSION

It is essential that improved PC program should be integrated into national health-care systems to control the suffering of all adult and pediatric patients including patients with cancer. This national policy enables to develop quality standards, funding, and accessibility of adequate care for most patients and families and serves a major role in facilitating to establish the PC units/teams and education like PC curriculum and availability of essential drugs for health-care professionals. PC units/teams, hospices and home care services should be established both for adults and children. Health-care professionals should have postgraduate PC education. Governmental attempts are needed to increase the number of nurses, psychologists, psychiatrists, social workers and art therapist and in the centers. Evidence-based pain and symptom management and PC written guidelines should be available for the clinical use of doctors and nurses in all oncology centers. Non-governmental organizations may be incorporated in the PC efforts. The media may be used to improve the awareness of PC in the public. Government, non-governmental organizations and health care professionals should collaborate to improve PC in Turkey.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Cultural Challenges in Implementing Palliative Services in Lebanon

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Cultural Challenges in Implementing Palliative Services in Lebanon

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ABSTRACT

Palliative Care (PC) is a relatively new discipline in Lebanon with some progress being made in recent years. Based on our clinical experience, we describe and discuss the cultural aspects of palliative care, the attitudes and the practice of physicians and nurses in PC, and the challenges to implement it in our country. In our society, death is a taboo subject that is rarely discussed, even with patients at the end-of-life. Under family pressure, physicians do not inform the patients about their diagnosis or prognosis. With the extraordinary progress of medicine, more deaths occur in institutions. These advances, in a context of repression of death, lead to over-medicalization of the end-of-life and to the exclusion of the dying person. Several trends in health care today decrease the chance of cancer patients to have access to palliative care. These range from limited availability of palliative care services, to the philosophy of patient care that dominates our health care system. Most patient care in our country is disease oriented. Care is usually complex, and treatment involves many medical specialties with fragmentation and limited coordination of patient care. One approach is to transform the current disease-focused approach to a patient-centered philosophy. With the aging of our population and the increasing number of cancer patients in Lebanon, the need for PC teams and programs will also increase. The recognition of the specialty by the Ministry of Health and the adequate reimbursement for PC services will encourage physicians in training to consider careers in PC. Education of professionals in palliative care and clarification of the concept to the general public are also essential steps to improve PC.

KEY WORDS: Palliative care; End-of-life; Death; Patient-centered care; Supportive care; Cancer patients; Quality of life.

ABBREVIATIONS: PC: Palliative Care; WHO: World Health Organisation; QoL: Quality of Life.

CURRENT STATE OF PALLIATIVE CARE SERVICES IN LEBANON

Palliative Care (PC) has been defined by the World Health Organisation (WHO) as 'an approach that improves the quality of life (QoL) of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of sufferings and early and precise identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems'.¹

By current estimates, Lebanon has an annual mortality rate of 4-5/1000, or over 22,000 deaths a year. There are more than 8000 new cases of cancer each year, and around 12,000 patients are in need of opiates. Sixty percent of patients need pain relief and PC but only 5 to 10% receive PC.²

Palliative care is new to health care in Lebanon. The concept was first introduced in 1995 at the WHO National Cancer Control Workshop and later at the Middle East Oncology Congress in 1999. These workshops helped launch the first efforts to establish PC services in the country.

On 2004, the Ministry of Public Health introduced a law confirming the patients' right to PC and informed consent and established on 2011 a National Palliative Care Committee,³ with the mandate of elaborating national plans for research, education, practice and policies related to PC. This Committee launched on October 2012 a national strategy to raise public awareness. It incorporated the standards for essential PC into the new hospital accreditation criteria to ensure that all hospitals in Lebanon are providing a minimum level of PC to their patients, recognized PC as a new specialty, introduced new narcotic drugs to the market and facilitated their renewal procedure.⁴

Many hospitals already have special pain clinics and some have recently introduced a consultant PC team; only 2 hospitals have inpatient PC unit.

Three years ago, we launched in our hospital, an interdisciplinary PC consultant team, consisting of a specialized physician in PC, a specialized nurse, a psychologist, a social worker and a priest and prepared for a PC unit with adequate ward and equipments.

Attitudes and approaches to PC vary widely amongst religions and cultures. Decisions are influenced by the beliefs of the caregivers, patients and their families. Several studies stressed the importance of cultural issues when practicing PC. Concepts such as decision-making, life support and advance directives, family involvement in patient care, suffering and expression of pain, as well as religion and faith differ from one culture to another, and play important roles in how end-of-life care is perceived (Table 1).⁵

We describe the cultural aspects of PC in our country and discuss, based on our clinical experience, the attitudes and practice of physicians and nurses in PC and barriers to its development. We also propose some recommendations as to how to address the barriers to providing PC in our country in a culturally appropriate way.

CULTURAL ASPECTS OF PC IN OUR COUNTRY AND THE BARRIERS TO ITS DEVELOPMENT

In our society, death is a taboo subject that is rarely discussed even with patients at the end-of-life. In a recent survey we conducted with university students to test the attitudes of our society towards death and the end-of-life, more than half of the students considered that our society refuses to face death and does not even allow us to choose the place to die.⁶ Although, 76% of these students say they would like to die at home, the majority of the patients in our country die in the hospital.

Patients and family members request sophisticated treatment to prolong life at any cost, even with great sufferings. They accept physical and psychological pain as a price to pay for an illusional prolongation of life upto the last moments.⁷ This new attitude has replaced the formally accepted and embedded social tradition of dying with dignity in the warmth of a family. Now-a-days our society prefers to die in hospitals surrounded by beeping and whistling machines. Also, uncovered financial costs, and insufficient specialized PC teams are important barriers to home support.

With the extraordinary progress of medicine in our milieu, it is logical that more deaths occur in institutions. These advances, in a context of repression of death, lead to over-medicalization of the end-of-life and to the exclusion of dying person, especially when he perceives the gap between his worsening situation, and the promises held, thus creating an additional factor of anxiety.

The idea of a crisis of death was experienced in western societies in the 1970s. Thomas⁸ published in 1975 his book *Anthropologie de la mort*, in which he made a comparative research on the experience of death in the West and in Africa. Thomas opposes the good traditional African death, characterized by the acceptance and integration of the latter, the paternalism and securing of the dying person taken in charge by the group, to the

Table 1: Cultural Issues Specific to the Development of PC Services in Lebanon.

Cultural aspects of PC	Current attitudes and practice
- Death is a taboo subject.	- Professionals rarely approach death even with patients at the end-of-life.
- Truth will lead to grave and even lethal consequences for the patient.	- Paternalistic approach in care provision. Physicians often cannot inform the patients about their diagnosis or prognosis by resigning to the wishes of the family;
- Surrogate decision making is frequent.	- Exclusion of the dying person even from the important decisions concerning his life.
- PC is equated with failure of treatment.	- Late consultation of PC team and late referral of patients.
- Narcotic prescribing is equated to some patients or their families with the end-of-life.	- Narcotic prescribing necessitates often a long discussion.

repressed death of the Western industrialized world, lived in anguish, loneliness and denial.^{8,9}

Another aspect of PC in our country is reluctance to tell the truth which is a human right. In our country, physicians often cannot inform the patients about their diagnosis or prognosis by resigning to the wishes of the family who consider that the truth will lead to grave and even lethal consequences for the patient. In Abu-Saad Huijer's survey published in 2007, the majority of nurses and physicians reported that the patients should be informed of the diagnosis and prognosis; however, only 19% of physicians routinely inform terminally ill patients about their diagnosis.⁵ These results are not surprising because in Lebanon, the family plays an important protective role in the life of individuals. However, with the advancement in education and technology, patients are becoming empowered and as such increasingly knowledgeable on diseases and treatment modalities, leading to their increased involvement in the decision-making process. This need to move from the paternalistic approach in care provision to patient-centered care that promotes patient autonomy has also been reported in studies from other countries in the Mediterranean Basin.^{10,11} We should also notice that narcotic prescribing could be equated to some patients or their families with an end-of-life.

Several trends in health care today decrease the chance of cancer patients to have access to palliative care. These range from limited availability of palliative care services to the philosophy of patient care that dominates our health care system.

With the aging of our population and the increasing number of cancer patients in Lebanon, the need for teams and programs that provide PC services will also increase. The expansion of the pool of PC providers is an essential step towards ensuring that PC services are available to anyone who may need them in the future. The role of nurses should also be recognized and rewarded appropriately.

Most patient care in our country is disease oriented, focusing on specific treatments, delivered frequently by a multitude of poorly coordinating medical specialists. This results in a complex and fragmented medical management of patients. One approach is to transform the current disease focused approach to a patient-centered philosophy, where the needs and the goals of the patient and the patient's family become essential in planning patient care. The interdisciplinary PC team should include at least a physician, a nurse, a mental health specialist, a social worker and a spiritual consultant to respond to all of the needs of the patients and of their families. Spiritual support, often neglected in the routine management, is an integral aspect of PC. It is essential in a "multi-confessional" country like Lebanon in order to insure community buy-in and collaboration.⁴

Another difficulty that we encountered during our practice is late consultation of the PC team and late referral of patients. This is not surprising in a private system where indi-

vidualistic culture predominates. Reasons for the late referrals also includes the fact that PC is equated with failure of treatment, making it difficult for patients, families, and medical staff to switch to a "non-treatment mode" and to give up the search for a cure. Even health professionals often have misconceptions about PC and consider it as terminal care or care applicable only to oncology patients. A change in health care to include PC early in the course of cancer, in parallel with conventional curative medicine, may familiarize the family with PC services, start communication about death earlier in the course of treatment, and provide an opportunity for a discussion of goals of care between physician, patient, and family. The better understanding of the mission of PC team by the patient and his family, and the understanding of its role in supporting and advising the initial medical teams in the management of patients is an important step to change this practice.

An additional challenge to implementation of PC is the limited evidence for this specialty. Needed are studies that provide evidence to guide better decisions on symptom management, different health care models, decision-making approaches about treatment options, communication on sensitive topics such as death, and support for family caregivers.¹²

SUMMARY AND RECOMMENDATIONS

PC is a relatively new discipline in Lebanon. Although, progress has been made in recent years, only 5 to 10% of patients who need PC receive it. Most PC services are provided in large cities, leaving a large segment of the population without access to PC. Furthermore, over 50% of patients cannot afford PC services or medications.

In order to provide the best possible care to patients and families in end-of-life situations, it is important to understand their cultural constructs as well as their individual preferences.

In our society, the terminal phase of existence and death constitute a crisis that is poorly managed. The policy of non-informing the patient about his diagnosis must be contested and public education is necessary.

Introducing early PC for cancer or other life-threatening illnesses and recognizing PC as new medical specialty, may help accepting the actual situation of patients and reduce the taboo of death among people. PC can provide better QoL for the patients and their families by managing all the unpleasant symptoms.

Recommendations to improve PC in our country,

- Education of professionals in PC is urgently needed. Primary palliative care curriculum should be introduced into medical and nursing schools and primary care residency programs should be added to ensure that all primary care physicians can provide a basic level of palliative care to the community.

- Education and clarification of the concept of PC to the general public who needs to learn what palliative care entails and how palliative care teams operate in many general and specialist hospitals (media, press, leaflets, etc.).
- Adequate reimbursement for services is essential if palliative care programs are to be established. This will allow the expansion of palliative care services, and will also encourage physicians in training to consider careers in palliative care.
- Standards for Palliative Care Programs and Centers of Excellence in Palliative Care should be publicized to allow hospital administrators to work towards these goals. It is essential to create in-hospital PC services adapted to the cultural, social and economic specificities of our country, involving the private and public sectors. It is also essential to improve the management of these patients at home and to create of specialized teams in this field, especially that patients often wish to be treated at home.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Cultural Challenges in Implementing Palliative Care Services In Iraq

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Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Mini Review

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Cultural Challenges in Implementing Palliative Care Services In Iraq

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ABSTRACT

Culturally compatible palliative care presupposes understanding of that culture's perspectives of cancer and death. Iraq is a culturally diverse country with different perspectives towards cancer and death. The concept of palliative care among Iraqi people and patients is primitive; the majority of them have no idea what palliative care is about. As long as there is no national palliative care program – most of the medical health care providers themselves are also not familiar with palliative care – it is not more than a terminology they had read about during under- and postgraduate course if this ever happened. The strength of the palliative care field in this country lies in the area of culture, religion and psychosocial entities. Yet, negative impacts also exist in the same culture. Health care in Iraq has witnessed remarkable regression in the last three decades parallel with political and economic troubles, struggling to provide basic diagnostic and therapeutic facilities. Hence, the idea of palliative care seems to be "luxurious" in these bad circumstances. Those in power and decision makers may think in this way: "budget from Ministry of Health or from NGOs is to be spent on buying essential medicine rather than improving the quality of life (QoL) or decreasing the suffering of patients". Community awareness is very important and even within the medical community palliative care terminology is still embryonic and limited to part of the oncology medicine.

KEY WORDS: Culture; Palliative care; Barriers; Service; Death.

INTRODUCTION

"Culture and heritage are not about stones and buildings; they are about identities and belongings. They carry values from the past that are important for the societies today and tomorrow".¹ This statement was made by Irina Bokova on December 2, 2012, during the ICOMOS Gala commemorating the 40th anniversary of the World Heritage Convention. Modern Iraq is the location of the ancient Mesopotamian civilization, the patrimony that shaped the other ancient civilizations. The Iraqi culture is a profuse composition of traditions and rituals from the different civilizations that emerged in the region. Cuneiform script which seems one of the earliest systems of writing, originated by Sumerians who lived in Iraq. Understanding ancient cultures help us to evaluate the diversity of human experience.

HISTORICAL, ETHNIC AND RELIGIOUS KEY POINTS IN IRAQ

Sir Edward B. Taylor, writing from the perspective of social anthropology in the U.K. in the late nineteenth century, described culture in the following way: "Culture or civilization, taken in its wide ethnographic sense, is that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society".² Recently, the United Nations Economic, Social and Cultural Organization (UNESCO) in 2002, described culture as follows: "Culture should be regarded as the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions, and beliefs".¹ The culture of any nation symbolizes its manner, values, and way of behavior rooted

in history and collective memory. However, the shape of any culture keeps changing and cannot be constant over time.

The capital city of Baghdad, founded in 762 C.E. by the Abbasid Caliphate, became an important commercial, cultural, and educational center. This era was followed by the Mongol invaders in the 1200s, who ruled until the 1400s, ending with the arrival of the Ottoman Turks who gained control in the 16th century and ruled until the end of World War I. These periods left their influences in shaping the culture and rituals of the country.

One of the most distinctive aspects characterizing the population of Iraq is its unique religious and ethnic diversity. Based on World Bank statistics, Iraq's population today is approximately 33 million, consisting of a number of ethnic and religious minorities including Christians, Kurds, Turkmens, Assyrians, and Yezidi's, among other minority groups in Iraq. According to Minority Rights Group International (MRG), approximately 96% of the country are Muslim. The overwhelming majority is divided into a large Shi'a Arab majority, a Sunni Arab minority, and an ethnic Kurdish minority that is also overwhelmingly Sunni. An estimated 10% of the population is composed of ethnic Shabaks, Turkmens, Faily Kurds, Palestinians, Roma, Christians, Sabian-Mandaeans, Yezidis and Baha'i's, with the majority being both Shi'a and Sunni adherents.³ The Arabic language is spoken by the majority, followed by Kurdish in about 15% of the population. Other languages are spoken among minorities only, including Turkmen, Neo-Aramic, Mandaic, Shabaki, Armenian and Persian.

SOCIETY AND FAMILY IN IRAQ

Iraq is an upper middle-income country with free public health care and education for all, which are remarkable gains. Education is greatly respected, especially for those who want to achieve a higher level of education in the field of science. The families in Iraq are large and extended, and loyalty to the family and tribe is sustained, manifested in business and personal life, including major decisions regarding health and wealth. Extended families may all live together, which is the more traditional pattern, or they may reside separately. Iraqi society has become increasingly urbanized, but retains a tendency of closeness to the nuclear family. Hospitality and honor are of paramount importance in this culture, especially in the southern and western parts of Iraq which retain their original moral codes and where the tribes are authoritative and powerful. Elderly people are treated with priority, and children are overprotected by the family. Women are vital components of the culture, they have a higher status in comparison to other Islamic cultures, and many are educated and professionals. Iraq sanctioned the convention on the elimination of all types of discrimination against women in 1986. The dynamic process between religion and Iraqi culture in the last fifteen years is mystifying as yet unclear.

CULTURAL ASPECTS OF HEALTH AND DEATH

All cultures have their own beliefs about illnesses and death.

Understanding these beliefs expedites a comprehension of how the culture views the state of wellness and illness, what the response is to disease, and what actions can be implemented regarding the disease. Nevertheless, variations exist within the culture, depending on level of education, personal history, and socioeconomic state. In Iraq, the response to disease and health represents a mixture of Eastern and Western approaches. The first response is to consider health as a balanced state and disease as unbalanced state, with the usual reaction being to adapt the state to the environment, while the Western approach is to change the environment as much as possible.

Generally, the Western concept of causality and response to illness is accepted in Islamic culture. The majority of people in the Iraqi culture view illness as a test of faith that should not be resisted. To date, cancer represents a "death sentence" in Iraq, and this makes death very complicated. Mental health problems, cancer, and various chronic illnesses are viewed as stigmas by most Iraqi people, and most families follow the trend of hiding the truth and the facts of the disease from the patient, and particularly from geriatric and pediatric cancer patients. Culturally, Iraqis avoid discussing death and serious issues such as palliative or end-of-life care. Death is barely accepted as a natural phenomenon and is considered as an end of the divine plan. The expression of grief varies among different regions and families; some are restrained while others behave distressingly. Some ethnic and religious groups believe the fact that death is a transition to a more glorious place, and both groups believe in life after death, and accept death as God's will.

The funeral generally represents a somber event that lasts for three days and sometimes extending to seven days in the tribal areas, during which the bereaved family welcomes the mourners who come to express their grief and condolences. Expressions of grief, including crying and wailing, are appreciated by the deceased family, and the more intensive the grief displayed by the guests, the more beloved the deceased was considered to be. The family members are never left alone, friends and relatives visit the house of the departed member wearing black clothing and talk with the family members, encouraging them to discuss how the death occurred. The attendance of friends and relatives may give meaning and support to the family, financially and spiritually. The period is fraught with both pain and relief simultaneously. Are Iraqi health-care providers culturally competent?

Cultural competence is defined as the ability of providers and organizations to effectively deliver health care services that meet social, cultural, and linguistic needs.⁴ It is an amalgam of varied behaviors, practices, and abilities that are important in establishing a good relationship with people of different beliefs and rituals. Working in an Arabic and Islamic culture, Iraqi health-care providers are sensitive to the clients with whom they communicate and most of them are familiar with the cultural background of the society, with special issues regarding children, women, and certain groups from different regions with special rituals and beliefs. There are no special training courses

for health competence in the country, but most of the individuals, being health care providers or general public follow tribal laws and attitudes. Health thoughts are certainly tied to cultural background and religious affiliation.

CULTURAL IMPACT ON PALLIATIVE CARE

The concept of palliative care among Iraqi people and patients is primitive and the majority have no idea what palliative care is. As long as there is no national palliative care program, most of the medical healthcare providers themselves are also unfamiliar with palliative care. It is no more than a terminology that they came across during under or postgraduate course, if it happens at all. The strength of the palliative care field in this country today lies in the area of culture, religion and psychosocial entities. Yet, negative impacts also exist in the same culture. There is great respect for, and loyalty to religious leaders in most cases, although these leaders have no role in health institutions and in palliative care.

Religion and spirituality have a great impact on palliation and the stress and fear of chronic illness and death. Prayers, visiting holy places and receiving blessings from religious leaders represent the most acceptable coping mechanism with chronic illness, suffering, and death. Large and extended families in our culture have a positive impact on coping with chronic stress. During health crises, relatives and friends can provide both moral and psychological support, and furthermore they can help financially. Living in an extended family also has an impact on this issue, as the decisions about health issues can be hampered by any of the effective authoritative family members, or, conversely, they can have a positive impact.

Factors that are important to seriously ill patients are adequate control of pain and other symptoms, achieving a sense of control, relieving the burden on family members, and strengthening relationships.⁵ Other factors that are important are gaining a realistic understanding of the nature of the illness and the pros and cons of available treatment alternatives weighed in the context of the patient's own goals and values, naming decision-makers in the case of loss of decisional capacity, and putting financial affairs in order.⁶

CURRENT STATUS OF PALLIATIVE CARE IN A HEALTH-CARE INSTITUTION IN IRAQ

Palliative care is a relatively new concept in Iraq, and the program is not yet established, but the concept has been introduced to the pediatric oncologists working in the hematology-oncology unit in the Children Welfare Teaching Hospital in Medical City, Baghdad, during workshops that has been designed for this purpose, moderated by external organizations. The hospital is one of two main centers for treating childhood cancer (leukemia and solid tumors) in Iraq, with an average of 300 new cases per year. The practice is still mainly limited to the field of pain management and patient's family education; the work is based on individual abilities rather than a collaborative group; and no

professional team is assigned to be responsible for this issue. No special unit or outpatient clinics have been established. Social workers and psychotherapists are not available; the pharmacists have nothing to do with this field; and the majority of the pharmacists are reluctant to give any help. There are eight pediatric hemato-oncologists working in the unit, and each one struggles to work as an oncologist and psychotherapist, spiritual care provider, pain control specialist and even sometimes religious counselor for the patients, although the latter is sensitive in terms of diverse ethnicity. Actually, they are working in an abyss of fire, considering the damage in the infrastructure and a state of chaos on all levels. In the last 2 years, 4 volunteers have joined us to work in the hematology unit offering help, and one of them was assigned to work as a social worker in very limited aspects such as talking with the patients and offering crayons and paints to them. Adults still lack such services.

After attending several workshops in this field in Turkey and Oman, moderated by the Middle East Cancer Consortium and the American Society of Clinical Oncology during the years 2011-2016, the pediatric hemato-oncologists in the Children Welfare Teaching Hospital are now familiar with this concept. Several lectures were delivered to the working staff about palliative care. In 2013, one of the nurses had an opportunity to attend a training course for palliative care in Oman. Thereafter, the hospital started to offer some of the opioids in a semi-constant manner, but no policy has been set for the prescription of these medications. It is mainly based on the experience of the working physician and is not allowed to be prescribed on an outpatient basis. The inpatient's prescription itself requires strict documentation and is only permitted for two physicians according to the hospital regulations. Funds are available for oncology but not for palliative care. The dissemination of opioids is limited to a few hospitals in Iraq and authorized by physicians only. The available pain medications are injectable morphine, with codeine and transdermal fentanyl patches available only occasionally. All these medications are provided free to the patients. The palliative care team consists only of the patient, the oncologist, and the patient's loved ones, with no palliative doctor, nurse, social worker, pharmacist, physical therapist, chaplain or sheik, or dietician.

CULTURAL BARRIERS FOR IMPLEMENTING PALLIATIVE CARE SERVICES IN IRAQ

Responses and behaviors to palliative care vary enormously among cultures. The decision is always influenced by the beliefs of the family as well as the health professionals. Even within the same culture, the decisions vary according to each member's beliefs and thoughts.

Many barriers hinder the establishment of palliative care services in the country, most importantly the lack of public awareness, lack of education and training programs, inadequate availability of painkillers, and last but not least the failure to recognize palliative care as a specialty. The main issue in Iraqi society is that chronic illness and cancer represent a stigma to

the family and the patient. Public awareness is at the top of the list of the challenges, followed by level of education, political dangers and conflicts, administrative and financial corruption, and security failure from terrorism and uncontrolled parties. All these issues prompt people to think only of securing their physiological needs and make them reluctant to seek new ideas and are resistant to any new concept and/or changes in treatment.

Culturally, healthcare providers struggle to tell the truth to the patient's family, as this may cause psychological trauma to the family, who might then decide to leave treatment and seek another health professional who might be ready to deceive them. Discussion with the family about palliative care issues is a difficult task, and depends on the beliefs of the physician and the family. The perception of palliative care is almost always affected by these beliefs. Education plays another role in understanding the palliative care issue. In Iraq, as in many other regional countries, the health care system seems to be ill-equipped to deal with a dying cancer patient.

The majority of families refuse to tell the patients about their diagnosis, especially cancer patients, no matter how old they are. They think that this will affect the daily quality of life (QoL) of the patient and possibly cause a lasting negative psychological effect. The decision of the family about labeling their child as a candidate for palliative care is a particularly difficult emotional issue in the Iraqi community. Moreover, issues such as stopping active anti-cancer therapy and starting pain therapy are also difficult options for the family, and physicians face great difficulties in persuading the patient's relatives about these decisions. Physicians address families from all strata, and they often find it difficult to convince families having advanced cancer patients that palliative care is about easing death and letting the process be pain-free so that the patient will die with dignity.

Most families continue arguing with the medical staff, asking for more chemotherapy and in some cases even refusing pain management, as they think that the use of painkillers means that the disease is going to end with death – the tragedy which they refuse to contemplate. They cannot grasp that palliative care, although not curative, nevertheless prolongs and improves quality of life. Talking with the family about the death of a terminally ill patient is not accepted in most sectors of society, as it might (mistakenly) be understood to be an expression of contempt by the physician towards the feelings of the family. Sometimes, the physician may need to talk to other persons in the extended family, in as much as talking with parents may cause shock and psychological trauma even if they are aware of the course of the illness.

Some parents in an extended family do not have the ability (and sometimes the will) to decide about the treatment of their newly diagnosed child with cancer without the backing of the family. In other instances, the doctor's first meeting with the family after the diagnosis has been determined, cannot take place without the attendance of another member of the family, such as the maternal or paternal uncle or aunt, or even the grand-

mother and grandfather from either side. The same procedure applies to the decision about starting palliative care, withholding treatment, or shifting to other modalities of culturally-based treatment such as going to spiritual and religious persons or to holy shrines. Such rituals and ceremonies can create stability within the family of the terminal patients and help in understanding and realizing at what stage they are. The journey of the family between herbal, religious and spiritual therapies during this period may result in despair for some, comfort for others, or both despair and comfort for many.

In Iraq, there is no clear definition of who is a spiritual person and who is a religious person. In fact, there is no recognized spiritual person and the term relates only to religious persons, while a sizeable group of reputable physicians consider religion as having a negative impact on mental health, physical health, or both. The religious man's role is confined towards family of a terminal patient is to give thoughts about life after death to alleviate the suffering of the family. Studying the pros and cons of the influence of religion is difficult, as it conveys a sensitive issue in a community that sanctifies religious leaders. The tendency to visit holy shrines is ill-mannered among Shi'a adherents. Death is something to be avoided in Iraqi culture, and the emphasis is placed on a cure.

The majority of people in Iraqi society believe in Western medicine, as it follows the hypothetical deduction *versus* the inductive method of the Eastern approach to treatment. Yet, part of the culture refuses this type of treatment and prefers traditional medicine, including herbal and diet therapy. In the same context, some patients seek the care of spiritual and religious healers and some visit the holy places seeking a cure. It is difficult to judge spirituality or religiosity as right or wrong, but certainly, both have considerable effects on most of the population. In a study conducted with the elderly in a city in Brazil, religious practice was reported by 94.27% of the participants. According to this study, spirituality and religiosity are important sources of emotional support, influencing physical and mental health.⁷ The role of faith is paramount for Muslims, as Islam views life as short and finite, and death or illness as tests of faith. Prayer assumes a vital role in the diagnosis of cancer and at end-of-life. Reading the Quran at the dying patient's bedside and supporting and visiting his family frequently seems to be of great help.

Other religious groups, such as Christians and other minorities, have their own coping mechanism, and the church can help and support its followers by group prayer and spiritual counseling by the chaplain. The family of the terminally ill child may find comfort, hope, and strength when talking to a chaplain.

Terminal elderly patients usually die at home, while the majority of dying children die in the hospital, even if the sick child asks to go home, as parents usually try to avoid dealing with the terminally sick child and the process of death at home, thinking that he can be saved in the hospital. Talking about death and existential ideas with the dying person is something forbidden and disrespectful.

Lastly, health care in Iraq has witnessed a critical regression in the last three decades, in parallel with political and economic troubles, and is struggling to provide basic diagnostic and therapeutic facilities. Hence, the idea of palliative care seems to be a “luxury” in these difficult circumstances. Those in power, and decision-makers, may thus think that budgets from the Ministry of Health or from NGOs should be spent on buying essential medicine rather than improving QoL or decreasing the suffering of patients. Community awareness is very important, and even among the medical community, the palliative care terminology is still embryonic and is confined to oncology services.

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Cultural Challenges in Implementing Palliative Services in Emerging Countries

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Special Edition
"Palliative Care and Oncology:
Time for Increased Collaboration
and Integration"

Short Communication

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Cultural Challenges in Implementing Palliative Services in Emerging Countries

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ABSTRACT

Palliative Care is Unique: It is a new specialty that helps patients and their families as fully as possible when faced with a life-threatening illness. The population is aging which means more people will need Palliative Care (PC) services in the future. Palliative care responds to the population's health needs and helps to build a bridge for better understanding amongst all people. Palliative care involves the belief that no life is disposable or dispensable and that each and every human being deserves to be heard and helped. The scope of palliative care is the quintessential scope of the culture of peace.

Background: We have to respond to the needs of public health and provide services of optimal care. To establish a palliative care system in Palestine, it is necessary to identify barriers to provide palliative care service to the patients who are suffering with cancer or chronic illness during treatment or at end-of-life.

Aim: The aim of this study is to identify barriers against providing palliative care in Palestine from nursing perspective.

Methods: Family questions, staff and informal discussion, communication, attitude, psychosocial and emotional needs have been noted as per author's direct observation and experience. The study was done at Pediatric Intensive Care Unit (PICU) at Makassed Hospital, East Jerusalem between February 2014 to February 2017. The study is prospective and descriptive in design.

Results: The findings of this study are based on views and perceptions of patients as well as the health professionals regarding the challenges of providing palliative care which include lack of government strategies, lack of awareness among the professionals, insufficient training for physicians and nurses, family concerns about cost and inadequate financial coverage from health insurance. To establish structured palliative care services, we need to meet the challenges and remove barriers by enhancing knowledge and awareness of healthcare professionals, educate professionals and develop updated standards and treatment protocols.

Conclusion: In Palestine, there are no palliative care services or any other related services or support towards patients and families, especially in case of life-threatening conditions in case of emergency.

KEY WORDS: Palliative care (PC); Barriers; Culture; Quality; Education; Chronic.

INTRODUCTION

Palliative Care (PC) services in the healthcare system in Palestine still remains undefined, with in-existent home care, lack of rehabilitation program and inefficient insurance. The healthcare system in Palestine is unable to meet the needs of its population, forcing patients and their families to rely on international aid in order to receive medical attention. The healthcare system is not equipped to confront many of the devastating illnesses from which the population suffers. Most of the time, the only solution for patients is to request a referral to a Jerusalem hospital, which is only possible if the necessary permission is granted by the Israeli Government.

As a Head Nurse in the Pediatric Intensive Care Unit (PICU) at Makassed Hospital East Jerusalem, I have observed the economic challenges, the patient's efforts, and the suffering of the families. They are unwilling to discuss and accept issues related to death due to the lack

of family health services and adequate methods of pain relief. This situation should be improved by introducing an awareness of a holistic approach to patient and family needs. Caring for a critically ill patient is always stressful and difficult.¹ Planning must be made for end-of-life that should be dignified. Because of increased mortality rates and the admission of adults as well as children with life-threatening illnesses to the Intensive Care Unit (ICU), palliative care is essential. We need to have a palliative care team that offers referral services to community agencies for practical services and provides community resources to help meet family needs and strengthen coping strategies for family members assisting in the treatment and care of their loved ones. Untreated pain leads to greater suffering and further complications, resulting in longer hospital stays and greater costs to families.

BARRIERS TO PALLIATIVE CARE

Barriers to the provision of palliative care is a major problem. Governmental health ministries and non-governmental organizations (NGOs) have to standardize and coordinate palliative care services and educate healthcare providers.² Palliative care services do not exist because of a lack of Government strategies.³ Cancer incidence and death rates are rising, and unfortunately many patients are diagnosed in advanced stages of their illnesses.² Palliative care is an important public issue due to aging of the population.⁴ The increase in the rate of cancer in Palestine is partly due to lifestyle factors such as heavy smoking and less physical activity levels, which increase the risk of cancer.⁵ One barrier is a general lack of awareness among the professional caregivers and the general public about what palliative care is.⁶ They think that palliative care is for people close to death. Healthcare providers are influenced by their own cultural and personal values; patients rely on physicians to guide them in end-of-life care, but this care is usually requested by relatives. Unfortunately, there are numerous problems in making early diagnosis because many patients become late in their checkup and have advanced stage of cancer.⁷

There aren't enough adequately equipped public hospitals because of limited resources. In our culture, decision making is family centered.⁸ Illness is shared with the family and is linked with not losing faith in a cure.⁹

LIMITED PROFESSIONAL TRAINING IN PALLIATIVE CARE

Physicians and families often feel that withholding information is in the best interests of the patient.⁹ The family is responsible for managing the information and patient treatment during illness.⁹ Medical professionals focus on curing the disease, which limits palliative care development.² Many patients with chronic diseases suffer unnecessarily during treatment and at their end-of-life.¹⁰ All patients should have a right to get palliative care services.¹¹ Our challenge is to provide a healthcare service that is equivalent and accessible to all individuals in the country. The family is concerned with the cost of treatment and worried about

inadequate financial coverage by health insurance, insufficient training of physicians and nurses and a lack of familiarity with various prognostic tools.¹² Additionally, there are strong cultural and social attitudes against talking about death; some family's view on discussions about end-of-life and are just limited to not giving up hope, and are not comfortable with end-of-life conversations with physicians.¹³ However, the family wants the physicians to be accessible and to provide honest and complete information, and not to give prognostic information to patients, which may lead to false hope and feelings of anger.

Barriers to palliative care are a major health issues. The Makassed Islamic Charitable Society Hospital is considered one of the leading medical institutions in Palestine. Currently, it has a staff of 750 employees, which includes 48 specialized doctors and consultants, 74 residents working in the training program sponsored by the hospital, 3 emergency doctors, 344 nurses, 77 technicians, 146 administrators and 40 hired employees. As the Head Nurse of the PICU which cares for children with a chronic life-limiting illness, the work can be emotionally and physically challenging. Just as families struggle with whether they are making the right decisions or not, care providers struggle as well. Increase in advanced medical technology and in dealing with chronic diseases in children prolong the dying process. Palliative care is thus essential in the PICU because of the increased mortality rate and the presence of life-threatening conditions in patients admitted to this unit. Palliative care helps patients and their families as fully as possible when faced by a life-threatening illness. It is a human right for everyone to receive pain relief and have access to pain treatment. Palliative care is essential in the PICU to provide relief to the children as well as their families from suffering.

WHAT NEEDS TO BE DONE?

As there is no organized structure for palliative care services in Palestinian hospitals, we need to develop teamwork to provide high quality care, to provide a support system, and to provide the best quality of life (QoL) for all individuals. We must focus on the ways that must help to decrease physical and emotional suffering throughout the life and to achieve the best mode of treatment for the patients and their families. We have to strive to make palliative care available for all.

From direct observation and experience as a Head Nurse in the PICU in Makassed Hospital, I believe that all family questions, staff and informal discussions, communications, attitudes, and psychosocial and emotional needs must be noted. Families are confused about trying to cure the patient's disease or just managing pain. There are no support services for the patients and family, especially in the case of an emergency life-threatening condition.

SUFFERING

I have observed how the patients and families suffer in different

ways. For example, they are unwilling to discuss the economic costs and efforts that must be made, and the issue of death due to the lack of family health services and adequate pain relief. The patient gets support from family members, not from professionals. We need a palliative care team to provide family education and to develop and strengthen coping strategies for family members assisting in the treatment and care of their loved one. Families and friends need a reliable support system to provide the best QoL possible for the patients at end-of-life.

Makassed Hospital is a referral hospital from the West Bank and Gaza Strip as well as East Jerusalem. The PICU that I lead at Makassed Hospital provides comprehensive services for a variety of critically ill medical and surgical young patients with acute life-threatening diseases or injury such as when an infant or a child becomes critically ill and requires complex surgery, or is in need of very close medical attention for any reason, the beds in the ICU are available to them. The PICU has 9 beds for medical and surgical trauma. It is a multidisciplinary unit which admits all children from newborns up to and including 14.5 years of age. Most of the time we also care for the family who accompanies the child. Because of the advances that have been made in medical treatment, more children with life-threatening conditions survive for a longer time and require a longer period of palliative care. In Palestine, it is common to get help from the extended family in caring for both healthy and ill children.

No patients' representative is available to help families, cope effectively with difficulties that may be present, or to help alleviate tensions. There is no training in palliative care at the undergraduate level; palliative care has not been integrated in their professional training programs.¹⁴

WHAT WE HAVE IN MAKASSED HOSPITAL

Previously, patients with chronic conditions failed to receive adequate care because of the poor quality of health services. Typically, the healthcare providers struggled and were left wondering if they did all they could, they feared death, and being confused. Nurses, too, struggle with difficult decisions that parents and families often have to make. Caring for the critically ill patient is always stressful: and,

Mostly we offer: Post-operative care for patients, pain control and management (as much as possible, but not enough), and recreational activities; support; however, mostly by family members.

What we have to do: We must respond to the population's health needs and provide insights into healthcare services and the needs of palliative care for parents, children and extended family. Palestinian hospitals lack palliative care. We need to provide a support system for family and friends to achieve the best QoL for patients and their families with a concern for comfort rather than cure.

CULTURAL AND RELIGIOUS BELIEFS

There is an increasing prevalence of chronic disease, with advanced medical technology prolonging the dying process. As technology improves, sick people are able to live longer, but this requires more effective pain and symptoms management at the terminal stage. Traditional families treat illness as a top secret. Parents and medical providers refuse to talk about issues of death and dying with children who have a life-threatening disease, although children are usually aware that they are dying.¹⁵ Thus, caregivers need training in understanding the psychosocial aspects of children and death, and the techniques of counseling. For example, the patient's siblings are often forgotten members of the family during the time that their parents focus their attention on the ill child. With services in place this could be prevented.

BENEFITS OF PALLIATIVE CARE

If we have Palliative Care Teams, large number of families will come to know easily about how to get involved in patient's care properly. Team members provide family education to develop and strengthen coping strategies for family members assisting in the treatment and care of their loved ones.¹⁶ This improves QoL by reducing or eliminating pain and supporting the patient, which also builds staff confidence and satisfaction.¹⁷ People with life-threatening diseases will live more comfortably. After looking at other models of palliative care, team members will offer referral services to community agencies for practical services and community sources to meet the family's needs. It will effectively manage and coordinate the care of the critically ill patients by maintaining high standards of care in the ICU. Services will improve for patients by continually evaluating the effectiveness of nursing intervention, by learning new skills, and by having families help loved ones to deal with issues of grief. Parents of chronically ill children will be involved early in discussions of daily scheduling and behavioral expectations to help establish realistic goals.

CONCLUSION

Doctors and nurses should have awareness and skills in the area of palliative care. When the physical condition of patient deteriorates, he/she needs palliative care and we must strive to make palliative care available to them. It must be available to all populations and be given by a team of people knowledgeable in end-of-life care. They should provide the best QoL for individuals, with a focus on life, not on death. Therefore, nurses and doctors need proper education and training to provide palliative care.

RECOMMENDATION

Palliative care is essential to relieve suffering in children, adult and families. We must try to do our best to improve access of palliative care in Palestine.

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Religious Cultural Sensitivity in Israel: A Case Study of an Orthodox Jewish Family

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**“Palliative Care and Oncology:
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Case Study

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Religious Cultural Sensitivity in Israel: A Case Study of an Orthodox Jewish Family

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ABSTRACT

The challenges of hospice care can scarcely be overstated, considering that the complexity of managing the physical, psychosocial and spiritual issues of the patient and of the family may seem daunting. The task becomes even greater when accommodating differences in culture and religious beliefs. This study focuses on a case of bridging cultural gaps by a 26-year-old medical student and his modern Orthodox Jewish family in Israel. The patient was diagnosed with aggressive squamous cell carcinoma of the tongue two months before. The authors joined the family as part of his palliative care team in January and accompanied them for 7 months until his death in July. The case was not only medically and psychosocially complex, but religion was an added factor which needed to be carefully managed. The family identified as religiously observant Jews, while the hospice team, although Jewish and familiar with the traditions, identified themselves as secular. The palliative care team worked with the patient and family to provide a course of treatment that was acceptable for both parties. The team worked to alleviate the patient's suffering and ultimately enabled the patient to have the death of his choice, at home with his family. Identifying as a member of an ethnic group, or as practicing a religion, does not necessarily entail maintaining beliefs that may be associated with ethnicity or religion.¹ As a team, we needed to be sensitive to cultural nuances and family dynamics so that the family felt comfortable to share their struggles of faith with us during their son's/brother's illness.

KEY WORDS: Hospice care; Culture; Israel.

INTRODUCTION

In an early conversation with the patient's mother, she expressed her wonder: “How can God do this to us?” and acted out her fury once the diagnosis was given. How does the care team regard this information? Does one ignore it or acknowledge this crisis of faith openly?

A pilot study by Sabar et al² indicates the potential for a better outcome when an increased focus is aimed at culturally sensitive care for patient's families. As palliative care professionals, we are aware of cultural differences and our need to tend to our patients and their family's needs with consideration for their culture. Koenig & Gates-Williams stated the importance of treating patients as individual unique people in the context of their support systems.^{3,4}

This case study highlights the struggles of a hospice team that delivers services to families throughout Israel – an ethnically and culturally diverse country in the Middle East.

CASE PRESENTATION - MEDICAL ASPECTS

The team consisted of a doctor, a nurse and a social worker, treating the patient and his family initially with palliative care and later with home hospice for 6 months until he passed away in presence of his family members and girlfriend beside his bed at home. He was 26-years-old, the youngest of 4 boys, one of whom was a physician, living at home with his parents, and in a relationship with a nursing student. Two months prior to our first meeting, the patient was di-

agnosed with aggressive squamous cell carcinoma of the tongue base, metastasis to the brain, lungs and right neck lymph nodes. A transnasal biopsy was performed, resulting in bilateral diplopia due to damage to the 6th cranial nerve. His oncology treatment consisted of Cisplatin and Fluorouracil, Cetuximab, and a series of neck-lymph node radiation. Initially, the patient was functioning at a level of Eastern Cooperative Oncology Group (ECOG) 2. His symptoms included severe headaches, oral mucositis grade 2, and constipation with no bowel movement in the previous week. This caused a decrease in oral intake and appetite. He refused tablets or syrups such as lactulose or oxycodone. Several treatments were suggested for constipation and headaches. The patient chose fentanyl citrate transmucosal Lozenge 600 mcg for headaches and breakthrough/incidental pain, 2 Tabs Bisacodyl 5 mg at bedtime, and Glycerin suppositories. The staff emphasized the importance of fluids and nutrition. A daily menu was introduced. Medical cannabis as cigarettes were used before bedtime. These changes proved effective in improving the symptoms, and the patient remained stable while our weekly visits continued.

Three months into our service, a positron emission tomography-computed tomography (PET-CT) was taken and the patient was found clear of disease. The oncology team decided on completion of chemotherapy, and continued Erbitux fortnightly.

Two weeks later pain arose below the left jaw and gradually worsened, radiating toward the neck, causing swallowing problems and limiting neck and face movement. During the fortnightly treatments, he was examined by an oncologist team, ENT specialist, and maxillofacial specialist, with no results. When hospitalized for Erbitux, acute renal failure and severe hypomagnesemia occurred, which was resolved. He was referred to a physiotherapist, and reported that it alleviated his discomfort. Over the next weeks there was marked weight loss, rising levels of pain and functionality deterioration: ECOG 3.

A biopsy was taken, indicating that the cancer was back. The oncologist recommended that the patient should return to the hospital to be fed with a nasogastric tube. Pembrolizumab was brought up as a treatment option. He refused to be hospitalized and fed artificially, but as his condition deteriorated he agreed to a nasogastric tube feed in the hospital. A few days later he requested to remove the tube and take him home. The team sat with the family, explaining the grave situation and available options. The family had chosen to try to obtain Pembrolizumab and continue treatment. This required transfer to a different hospital.

After 3 days in the new hospital, his condition deteriorated rapidly and he was adamant about going home. His physician brothered and managed to obtain a family consensus to bring the patient home on the condition so that current treatments would continue. The treatment consisted of Ranitidine 100 mgx2/daily, Dexamethasone 20 mg/daily, Metronidazole

500 mgx3/daily for 5 days, Fluconazole 200 mgx1/daily for 2 days, Ceftriaxone 1gx1/daily, PCA - Basal Morphine 5 mg hourly, Bolus dose of Morphine 10 mg every 10 min, and Midazolam 5 mg prn every 10 min for seizure. The palliative team arranged the treatment at home, with clear and concise instructions for treatment. Our goal was to enable the brother to be a family member assisting his brother, rather than a doctor. The patient arrived home late in the afternoon and passed away early in the morning in peace with his family at his bedside.

Psychosocial and Religious Cultural Aspects

It was clear that the patient was aware of his condition and prognosis. His main concern was for his family, aware of the central role he was playing in their lives and voicing these concerns to the palliative care team. "How will they manage the void in my absence"? In contrast, his family members seemed certain that the cancer was curable. The mother repeated that "a miracle from God" would occur. The father kept busy with the needs of the family - work, attending synagogue daily, running errands. While willing to assist in any way he could, he supported his wife as care-coordinator and refrained from joining the palliative team on their visits. The brothers were not involved in the early stages. The extended families met regularly over the weekend for the Jewish Sabbath and on Jewish holidays. The girlfriend was present at times and, while refraining from participating in conversations, was perceived as a family member. Everyday care and decisions were the province of the patient, while his mother executed the recommendations and instructions.

At first, upon receiving the all-clear PET scan results, his mother was certain that her prayers had been answered. The patient; however, was not convinced and when the facial pain began, he knew the cancer had returned. This was never mentioned in front of the family, since he chose to protect them. As the deterioration progressed, in a meeting with the palliative care team, the patient expressed his feelings that his family was complacent, and that none of them was acting as his advocate, not asking the oncologists the right questions. A family member – the physician – had to step in and take over. He saw the deterioration in his brother's condition and realized that he was dying. He had not expressed his opinion to the family. We realized the need to respect their preferences under the brother's guidance.

The palliative care team suggested a plan of action, namely, the patient discussed his feelings with his family. The meeting resulted in a list of questions for the oncologist and an agreement to implement a shared decision process.

We had a frank discussion with the patient about the possibility of a recurring cancer and his preferences in such a case.

A biopsy confirmed that the cancer had returned. Despite ongoing deterioration, the patient initially chose not to be hospitalized, against his oncologist's recommendation. The phy-

sician brother assumed his role as mediator between the patient, the family, the oncologists and our team. A family meeting was held in the hospital. The patient demanded that we should remove the tube and take him home. We sat and talked to the family immediately. This was the first time that the whole family was together for this conversation. It was clear to the palliative team and his physician brother that he was dying. The conversation was managed by the palliative physician. The family was in shock and disbelief.

They then decided that he should come home, on the condition that all the current treatments to be continued.

His mother prepared his room, even though he had been using his mother's bedroom as a sick room previously. Knowing that using his mother's bedroom would be his choice, the team asked if it would be possible to use her bed. His mother expressed concerns about the death occurring in her bed, but agreed. When the ambulance team wheeled him inside, he directed them to continue straight to his parent's room and to his mother's side of the bed. As the end neared, and the patient was unconscious, the team advised the family to move him to his own bedroom, so that he did not die in his mother's bed.

The hospice team and extended family were present at the final hours. Out of respect for the family's religious beliefs, we suggested chanting the important prayers. *Vidui* – the traditional Jewish prayer said before death was recited at this point. We also recommended farewells, and attempted to create a tranquil atmosphere. The palliative team stepped in and supported those who had said their goodbyes and chose not to be at his bedside as he died. He died peacefully at home.

After the death, the patient's body was turned over to the *chevra kadisha* for a ritual purification and he was buried in the local cemetery within 24 hours of his death as it is accepted Orthodox practice. The family then observed the ritual mourning period known as *Shiva* according to the accepted Orthodox practice in accordance with their beliefs. In conversations with the mother in the days following, she commented that she was "still negotiating her problems and issues of belief with God". In a follow-up conversation several months after her son's death, she sounded more at peace with herself.

CULTURAL AND RELIGIOUS REFLECTIONS

Cultural Reflections

This case was particularly complex. Religious practice and faith both played a part in the treatment plan and although they were never explicitly discussed, they were ever-present. One of the benefits for an Orthodox Jewish family of receiving treatment in an Israeli hospital is not having to navigate the challenges of cultural sensitivity on a day-to-day basis. Orthodox patients do not routinely receive general treatments on the Jewish sabbath or festivals and major hospitals throughout the country operate

on special Shabbat mode where non-Jewish doctors and nurses are available to perform tasks – such as writing notes or answering telephones - that are forbidden on the sabbath. They are also well versed in the Jewish value of *pikuach nefesh* – saving a life – which obligates a person to violate the Sabbath under certain situations. All food in major Israeli hospitals is kosher and under Rabbinic supervision. This supervision extends to Passover when the hospitals offer kosher for Passover food. Patients in an Orthodox family will find daily *minyanim* made up of doctors, hospital staff, patients and family members that allow them to participate in the obligatory thrice daily prayer sessions with a quorum of ten men. The sight of a man wrapped in his tefillin – the phylacteries worn during the morning prayer session – and attached to a mobile IV standing next to a janitor on break and a physician in scrubs finishing a shift unit is common in Israeli hospitals.

With this as the background, being the hospice team we do not need to navigate the basic religious needs of a dying Orthodox patient and are free to focus on the medical treatment and larger spiritual issues surrounding death. There is no need for a basic staff training on not making phone calls on the Sabbath or education about a patient's desire to change their medication to refrain from ingesting chametz during Passover. As a Jewish hospice team practicing in a Jewish majority country, there are certain things that patients expect from us that are not explicitly stated but implicitly understood. The mother felt comfortable to speak about her "crack in faith," despite the fact that we were a clearly non-religiously observant team because all of the basic needs of her son's care were taken care of. G-d and our relationship with him or lack thereof is part of the lexicon in Israel. If, despite our religious differences, a patient feels comfortable to have this conversation then we do our job as culturally sensitive practitioners. Health practitioners in Israel must navigate the presence of G-d in the lives of their patients. Had we been busy trying to secure kosher food, both the mother and the hospice team might not have had time or energy for a crisis of faith.

(It should be noted that whereas all of this is true with the modern Orthodox patient, with an Ultra Orthodox or Haredi patient this would not necessarily be true. Ultra Orthodox patients adhere to a stricter interpretation of Jewish law and will not necessarily rely upon the Rabbinic authorities that oversee general hospitals and in some cases request treatment only by religiously observant medical staff.)

The treatments that the family chose were aggressive. While that is partially attributable to the age of the patient, in our experience, Orthodox patients as a rule treat more aggressively. According to virtually all rabbinic authorities who follow *Halakha*, food, water, and oxygen are considered essential components of life that must be offered to the patient.⁵ In contrast with many medical authorities, according to many *halachik* authorities the insertion of a nasogastric feeding tube or a percutaneous endoscopic gastrostomy (PEG) tube is considered indispensable in providing food and water to the dying patient.

Therefore, when the oncologist and the patient's family requested the insertion of a nasogastric feeding tube after his transfer to the second hospital, the hospice team was not surprised and certainly had no objection. Nor did we feel conflicted when he asked for its removal. "If the patient is competent and expresses clear opposition to a feeding tube; however, this choice should be respected." (Ibid)

In this particular case – and in many families from Israel's modern Orthodox community, the family was not directly consulting with a Rabbi for day-to-day questions about what to do. Despite the fact that there were medical professionals in the family and the patient himself was a medical student, they clearly followed the mainstream Orthodox tenet of extending life at all costs. As the patient got sicker and neared death, we viewed our job as simultaneously, facilitating all of the treatments necessary that could allow for a miraculous intervention by G-d and preparing the family for the possibility of death without trampling faith. The mother's faith seemed to delay her understanding of her son's case. Her faith was in a coming miracle, since her religious perspective implied that God would not allow her son to die. We felt that this faith led to denial, which is common in palliative care situations. It is clear that if the patient were not orthodox and this was not the need of the family, we as secular practitioners that place medical standard of care above Jewish law would have acted differently in at least some of these areas.

GENERAL REFLECTIONS

Research shows that there is a growing need to overcome barriers in the delivery of hospice services. These barriers include cultural differences between healthcare providers and patients; cultural differences between patients approaching end-of-life and their family members; under-utilization of culturally-sensitive competencies designed to improve end-of-life care; language barriers; lack of awareness of cultural and religious diversity issues; exclusion of family members in the decision-making process; personal, racial, and religious discrimination; and lack of information to facilitate decision-making.⁶

This case demonstrates the multiple levels at which a hospice team strives to operate every day with every patient and family. The family in this case identified as religiously observant Jews, while the hospice team, although of the Jewish religion and familiar with the traditions, identified as secular. As an interdisciplinary hospice team, our care emerges from the assumption that patients deserve the best care possible. Equity

and equality are the cornerstones of care, and cultural sensitivity is crucial.

It is our responsibility as a hospice team to place the patient and family at the center of care. This patient was very clear in his desire to die at home. His family was clear that they wanted to use every medical intervention possible to prolong his life. In accord with changes and developments, we broadened our scope to include the various parties who needed to be involved, including the brothers, the hospital teams, and finally setting up a "mini hospital" at home, allowing the family to respect the patient's wishes to die at home while respecting the family's wish for the patient to receive medical care up to the very end.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Holistic Total Pain Management in Palliative Care: Cultural and Global Considerations

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Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Mini Review

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Holistic Total Pain Management in Palliative Care: Cultural and Global Considerations

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ABSTRACT

Pain is a significant symptom in patients with chronic and life-threatening illness. While pain is traditionally thought of as a physiological experience, total pain recognizes the interplay of psychological, cognitive, social, spiritual, and cultural factors that influence the pain perception and total experience. Comprehensive pain assessment and management are foundational goals within the scope of palliative care, and optimal management depends on addressing each domain of the total pain experience. An overview of the total pain experience is provided, and clinicians should consider psychological, cognitive, social, spiritual, and cultural aspects in assessing pain. Pain management also addresses all domains, and suggestions are provided which address pain management barriers and challenges. First, patients should be educated about the benefits of pain management and importance to adhere to the plan of care. Second, healthcare professionals need education in order to manage pain properly and should adhere to internationally recognized evidence-based guidelines to provide care. Third, barriers to overcome system issues need to be addressed, such as working with governments and Ministries of Health to increase opioid availability for those in need and to ensure that patients can have access to opioids whether in the hospital, home, city, or rural area. While pain is a complex phenomenon, a comprehensive management plan can alleviate suffering for patients and their families.

KEY WORDS: Total pain; Holistic; Palliative care; Culture; Opioid availability.

INTRODUCTION

Palliative care encompasses the physical, psychological, social, spiritual, and cultural domains of patients and their caregivers.¹ Physical symptoms can be problematic when they occur as patients have difficulty focusing on other quality of life (QoL) issues. Pain is one of the most common and problematic symptoms that occurs in conjunction with chronic and advanced illness and requires specific attention. Incorporating comprehensive pain services into any palliative program is paramount.² This review will address the multitude of culturally relevant challenges in implementing pain management services into a palliative care program. The holistic components of pain and their influences on the pain assessment and management plan, and pain assessment and management barriers will be discussed.

TOTAL PAIN

Total pain is a holistic experience that extends beyond the physiological domain and was first introduced by Dame Cicely Saunders in the 1960's. Total pain recognizes the holistic nature of pain and the interplay of psychological and social well-being, spirituality, and culture. Symptoms rarely occur in isolation; rather, they cluster with other symptoms and are influenced by the psychological, social, and cultural characteristics of the individual. These holistic aspects of pain are discussed in the following section.

PHYSICAL PAIN

According to the International Association for the Study of Pain, pain is "an unpleasant sen-

sory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.” While physical pain is the physiological component, this definition emphasizes the importance of the physical impact on the entire person.³ Other deleterious physical symptoms can occur in conjunction with pain. The most common of these is fatigue.⁴ Dyspnea, drowsiness, sleep disturbance, nausea, and loss of appetite are other physical symptoms that need to be assessed when an individual is experiencing pain.⁵⁻⁷ Depression is a common problem that also co-occurs with pain. Current research is focusing on underlying mechanisms that may be responsible for co-occurring symptoms, also known as symptom clusters. Most importantly, clinicians should recognize that pain may contribute to other symptoms; thereby, managing pain may eliminate other symptoms as well.

PSYCHOLOGICAL PAIN

Emotional distress, depression, anxiety, uncertainty, and hopelessness are all forms of psychological pain that can co-occur with physical pain with depression being one of the most common psychological symptoms.⁸ One systematic review indicated that the co-occurrence of pain and depression is approximately 36.5%. The more intense the pain was, the more likely the individual was to be depressed ($p < 0.05$). Patients with depression may use more affective words to describe pain such as *fearful*. QoL has also been shown to be worse in those with both pain and depression.⁹ Depression is also found to be a significant barrier to manage pain, underscoring the importance of managing depression in order to improve pain.¹⁰

According to the National Comprehensive Cancer Network, distress is an “unpleasant experience of a mental, physical, social, or spiritual nature.” It can affect the way an individual thinks, feels, or acts and can make coping more difficult.¹¹ Distress should be screened for each patient visit. While pain can be a reason for the distress, other reasons should also be noted as all factors can increase the occurrence and severity of the pain experience.^{12,13} In one study, concurrent physical symptoms and psychosocial distress occurred in patients attending a cancer pain clinic compared to those who did not attend the pain clinic.¹⁴ Clinicians should recognize that pain and distress commonly co-occur.

COGNITIVE-BEHAVIORAL INFLUENCES

Cognitive-behavioral responses to pain are additional components of holistic total pain. One cognitive response could be the patient’s failure to acknowledge the pain for fear that this represents progressive disease. Other patients may feel the need to *tough* and endure the pain. This cognitive denial of pain, which could be stemmed from cultural or spiritual beliefs, can interfere with optimal management. The cognitive-behavioral domain can also be positively used to address overall pain. Cognitive behavioral therapy that can be used to ameliorate pain in some patients includes building self-esteem, optimism, and mastery of pain control.¹⁵

Catastrophizing is another recognized cognitive trait associated with pain. Patients who exhibit this behavior ruminate or exaggerate their pain, and catastrophizing is commonly linked to depression.¹⁶ Cognitive-behavioral approaches should be considered in the overall pain management plan.

SOCIAL INFLUENCES

The social context of cancer pain is well-recognized. Pain can lead to social isolation, disengagement from meals and other activities, caregiver burden, and inability to afford analgesics to control the pain. Adequate social support is predictive of less distress, depression, and anxiety.¹⁷ The National Comprehensive Cancer Network (NCCN) Distress thermometer includes measurement related to social distress. Again, distress assessment should be incorporated into daily practice. When social distress is detected, psychosocial interventions, including education and coping-skills training may be useful adjuncts to medical management of pain.

SPIRITUAL AND RELIGIOUS INFLUENCES

Spirituality, defined as the need to be connected to a higher power, has a significant association with pain. Religion, on the other hand, includes the practices associated with an organized system. Spiritual and religious influences of pain may vary by religion and even by individual belief within a religion. For example, some patients may feel that God is punishing them, and that their reward in heaven will be greater if they endure pain. In the Muslim faith, some patients feel that pain is considered a punishment from God; however, Islamic teachings report differently.¹⁸ Spiritual and religious beliefs can therefore, be misperceived and influence how an individual perceives the pain and manages the pain. Often a religious leader or chaplain can explore spiritual and religious questions with patients individually, which can add to the overall pain management plan.

Hope is a concept commonly associated with spirituality and is an important component of most religious faiths. Studies reveal hope to be positively correlated with spiritual well-being ($p < 0.01$) and negatively correlated with average pain intensity ($p = 0.02$), worst pain intensity ($p < 0.01$), pain interference with function ($p < 0.05$), anxiety ($p < 0.01$), and depression ($p < 0.01$). Depression especially influenced this relationship, which reinforces the need to manage pain in a holistic manner.¹⁹

CULTURAL INFLUENCES

Pain expression is an individualized experience, which is influenced by culture or ethnicity. It can represent the individual’s conceptual meaning of pain, pain perception, and coping abilities. One systematic review found that some ethnic groups expressed more severe pain. Asians tended to normalize pain whereas westerners were more likely to seek help for their pain.²⁰ A second recent systematic review of 26 studies compared pain responses of African Americans (AA) to non-Hispanic Whites (NHW) and found AAs demonstrated lower pain tolerance.²¹

Another large meta-analysis of 22 studies found Asian patients to have more pain barriers compared to Western patients such as concerns about cancer progression, drug tolerance, fatalism, and pain management barriers.²² This could provide rationale for why Asians may try to normalize pain.

Overall, patients from some ethnic or cultural groups may have difficulty in communicating with their care-providers about pain.²³ Providers as well may have barriers toward patients who are ethnically or racially different than themselves. For example, in one study, Western Caucasian physicians were noted to underestimate pain in 75% of AAs and 64% of Hispanics.²⁴ These patients also reported suboptimal pain management. These overall differences underscore the need for a patient-centered approach for the management of pain.

PAIN MANAGEMENT BARRIERS

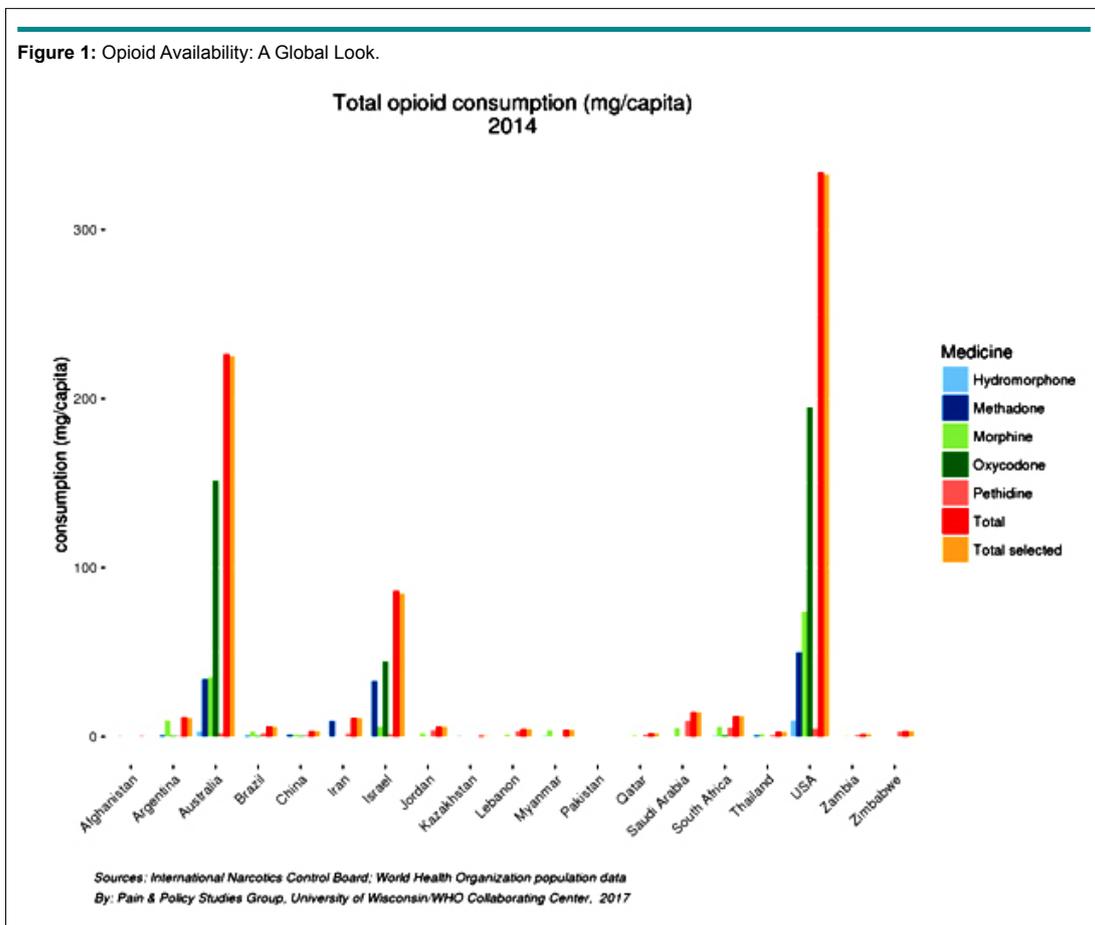
The holistic components of pain can strongly influence the individual pain experience. These influences can contribute to some of the major barriers that interfere with optimal pain management in many regions around the world. Pain assessment and management barriers commonly occur in most cultures and involve three levels: 1) patient and caregiver, 2) healthcare professional, and 3) systems. Sadly, these barriers have existed for

more than 20 years and have not been adequately addressed.

For patients and caregivers, stoicism, failure to report pain, and fear about addiction are common barriers. For health care professionals, failure to consistently assess pain, lack of knowledge about pain management strategies, fears of addiction and beliefs that pain is an inevitable component of cancer are common problems. When supportive care services are available for pain and symptom management, many patients may not even know they exist, because physicians and other professionals may not consistently refer patients to these services.^{25,26} In regards to systems, opioids and other management options may not be fully available in some countries. Opioid use outside of Western societies is minuscule in most of the world (Figure 1). Tight regulations through the governmental agencies such as the Ministry of Health can be a barrier for optimal pain management.²⁷ Additional efforts that address these barriers are imperative to achieve meaningful progress.²⁸

INTERVENTIONS TO ADDRESS BARRIERS

Multiple efforts to address pain management barriers are occurring around the globe. Education for all stakeholders is important to overcome both knowledge and attitude barriers. Education, guideline adherence, medication coaching, and addressing



fears of addiction and substance use disorders are all potential solutions for improving pain management quality.

PATIENTS AND CAREGIVERS

Educational Approaches

Educational efforts are occurring worldwide. The Middle Eastern Cancer Consortium has played a role to provide pain management education throughout the Middle East for the past two decades.^{27,29} Palliative care education includes the management of pain has also been instrumental in that same region.² Education includes conducting a comprehensive pain assessment and employing optimal management strategies for pain relief. Discussions should also ensue about belief systems regarding pain and fears of addiction which can assist to bridge the gap between suffering and comfort. Two systematic reviews (21 trials) and meta-analyses (15 trials included in one meta-analysis, 26 in another) found that education for patients, caregivers, and healthcare professionals can decrease pain intensity,³⁰⁻³² and the greater the dose of the educational intervention, the better the pain outcomes.³¹ In regards to patient education, repeated face-to-face interactions seem to be the most effective compared to written information.³³ When education is consistently delivered, sustained pain improvements have been demonstrated over time. Healthcare professionals should include pain education in daily care.³²

Education plays an important role in the overall management of pain. More studies and educational models should be proposed to suggest how best to implement educational interventions within the scope of care and to determine the combina-

tion of interventions that is most beneficial and cost-effective for patients and healthcare systems.³⁴

Analgesic Self-Management

One of the biggest patient level barriers is not following the pain management plan of care. Both patients and caregivers can influence the self-management plan. Common reasons for not following the plan are fear of addiction, forgetfulness, and untoward side effects. Studies found that analgesic adherence ranges from 49% to 91% for long acting opioids and as low as 20% for as needed pro re nata (PRN) opioids.³⁵⁻³⁷ Depression and older age were found to be predictors of not following the pain management plan in one study. Additionally, patients were unsure about what their exact medication regimen was comprised of and therefore, it was not followed.³⁶ Reasons for lack of self-management should be carefully assessed with patients and caregivers. Education about addiction, the importance of comfort, and clear instructions about the pain management plan should be provided. The overall message should not be paternalistic but rather coaching and collaborative.³⁸

HEALTH CARE PROFESSIONALS

Education

Not believing the patient’s report of pain is a significant barrier that can significantly impact the quality of pain management.³⁹ Health care professionals should have a therapeutic relationship with the patient, and listen carefully to the patient’s report of pain. While substance use disorders and addiction exist, the undermanagement of pain in palliative care patients is substantial

Table 1: Pain Terms to Know Data from American Pain Society, 2008; Federation of State Medical Boards of the United States, 2013; International Association of the Study of Pain; 2014.

Aberrant Behavior	Behaviors indicative of prescription drug abuse, some of which are more indicative of abuse or addiction.
Abuse	Use of a drug for nontherapeutic purposes to obtain psychotropic effects.
Addiction	A primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.
Diversion	Unlawful channeling of pharmaceuticals from legal sources to the illegal marketplace.
Illicit Substance	A substance that is not legally permitted or authorized.
Misuse	Use of a prescription drug without a prescription or in a manner that is not prescribed.
Narcotic	An archaic term for an opioid analgesic; currently the term is used by law enforcement to describe illicit substances with a potential for abuse such as heroin, cocaine, or methamphetamine.
Opioid	A medication that exerts its primary pharmacologic response by its binding to the opioid receptors in the central nervous system (CNS). This term is preferred to the term "narcotic".
Physical Dependence	A state of adaptation manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist.
Pseudoaddiction	Pattern of drug-seeking behavior in patients with pain who are receiving inadequate pain management; can be mistaken for addiction.
Tampering	Manipulating a pharmaceutical to change its drug delivery performance.
Tolerance	A state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug’s effects over time.

and professionals should advocate for better pain relief in their regions.⁴⁰ Understanding the differences between addiction, tolerance, and physical dependence, and understanding the differences of addiction and other high risk behaviors is the first step in overcoming this knowledge gap. A list of terms is included in Table 1.^{3,41,42} When clinicians have this knowledge, they can then educate patients and caregivers which will decrease some of the overall fears of addiction, especially in palliative and end-of-life care. Education has been shown to improve attitudes about pain.⁴³ Finally, education is important in improving health care professional knowledge and opioids, which opioids to prescribe, and co-analgesics that can improve overall comfort. Pain management is both an art and a science and requires specific education. Clinical guidelines are one way to educate clinicians and ensure that all patients receive consistent, quality pain management.

Clinical Practice Guideline Adherence. While a plethora of guidelines exist to assist clinicians in managing pain,^{41,44,45} studies reveal that only 22% to 45% of clinicians use a pain guideline.^{26,46} Some efforts are underway to encourage clinicians to use practice guidelines. In one study setting, nurse practitioners received weekly feedback on patient pain scores and how consistent their recommended interventions aligned with clinical guidelines. This audit and feedback intervention resulted in significantly less overall pain interference and interference with general activity and sleep. Satisfaction with pain relief increased significantly from 68.4% to 95.1%.⁴⁷ Environments and staff culture are important considerations prior to implementing evidence-based guidelines.⁴⁸ Electronic reminders and tools to translate guidelines into practice are additional strategies, but further work is needed in this area.⁴⁹

HEALTHCARE SYSTEMS

Healthcare systems around the world can interfere with quality pain management. Laws regarding who can prescribe opioids, which opioids are available, and access issues, especially for rural populations can significantly influence care. One of the most important systems issues is opioid availability, which is further discussed below.

Opioid Availability

Opioids are the mainstay of pain management, and yet opioids are not widely available in many countries. Opioids are usually regulated by each country's government, often the Ministry of Health (MOH). Historical problems with opioid addiction, other fears, and current use influence the amounts of opioids allotted in each country. Economics play an additional role. Some of the poorest countries in the world are often found to have the lowest opioid amounts per capita.⁵⁰ A recent analysis of global morphine consumption found significant disparity between high and low-income countries. Overall, 21% of the world's population (high income) consumed 92% of the total global morphine. And yet the majority of cancer deaths (70%) occur in low to middle

income countries (LMICs),^{51,52} demonstrating a desperate need to increase opioid availability and pain management efforts in these countries. However, richer nations can also have restrictions on opioids, and so each country should be individually assessed. Figure 1 includes opioid availability comparisons for a variety of countries around the world. To note is the high consumption of Western countries versus those in other parts of the world. Turkey has recently opened a morphine production plant, hoping to increase the availability of opioids in Middle East. Nurses and other health care professionals are meeting with their MOH to try and increase opioids in their respective regions in order to improve pain management in palliative care patients.

SUMMARY

A number of challenges interfere with quality pain management for palliative care patients. Understanding the holistic experience of pain is the first step in addressing the physical, emotional, social, spiritual, and cultural components of the pain experience. Once holistic total pain is embraced, addressing barriers is imperative to improve pain management efforts. Patient and caregiver related barriers, clinician barriers, and systems barriers.

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Delivering Palliative Care Education where there is Little Concept of Palliative Care: The Cultural Challenges

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Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Commentary

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Delivering Palliative Care Education where there is Little Concept of Palliative Care: The Cultural Challenges

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ABSTRACT

Volunteering to teach abroad in a country where palliative care is not well-established, either as a concept or service, is professionally stimulating and challenging. It provides an opportunity to learn about other social and healthcare cultures and challenges one's own views and attitudes. Sharing knowledge and skills with others, is a two way experience that enriches one's practice and provides motivation for change. It is also an opportunity for reflection and re-focusing for the busy professional and to be recommended. In this paper we seek to describe some of the challenges you may face and ways around them. We look at subjects such as the need to know and respect the culture we will travel to, explore ideas around truth-telling, concepts of honour and shame and training in countries where there are limited resources and opioids. We shall also comment on introducing new methods of teaching and making them relevant for different subjects. This is drawn from over 20 years of experience by volunteer educators working under the auspices of PRIME (Partnerships in International Medical Education), a UK charity.

KEY WORDS: Palliative care; Education; Teaching; Culture; Developing countries; Volunteer; Multi-disciplinary team.

INTRODUCTION

There are significant inequalities in the provision of basic healthcare in the world. Over a billion people worldwide lack access to even the most basic facilities, often because there are no trained workers. Palliative care and end-of-life care is recognized as an integral part of provision of good healthcare in many countries. However, where resources are limited it is often seen as a fringe benefit or not recognized at all.¹ Whilst delivering education in these circumstances is challenging, the transferable skills learnt can have far-reaching benefits in other areas of healthcare service provision. With sensitivity and humility, palliative care education can be delivered that is both culturally sensitive and relevant. In 2016 PRIME (Box 1) supported more than 100 tutors visiting 25 different countries and teaching over 4300 healthcare workers in a variety of topics.² You may find yourself in a position to be able to travel abroad to teach and this short paper seeks to share some of the cumulative knowledge that PRIME tutors have acquired over the years, beginning with:

Box 1

PRIME (Partnerships in International Medical Education) is an international network of professional healthcare volunteers, who deliver healthcare education. This education is based on the concept that the effects of illness impact on the whole person - mind, body and spirit - and attention to all aspects of the person are taught. PRIME tutors are Christian, however all the teaching is accessible and relevant to those of all faiths or none. The tutors fund their own travel and attend at the invitation of the host organisation.

Recognizing Where We are Coming from

We may live in a culture where palliative care has been established for a number of decades. Most of our colleagues and many of our patients embrace the benefits of palliative care in advanced symptomatic disease. Indeed society respects palliative care. We see advances in diagnosis and treatment leading to prolonged survival. We teach about palliative care happening 'early in the course of illness, in conjunction with other therapies that are intended to prolong life'.³ We recognize that we do not have all the answers and may therefore hesitate to volunteer. Maybe we are questioning how transferable our models of care and education are?

Having Some Understanding of What We are Going to: What We Need to Know

There are numerous pitfalls for the progression of palliative care for the unwary and uninformed. Here are some of the important questions we need to consider. Some may not be answerable until we have arrived. Many appear obvious and others less so.

What is the healthcare system, who delivers it and is it free? If not free, are people insured or do families incur debt to pay for expensive investigations and treatments, which may or may not have health value? What is the level of trust between the patient and doctor where healthcare is not free? How are the practitioners licensed and governed and what are their codes of conduct? What is the legal status of withdrawing life-sustaining treatments?

We operate in a society where choice, autonomy and individualism are highly valued. How is the diagnosis or bad news shared and with whom? What are the attitudes to nutrition and hydration, and how do people talk about life-prolonging treatments and stopping them? Can patients and families demand treatments? What are the societal and family rituals around death and bereavement? How do people make sense of pain? What are their expectations of confidentiality and privacy?

In many of the countries we have visited, we may become aware that honour and shame is of greater significance than truth-telling and guilt. This plays out in a wide variety of situations in which both parties will make cultural assumptions. Breaking bad news, place of death, classroom behavior and treatment of visitors, to name but a few, may all be affected.

Which palliative care drugs are available? When there is no morphine, teaching needs to be adapted to what is locally available. What are the beliefs and expectations regarding routes of drug administration? Are injections viewed as 'better treatment'?

What do our hosts expect from us? What do they want us to teach, and to whom? Are they doctors, nurses, allied healthcare professionals or volunteers and where are they

working? Perhaps they work in community clinics or people's homes or hospitals. How many will attend and is it in a lecture theatre, classroom, or around a patient's bed? Is the seating in the room fixed or can the room be changed to accommodate different styles of teaching? Perhaps we may find ourselves sitting outside under a tree in the shade.

What is the status and autonomy of nurses and other healthcare practitioners? Is multidisciplinary team working a concept that is understood or practised?

What language is spoken and read? Sometimes people will be able to read English but they would prefer teaching in their own language. A translator will need to understand medical terminology and we need to allow time for translation in our teaching. How will we get our slides translated? It can be helpful to have the English alongside the translated words on the same slide, keeping words to a minimum. What is the availability of teaching aids including the reliability of electricity supply and internet access? We must be culturally aware when using illustrations and photographs.

Finally, we need to be respectful in the way we dress and interact with our colleagues. Check about use of head cover for female visitors to Muslim countries.

As you can see these preparations are more than just finding out about the ethnicity, demographics and religion of the country. Without spending time answering these questions, we run the risk of our teaching being at best well-received but irrelevant, and at worst insulting. Remember hosts don't know what they don't know and polite enquiry and suggestion is better than proceeding in ignorance. We are now going to consider how we approach the education.

How to Teach About Relationships between the Healthcare Professionals, the Patient and their Carers

The palliative care concept of physical, psychological, social and spiritual suffering is promoted in teaching and the patient might be asked about their ideas, concerns and expectations. This involves respectful exploration of attitudes and gentle demonstration that there are alternative ways of working with the patient such as in partnership. This is in stark contrast to the biomedical model with the doctor or nurse knowing the 'answer' and the patient being required to simply listen and comply. In seeking to teach an holistic, compassionate approach to patient care this may be counter to both the professional's and the patient's and families' expectations. 'Why should anyone want to be interested in where I live, my family or that I have recently lost my job?' asks the patient. By recognizing the difference between patient and professional relationship and the power and prestige that is afforded the professional, we can sensitively explore alternative ways of providing care.⁴

We are frequently asked to provide communication

skill training and it may be framed as ‘Teach us how to tell the patient the bad news. Actually, normally we don’t tell the patient, we tell the family.’ You may be told, ‘When you are well you belong to yourself but when you are ill you belong to your family’.⁵

These apparent contradictions need to be approached with respect, great care and understanding of culture and the local financing of healthcare. The following story from a PRIME teaching session illustrates this:

When Mr A handed his doctor the slip of paper from the oncologist in the capital city, Dr M knew that her suspicions had been correct and that he had carcinoma of the larynx.

Then Mr A, who had not been ill before he noted his hoarse voice a few weeks earlier, asked her, ‘What’s wrong with me?’ Time stood still for them both.

What would Dr M do? A multitude of conflicting thoughts went flashing through her mind:

If Mr A knew the truth would he kill himself?

Would his family be angry and threaten her?

Would the oncologist feel that he had lost face in the eyes of the patient?

Was it against the law to tell him?

Dr M was prepared as she told him, gently, step by step with time for him to ask questions and to indicate if he had heard enough.

Two weeks later at a training meeting a few of us go with Dr M to visit Mr A and his wife.

What might we find? We had heard that his wife had indeed been angry.

We enter their backyard with trepidation. They are expecting us. There are smiles all round! Mr A’s wife is particularly warm to us and explains that initially she had been angry. However, when she saw how much calmer and at peace her husband was and that he now had hope she knew that it had been right to tell him.

We return to the training meeting and Dr. M shared the full story.

The initial response was... SILENCE....followed by:

“How could you?” “What if someone asked me?” “What would I do?”

Truth Telling

When a situation such as this arises during a training, we might create a safe discussion of pros and cons of truth-telling or perform a role play where the family’s view is respected, in order to explore these issues. Some attendees will recognize that there are times where telling the truth is beneficial to the patient and

family and carefully start to practice this way. Understanding the barriers is wise before launching into any discussion of the ethics of autonomy, or models of truth telling.⁶ Whilst truth telling is often cited as a difficulty, the ease with which spiritual or faith-based conversations occur may surprise the tutor, particularly in countries where openly practising one’s faith is the norm. Also, where family relationships are strong and there are large families it is usual that the family will provide the care at home.

How to Teach About Relationships between Ourselves (the Visitors), and Those We are Working Alongside

In order for our teaching to be acceptable and relevant, we need to adapt our teaching styles to the country we are visiting. A lecture is likely to miss the mark. An interactive, learner-centred session will be more likely to work for student and educator, providing the teacher has done the necessary homework and planning. PRIME not only promotes whole person care but also interactive teaching. This is often new in cultures where the didactic model predominates from primary school to university, where teacher is right and to be honoured and the learner is probably wrong and should listen and take notes. Experience has shown, particularly with the truth-telling issues that clinical case-histories, role play, quiz games, people’s stories and discussion will communicate best. Indeed, admission of fallibility in the educator may win credibility with the audience. This leads us onto looking at how we might introduce the concept of multi-disciplinary team-working.

The World Health Organization (WHO) states that palliative care ‘uses a team approach to address the needs of patients and their families’.³ In countries where palliative care is well established it may or may not be the doctor who leads care. We may find ourselves in a culture where there are pre-existing gender-based, academic, professional and educational level hierarchies. The best approach is to explain the role of the multidisciplinary team and then to illustrate this with a complex case that could only be palliated with the input of multiple professions acting on an equal footing. Simultaneously, the visiting teachers should role model multi-disciplinary respect and interactions within their team in front of their host audience. We will have succeeded when we get suggestions and questions from students and all professions present. You should not be surprised if you have to work to establish professional, clinical and educational credibility even if you have a degree or diploma in palliative care in your own country that has equal standing with other healthcare qualifications. Another model of education is mentoring as in the Integrate Project in Africa⁷ and is best described by Lao Tsu from 700 BC: “Start with what they know, build with what they have and work with the best leaders so when the work is done, people can say ‘We did this ourselves.’”

How to Work with Competition for Limited Resources

One must be aware that palliative care education may not be the highest priority for funding. When resources are limited we

may only reach a very small nucleus of motivated health professionals in the first instance. We are not discouraged! We may not be able to demonstrate an improvement in key performance indicators, but we will have shown that we care about the people enough to volunteer, and that matters. Feedback confirms that attitudes and practices have changed. Don't underestimate the value of going and being 'present'.

How to Take Account of Restricted Access to Medication and Opiophobia

Our own practice is likely to be in a culture where drugs for control of symptoms and strong opioids are freely prescribed. Opiophobia (fear of morphine) and a complete lack of any strong analgesic can be immensely frustrating. Whilst morphine is on the WHO essential drug list,⁸ there are still some countries where the government does not have a developed drug regulatory system to allow safe storage, transport and prescribing and it is not available.⁹ Where morphine has limited availability there may also be fear of prescribing it, or it is poorly prescribed, resulting in reduced clinical effectiveness. People may be reluctant to use it believing they will become addicted and that morphine promotes an early death. Most other drugs are usually available. If you are teaching away from main centres then delivery methods such as infusion pumps may not be available and you may be requested to teach how to use donated equipment. One needs to be mindful of the lack of servicing and consider the risk *versus* benefit principle of providing training for this.

SUMMARY

In summary, palliative care is universally important and there are good reasons for teaching, mentoring and educating in other countries. The key is to stop for a moment, be aware of our assumptions and the limitations of our 'western' model. PRIME provides training in interactive teaching with minimal resources. The whole person approach is not exclusive to palliative care and should be indicated in any healthcare encounter. We should be flexible and patient when our ideas of teaching timetables and topics change, time keeping is not what we expect, or a logistical situation frustrates us. It is unlikely that after our input there will be immediate changes in nationwide palliative care policy or that the government will suddenly divert large resources to this. Rather, we may be sowing a seed with one or two individuals who may become national palliative care champions in time.

CONCLUSION

When approaching an educational initiative in a country where we believe palliative care is unknown or poorly understood, it

behooves us to reflect upon our prejudices and assumptions. We need to be open-minded and attend with a willingness to share and learn together.

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CONFLICTS OF INTEREST

All the authors are volunteer tutors for PRIME.

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Cultural Aspects of Palliative Cancer Care in Iran

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Special Edition
 "Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"

Systematic Review

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Cultural Aspects of Palliative Cancer Care in Iran

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ABSTRACT

Palliative care is a human need, which is essential for patients with chronic disorders such as cancer, and aims to prevent and relieve pain and improve the quality of life (QoL) of patients and their families. Since culture is an important factor in predicting health behavior, it can be effective in providing these services. Thus, this review study has been conducted to assess the cultural aspects of palliative care in Iran. The findings were classified and provided based on the definition of palliative care on three major topics including early diagnosis, during treatment and disease period, and finally death and later. In the beginning of diagnosis, the most important element of palliative care is informing the disease to the patient and family. Disclosure of the disease in Iran is not culturally possible. The most important cultural barrier is cancer stigma in Iran, which affects the related measures such as screening diagnosis. The most important challenge in the treatment is pain management, which overshadowed factors such as cultural beliefs. Despite the challenges in the diagnosis and treatment of patients, which make the care difficult, the religious and spiritual context of Iranian people in the death and bereavement, as well as the strong family connections, are considered as a strong point that is helpful in the process of passing from the stage. According to the statement of the Union for International Cancer Control in 2008 based on "a better attitude toward cancer by 2020 and removing misconceptions about the disease", the available cultural opportunities in the country can be considered as areas in need of strengthening. The negative attitudes and beliefs can be reformed by adopting strategies such as increasing the awareness of the community as the first strategy in changing the culture.

KEY WORDS: Palliative care; Culture; Iran; Cancer.

INTRODUCTION

Cancer is the third cause of death in Iran after heart disease and accidents.¹ According to global statistics of GLOBOCAN, more than 85,000 cases are reported and it is projected to have an ascending trend over the next decade due to increasing life expectancy and changing lifestyles. Considering the fact that this amount is estimated as much as 1,56,000 people by 2030,² it will become one of the major health problems in Iran.

Since cancer patients experience many difficulties in all aspects of their lives, providing a comprehensive system in the form of a supportive and palliative care is required to avoid the influence of the negative consequences of the disease and improve the quality of life (QoL) of patients.¹ Palliative care is the set of measures that aim to improve the QoL of patients and their families, in order to solve the problems caused by the disease.³ Palliative care is a holistic approach, which considers the physical, mental, social, and spiritual aspects of patients and their families and it is provided at the time of diagnosis and after death for their families.⁴ Presenting these services depends on various factors such as the economic, cultural and social status of every society.⁵ Therefore, providing palliative care regardless of cultural, anthropological, and even linguistic and semantic considerations not only do not reduce patients' pain, but also do not work anymore to relieve it.⁶ Cultural factors overshadow their behavior by affecting attitudes toward health and disease and it is considered as an important factor in

treatment decisions especially in the end-of-life care. Iran is not excluded from this issue and the Iranian culture that will be dealt with in the following has a strong influence on such care. The fear of diagnosis leads to the lack of screening and the patient and the family would not be informed due to the concern of creating mental and spiritual distress in the patient. In such circumstances, it is clear that palliative care would not be possible easily. Even in the treatment stage, factors such as beliefs, cultural beliefs of different people with different religious and spiritual backgrounds and attitudes of individuals affect providing such services. Accordingly, this study was conducted to evaluate the cultural aspects affecting the palliative care at the time of diagnosis, during treatment, when dying, and after it in Iran.

Iranian Culture

Iran, with an area of 16,48,195 square kilometers and a population of nearly 75 million people and the official language of Persian and religion of Islam is located in the southwest of the continent of Asia and it is one of the Middle East countries.³ Iranian culture covers centuries of knowledge, wisdom, traditions, and customs. Thus, it can affect people's life in many aspects of life. Iranian population, due to the passage of historical migrations has ethnic diversities,⁷ which has led to the formation of subcultures. The geographical location of Iran and the onslaught of different ethnic groups with different languages and religions during the past 3,000 years have led to the deployment of three Aryan language family, Sam (Arabic, Hebrew, Assyrian) and Urals, Altai (Turkish and Mongolian) as well as religions such as Zoroastrianism, Jewish, Christian and Islam in Iran⁸ whose impact can be observed in the health behaviors so that different beliefs about the pain and mourning rituals of different ethnic prove this.⁹ On the other hand, given that the majority of Iranians are Muslims in particular, Shi'a and the national and official language is Farsi (Persian), these factors play an important role in cultural homogeneity between the different ethnic groups in Iran.⁸ In fact, the Iranian culture is the result of Iranian ethnic minorities' culture.⁷

Analysis Method

This study aimed to find information related to the cultural dimension of palliative care in Iran, by searching SCOPUS, Proquest, Ovid, PubMed, ScienceDirect, Google scholar, and

SID databases, with palliative care, cancer, chronic disease, and Iranian culture keywords. In addition, a wide range of data from journals, books, and publications were used on the sites. Finally, 53 relevant papers were selected (Figure 1). Inclusion criteria were, 1) papers were published between 2000 and 2016, 2) papers should have a variety of study methods, 3) papers should have full text, and 4) Papers are in Farsi and English.

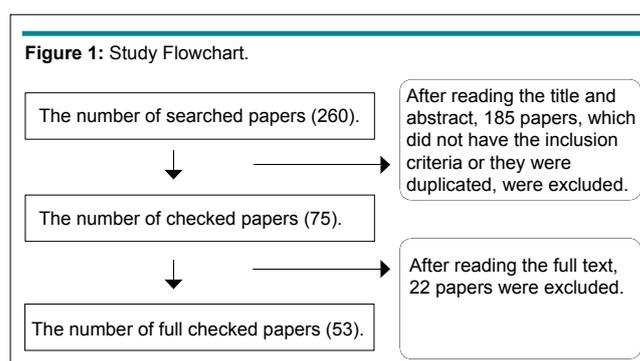
RESULTS

260 papers were obtained. 53 papers were selected based on the research purposes and inclusion criteria and the results express and the findings indicated that palliative care is provided in the three stages of diagnosis, treatment, death, and after death that culture is known as an important factor in its presentation. These three stages have been studied separately in the following.

First Stage

Diagnosis: Palliative care begins with diagnosis, which challenges the cultural factors to provide in two stages of screening and telling the truth to the patient due to the stigma of cancer in this country.

Cancer screening: Screening is a method for early detection of cancer in people with the aim of reducing the spread of disease and deaths from it.¹⁰ in the developing countries, fear of cancer, lack of resources and lack of effective knowledge in avoiding screening for cancer are involved.¹¹ The obstacles in Iran are factors such as fear of pain during mammography and its complications, high costs, lack of physician recommendation on mammography,¹² the diagnosis of a serious illness and fear of rejection by their husbands, family members, and friends. In addition, Iran's religious background was involved in this attitude so that belief in fate and the will of God lead to their reluctance to do preventive measures. The torment of women and shame due to religious reasons prevent them from visiting a doctor. Sometimes even self-examination is considered embarrassing and uncomfortable for them.^{6,9} It can be said that these behaviors are rooted in individuals' attitudes and they are affected by Iranian culture so that the result of the study on Iranian immigrant women in America was known as the most important factor of screening refusal.¹³



Telling the truth: Telling the truth in the medical profession is to provide the necessary information to enable the patient to make informed decisions about medical care and other aspects of life and informing him/her of the situation in which he/she is.¹⁴ 5 to 66% of doctors believe that revealing the diagnosis of cancer and its prognosis is essential for the patient,¹⁵ while 37% of cancer patients in Iran are unaware of their disease diagnosis and 93% are unaware of their disease prognosis.¹⁶ In Western societies, “individual possession principle” has confirmed telling the truth to the patient, but in Eastern societies “lack of harm principle” has a higher priority than the individual possession. Given the centrality of the family in these communities, truth is concealed.¹⁷ In some cultures such as the culture of the communities in the Middle East and especially Iran, hiding the diagnosis and prognosis of cancer patients is not uncommon. Even, the disclosure of cancer may be considered as a rude, disrespectful, and damaging action. Some cultures believe that speaking about the incurable disease, death, and end-life-care would become a reality.¹⁸ In Iran, people equate cancer with death, and they still have not broken the taboo.¹⁹ This has caused that most of the people even doctors rarely use the word of “cancer” in their speaking and they mostly use “illness” as an alternative.¹⁶ For this reason, the truth of disease is concealed in Iran and doctors say the disease diagnose to a family member.¹⁹ Although, studies have shown that, in most cases, this is done at the request of the family²⁰ because they believe that revealing the truth to the patient would lose hope and create additional distress.¹⁹ Some studies also showed that patients who do not know their disease have better life quality.²¹ Therefore, it can be said that the disease is highly considered as a family event rather than an individual event.²² For this reason, patients in Iran are primarily unaware of their diagnosis or they are the last one who becomes aware indirectly like seeing the folder, discussion with other patients, starting treatment such as chemotherapy, etc.³ However, the important point is whether the patients have a desire to know the truth or not? Several studies have shown that about 79 to 98% of patients want to know the diagnosis of their disease.²³

The lack of formal training for doctors and nurses to deliver bad news to tell the information to patients with incurable diseases such as cancer can lead to psychological complications, especially anxiety and depression. Due to the taboo of cancer in Iran, if the news is informed in an inappropriate manner, the patients and their families will never forgive the treatment team and this is done properly, they will forget the treatment team.²⁴

Cancer stigma: Stigma is the understanding and attitude of individuals from an unreasonably social judgment about a disease, which is highly influenced by the culture of that society. Factors such as imminent death, fear of symptoms and treatment, false beliefs regarding God’s punishment have made cancer a stigma,²⁵ which is interpreted differently by the required conditions of society and public opinion. It is also effective on the interaction of people with cancer patients, the patients’ attitude to their illness, and their response so that fear of stigma can be

a barrier to disclose a cancer diagnosis.²⁶ In Iran, most people avoid to disclose their diagnosis due to avoid attracting others’ sympathy, their curiosity, and the fear of losing connections. Even in cases, women hide their disease due to the fear of family members’ concerns, changing their role of parents and spouses, the stigma of cancer and its legacy for the future of their children, and fear of losing job and they cause delay in starting treatment. Although, other beliefs including self-treatment, traditional medicine, and attention to others’ recommendation cause delay in treatment, but the main reason is the cultural fields and stigma of cancer in the country.²⁷ In the field of cancer prevention, fear of stigma is a major obstacle in self-examination, screening, and delays in identification of cancer symptoms.²⁶

The Second Stage

Treatment: Palliative care in this stage is mostly focused on managing symptoms such as pain and supporting families because pain is a common symptom at this stage and taking drugs is an important factor in developing these services. Thus, this stage has discussed the cultural factors affecting pain management.

Pain and its management: Pain is an individual, subjective, and unique cultural experience and many factors have an impact on its experience that culture is one of them.⁹ Pain control is so important in the care of patients that the American Pain Society (APS) has introduced it as the 5th vital sign.²⁸ Pain in patients with cancer appears following primary tumor, metastasis tumor, radiation therapy, chemotherapy or surgery²⁹ and not only is influenced by biochemical factors, but also is influenced by psychological and social factors.³⁰ Pain created the most discomfort in cancer patients and it is seen in approximately 50-70% of these patients.²⁹ Uncontrolled pains in cancer are one of the causes that push patients toward suicide.³¹ Therefore, pain and its control are one of the major challenges that culture has a significant role in it.³² Pain management is a response individuals’ reaction to pain, which depends on individual beliefs and occurs in the form of behaviors such as drug seeking or no pain relief. On the other hand, understanding patients’ beliefs requires good communication, which one of the care challenges in Iran³³ and educational, managerial, organizational, and cultural factors are implicated in it.³⁴ On the other hand, different languages and dialects in Iran and the country’s religious principles because of the low relationship between men and women have doubled the problem.³⁵

Religious and spiritual beliefs are decisive as an integral part of the culture in understanding and managing pain³⁶ and they are known as a positive strategy for coping with pain. In Iranian mysticism, which is the origin of teachings of Islam, there are certain interpretations of pain and despite the emphasis on alleviating the pain and analgesia healthcare services, in some cases, not only people do not look for drug and treatment, but also seek voluntary pain because they consider the pain as a treatment and value.³⁷ From the religious view, pain and

suffering are atonement for the sins and the clearing agent for themselves and the community.³⁸ Even, there are beliefs that pain is from God. As a task, the human is committed to stand the pain. Pain is an anticipated form of life. Pain and disease arose from divine decree and wisdom and there should not be mourn and impatience in this process because its bearing will follow God's mercy and grace.³⁷ However, sometimes the lack of expression of pain is due to the family structure. Since parents are the pillar of the family, they do not express their pain to preserve the family and the lack of pressure on the family. This case is even seen in the different Iranian ethnicities certain races have greater pain tolerance and it is related to their culture.³⁹

Attitude is an important factor in behavior, which is rooted in the culture. Since taking drugs is essential in the management of cancer pain, negative attitudes towards opioids for fear of addiction is another pain management and palliative care challenges in Iran, which is a cultural challenge.⁴⁰ Statistics provided by The International Narcotics Control Board (INCB) regarding the consuming opioid analgesic showed that Iran ranked 115 in the world, 25 in Asia and 15 in the region is one of the countries with low consumption, which proves the claim.⁴¹ Although, one of the major reasons for this is the lack of knowledge and awareness of healthcare providers.⁴¹

The Third Stage

Death and bereavement: Palliative care ends by dying patients and 6 months after it, in which cultural factors is very effective on the two phenomena of death and mourning.

Death and dying: Death is the full and no return stop of critical actions. Patisson who provided a range of life and death theory believed that all humans have a trajectory based on the experiences and practices for their lives, but when a crisis arises, such as crisis awareness of death, the trajectory is changed and it passes three acute, chronic, and end stages.⁴² Iran is a country where about 98% of the population are Muslims, and death is one of the explained concepts in Islam.⁴³ Death is culturally well expressed in Iran and people believe that death is not only is not the cut off the chain of complex biochemical processes, but also the soul continues to exist in death and death is only a passage from this world to the other world.⁴⁴ This view of death and religiosity of the Iranian people leads to religious practices and worship when developing dangerous and serious diseases in the final days of life. From the cultural view, one of the cases in Iran that lead to peace or even slow death for patients with cancer is putting Quran overhead and bedside patient.³⁸ There are different rules in the Islamic Iran to provide a quiet death for dying according to a religious context. According to Iran's dominant Islamic jurisprudence, to provide a quiet death for the dying, those around the dying person are obliged to lie down the dying so that his/her feet are oriented toward Mecca. Sitting in front of the prayer, indoctrination if Declaration of Faith, reading verses from the Quran, not to leave along the dying, not to put heavy objects on the dying's chest and body, and not to

talk too much are the most important needs of dying person to overcome initial difficulties of death.⁴⁵ Therefore, to cope with the stresses of cancer and possible death, most of people turn to religious approaches to promote the mental health in patients.⁴⁶ Despite the negative attitudes of nurses towards death and dying in Iran, which is highly due to the lack of training for nurses and their academic curriculum in Iran,⁴ there are still many spiritual strategies used in oncology that has rooted in religious and traditional beliefs. For example, their belief in God, divine wisdom in the events, God's power in helping humans and power of the supernatural source, relying on the power of trust in God, and resorting to Imams and death as help them to show more adaptive responses.⁴⁴

Since in the dominant culture of Iranian society, it is preferred to perform the palliative care of the patient by families, especially in the final stages of life,⁴⁷ the death place is another challenge that is rooted in culture. Many families in Iran still want to receive services in their own homes. However, there is no evidence on the conducted studies that show the tendencies and preferences of patients with cancer in Iran.⁴⁸

Mourn: Mourn is one of the most common human reactions in all cultures and age groups in response to various types of loss, especially the death,⁴⁹ that one of the aspect of palliative care is care at the stage of grief and the most common reactions that occur including denial, believing disaster, a sense of abandonment and anxiety, the desire to meet and search for a lost one, grief and constant reminding of the deceased, anger, guilt, transaction and switching mourn conditions to get rid of deep inner sadness and chagrin.⁵⁰ One of the most important factors that can affect the bereavement process can be social factors, including the level of education, support systems, gender forms, especially in terms of and cultural, religious and ethnic fields.⁵¹ In Iranian culture, numerous ceremonies, funerals, religious and spiritual contexts and familial support in this period have a significant impact in preventing loneliness, coping with the loss of loved ones⁵² and this is one of the strength points.

CONCLUSION

Culture is one of the important elements in providing palliative care and has a huge impact on the development of these services in any society and its necessity in the International Union statement of cancer in 2008 based on "improving attitudes towards cancer in 2020 and removing misconceptions about the disease". Therefore, in the following also demonstrated identifying the cultural context of each society is necessary and this study aimed to determine the cultural aspects of palliative care in Iran.

The results showed that, religious background is a strong point for the development of palliative care despite the challenges in Iran and the results of studies confirm in Islamic countries.⁵³ In addition, misconceptions and negative attitudes towards the disease is rooted in the lack of knowledge as a major challenge

in the country that can be improved by strategies so that Daher et al. introduced education as an important component in changing the culture.²⁵ Therefore, the available cultural opportunities in the country can be considered as areas in need of strengthening. The negative attitudes and beliefs can be reformed by adopting strategies such as increasing community awareness as the first economic strategy in changing the culture in the form of public education and the importance of early screening in cooperation with charities, using media, training in schools as well as holding cancer campaign by the Ministry of Health, Medical Treatment and Education on the World Cancer Day.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Cultural Thoughts on Palliative Care in UAE

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ABSTRACT

The focus of this article was to highlight the influence of culture based on compiled notes and observations, that resulted following various interactions with the Emirati and expatriate care providers, in addition to the observed situations in a clinical setting, as patients and their families try to steer their way through the complexities of making decisions related to the end-of-life. The emergence of a new policy like "Allow Natural Death", may have brought a certain degree of relief to the clinical practitioners, but to implement this policy, many measures should be taken into account. Culture is one of the most important factors that influences communication, the decision-making process, and perceptions regarding wellness and illness. As a result, cultural factors must be considered while planning care and hospitality, especially in the treatment of terminal diseases. The real challenge lies in understanding the unique structure of the community and the work force in the healthcare sectors of United Arab Emirates (UAE). This article presents culture as a unique example to run a fully functioning palliative care service in UAE, where cultural diversity poses a challenge to the holistic approach we aim for when dealing with patients as individuals.

KEY WORDS: Culture; Palliative; UAE; Barriers; Cultural competency; End-of-life care.

INTRODUCTION

Palliative care demands urgent attention for many countries, especially the developing ones. As a matter of fact, according to the World Health Organization (WHO), all countries should have a standing program of palliative care services established by 2020. It should be a fundamental right of every human-being to live a life free of pain, and to improve their quality of life (QoL) in the shadows of chronic debilitating diseases. Since we discuss about a global emergency, it is important to mention that; according to the WHO Palliative Care Fact Sheet, July 2015, it was estimated that around 40 million people required such services each year, but only 14% of those people were actually receiving it.¹ This percentage could be higher when targeting countries that suffer from economic crisis, or deal with situations of political unrest and thereby serve as a major barrier for establishing and delivering palliative care. Such barriers were summarized in the WHO fact sheet as: lack of supporting policies, inadequate opportunities of palliative care educations or training, and finally, unavailability of essential drugs to eliminate pain and provide palliative care. These barriers are common to many countries which are struggling continuously to provide access to palliative care. An additional significant barrier that has been mentioned is the culture and beliefs of the population concerning death and end-of-life care.

IMPACT OF CULTURE ON PALLIATIVE CARE IN UAE

Culture is a term that describes a set of behaviors, norms, and practices that are adopted by a group of people with shared roots. Eventually, these practices have become a way of thinking that will influence their tendencies to behave and react. Culture and people share a reciprocal association such that culture affects people as much as human behavior affects the culture over time.²

For a better understanding, the present study will provide a brief overview of the existing culture and beliefs in UAE, before wading into the impact of culture on palliative care.

The United Arab Emirates houses a diverse and vibrant community. The residing population originates from a number of Arab tribes. Over the time, the existing community has started to diversify with the arrival of the Iranians in 1800's, followed by Indians (both Muslims and Hindus), especially in Dubai due to its prosperous pearl market, given its location on the coastline.³

The Emirati Arabic culture is a perfect blend of the Islamic, Persian and even Indian culture. This is evident in the architecture, dressing norms, cuisines, folk dances, and the usage of certain words in everyday language. But the Arabic Islamic culture remains the strongest, and the most obvious influence on the UAE community.

Palliative care has started to gain more attention in the recent years, as a part of a fast developing healthcare system that aims to meet the needs of the residents and citizens, with a vision of achieving the objectives of WHO 2020. But these efforts are hindered by different factors related to government policies, education and training of the healthcare providers and the complexity of the community served; that poses a challenge specifically to the health care providers. To be culture competent in providing palliative care, is a challenge in itself; due to the uniqueness of the community.⁴

Although, when a search is run in academic search engines, limited information on the Emirati culture will be available. Availability of literature related to the Emirati culture can be a concern especially in terms of health belief system, illness perception, or factors affecting the decision-making process when faced with an intense health crisis such as a terminal illness. Healthcare service is an open arena promoting interest for further research in the Arabic Islamic world. On the basis of a few existing studies, there have been observable similarities between Islam and the Arabic culture due to their common roots. The discussion in the upcoming paragraphs are based mainly on my personal interactions with Emirati citizens, and expat residents, of different age groups, economic backgrounds and occupational roles. I initiated discussions with the healthcare providers to understand their perspective towards treating patients and dealing with the involvement of their families.. Amid all these discussions, I observed that certain reactions are almost universal to terminal illnesses, and can also be projected on the general attitudes of people residing in the Arab world.

To facilitate the understanding of the cultural barriers faced in UAE to launch palliative care services in all sectors, I have clustered the findings of my observations, interactions and feedback into distinct themes. In each of these themes, I will reflect on the information available from international or regional literature, due to the lack of specific studies conducted on the Emirati culture.

I have concluded that most of the cultural barriers encountered during the launching of palliative care services in UAE, are evolving around the following themes: a shortage in

the national workforce in the healthcare sector, combined with heavy reliance on the expatriate's workforce, who face the difficulties of establishing cultural competency as holistic healthcare service providers. To add to the complexity of the situation, the healthcare service providers are expected to serve a multicultural community in return, not just the locals. These parameters give rise to the dilemma as to how public awareness of palliative care can be promoted and thereby accepted by the public in general with regards to cultural values and religious beliefs, especially due to the limitations in the availability of adequate information that addresses the Emirati family dynamics, and the influence of cultural values or religious beliefs on health/illness perceptions, consequently affecting the decision-making process under extreme situations of acute crisis. Interestingly, these themes seem to be quite interconnected, both enhancing and aggravating the effect of one and another.

CULTURE AS A COMPETENCY

In my previous article, I have talked about another type of barrier, the governmental regulations in accordance to which providing cardiopulmonary resuscitation (CPR) was obligatory regardless of the patient's wish, or health condition, and a strict zero-tolerance drug addiction policy was implemented, that indirectly affected prescribing drugs to cancer patients for pain management (Federal law No. 14, 1995). In this article, I will not discuss the myths and the lack of education concerning the usage of prescribed opioids, and how that indirectly affects the addiction stigma to a certain extent. But these policies will need to be further elaborated when educational needs, and governmental policies that can hinder the establishment of palliative care will be discussed.

Mainly, the rule for incriminating healthcare providers to not perform resuscitation on the patients including the ones who are terminally sick, or are about to die, has been considered as a big obstacle that forces the healthcare providers, to gear all their care decisions towards the active cure intentions, instead of focusing on comfort care and symptom management, as suggested by the WHO model. In September, 2016, finally, a royal decree was announced by the Ministry of Health, permitting the adoption of "Allow Natural Death" concept for those patients who are terminally affected by a debilitating disease.

This change in the policy structure has brought a certain degree of relief to the healthcare providers, but it elicited thoughts about how the public would perceive this concept? Especially, to implement the execution of such policies, that are being drafted currently to specify the guidelines for the end-of-life care by multidisciplinary healthcare providers by a task committee, requires qualified staff who are equipped with palliative care skills, which includes communication and the competency to break bad news. To make the public understand, you must be able to explain it, establish their faith in the healthcare system, and respect the patients irrespective of their cultural background. This is a big challenge to overcome on account of the lack of op-

portunities for such training and skills.⁵

UAE holds a small local Emirati population, estimated as 11.5% of the total population in 2010⁶ and a large expatriate population of different nationalities. Arabic is the national language, and English is widely spoken by the residents.

Looking at these figures, can help us draw a few inferences concerning the difficulty of the situation. Statistics confirm that nearly 6% of the work force among the citizens are involved in the healthcare sector, out of which only 1% of the healthcare workers are Emirati physicians, and those associated with the nursing field; mainly occupy administrative or managerial positions.⁷

Though this blog dates back to 2014, the recently recorded statistical data is not much different. This indicates that the population relies heavily on expatriates as a working force. The nurses working in the healthcare sector of UAE come from all over the world, mainly from India and Philippines. However, a smaller percentage of nurses may come from the Middle East, Somalia, Canada, Europe, and the USA.⁸

Having said that, a clear understanding of the cultural mesh in the emirates needs to be established to build a competency program that can help overcome such issues, but the investment to be made on an expatriate working force, residing mainly in UAE for a determined period of time, has to be planned systematically, depending on their contracts, or personal circumstances. Programs that need to be launched at a national level, demands momentum and the determination of the local residents, aspiring to build a program that they own, aiming at evolving it's objectives for the generations to come. Stability and consistency are needed, but it seems to pose a challenge to the introduction of a related program on account of a shortage in the number of Emirati healthcare providers.

A qualitative descriptive study was conducted in 2015 by Al-Yateem⁹ in the Sharjah university (Sharjah being one of the 7 emirates in federation), which clearly stated that nurses who come overseas in the pursuit of their careers, need a special training on how to deal with the Arabic Muslim population, with special focus on religious considerations, plus family dynamics and interactions according to social familial norms.

The previous study correlates to another study conducted by Halligan,¹⁰ though performed almost 10 years ago, because of the many shared similarities between the Emirati and the Saudi culture in terms of norms, and geographical proximity and religion. In this phenomenological study, the narration of 6 expatriate nurses working in critical care unit, were analyzed. The results revealed that the nurses felt emotionally stressed having to deal and communicate with the patients and their families. Family relationships and dynamics were crucial in providing care for those Muslim Saudi patients, and religious affiliation had an impact on the nurse-patient relationship, an influence on the patients' health, and was not necessarily always in alignment

with the international understanding of known policies. Though the setting in the study was of a critical care unit, but the level of complexity in making decisions and striking conversations, was ranked similar to conversations that took place in a palliative care setting, especially when discussing end-of-life care choices; such as advanced directives

I can relate such findings to a few incidents I have noticed in the hospital setting. The decisions concerning the planning of care were put on hold till the family members came together to discuss the issue of the patients. Older ages hold a special position for these discussions. Male patronage is quite evident, whether it be practiced due to their role as the care-taker, which stems from Islam, then slowly reformed or misinterpreted, because of social norms that leads to the dominance of males over females. Either way, the healthcare providers were stressed to go through such conversations of planning, especially when trained to provide patient-centered care, and then discover that it may not be the patient's wish after all. One nurse explained to me: "I am just never sure to whom shall I talk to: the patient? Or is it the husband? Or it could be the elder of that family such as a father, or even a grandfather". An Emirati nursing educator explained to me that this situation is similar to that for many other Arabic cultures, where respect is given by showing obedience to the wisdom of elders, and the guardianship of "man of the family". She continued to elaborate on the possible dilemmas that might be faced even within a family, before it even emerges as a point of conflict with the attending team: It is true that they can be wise, offering you the pearls of their life, but in healthcare crisis not all of them have enough understanding of the situation, thus, age is just a factor among many others". She explained that the level of education, background knowledge about medical conditions, and even personal interpretations of what is allowed or prohibited in Islam, can influence decision-making concerning palliative care on all scales. But of course, life and death remain as the most difficult circumstances to deal with, even for the highly educated members of the family.

This protective function of the family is also displayed while breaking a bad news. Many family members are still approaching the oncologist with requests to hide any details on the actual status of the diagnosis, believing that such news could devastate the patient's morale and strength to fight the unspeakable disease "cancer", holding them back from any genuine conversations that can affect the patient's wishes, or any such plan addressing QoL. Despite such circumstances, the hospital policies dictate the physicians to disclose the truth to the patients, regarding their health conditions, however, some hospital care service providers are unable to break the news on account of the pressure created by the family members. The realization that we are all here to make a living, and the tendency to avoid any conflicting situations with families (especially if they were Emirati focused on curative measures only), becomes a matter of paramount importance, in order to ensure the possibility of having a peaceful career combined with renewed work contracts and permits. This understanding often influences the response

of the healthcare providers, who find themselves compromising their duty of telling the truth to their patients. A much similar situation was existent in Jordan, except that we were determined that avoiding conflicts resulting from telling the truth to the patients, was not going to help us develop the national palliative care services for the long-term, and we all knew that we were not in the transient working phase of our lives, we were here to stay; so facing the circumstances were unavoidable.

INFLUENCE OF RELIGION ON PALLIATIVE CARE

Though religion is more of a spiritual belief rather than a matter of cultural significance, Islam as a religion regulates many aspects of the lives of Muslims. Religion guides the way of living of an individual and is not restricted to just rituals and practices. Eventually, religion becomes an integral part of culture, as many norms and values of virtue are derived from it. In addition to what is allowed or prohibited, many concepts of religion are mirrored by what is acceptable or rejected in the society, when deemed as favorable or not. For sure, this factor influences the decision-making process when discussing palliative care plans. An important pillar in Islam, is the belief in destiny, and accepting your fate (*Qada`awaQadar*). This has created two opposing concepts in an unexpected way, depending on how believers want to interpret it. One of the most difficult situations in palliative care is when communicating bad news regarding the anticipated or actual death of a patient due to terminal illness. The reaction would be total acceptance and submission to Allah's will, because it is destined or total emphasis on gearing everything towards whatever curative possible treatments exist, even if they may be scientifically proven as futile. But, the ideology behind doing "our best" becomes the mantra of such families, based on the belief that Allah, the most merciful is capable of performing miracles, leading to the acceptance of the destiny decided for the patients *having performed their duties*, understanding that whatever happens next is fate, and bringing relief to the patient following their struggle to survive. A majority of my encounters with the Emirati patients and their families, mostly adopt the second stance in such situations.

After several discussions, I have noticed that due to the wealth, and the generous financial support that the government has bestowed to the citizens, a majority of them have developed the attitude as "we will try everything, because we can". Unfortunately, having such a perspective can only add to the agony of some of the patients who are terminally ill, who are in some cases forced to go through chemotherapy or major surgeries without any gain, while the others will be spending their last few days away from home, if their families manage to get an approval for an overseas treatment. In the middle of such a drive, even the most skilled physicians cannot talk the patients through to gear the clinical process towards comfort care, finding himself to be alone with the patient, who in turn is torn apart between his/her wishes, and the hopes of being cured if they travelled abroad, or tried harder despite the given challenges.

It might sound confusing but maybe if I can narrate an

incident relevant to one of the encounters I witnessed, the reader can see what I mean.

I could not ignore the confused look over one critical care specialist; as he was trying to deal with the grieving family members, in total denial and shock, after hearing about the loss of their 87-year-old grandmother. They all had high hopes that she would get better, even if she was bedridden for 3 years, and in a state of coma due to a hemorrhagic brain stroke. At the same time, another bad news was conveyed to the same family. One of the grandsons was obviously on his way to say goodbye to the deceased, died in a car accident due to speeding. The physician thought that now the situation escalated to a whole new level, things would go out of control. Contrary to that, they were all very sad but calm, and in total acceptance of the grandson's death. The physician and nurses in the unit could not understand how everybody could be so shocked about the death of a sick debilitated woman, who was hospitalized all that time, but graciously accepted the sudden death of a 27-year-old man in a car accident? And the answer was: "It was his fate, he was speeding and got himself killed in an accident, but our grandmother was sick, and medicine is capable of so many things. We got her hospitalized to solve her health issues, we had hope and trusted the expertise of the medical team, and we know that we all have tried our best".

So with such a perception, comfort care may not be an option that most of the Emirati people would opt for easily. Let us not forget, that UAE has evolved in recent years in a tremendous escalation. The wealth gained from the oil, promoted the economic conditions of the country tremendously. This has reflected positively on the life of the citizens, leaving them with different options to choose from, including the availability of healthcare services. UAE has definitely proved that it can achieve a lot as a nation, from boosting economy to building skyscrapers. Driven with the confidence that they "can do anything", the tendency of the citizens to generalize this ability has tainted different aspects of their way of thinking. But ensuring good health is not something that can be obtained, with financial power or determination combined with positivity.

But here I have to interrupt myself, and say that the younger generations, who had access to excellent opportunities of education, were more open to the concept of palliative care, and comfort measures. Interacting with people belonging to other communities and societies through different social media channels, has instilled a sense of realism and awareness among the citizens concerning their medical abilities. Talking to the different Emirati people, made me realize that once the concept is explained in terms of religion, it is more widely accepted. Many of these young individuals have heard or read stories, some have even stated how watching certain movies made them aware of what QoL means, and how life limiting illnesses can leave you medically helpless (even in western countries which are considered scientifically and technologically advanced in terms of medical science) thus, directing a different course of action, based on a different way of thinking. But their great-

est anxiety was: is it Halal (allowed), or Haram (prohibited) to simply reject treatments if no benefits are gained? When asked, in their opinion, palliative care options seemed a favorable approach to implement in palliative care. Likewise, I observed the elders who often discussed matters as simple facts of life. According to their belief, when you are old enough, have seen enough, tried enough, it is time to leave in peace and quiet, as you cannot change what is destined for you. The people who I found to be quite argumentative, and quite opposing, were actually the middle-aged ones. I found it personally interesting, as those middle-aged people were actually the ones who witnessed UAE blossom in full radiance, without allowing any force from to hindering its growth. While the elders still remember the old days of hardship, and learnt patience, keeping their feet on the ground, the younger generation, has simply opened their eyes to discover life as we all know today. Again, these are personal observations, further studies are needed before we can draw such inferences.

And though, I have talked mainly about the Emirati population, but let us not forget that the patients belong to as diverse a community as the work force. So when we say we need to invest on building a program that can empower healthcare providers in managing cultural differences, it is important to consider how many cultures should be included for the training. Though in the program that addresses Emirati culture, the Arabic and Islamic values will get the highest priority, but from a pragmatic point of view, it will help serving a small percentage of the population in such a community. To be able to provide palliative care for all, the overseas workers not only have to know about Arabic Islamic values and Emirati culture, but also about the cultures of the people who are residing in UAE away from their countries. To be fair, workers who are Arabic and Muslim, or even those who are educated and raised in UAE, need to be aware of the customs and practices of the other communities. Otherwise, the holistic care that we are promising of in palliative care, will not be delivered. In certain occasional incidents, I found it even frustrating when the hospital could not find a translator to mediate the communication with certain patients, leaving us bewildered as to how the basic needs of such patients could be addressed this way. Communication skills to facilitate discussions concerning end-of-life issues require training indeed, however, the situation is further complicated by having to do it in a language other than your mother tongue, or by communicating with the help of a translator (when available) who even as a professional interpreter may lack the ability to initiate conversations on such sensitive issues as a third party.

To overcome the cultural barriers towards establishing palliative care, intense study in a related area becomes necessary. UAE offers a promising research avenue to explore marked by the uniqueness of the Emirati culture through the generations, and the diversity of the constitution of the community served, and the healthcare providers in service. Careful consideration and interpretation of religious scriptures should be addressed when introducing new concepts of palliative care. And finally,

the most important aspect to address in my opinion, is the sustainable development of the program, which cannot be achieved without the actual involvement of the Emirati healthcare providers, who will be driven by a feeling of patriotism to establish an effective program for their own community and others. The Emirati healthcare service providers will be a constant pillar of support to help provide palliative care services in an ever-changing working environment.

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Palliative Care in Moroccan Children with Cancer: What are the Parent's and Children's Needs?

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Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Commentary

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Palliative Care in Moroccan Children with Cancer: What are the Parent's and Children's Needs?

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Palliative care has been well defined by the World Health Organization (WHO) as a comprehensive care approach which "improves the quality of life (QoL) of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."¹ In 2000, the American Academy of Pediatrics (AAP) emphasized the importance of offering an integrated model of palliative care that continues throughout the course of the illness.²

Yet despite the fact that palliative care has been accepted as a human right, it is widely recognized that palliative care for paediatric cancer patients and their families varies across settings and resources.³

Morocco is a North African country with a total population of 33 million, considered as a middle-income country, ranked 126th out of 188 countries and territories in the Human Development Index (HDI). Paediatric oncology in Morocco was initiated about 30 years ago in two general pediatric units (6-8 beds in each) sustained by parents' associations (AVENIR and AGIR). In the last 10 years significant progress has been made, benefiting by the formation of the princess's foundation - the "Lalla Salma Foundation, Cancer Prevention and Treatment"; the development of a cancer control plan by the Ministry of Health; and international cooperation with the St. Jude Children's Research Hospital and the French African Paediatric Oncology Group partnership.

A report on palliative care in Morocco published by Human Rights Watch, in 2016 found that several positive steps had been taken by the government of Morocco in recent years to develop palliative care services and to expand access to analgesics. Significantly, the government released two national health policies that together set out a vision for the development of palliative care: it reformed the undergraduate medical curriculum to include a module on pain and palliative care, and it removed a large regulatory barrier to accessing opioid analgesics—strong pain medications that are indispensable for pain management.

However, the availability of palliative care in Morocco is very limited. Human Rights Watch (HRW) was unable to identify any palliative care services at lower levels of the health-care system, such as regional, provincial, and local hospitals. Although, some healthcare providers, particularly tertiary level hospitals, have integrated palliative care interventions into their general practice, HRW believes this to be the exception, as most facilities simply do not have staff trained in palliative care or access to key palliative care medications such as morphine.⁴

Since the publication of the HRW report, significant improvement has been achieved with the establishment of dedicated palliative care teams in certain adult oncology departments following international standards and guidelines.

The most relevant guidelines for children have been published by the national hospices

and palliative care organization, and by the AAP.^{5,6} They provide a framework and a certain amount of substance in the provision of adequate palliative care. Importantly, however, other specific factors, such as religion or beliefs prevalent in the country, can affect the attitude toward palliative care.

As a healthcare provider in pediatric oncology with 17 years of experience, we were never trained in how to manage or communicate with a dying child and his/her family in Morocco. We are not aware of their specific needs beyond the physical ones which have been well described in the literature.⁷

To assess the needs of Moroccan terminally ill children and their families, their parents were asked to fill out a questionnaire in a study conducted in the Pediatric Hematology and Oncology Institute of Rabat, Morocco. We interviewed the parents of children who were in palliative care regarding physical symptoms, psychosocial needs, and other issues related to death. Some 80% of the parents interviewed were mothers, and the children's median age was 11 years (range 5 to 16). Most of the cases underwent palliative care after a relapse. The parents interviewed were aware of the disease status, and that the objective had shifted from curing to relieving the symptoms and improving QoL.⁸

We are one of the most important pediatric oncology units in Morocco, dealing with about 300 new cases of pediatric cancer per year. Moreover, the lack of specialized palliative care teams with adequate human resources and financing makes the end-of-life situation a face-to-face interaction between the attending doctor and the patient and his/her family.

The parents were asked to describe their feelings in the above-mentioned survey. They mainly reported the anticipation of the death, resignation, surprise and sometimes denial. Most of them refused that we inform their child. However, they also reported that they indirectly discussed matters related to death with their child by referring to the death of another person or through a religious approach.⁸ Morocco is a majority-Muslim country where faith and religious beliefs are central in the culture. Islamic beliefs continuously remind humans to be prepared for death. As a patient reaches his/her final hours, the family often wishes that death occur with as little suffering as possible. Islamic theology does not allow anger at God as an acceptable response to suffering, although frustration and disappointment in the limitations of the medical interventions are acceptable.⁹

The impact of the Islamic traditions and practices in cancer care and the cultural consideration in palliative care has been reported in several studies. The authors emphasize the fact that Islamic societies are more accepting of death and acknowledge the inevitability of death.¹⁰ These cultural and religious

considerations should be taken into account when interacting with terminal patients and their families.

The interaction and the broader communication within oncology is a core clinical skill yet few oncologists or specialist cancer nurses have received the formal training involved.¹¹ Poor communication between practitioners and patients is associated with patient dissatisfaction with care, uncertainty, denial, anxiety, depression and poor psychological adjustment to the illness.¹²

Practitioners who care for cancer patients acknowledge that insufficient training in communication and management skills is a major factor contributing to their stress and emotional burnout.^{11,13}

In addition to these non-technical elements, which are crucial and require thorough reflection and consideration, the parents in the Moroccan study reported more specific and concrete needs⁸:

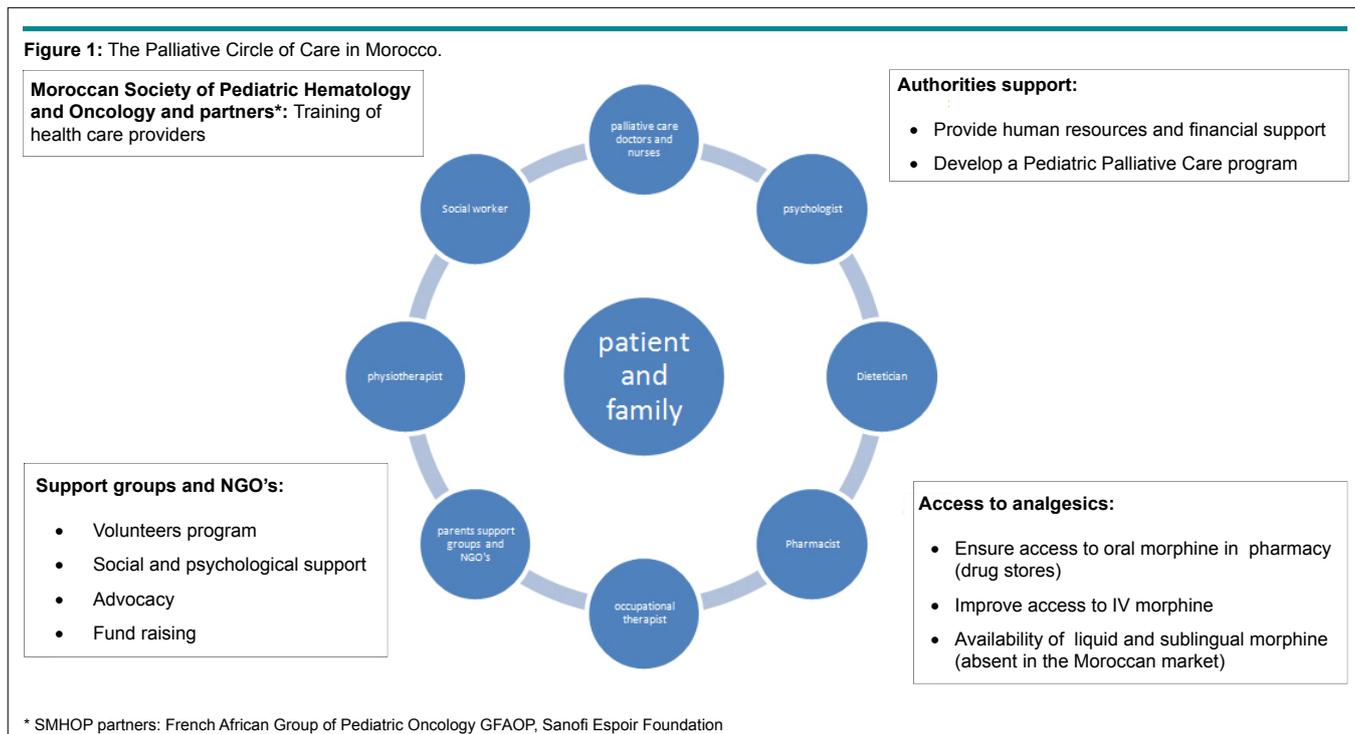
- Physical needs: The most reported symptoms were pain, fatigue, dyspnea, nausea and vomiting. The parents mainly requested improvement of symptom management and an alternative treatment line (chemotherapy, radiation therapy)
- Psychological needs: The parents wished to strengthen family links and resume normal life (school for the child, entertainment, etc.)
- Social needs: The parents requested financial support for daily expenses (transportation, medication, medical hardware, etc.) and for the child's entertainment (toys, computer, video games, etc.)

At the physical symptoms management level, significant progress has been achieved in pain management through a "My Child Matters" initiative complemented by the Lalla Salma Foundation Cancer Prevention and Treatment Project.

It is obvious that we need to accelerate the implementation of palliative care in pediatric oncology primarily by providing sufficient human and financial resources. At the technical level, we can refer to the international guidelines (Figure 1) and replicate the Moroccan adult program which is leading the way. However, developing a culturally-sensitive pediatric palliative care system is mandatory.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.



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Effects of Perception of Prognosis on Existential Well-Being and Ego-Integrity Among Advanced Cancer Patients

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Special Edition
 "Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"

Systematic Review

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Effects of Perception of Prognosis on Existential Well-Being and Ego-Integrity Among Advanced Cancer Patients

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ABSTRACT

Background: Based on literature review, advanced stage cancer patients hold over-optimistic perception of their prognosis. This phenomenon is presumed to be an implication of defense and coping mechanisms, aiming to alienate the proximity of death. At such circumstances, existential issues arise and when adaptive, serve as powerful psychological resources against distress and despair. The first purpose of the study was to investigate the influence of advanced stage Israeli cancer patients' perception of prognosis on their existential well-being. The second purpose of the study was to explore the role of ego-integrity as a mediator within the equation of perception of prognosis and existential well-being.

Methods: Two hundred and ten Israeli stage 4 cancer patients completed self-report measures of their perception of prognosis, ego-integrity and aspects of existential well-being: personal meaning, inter-personal meaning, death and dying anxiety, satisfaction with life and will-to-live.

Results: Positive correlations were demonstrated between perception of prognosis with personal meaning, interpersonal meaning, total meaning satisfaction with life, will-to-live and ego-integrity. In addition, negative correlations were demonstrated between perception of prognosis with death-anxiety and dying-anxiety. Perception of prognosis was found to be a predictor of existential well-being, so that the better the perception of prognosis the higher were satisfaction with life ($\beta=0.39, p<0.01$), will-to-live ($\beta=0.12, p<0.05$), total meaning ($\beta=0.22, p<0.01$), personal meaning ($\beta=0.24, p<0.01$), interpersonal meaning ($\beta=0.13, p<0.05$) and ego integrity ($\beta=0.24, p<0.01$). Furthermore, the better the perception of prognosis the lower was death anxiety ($\beta=-.24, p<0.01$). Moderating analyses revealed that only among patients low in ego-integrity a positive association existed between perception of prognosis and personal meaning ($\beta=0.30, p<0.05$).

Conclusions: The study highlights the significant effect of the perception of prognosis on existential well-being in advanced stage cancer patients. When death is imminent, an overestimation of prognosis has a role of preserving existential well-being. Also, ego integrity was found to be attributing for preserving existential well-being of people with terminal illnesses. In addition, the moderating effect of ego-integrity emphasizes its virtue as a source of resilience for the wholeness of the self at times of threat. A possible influence of cultural – ethnic attributes on results is discussed, thereby emphasizing the complexity of the argument, whether acknowledging one's death has a positive or rather negative effect on one's existential well-being.

KEY WORDS: Perception of prognosis; Meaning; Ego integrity; Cancer; Existential well-being.

BACKGROUND

Self Perception of Prognosis

People suffering from advanced illness tend to react differently to the actual threat to life. One of the overwhelming sources of such threat is the awareness of a life limiting prognosis.

Previous work on advanced cancer patients' awareness of prognosis concluded, that doctors frequently make errors in prognostication, usually towards optimism.¹ This is not surprising, considering that the topic of death and dying can be an area of discomfort for many health professionals.²

This over-optimistic bias in prognostication may, in part, explain why patients often appear to have unrealistic expectations of survival,³⁻⁵ and hold a far more overestimation of prognosis than their oncologists.⁶ For instance, studies revealed that 82% of stage 4 cancer patients perceive their prognosis as much better than their oncologists.⁷ It was also found, that awareness of prognosis is not necessarily an outcome of the information given by the physician.⁸ In addition, although physicians' propensity to discuss prognosis was associated with better awareness by patients, still rather few eventually articulated a realistic estimation of their prognosis.⁹

Several studies have consistently found evidence of over-optimistic perception of prognosis among advanced cancer patients. For example, when patients with advanced colon and lung cancer (facing a prognosis of 6 months or less), were asked to estimate their numeric probability of 6-month survival, more than 75% of the sample estimated their likelihood to be at least 90%.¹⁰ In a similar study, only 33% of the sample admitted awareness of the high likelihood of death from cancer within 5 years, and only 16% admitted awareness of death within one year.⁵ Thus, overwhelmingly, patients in both studies placed themselves into the most optimistic category provided by the instrument or interview. Moreover, several studies found that only one-third of the patients with advanced cancer recognized that their cancer is not curable even with treatment, whereas one third of patients perceived their cancer to be curable.^{4-7,11}

Since disclosure of terminal prognosis of cancer is a common norm in western countries, it can be assumed that it is not a matter of understanding the facts, but a matter of perception. Still, there are quite enough reports of significant numbers of cancer patients in western countries, who are unaware of their prognosis.^{12,13} Another reasonable explanation for the patients' over-prognostication may be the misleading relatively stable physical status at the time-point of prognostication, while when getting closer to death, patients are more likely to acknowledge being terminally ill.¹⁴

Several patient-specific factors have been considered as influencing the perception of prognosis, such as level of social support, spirituality, hopefulness, locus of control and other per-

sonality characteristics.^{4,15-18} Their actual contribution, however, is not well established.

For many years and even currently, the debate of whether the realistic awareness of having a terminal prognosis is helpful to the patient and to which extent, is still in contention. There are clinicians who claim that people perceiving their prognosis realistically tend to take the liberty of choosing their treatment preferences, such as continuing or avoiding aggressive chemotherapy, accepting palliative treatment and focusing on quality of life (QoL) rather than longevity^{3,7} and dedicate their remaining time to closures and farewells. Research too, has been controversial; on one hand, several studies supported the same standpoint with their findings, in which terminally ill people who had difficulties with accepting prognosis also suffered from deprived emotional well-being.¹⁶ More specifically, patients lacking of prognostic awareness suffered from three times higher rates of depression.¹⁹

On the other hand, other psychological theories, such as denial of death²⁰ and terror management theory²¹ believe that denial of death is a useful defense mechanism and therefore do not find full disclosure at all cost to be necessary. These assumptions have been supported by several studies. For example, preliminary evidence revealed that having a more realistic perception of one's prognosis in the face of terminal illness may be associated with reduced hopefulness and a poorer sense of coping.⁵ Another study demonstrated that complete disclosure of prognosis has bad influence on the patient's psychological well-being, QoL and even survival rate.²²

It is highly important to notice that most studies justifying prognosis disclosure were examined among western populations, whereas in non-western countries, disclosure was not only less frequent,⁴ but also proven to be potentially harmful.¹⁷

Existential Well-Being

Coping with life threatening illness is frequently accompanied by distress and suffering, whether physical psychological, social, or existential/spiritual.^{23,24} Hence, even without discussing prognosis, facing cancer causes people to reflect more intensely upon existential issues, such as the meaning and purpose in one's life² and fear of death.²⁵

Existential well-being is a result of a person's successful and adaptive processing of existential issues, such as meaning, satisfaction with life and feelings of acceptance of death. It is considered an internal coping resource, so confronting or initiatively dealing with those issues may imply of existential well-being.^{2,31,32} Although, recognized as an important dimension of QoL,³¹ existential well-being is not fully understood.² Virtually, some of the characteristics of existential well-being tend to overlap with psychological and spiritual well-being³³ and therefore are difficult to study. Yet, there are several agreeable variables for evaluating existential well-being; Among terminally ill can-

cer patients the consensual existential needs include overcoming fears of death and dying, finding hope, finding meaning in life and satisfaction with life.^{25,33,34}

Existential distress is considered to be the most common and challenging to treat²⁶ and when suffering becomes agonizing, one might feel life is no longer worth living²⁷ and may wish to hasten death.²⁸ Existential suffering has different sources and themes, such as death anxiety, loss of control, loss of meaning and purpose in life, loss of freedom of choice and dignity.²⁹ Nevertheless, not all existential concerns necessarily become distressful. In fact, according to the Salutogenic approach,³⁰ adaptive process of introspection and reflection of existential issues may also result with existential well-being.

In order to prevent existential distress and assist patients with evolving existential concerns into well-being and personal growth, evidence-based psychotherapeutic techniques have been developed over the years which successfully improved existential well-being of people with terminal illness.^{11,35,36}

Existential quest is without any doubt an intrinsic, introspective process, and as noted, tends to intensify related life-threatening situations. The individual's perception of prognosis is in a way a measurable estimate of that subjective sense of threat. This study aims to explore the influence of the patient's perception of prognosis on existential well-being, with emphasis on the associated aspects of end-of-life: meaning, death and dying anxiety, satisfaction with life and will-to-live.

Meaning: is defined as a general sense that one's life has order and purpose.³⁷ It is one of the main existential issues of which a person deals with at some point in life, especially towards their end.^{29,36,37} Despite the sense of threat to life, meaning provides people the motivation to engage in life alongside with the physical, psychosocial, spiritual, and existential changes imposed by the illness.³⁸ Due to its dynamic characteristic, it assists the person in transcending suffering and restoring sense of coherence.³⁹

Death anxiety: is another universal existential challenge, especially for people with an imminent threat to their lives. Becoming fatally ill can cause people to become stricken with anxiety by realizing their finity. Some of the common subjects of concern among such people are the fear of leaving loved ones and the fear of what occurs after death.²⁵ On the other hand, the fear of dying mainly focuses on pain, suffering and hopelessness.

Satisfaction with life: is considered to be one of the most essential factors reflecting individual's subjective appraisal of his overall well-being and QoL, especially towards its end.^{40,41} Thus, has been used very commonly in the research field of aging and coping with illness.

Will-to-live: is not only a natural instinct, but also an expression of physical, psychological, social and spiritual factors which lead to the desire of preserving one's life.⁴² It has been noticed,

that people suffering from severe illnesses tend to be at risk of diminishing their will-to-live, due to the actual or potential harm in one or more of the factors, even up to the point of wishing to hasten death or suicide. Furthermore, it has been demonstrated that some existential variables were strongly associated with the will-to-live.⁴³

The last stages of life are not followed only by dealing with existential issues. They are also characterized by a developmental process of striving towards ego-integrity, a concept introduced by Erik Erikson⁴⁴ and defined as a sense of wholeness, integration, and a deep acceptance of life as it has been lived. Hence, achieving ego-integrity seems to offer a steady psychological-developmental platform for reaching a sense of existential well-being.

Therefore, the second purpose of the study was to explore the role of ego-integrity in the relationship between prognosis and existential well-being.

METHODS

Participants and Procedure

Two hundred twenty eight stage 4 cancer patients were recruited from a general hospital's oncology institute in Israel. All of them agreed voluntarily to participate in the study. After 17 dropouts (7%), due to patients' difficulty with cooperation, the final sample included 210 men (46.2%) and women (53.8%), between the age of 35 and 86 years ($M_{age}=63.17$, $SD=12.32$). The majority of participants (75.1%) were married, 2.4% were single, 8.1% were divorced and 14.4% were widowed. All of patients in the sample were Jewish, while about half of participants (55%) were secular, 34.4% reported conducting traditional lifestyle, and 10.6% were Orthodox. Only 27.6% reported having academic education.

All participants were diagnosed with advanced stage cancer: 35.4% had lung cancer, 26.2% had breast cancer, 22.8% had gastro-intestinal cancer, 11.7% had urological cancer and 3.9% had ovarian cancer. The participants were aware of their diagnosis (name of illness, origin, stage), which was given to them at least 3 months before the study. They were also cognitively intact and not diagnosed with major psychopathology. All were able to speak fluent Hebrew for completing the questionnaires. Based on a structured questionnaire, a trained psychology student interviewed all the participants in intimate conditions.

Measures

Perception of prognosis: was assessed by a single question: "How do you estimate the chance of surviving cancer?" with a scale of 1 ("I am sure that I will not get cured from cancer") to 5 ("I am sure that I will get cured from cancer"). Unlike other studies, in which patients were asked to estimate the likelihood

of their death from cancer, this study used one question of self-estimation of the likelihood of surviving their cancer, in no specific time frame.

The reason for using positive statements (survival) rather than negative (death) was due to the threat of distress that might result by direct referral to actual personal death, as well as possible poor response rate.⁵

Patients were not asked specifically how they had previously been informed of their prognosis, since the perception of prognosis was established on subjective appraisal, rather than objective information.

Existential well-being: was measured by several variables, representing main concerns of cancer patients:

Meaning in life: was measured by 2 questions: one intended to personal meaning (“How do you evaluate the meaning in your life to yourself?”) and one intended to interpersonal meaning (“How do you evaluate the meaning in your life to others?”). Rating scale was of 1 (“without any meaning”) to 6 (“extremely meaningful”). A correlation of 0.50 was found between two items.

Ego integrity: was measured by The Adult Ego Development Scale (AEDS).⁴⁵ The structure of AEDS enables each sub-scale to be used independently, so for the purpose of this study, only the last sub-scale, referring to Erikson’s last developmental stage⁴⁴ was used. The sub-scale included 10 items (e.g.: “I feel I have accomplished my purpose in life”) with a scale of 1 (“not typical of me at all”) to 7 (“very typical of me”). In the current study, internal reliability was acceptable (Cronbach’s Alpha=0.66).

Death and dying anxiety: was measured by a 12 items scale.⁴² 6 of its items referred to fears of death (for example: “I am afraid of death”) and the other 6 items referred to fears of dying (for example: “I am afraid of dying slowly”). Rating scale was of 1 (“do not agree at all”) to 5 (“completely agree”). In the current study, death anxiety and dying anxiety were measured separately. Internal consistency was relatively high for both scales: Cronbach’s Alpha=0.85 for death anxiety and Cronbach’s Alpha=0.84 for dying anxiety.

Satisfaction with life: was measured by a 6 items scale,⁴⁶ referring to the person’s satisfaction in physical, mental, social, functional aspects (for example: “How satisfied are you of your life, as it is today?”). Rating scale was of 1 (“extremely unsatisfied”) to 5 (“extremely satisfied”). In the current study, internal reliability was within the accepted range (Cronbach’s Alpha=0.67).

The will-to-live: was measured by a 5 items scale,^{47,48} evaluating a person’s will-to-live as it is in the present, in comparison to that of other people and changes in it over time with 6 possible responses on a Likert scale (e.g.: “If you could describe your will-to-live, you would say that it is:”). Internal reliability in the

current study was Cronbach’s Alpha=0.79.

Socio-demographic variables included age, gender, marital status, level of education, country of origin, religiosity and type of cancer).

Data Analysis

Data were analyzed using SPSS software version 24. Associations between study variables were calculated using Pearson correlation coefficients. Hypotheses regarding predicting existential aspects by perception of prognosis were tested using linear hierarchical regressions, controlling socio-demographics, which were found to be associated with study variables in univariate analysis. Moderation hypotheses were tested using hierarchical regressions, while interaction effect was calculated by multiplying z scores of independent variable and moderator. To interpret moderation, associations between the independent variables and dependent variables were calculated after dividing sample into three groups: lower than 1SD from moderator, between -1SD and +1SD, and higher than +1SD. Level of significance was 5%.

RESULTS

Means, standard deviations and Pearson correlation coefficients are presented in Table 1. As can be seen, perception of prognosis positively correlates with satisfaction with life, will-to-live, personal meaning, interpersonal meaning, total meaning and ego-integrity, but negatively correlates with death-anxiety and dying-anxiety.

Satisfaction with life positively correlated with will-to-live, meaning and ego-integrity, but negatively with death and dying anxiety. Meaning positively correlated with ego Integrity.

To examine whether perception of prognosis predicts existential well-being, hierarchical linear regressions were conducted. In step 1, age and gender were included, while in step 2, perception of prognosis was added. As seen in Table 2, the older the patients the higher their satisfaction with life. Also, the older the patients, the lower were death anxiety, will-to-live, personal meaning, interpersonal meaning and total meaning. Males and females did not differ in most existential aspects, aside from dying anxiety, which was lower for males.

After controlling for gender and age, the better the perception of prognosis, the higher were the scores on satisfaction with life ($\beta=.39, p<0.01$), will-to-live ($\beta=0.12, p<0.05$), total meaning ($\beta=0.22, p<0.01$), personal meaning ($\beta=0.24, p<0.01$), interpersonal meaning ($\beta=0.13, p<0.05$) and ego integrity ($\beta=0.24, p<0.01$). In addition, the better the perception of prognosis the lower was death anxiety ($\beta=-0.24, p<0.01$).

To examine the moderating role of ego integrity, the relationship between perception of prognosis and existential well-being outcomes, several moderating analyses were conducted,

Table 1: Descriptive Statistics and Pearson Correlation Coefficients between the Study Variables (n=210).

	M (SD)	1	2	3	4	5	6	7	8
1. Satisfaction with life	3.89 (0.62)								
2. Death Anxiety	1.92 (1.04)	-0.30**							
3. Dying Anxiety	3.88 (0.75)	-0.18**	0.24**						
4. Will-To-Live	3.95 (0.76)	0.35**	0.14*	-0.08					
5. Personal meaning	5.22 (0.99)	0.36**	0-.11	-0.02	0.41**				
6. Inter-personal meaning	5.59 (0.79)	0.29**	-0.19**	-0.07	0.25**	0.49**			
7. Total Meaning	5.40 (0.77)	0.38**	-0.17*	-0.05	0.39**	0.89**	0.82**		
8. Ego Integrity	5.10 (0.67)	0.53**	-0.43**	-0.18**	0.29**	0.36**	0.27**	0.37**	
9. Perception of prognosis	3.70 (0.97)	0.33**	-0.16*	-0.13*	0.23**	0.27**	0.18**	0.26**	0.23**

*p<0.05, **p<0.01

Table 2: Beta Coefficients and Standard Errors of Gender, Age and Perception of Prognosis Predicting Existential Well-Being Variables (n=208).

	Satisfaction with life	Death anxiety	Dying anxiety	Will-to-live	Personal meaning	Inter-personal meaning	Total meaning	Ego integrity
Gender	-0.01 (0.08)	0.00 (0.14)	-0.27** (0.15)	0.01 (0.10)	-0.07 (0.13)	0.00 (0.11)	-0.04 (0.10)	-0.09 (0.09)
Age	0.17* (0.01)	-0.26** (0.01)	0.11 (0.01)	-0.36** (0.01)	-0.11 (0.01)	-0.14* (0.01)	-0.14* (0.01)	0.04 (0.01)
Perception of Prognosis	0.39** (0.04)	-0.24** (0.07)	-0.09 (0.08)	0.12* (0.05)	0.24** (0.07)	0.13* (0.06)	0.22** (0.06)	0.24** (0.05)
Addition to R² by perception of prognosis	0.13**	0.05**	0.00	0.01*	0.05**	0.02*	0.04**	0.05**

Note: Gender was coded as: 1-males, 0-females. *p<0.05, **p<0.01

as shown in Table 3.

Examining moderation of personal meaning yielded a significant interaction effect ($\beta=-0.20, p<0.01$). To interpret moderation, sample was divided into three groups by low than 1SD from ego-integrity average, between -1SD and +1SD, and higher than +1SD. Analysis showed a positive association between perception of prognosis and personal meaning only among patients low in ego-integrity ($\beta=0.30, p<0.05$), to lower extent among patients who are moderate ($\beta=0.16, p=0.10$) and non-significant association among patients who are high in ego-integrity ($\beta=0.01, p=0.97$).

Examining moderation of dying-anxiety yielded a significant interaction effect ($\beta=-0.12, p<0.05$).

DISCUSSION AND CONCLUSIONS

This study focalized on the existential aspect, which is considered as one of the major sources for concern and distress among

patients with end stage diseases. Our findings contribute to the persistent discussion regarding the effectiveness of defense and coping mechanisms, such as denial of death or false hope, in preserving existential well-being. Specifically, addressing the continuous query, whether acknowledging one’s own impending death affects existential well-being.

Patients in this study are highly overestimated with their prognosis. In fact, the average grade of perception of prognosis indicates that most of the patients in the sample believed there was a likelihood of getting cured from cancer. This result is consistent with previous studies,^{5,10} all of which strengthen the assumption, that the process of perceiving threatening information (such as bad prognosis) evades cognitive mechanisms and is mediated by complex, intrinsic defense mechanisms.

In addition, significant correlations emerged between perception of prognosis and the existential well-being aspects (positive correlations between perception of prognosis and meaning, ego integrity, satisfaction with life, and will-to-live

Table 3: Beta Coefficients in Regressing Prognosis Perception and Meaning in Life Predicting Existential Aspects in Final Step (n=208).

	Personal meaning	Dying anxiety
Gender	-0.03	-0.20**
Age	-0.13*	-0.07
Perception of Prognosis	0.15*	-0.13*
Ego integrity	0.29**	-0.39**
Perception of Prognosis X Ego integrity	-0.20**	-0.12*

Note: Gender was coded as 1-males, 0-females. *p<0.05, **p<0.01

and negative correlations with death and dying anxiety). These associations support the assumption that those variables represent existential themes among people with advanced cancer. In addition, these interrelations among all variables are similar to those reported in previous studies⁴⁹⁻⁵¹ and demonstrate the mutual influence on each other. The only exception was dying anxiety, which correlated with only some of the variables and therefore may not be considered as an indicator of existential theme.

The main finding of this study is the significant effect of the perception of prognosis on existential well-being in advanced stage cancer patients. When prognosis is poor, a false positive perception (overestimation) has a role of alienating the feasibility of death or meaninglessness and thereby preserving existential well-being. Given that false positive perception of prognosis has a protective effect against existential distress: death becomes less proximate and levels of meaning (personal and interpersonal), ego integrity, satisfaction with life and will-to-live remain high or are elevated.

Our findings support previous findings^{2,14,17} and may provide explanation for cancer patients' false positive bias of their prognosis. In a way, overestimation of prognosis is analogous to denial of death.

The demonstrated positive correlation between ego integrity and perception of prognosis, as well as with all existential factors indicate that ego integrity serves as a powerful attribute for preserving the emotional, spiritual and existential well-being of people approaching their end-of-life.

The moderating effect of ego-integrity emphasizes its virtue as a source of resilience for the wholeness of the self. The positive correlation between overestimation of prognosis and personal meaning among people with weak ego-integrity implies that the stronger is the sense of personal meaning in life, the more patients with weak ego-integrity seem to hold on to defense mechanisms while dealing with the fear of death accompanied to bad prognosis. Those, in turn, create false positive perception of their prognosis followed by preserving strong personal meaning. Otherwise, realistic perception of prognosis might cause acute existential distress and despair. Patients with strong ego-integrity seem to have adequate resilience resources to cope adaptively with poor prognosis, and hence, seem to be able to preserve a sense of personal meaning, despite the threat of death.

The moderating effect of ego integrity on personal meaning whereas not on interpersonal meaning is reasonable, while leaning on the conception that in the course of striving for ego-integrity, the individual converges into himself for the purpose of introspection, instead of externalization, which is often expected at earlier stages of development. The resolution of such a process is mostly intrapersonal.

Conclusions, however, have to take into consideration

the cultural-ethnic attributes, which may have an influence on the results; Israeli society has many characterizations which resemble Western countries. Despite the patterns of doctor-patient communication, which are becoming more Western-like, still some of the attitudes and tributes of Israelis do not entirely meet customs of Western societies. In fact, even within Israeli society itself there appears to be a variety of typical communication patterns around illness and death.⁵² Today, there is still a non-negligible similarity with non-western cultures' communication patterns, such as the tyranny of positive thinking and the evasion from leading an open communication about death, even with loved ones. Not surprisingly, our study shares quite similar results and conclusions with a study conducted on Iranian cancer patients.⁴ Yet, studies both from Western countries and non-Western countries showed consistency with the fact that cancer patients, especially at advanced stage, overestimate their prognosis.^{3,4,7} The consequent conclusion, if so, is that not the type of communication, but the personality characteristics, defense mechanisms and spiritual and existential views are those that mostly influence the patients' ability to cope with a terminal prognosis. This conclusion, however, should be further examined by comparing between type of communication and psychological attributes and estimating the impact of each on the perception of prognosis.

LIMITATIONS OF THE STUDY

Besides the socio-demographic profile of the sample discussed above, several methodological limitations of the study should be taken into consideration. First, perception of prognosis, as well as personal and interpersonal meaning, had been evaluated by a single question each. Second, since no unified tool had been detected at the time of performing the study, different tools had been used for measuring each aspect of existential well-being. However, due to the recently developed Existential Concern Questionnaire (ECQ),²⁵ perhaps further research, using the ECQ, may reveal more novel findings.

Third, as described, perception of prognosis had been measured by using a positive statement question (the likelihood of surviving). Indeed, positive wording helped avoiding emotional intimidation and dropouts, but on the other hand, positive cues may lead to a positive bias, due to the subjects' tendency to report of their wish or desire. Also, measuring perception of prognosis is likely to be confounded by other psychological variables, which were not detectable.

Another question for further examination is whether existential well-being has a general profile for the entire population or perhaps its validity has to be differentiated in accordance with the focus of concern, or sample of people. For example: the Existential Concerns Questionnaire (ECQ)²⁵ was proven to be valid and reliable for the general population and for people suffering from psychiatric disorders. In our present study, only part of the ECQ factors were examined (meaning, death anxiety), while others were not examined, since literature review

reported other topics to be main sources for existential concern among people suffering from terminal illness (e.g., satisfaction with life). The evolving question is whether questionnaires such as ECQ are capable to reflect the unique existential concerns of people suffering with life threatening illnesses.

Furthermore, aside from the existential issues examined in this study, one must not neglect other essential concepts of end-of-life, such as hope. Although, level of hope was not examined in this study, it is known to be an internal source of great value for people with imminent threat to life.

RECOMMENDATIONS

Despite the limitations of the study, its conclusions have a clinical implication on healthcare providers, while discussing difficult issues. Due to the high likelihood that patients are holding false positive perception of prognosis, healthcare providers should take into consideration that discussing prognosis might shake their patients' existential thresholds. Therefore, a form of dialogue which refines facts with realistic sources for hope may offer patients to process the information in accordance with their defense mechanisms and psychological abilities of preserving existential well-being. Moreover, even for people who appear resilient enough to perceive bad prognosis, sentencing a statistically based time frame, not only might be unnecessary, but also harmful.

Although, professional guidelines for effective communication have been developed,⁵³ further resources and training programs focusing specifically on existential support would be beneficial.

Finally, the clinical implications of understanding the role of ego-integrity would recommend assessing ego-integrity resources in patients who represent existential distress while receiving bad prognosis. Psychotherapeutic intervention, with the focus on promoting ego-integrity perhaps should be considered even prior to existential work. Strengthening ego-integrity may even result with facilitating patients to perform existential work by themselves. This recommendation, however, has to be further examined both clinically and empirically.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Cultural Challenges in Implementing Palliative Care Services in Jordan

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Cultural Challenges in Implementing Palliative Care Services in Jordan

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ABSTRACT

Palliative care in Jordan is considered to be advanced in comparison to that of other Middle East countries. According to Jordanian leaders of palliative care, Jordan is not different from advanced countries in applying principles and approaches of palliative care. There are many cultural challenges hinder provision of these services. First, fear of addiction by patients, family and healthcare providers prevent them from providing adequate pain management. Second, lack of adequate knowledge regarding pain management among healthcare providers is also a great challenge. In addition, health policies and inadequacy of palliative services make the problem worse. Third, fear of family and physician to refer patients to palliative care as it is considered to be failure of treatment. Fourth, lack of family participation in most medical and end-of-life decisions deprive patients from receiving proper palliative care. Finally, religious misconceptions force patient to suffer pain to an intolerable level and prevent them from seeking immediate medical help. To overcome these challenges, it is recommended to improve palliative health policy at national level, include palliative care materials in health curriculum, raise public awareness of palliative care, and provide more opportunities for palliative training and research.

KEY WORDS: Palliative care; Cultural challenges; Health policy; Jordan; Pain management; Addiction; Religious.

INTRODUCTION

Jordan has 4,600 new adult cancer cases per year. More than 60% of all the present cases cancer are received in a late stage which severely need palliative care.¹ Palliative and hospice care were first provided by a non-governmental organization, the Al-Malath Foundation. It provided palliative care services to a limited number of patients in the capital of Jordan.¹ At the present time, the majority of specialized palliative, hospice and home care services are offered by the King Hussein Cancer Center (KHCC). Both palliative and hospice care are introduced in one ward with no separation between them. Other institutions that treat cancer patients do not have specialized palliative care units or interdisciplinary palliative care teams (e.g., Ministry of Health Hospitals, Royal Medical Services).²

Palliative care programmes in Jordan have been growing with the support of the World Health Organization (WHO) and Jordan Ministry of Health.³ Palliative care services in Jordan developed better than that of most of its neighbors in the Middle East but lagging behind advanced countries. Like many other countries, palliative and end-of-life care in Jordan is provided mainly to cancer patients.⁴ The palliative care program was started in 2004 at KHCC. It is limited to adult patients in Amman, the capital of Jordan. There was severe deficiency in patient support services such as palliative care, nutrition, psychosocial support and rehabilitation.⁵ The provision of standardized palliative and home care by one center is considered as the major problem, and besides that not all cancer patients have the chance for admission due to logistic issues, financial issues, or the lack of vacancies in the center.⁶ The number of beds and healthcare providers are limited. In addition, the KHCC budget is mostly based on financial

aids from national and international agencies.

Palliative and hospice principle care is practiced and applied in Jordan like any other advanced country. Jordanian people have no differences in their reaction to terminal illness and their experience of suffering. Therapeutic communication skills, effective symptom management and effective end-of-life care are necessary skills in any palliative program.

Dr. Mohammad Bushnaq, president of the Jordanian Palliative Care and Pain Management Society, presented a case study in Jordan in 2008 and assured that approaches developed in Europe and the United States can be integrated into traditional Arab culture. He also added that values and principles of palliative care are same everywhere, but the way we apply it needs to be tailored to local culture and norms. This is also supported later by Dr. Omar who said that there are many similarities of practice between the US and Arab country's palliative care services, like in Saudi Arabia or Jordan or any other Arab country. They are similar in using opioids, withdrawing and withholding some unnecessary interventions and applying "do not resuscitate" order. The only thing which is forbidden for Islamic rule is euthanasia which is allowed and practiced in some parts of the US.⁷

BARRIERS TO PALLIATIVE CARE

There are many challenges hinder the provision of palliative care. One of the effective barriers on the flow and development of providing standardized palliative care is cultural barriers. Some of these related to healthcare providers, patients, and healthcare settings.⁶ Other barriers are related to policy and legislation, clinical practice, education, and research.²

CLINICAL PRACTICE

The major barriers that are associated with the healthcare providers include:

- Delay in referrals, due to physicians' denial of the need to refer and the sense of failure, palliative care as a discipline is being seen as less prestigious and caregivers are often uncomfortable caring for terminal patients.¹ Delay of referring patients to the palliative care because many physicians (e.g., oncologists) still equate palliative care with hospice care.
- Truth concealment from cancer patients is still common in Jordan especially with elderly cancer patients. Thus, it would be difficult for palliative care nurses to provide quality care to a cancer patient who is not aware of his/her diagnosis and/or prognosis.²
- Some Barriers are associated with the palliative care team; the team is not well supported which leads to staff burnout and lack of training.¹ In Jordan, the role of nurses in pain management is to fulfill physicians' orders without any obvious guidelines.⁸

NARCOTIC AND PAIN MANAGEMENT

The most dominant one was perception and attitude of patients, family, society and healthcare providers toward narcotic drugs as a pain killer. According to Dr. Bushnaq, Jordan's first international palliative care conference was held in Amman. There he mentioned that 90% of patients with chronic diseases who need palliative care do not receive it, adding that 10,000 cases out of the 18,000 deaths registered annually in Jordan, die while suffering from pain.²

According to the International Narcotics Control Board (INCB) survey of countries where access to controlled medicines such as morphine and methadone is low-to-inadequate, fear of addiction is the main barrier to access.⁹ The same notes were stated by Dr. Bushnaq who considered fear of addiction is one of the most important drawbacks towards provision of palliative care in Jordan. This was supported by a previous study that revealed healthcare providers (physicians and nurses mainly) erroneously believe that taking narcotics means addiction in cancer patients.¹⁰ The "opioid phobia" was used as a synonym for the fear of addiction. The term was used by Alaa Bashayreh, a master degree registered nurse in an article in the Journal of Pediatric Hematology/Oncology. He defined provider "opioid phobia" as the fear of both addiction and opioid-induced side effects. Fear of addiction is experienced by both patient¹¹ and healthcare providers.¹⁰

The fear of provider may arise from inadequate knowledge about the management of cancer pain, not having adequate training in opioid therapy, not following prescribed guidelines of narcotic use enacted by government and focusing more on treatment of cancer than on pain management. Concerns over nausea, vomiting, constipation and respiratory depression may cause some oncologists to hesitate before continuing opioid therapy.¹²

PALLIATIVE EDUCATION AND RESEARCH

The lack of palliative care education and training programs is a significant barrier to the development and progress of palliative care in Jordan.¹³ Unfortunately, palliative care services in the Eastern Mediterranean (EM) region are limited and the number of physicians trained in palliative care in the region is well below as per the needs of the population. Physicians and nurses lack the skills needed to support their patients.¹⁴ Only, few educational and training opportunities exist to this point.²

Nurses in Jordan have a lower level of pain management knowledge than that reported worldwide. In Jordan, the role of nurses in pain management is to fulfill physicians' orders without any guidelines.⁸

A previous study result demonstrated knowledge deficit and attitude; nurses underestimated and undertreated patients' pain.⁸ This is related to insufficient pain material in medical programs especially nursing programs.¹¹

Research on palliative care topics are limited. Most of the publications focused on issues related to pain management.² There are few studies on symptom management, feeling and attitudes of nurses towards death and dying, experience of patient and family towards death and dying.

CULTURAL BELIEFS

The dominant culture among Jordanians discourages patients, and sometimes prohibits them from receiving opioids, based on religious misconceptions. In Islam, tolerating pain can be rewarded from God and expiate sins.¹⁵ But Islam encourages seeking treatment and pain reliever as narcotic.¹¹ The religion of Islam and the family structure are the most influential factors in shaping the Jordanians' beliefs. Islam is the religion of the majority of the population, thus, with concordance with the Islamic teachings most Jordanians believe that illness and wellness are God's will and religious practices (e.g., prayer, reading holy Quran) are widely used to help people cope with illness especially in case of life threatening illnesses.²

A traditional Muslim accepts suffering as a way of atonement of one's sins. This way of handling helps the Muslim cope with the illness and to die in peace with self, God, and others.¹⁶ Jordanian nurses work with patients among which 97% of population are Muslims and they believe that suffering is a test from God and a person should tolerate his/her pain and hide it from others.⁸ Moreover, traditional Muslims respond well to euphemisms which mean represent the truth in a different way that can be accepted.¹⁶ Most are seeking reassurance and empathy rather than information about diagnosis.¹⁶ Cultural and religious beliefs and practices may be a barrier for cancer patients and care providers are reluctant to talk about death or hospice care.¹³

HEALTH POLICY

Jordan lacks health policy to develop, improve, and sustain palliative care.² Today, Jordan does not have a national palliative care policy. Thus, with the exception of KHCC, palliative and home care services are not available at the national level leaving a large proportion of Jordanian cancer patients without access to palliative care.^{2,13} Moreover, opioids administration policy in Jordan makes delay in prescription and dispensing, and unnecessary cautions among health providers.¹¹ Also, restrictions on the length of opioid prescriptions for outpatients are implemented and followed strictly.¹³ Uneven distribution and coverage of palliative care services always been a barrier to the provision and maturation of a palliative care program in Jordan.¹³ The absence of a multidisciplinary approach to palliative care services is also a barrier. Lastly, the underutilization of other professionals, such as social workers, who could help physicians and patients increase the awareness of palliative care services is an additional barrier.

PUBLIC AWARENESS

An absence of public awareness of palliative care is a consid-

erable barrier. People are not informed about palliative care services and retains myths and misconceptions about palliative care. Moreover, there are absence of government recognition of palliative care as an integral part of the Jordanian healthcare system, and finical support is very limited.¹³

PATIENT AND FAMILY

The conception of patient's family is another challenge. The family perception of referring a patient for palliative care deprives patients from receiving adequate palliative care. They consider referral as a sign of treatment failure and view physicians as weak healthcare provider.

Decision-making on health issues is considered a social process and many family members (e.g., spouse, children) could be involved in that process.² For example, the order "do-not-resuscitate" has many cultural difficulties. The patient and family feel big burden to choose, and many family members said they would feel guilty if they make that decision.¹⁶ On the other hand, the patient family is not usually considered a target of medical or nursing care among healthcare providers in Jordan. Thus, to promote palliative care, there is a need for a cultural change that entails considering the family in the care provided to Jordanian patients.²

Barriers associated with families include' feeling of alienation and isolation; along with the fear of being neglected by the primary physician, unrealistic expectations of future prognosis, refusal of admission to hospice which is considered as a place of death.¹ Since the family views palliative care as a sign of "giving up" on the patient, physicians may perceive referring a patient for palliative care as a failure of their medical capability and a sign of loss of prestige when explaining the true situation to patients or their families.¹³

Finally, there are many other cultural challenges to study and overcome. These challenges include increased availability of opioid and access in the peripheral governorates of Jordan, to increase the number of palliative care services in all healthcare settings and to create a hospice and home care national insurance plan to improve access and make these service affordable to all.¹⁷

RECOMMENDATION

Palliative care in Jordan is evolving but has far to go. Adequate resources provision, educational programs, credentialed healthcare providers are crucial elements that palliative care in Jordan needs.²

It is recommended to build palliative care services into existent primary care systems and hospitals as an approach to build capacity in palliative care in all settings.¹⁴ The new and better concept is that supportive and palliative care should start at diagnosis of a life-threatening illness and gradually increase while disease-modifying care may decrease.¹⁸

Table 1: Barriers to Palliative Care and Recommendations.	
Barrier	Recommendations
Clinical practices	-Palliative education and training -Clear health policy
Narcotic and pain management	-Improve health policy -Pain management education -Increase availability of narcotics
Palliative education and research	-All health curricula should have some materials about palliative care -Conducting research in various palliative and hospice aspects of Jordanian patients
Cultural beliefs	-Determining myths and misconceptions and give proper education
Health policy	-Restructuring health policy and stress the importance of palliative care on a national level.
Public awareness	-Palliative health education in mass media
Patient and family	-Education cancer patient and family about palliative and hospice care and support them -Involving patient and family in all stages of treatment.

As remedy, the government must first adopt a national palliative care program which should be implemented in all the healthcare settings in the country. Once this policy gets formulated and implemented, several barriers to palliative care in general and palliative care nursing in particular would be resolved.²

Because of the absence of a national policy on palliative care, palliative care nursing is not included in the undergraduate or post-graduate curricula of many nursing schools in Jordan.² Introducing palliative care courses on the undergraduate level for all medical studies, postgraduate studies and subspecialty training is urgently needed.

Lastly, research in the palliative care field should be encouraged and funded to enable a continuous evaluation of our progress and to reduce the suffering of cancer patients as the ultimate goal of the healthcare system.¹³

Mass media campaigns to increase public awareness about palliative and end-of-life care are on the top priorities. It is important to declare Islam opinion about meaning of suffering and disease and treating pain. Overcoming health and religious misconception of public will greatly support palliative care. Barriers to palliative care and recommendations are summarized in Table 1.

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Difficulties in Developing Hospice or End-of-Life Care Hospitals in Developing Countries

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Commentary

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Difficulties in Developing Hospice or End-of-Life Care Hospitals in Developing Countries

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According to the United Nations (UN) statistics, Pakistan is currently listed as a developing country. Implementing palliative services has come across as a big challenge and possesses various risks, not only because it is a developing country but also due to communal extremism. Muslims being the predominant community, the country has been dealing with extremism in the name of Islam. The citizens are constantly under the threat of extremists and religious leaders who enforce them to follow stringent rules and restrictions, defying which can lead to dangerous consequences.

Pakistan being an Islamic Republic, females are the most affected amongst all when it comes to seeking medical or palliative services. The strict rules and regulations restricts female patients from seeking palliative support, since they are expected to be handled by female staff nurses only. This comes across as rather inconvenient when treatment is sought for terminally ill patients as well as for sexual, gynecological dysfunctions.

Another major concern being that majority of the palliative service providers and institutes are biased, entertaining only patients belonging to their own community. It has often been observed that Muslim patients have better access to these services and are treated well when compared to those belonging to the other religions, presumably because they are considered unrewarding.

Reportedly, 40% of the country's population lives below the poverty line, where access to basic necessities such as clean food, water and sanitation is a luxury; things that only the privileged can afford. Apart from this, famine, starvation and susceptibility to infections and deadly diseases have been major causes for massive mortality. For families of patients with such advanced or end stage diseases, it is often a huge liability and hence they are at times just left to die unattended, or fall prey to mercy-killing by some quacks, where they are quite inhumanly gotten rid off.

Expatriated below are some of the cultural challenges in Pakistan, which need urgent attention:

Gender-Based Challenges

As elucidated above, lack of female staffs, nurses and healthcare providers for treating female patients and *vice versa* is a constant challenge for implementing gender unbiased palliative services, in an Islamic Republic like Pakistan.

Lack of Proper Palliative or Hospice Care Centers

The lack of enough palliative or hospices care centers in Pakistan shows just another loophole in the country's system and incomprehensiveness of the authorities, which is the biggest of all concerns.

It is not only the officials in charge of the medical care of the country, but also the negligent and injudicious attitude of medical professionals/clinicians which adds to the poor

state and under-developed facilities. Underprivileged families of patients who are declared terminally ill by the doctors, although reluctantly, often prefer to discontinue further treatment and medication, discharging them from medical facilities and care. This is either due to lack finances and help from the government or at times to decrease the liability this brings on the family and the healthy feeding stomachs. However, the better educated and financially sound sect of the society who can afford the required treatment and life support machinery, tend to arrange for healthcare professionals and treatments at home, if not for visiting doctors. Such patients often find themselves isolated in their own homes for the rest of their lives, in the hands of home nursing staff, physiotherapists and doctors. Certain hospitals refuse to treat the elderly patients in their advanced stage of illness due to the huge turnover of younger patients, especially the ones in Lahore like Shaukat Khanum Cancer Hospital.

Unregulated Old Age Homes

There are very few old homes in Pakistan to documents and most of the times they are actually the places where the terminally ill elderly are left by choice or by their TOO BUSY near ones till they breath their last.

Low Socio-Economic Status

Low employment rate in developing countries like Pakistan, comes across as a serious add on to the present socio-economic situation, forcing people to indulge in crime and other inhumanely activities. Deadly diseases, inaccessibility to clean water, food and sanitation, as well as famine, starvation and reportedly, 40% of the country's population lives below the poverty line, where access to basic necessities such as clean food, water and sanitation is a luxury; things that only the privileged can afford. Apart from this, famine, starvation and susceptibility to infections and deadly diseases further explain the reason for the stagnant, if not deteriorating socio-economic status.

Social Stigma

In our society, certain diseases are looked down upon, for example, sexually transmitted diseases (STDs) and acquired immuno deficiency syndrome (AIDS). Lack of diagnostics and the required infrastructure for research on such diseases are poorly developed due lack of funding from the Scientific Research Council. Moreover, if at all diagnosed, people are too shy to disclose their disease until death.

Lack of Awareness at the End of Patient

In cases where the patients themselves are uneducated or under informed about the disease condition, available treatments and facilities or any available help for the poor, the situation worsens. In general, there is a lack of awareness amongst the people on emergency measures, precautions and about their right to free or subsidized medical care, if any.

Lack of Awareness amongst Attendants or Caretakers

In many cases, patients, when diagnosed with end stage diseases, are completely unaware or uninformed by the doctors about the gravity of the situation. For example, when it comes to treating end stage cancer, many are still subjected to chemo and radiotherapy with little chances of survival. Research has shown that many a time's doctors are involved in making money without counseling the patients how bad the stage of the disease is, with little or no benefit of chemo or radiotherapy. Here, some doctors have more focus on commercial point of view, than the actual benefit of the patients. They linger on to the situation until the patient reaches end stage.

Sometimes, interventions like chemotherapy and radiotherapy at the wrong stage play havoc with the patient's life, decreasing their span of survival and increasing their agony.

ICU Setup

End-of-life management requires a specialized setup, especially ICUs for managing critical care patients, even though most end stage patients are DNR (Do Not Resuscitate). However, patients other than cancer patients deserve all the life support including ventilators, cardiac shock, life support medicine like adrenaline, atropine, etc. Hence, hospice should have well-organized ICU setups as well.

DONOR Recipient

In cases of liver and kidney transplants, patients who are given immune-suppressing drugs needs critical care, whereas, transplant rejection patients again need hospice because as there is little chance of survival otherwise.

Financial

Most of the times, hospice care, although available, is not affordable to the financially lower class, reasons of which are well explained above.

Registration

Since the government of Pakistan does not permit registration of any hospice units without proper grant permissions, there are very few centers with the required facilities for treatment.

CONCLUSION

Timely implementation of the above mentioned suggestions will help in the overall improvement of the conditions in the country. The responsibility of creating social awareness regarding the medical conditions, technological and global progress should be taken over by the government. Moreover, it is the employment of well trained caretakers, and efficient staff in well facilitated hospitals without the interference of religion or extremists that will help the people grow.

Cultural and Ethical Challenges in Providing Palliative Care for Cancer Patients at the End-of-Life

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Special Edition
"Palliative Care and Oncology:
Time for Increased Collaboration
and Integration"

Opinion

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Cultural and Ethical Challenges in Providing Palliative Care for Cancer Patients at the End-of-Life

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ABSTRACT

End-of-life (EOL) care presents many challenges both for clinicians, as well as for patients and their families. Moreover, the care of the dying patient must be considered within the context of the psychological, physical, and social experiences of a person's life. Foremost among those who require EOL care are cancer patients at the EOL. Unfortunately, clinicians who are responsible for the treatment of patients at the EOL commonly lack adequate training to help guide EOL decisions and to deliver bad news to patients and families. They must also face their own discomfort with discussions about death and deal with poor compensation for the time spent discussing EOL care with patients and families. Given the unique process of each person's death, strategies are often inadequate to guide patients, their families, and the clinicians who care for them through this complex and emotionally challenging process. It would stand the clinician in good stead to be aware of these challenges and have an approach towards dealing with such problems. In addition, organizations have a responsibility to ensure that systems are in place to minimize its occurrence and ensure that staff are supported through the process of resolving issues and conflicts that may arise.

KEY WORDS: Culture; Ethical; Challenges; Palliative care; Cancer patients; End-of-life (EOL).

INTRODUCTION

Cultures vary across countries in terms of economic status, education and resources, as well as by traditional and family values, and religious or spiritual aspects pertaining to illness and health. Cultural beliefs and values shape our approach to death and dying, and need to be acknowledged and included in the delivery of palliative care services, it also provides us with a framework for understanding death, and give meaning to our experiences of suffering and loss. Cultural background has a significant role in coping with the difficult situations at the end-of-life (EOL), where health professionals, specially nursing staff and social workers, may be very helpful. Cultural beliefs impact on many aspects of EOL care, including the disclosure of information, decision-making, the use of life-prolonging treatments, and the experience of grief and bereavement. Our traditional practices around death are often linked to our beliefs about the meaning of death and what lies beyond, and have both emotional and spiritual significance.^{1,2} Furthermore, some cultural aspects of death and terminal patients' care should be considered while providing palliative care for those patients in our country. We should pay attention and focus on cultural and social aspects because the whole family is usually involved in a patient's problems as family ties are very strong among people. Understanding medical, ethical, legal and economical challenges which may be experienced by physicians and other cancer care providers in our healthcare system in the special sociocultural context will help in providing an appropriate care for cancer patients at EOL.

Cancer is an illness that affects large numbers of people and their families in Egypt; and the burden of this life-threatening condition have caused many challenging problems for

the patients, their families, and the public health system in the country, it is a major cause of mortality and morbidity worldwide. In fact, cancer, being a life-threatening disease, makes the inevitable need for the implementation of an effective EOL care strategy in healthcare services more than ever.³ Physicians should consider the patients' best interests; and the treatment they choose should be beneficial to the patients and should not do any harm. Moreover, the treatment should be selected on the basis of the patients and their families' views on EOL care and financial costs of terminal care.⁴ Oncologists can fairly decide on EOL provided that they know patients' and their families' values and preferences,⁵ and can communicate with them honestly.⁶ Many physicians avoid informing patients of their survival chance, because they believe that discussing this issue may diminish patient's hope.⁷ In addition, healthcare costs are high in many healthcare units and financial discussions about the cost of treatments and care of end stage cancer patients can be of paramount importance.⁸ Consequently, considering differences of healthcare services in various cultural backgrounds and social structures, the professionals in service providing face with numerous ethical problems for decision-making.^{9,10}

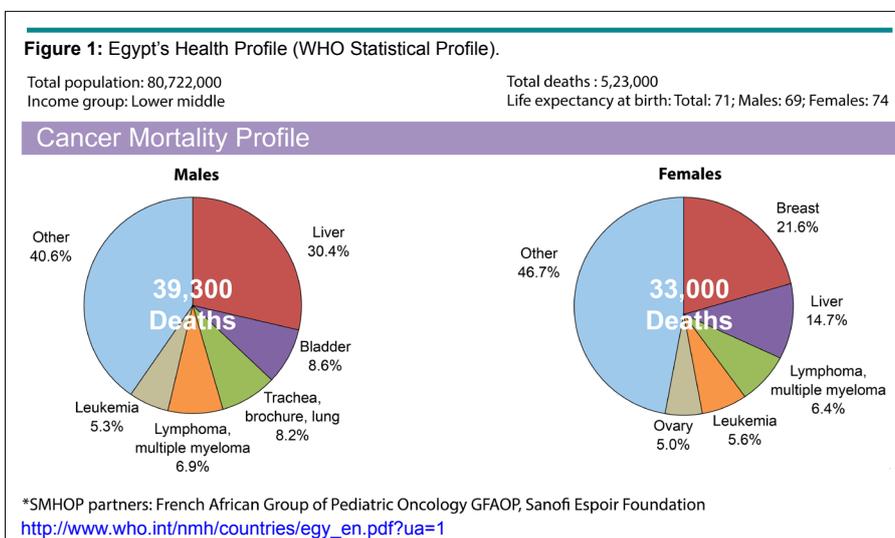
EOL care is challenging and can be influenced by cultural and religious values. The specific practices at the last

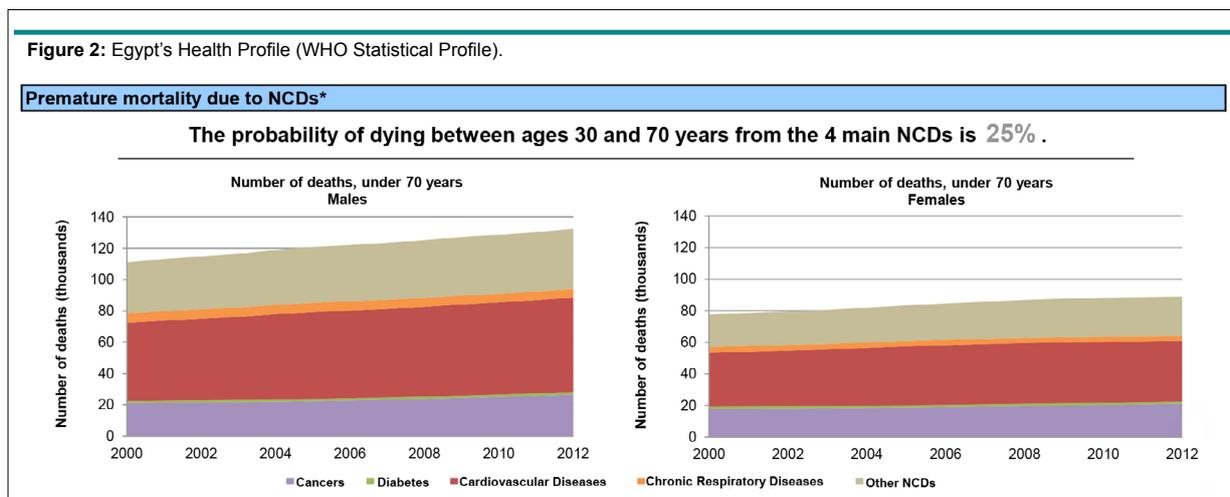
moments of life differ among the religious sectors. It is also important to note that individuals within the same community may have different levels of observance for religious or cultural practices. Consequently, healthcare professionals must be prepared for a diversity of attitudes, values, and practices of dying and bereaved persons. Religions consider death to be a transition from one form of being to another: 'death is a natural end for humans.' Life on earth for a Christian, Muslim, and Jew is an examination and an opportunity to be prepared for life after death, where one's deeds on earth will be judged and accordingly people will be sent to either Heaven or Hell. To optimize our care, we must ensure that social and cultural aspects of life and death are identified, embraced and understood by health professionals so that the needs of patients and their families are met as they approach death. Planning and preparation will ensure that practitioners understand different cultural perceptions of dying and death and respect patients' belief systems and cultural norms.^{11,12}

Egypt' Health Profile (Who Statistical Profile)

World Health Organization - Non-communicable diseases (NCD) Country Profiles, 2014 (Table 1), (Figures 1 and 2).

Total population (2015)	91,508,000
Gross national income per capita (PPP international \$, 2013)	10
Life expectancy at birth m/f (years, 2015)	69/73
Probability of dying under five (per 1000 live, 0)	Not available
Probability of dying between 15 and 60 years m/f (per 1000 population, 2015)	196/119
Total expenditure on health per capita (Intl \$, 2014)	594
Total expenditure on health as % of GDP (2014)	5.6
Web site: http://www.who.int/nmh/countries/egy_en.pdf?ua=1	





An Overview of EOL Care

Common Approaches to EOL Care

Hospice care: Dying patients may choose hospice care. A holistic and philosophical approach to EOL care, hospice brings doctors, nurses, social workers and other professionals together as a care team. The hospice team’s goal is to make the patient as comfortable as possible during his or her final days. Hospice emphasizes pain control, symptom management, natural death, and quality of life (QOL) to comfort the patient’s physical body.¹³ The hospice team cares for the dying patient wherever that patient is: at home, in a nursing home, in a hospital, or in a separate hospice facility. In addition to medical care, the hospice team may provide emotional and spiritual support, social services, nutrition counseling, and grief counseling for both the patient and loved ones.

Palliative care: Palliative care works to achieve one of the primary goals of healthcare relief of symptoms. Palliative care is an option for patients who are seriously or terminally ill. It focuses on achieving the best possible QOL for a patient by emphasizing on over all comprehensive care for all of patient’s needs: pain and symptom management, spiritual, social, psychological, and emotional well-being.¹⁴

Palliative care is similar to that of hospice care. One striking similarity between hospice and palliative care is the use of an interdisciplinary team of professionals including doctors, nurses, social workers, psychologists, chaplains, and others to provide comprehensive care.

Traditional American medical practice focuses primarily on curing illnesses and healing injuries. Symptom relief is often a secondary focus.¹⁵ Palliative care supporters believe that failing to address the suffering of a patient with a terminal illness violates two of the main ethical principles

behind healthcare.¹⁶

- 1) Providing help or benefit to a patient (beneficence) – Failing to relieve pain and other symptoms does not help the dying patient.
- 2) Not harming a patient (non-maleficence) – Failing to relieve pain and other symptoms can actually harm a patient and the patient’s loved ones. For dying patients, palliative treatment provides relief of suffering from pain and other symptoms.

Most Common Symptoms in Dying Patients

Dying patients frequently experience significant suffering in form of difficulty in breathing, pain, and depression, as:

Difficulty in breathing: Nearly 75% of people who are imminently dying, experience dyspnea, or “air hunger.”¹⁷

Pain: Research finds that the number of seriously ill patients who experience substantial pain ranges from 36% to 75 %.¹⁸

Depression: In a representative study, about 1 in 4 patients admitted to a palliative care unit, mention depression as a significant symptom.¹⁹

Common Elements of a Good Death

- Adequate pain and symptom management.
- Avoiding prolonged dying process.
- Clear communication about decisions with patients, family and physician.
- Adequate preparation for death of the patient, for both patient and family.
- Feeling a sense of control.
- Finding a spiritual or emotional sense of completion.
- Affirming the patient as a unique and worthy person.
- Strengthening relationships with loved ones.
- Not being alone.

Challenges due to Considerations of Patients' Illness and their Families involved with EOL Care

Cultural background is one of the most important issues in providing cancer care. Social and cultural issues affect the patients' care very much, and they are very important. Based upon our culture, many families do not allow their patients to be aware of the nature and severity of their disease. Therefore, the patient has no active role in decision making. Cancer patients towards their EOL know from the physicians that the disease is not curable, and they are not treated for overcoming the disease to increase their survival, but they are only treated to improve their QOL, and thus the purpose of palliative treatments is to increase patient's life quality, this situation affect their psychological condition.

Access to care: According to experts studying access to care, many Americans approaching the end of their lives are not able to receive hospice care. Fair and equitable access to hospice services does not exist in Egypt because the place where you live may affect the access to hospice care, for example, rural residents have less access to hospice care than the urban residents. In addition, public awareness and the training of healthcare professionals also play a role in the availability of hospice care. From my experience, I can say that very few nurses and physicians in Egypt were trained and certified in hospice and palliative care and that both rural and urban healthcare professional were not sufficiently knowledgeable about pain management, disease management and EOL issues. In addition, the difficulty of accurate prognosis may limit hospice effectiveness. Moreover, hospice programs may put additional limits on the patients if they accept, such as requiring patients to forgo specific treatments or sign a do-not resuscitate order before receiving services

Assessment of cancer patients: Many cancer specialists emphasized that they assessed their patients on the basis of performance status and their co-morbid conditions. They believed their experiences affect the patients' assessment. Some newly graduated physicians treat the disease rather than the patient especially if they work in rural areas, while experienced physicians apply special treatments for each patient, and apply their experiences in cancer patients' care, rather than relying only on text book. So, physicians who have more experience can make better decisions.

Prognosis: The ethical questions concerning prognosis include: accuracy, developing an accurate prognosis is difficult to do considering the unpredictability of disease, the large number of life-extending technologies available, and the great number of unknown and unmeasurable variables that influence how and when a person will die. Prognosis communications with patient, asking a physician to make a prognosis and inform the patient of this prognosis mostly unethical, and the patient does not embrace full and open discussion between doctors and patients about either health status or death.

End stage definition: Some of the patient's relatives ask about how long the patient will survive. So, physicians avoid answering this question because it is hard to accurately define end stage, as they would not be able to determine the patients' precise time of death, since many factors affect the patients' survival, thus each patient should be assessed separately according to their condition.

The aim of cancer therapy: Treatments for cancer patients can be classified into two main categories; palliative and curative. Most of the time, physicians do not treat cancer to increase the patient's survival, but they only treat the patient to improve their QOLe. So, the purpose of palliative treatments is to increase patient's life quality. At a stage which they know that the disease is not curable, they resort to palliative treatments.

Pain management: As a patient with serious illness approaches the EOL, symptoms, including pain, may intensify. A major part of symptom relief is the use of drugs to relieve pain, soothe anxiety, and encourage rest. Due to continuous pain patients may undergo unhappy death. Family members are repentant with sorrow due to miserable death of their loved one. Pain relief can be successfully achieved by the scientific and holistic approach of analgesic administration in palliative care. Unfortunately, some of patients still die in pain and few of these patients experience severe pain during the last days of their lives. Lack of knowledge and skills in pain assessment, improper medication, and unavailability of morphine and fear of opioid addiction are some of the challenges of palliative care. There is fear that drugs (sedatives and opioids) prescribed in the terminal stage hasten the death process. Fears of addiction to narcotics plays a key role in how people view pain management. Physicians are sometimes worried of legal and criminal scrutiny and punishment from prescribing narcotics excessively or to the wrong person. Fear of overdosing and hastening death in terminally ill patients may be unfounded However, fear of overdose and criminal punishment still remain and may lead many physicians to under-prescribe drugs.

Withholding and withdrawing medical treatment: When seriously injured or ill and approaching death, medical interventions may save or improve the life of a patient. Most people die in hospitals who are in long-term care facilities, and a majority of deaths in these settings involve withholding or withdrawing at least one of the medical treatments. Therefore, this issue will likely affect many people as they make decisions for themselves, a family member, or a loved one. Nearly many numbers of seriously ill patients are unable to speak for themselves when the time comes to decide whether or not to limit treatment.

Resuscitation: Resuscitation treatments and technologies restore and maintain breathing and heart function. However, cardiopulmonary resuscitation (CPR) doubles a person's chance of survival from sudden cardiac arrest, which is the leading cause of death in adults. While CPR is valuable for treating heart attacks and trauma, using CPR towards some dying patients may

be inappropriate and cause complications. For some terminally ill patients, CPR is an unwanted procedure. However, the universal use of CPR makes it difficult for health professionals to stop using CPR with dying patients. Patients who do not wish to receive CPR may seek a do-not-resuscitate (DNR) order from their doctor. Family members of patients who cannot speak for themselves may also seek a DNR order on their relative's behalf. It may be easier for patients and families if physicians initiate the discussion about a DNR order. Physicians should talk with patients who are at risk of cardiopulmonary arrest (or that patient's healthcare decision-maker) and learn about their wishes regarding resuscitation, which the physician then has an ethical obligation to honor. Whether or not it is ethical to apply CPR to all patients who will stop breathing, some physicians do and others don't, it depends on personal values. One argument suggests that DNR orders would not be necessary if CPR was limited to those cases where it is a potentially beneficial treatment.

Mechanical ventilation: It uses a machine to inflate and empty a patient's lungs allowing oxygenation of the blood. Mechanical ventilation is delivered through tubes inserted through the nose or mouth into the trachea, or through non-invasive ventilation (NIV) where air is delivered with a mask. The majority of dying patients experience breathlessness, or dyspnea, and they die. The feeling can be uncomfortable to patients and frightening for loved ones to witness. Ventilation may be given to these patients, not to extend life but to help with breathlessness. Ventilation may help them to sleep better, experience less anxiety, and eat and drink more comfortably. Mechanical ventilation is the most common life support treatment withdrawn in anticipation of death. Mechanical ventilation is such a common treatment at the EOL, that some care providers may regard mechanical ventilation as "death-delaying" rather than "life-prolonging." Some patients become dependent on the ventilator or die.

Nutrition and Hydration: Patients who are unconscious or cannot swallow can be treated through providing nutrients and water.

Enteral nutrition with feeding tubes: Delivers nutrients directly into a patient's stomach or intestines with a feeding tube. Feeding tubes are either gastrostomy tubes inserted into the stomach through an incision in the abdomen or nasogastric (NG) tubes inserted through the nose and esophagus into the stomach.

Parenteral nutrition: Delivers nutrients directly into the bloodstream. One such treatment, total parenteral nutrition (TPN), can supply a patient with nutrients to maintain his or her body weight over a long period of time.

So, nutrition and hydration can not be withholding, because food and water is similar to the act of killing a patient or allowing a person to die. A person cannot live without food and water. If nutrition and hydration are withheld or withdrawn the patient will die within a few days, even in practice, if health professionals and loved ones considered providing nutrition and

hydration is to extend life will be beneficial or burdensome to the patient. A dying patient receiving nutrition and hydration *via* artificial way may not be ethically withheld or withdrawn – whether or not the patient will die as a result of this action.

Antibiotic treatments: Dying patients are susceptible to infection. Many patients with life-threatening diseases, infection will affect their final days, and antibiotics may be given as a result. Antibiotic treatments may not cure an underlying cause of illness, but rather alleviate symptoms.²⁰ Physicians often find it difficult to withhold antibiotic treatment from patients. One ethical concern raised by health professionals is that excessive use of antibiotics may cause mutation of bacteria, which become resistant to treatments, they express concern that over-prescribing antibiotics may result in resistant bacteria that could be more harmful to the future of the patients, particularly in light of evidence that antibiotics may not be effective for treating infection in terminally ill patients.

Euthanasia: Euthanasia is an act where a third party, usually implied to be a physician, terminates the life of a person—either passively or actively. People who are kept alive without hope of recovery for lengthy periods of time can cause their loved ones much grief, survive in a state that the patient would not have chosen or wanted, and their care can cost a great deal of money.²¹

Passive euthanasia allows a patient to die by stopping or refraining from beginning some type of medical intervention. For example, withholding ventilator support for breathing may be considered an act of passive euthanasia because the person would die on his or her own without the ventilator. Discontinuing dialysis is another example. Passive euthanasia is often thought of as a "allowing a person to die" because while the action of the physician removes the supportive treatment, the life-threatening illness or medical situation actually ends the patient's life.

Active euthanasia refers performing some action that terminates the life of a person. An example of an active euthanasia intervention would be a situation if a physician would inject lethal dose of a drug to a patient.²²

Some physicians withdraw the treatment procedure from cancer patients at end of their life, they considered withdrawing a treatment as one of the most difficult decisions in treating cancer patients. While others don't be able to withdraw the patient's treatment themselves just because they are end stage patients. Another insisted to maintain patient's hope and they don't let the patient think they are leaving them alone to die.

There is an impression that palliative care is confused with euthanasia, which is totally forbidden by Islam. Palliative care is the moral and ethical alternative to euthanasia. Providing comfort, relieving distress, controlling pain, and offering a service that is available 24 hours a day, sustains the patient's hope. It is not based on the false hope of providing inappropriate and ineffective treatments. This society quite rightly sets great store

on hope, and palliative care increases that hope, that each day may be more comfortable than the last. This act is Islamically forbidden because it encompasses a positive role on the part of the physician to end the life of the patient and hasten his death *via* lethal injection, electric shock, a sharp weapon or any other way. This is an act of killing, and, killing is a major sin and thus forbidden in Islam, the religion of pure mercy.”

“Islamic jurisprudence, based on a convincing interpretation of the holy Koran, does not recognize a person’s right to die voluntarily. The Islamic arguments against euthanasia can be summarized in two main reasons: Life is sacred and euthanasia and suicide are not included among the reasons allowed for killing in Islam”. And Allah decides how long each of us will live and two verses support this reason. According to Islamic teachings, life is a divine trust and can not be terminated by any form of active or passive voluntary intervention. All the Islamic scholars regard active euthanasia as forbidden (Hiram) and there is no difference between Sunni and Shiite schools.

The moment of death, *ajal*, is under the control of Allah and the human has no say in this matter; the human can not and should not attempt to hasten or delay the *ajal*. The prohibition on life applies equally well whether for self, suicide, or others, homicide or genocide. The concepts of autonomy, freedom and individual choice is not applicable here for these two reasons: a. life does not belong to the human; and b. taking life will cause harm to the family and society in general. An individual’s freedom of choice is constrained by the harm it causes to others. As a conclusion we can say that the Islamic concept is that life belongs to Allah. It is He who gives and takes away life. No human can give or take it. Muslims are against euthanasia. They believe that life of human is sacred because it is given by Allah, and that Allah chooses how long each person will live. Human beings should not interfere in this.²³

Clarifying influencing factors and barriers: Discussions with patients over options would be meaningless without adequate knowledge of the medical facts (e.g., discussion on benefits of whole brain radiotherapy cannot take place unless one is cognizant of the benefits and risks in a patient with brain metastases), study of the possible barriers (e.g. if intensive care support is not available, it makes no sense to offer it to a patient who is terminally ill) and understanding of individual characteristics of the patients (e.g., if the patient’s religion dictates that artificial nutrition is an obligatory act, insertion of a feeding tube would probably be non-negotiable)

Financial consideration and cost of treatment: EOL care is a significant cost to payers and patients. Healthcare and oncology drugs are very expensive; the financial and economical problems and lack of optimal insurance system are one of the most important challenges that can affect patients and their family at the time of decision-making. Discussions about the cost of treatments and care of end stage cancer patients can be of paramount importance. Consequently, considering differences

of healthcare services in various cultural backgrounds and social structures, the professionals in service face numerous ethical problems for decision-making.

Most physicians would choose the standard treatment on the basis of scientific evidence and the high cost of treatment would not change their decisions. So, they may have to discuss with their patients and families about financial issues whereas they cannot avoid effective interventions on the basis of cost and they are responsible to advocate for their patients. Actually, the decision-making in this situation will be very difficult and distressful for our physicians. Financial problems are also a challenge, which can affect physicians’ practice in regards with decision-making as they cannot tell patients that some treatments are more beneficial but more expensive. Furthermore, healthcare and insurance system face many challenges in regards with terminal illness and healthcare providers and planners need appropriate resources and programs to improve the quality of EOL care.

Challenges may also arise due to lack of optimal insurance system. The insurance system does not currently pay all of the oncology drugs’ costs because the existing insurance coverage is not optimal, patients and their families have to pay out of the pocket to undergo these high expenditures treatments or to deprive themselves of some treatment options. In fact, if our patients can use an appropriate insurance coverage and governmental financial support, they can enjoy better treatment services and our physicians endure less distress.

Psychological, social, and cultural challenges: The development of palliative care has been limited by additional human factors. Both hospice and palliative care have come to be associated with the EOL. Psychologically most people fear and avoid things related to death. There is often a belief that even acknowledging the possibility that one may die soon is harmful. There is no evidence to support this belief and recent evidence points to the possibility that palliative care may actually improve survivality. In our country, informing patients about their diagnosis and prognosis under life threatening illness is prohibited or strongly discouraged. Previously this had been the case in most cultures, but views have been changing in the past several decades to the point where there is now some acceptance of the idea that patients themselves should be given the choice as to whether to receive this information. Life-threatening illness can have a major impact financially. In our country effective medical treatment may be available to those with the financial resources to pay for care.

Other aspects of the dying process: Patients who reach the end stage of advanced illness may also suffer from a variety of complications, including anorexia, weakness, and sexual dysfunction. Multiple interacting symptoms contribute to suffer (which is manifested by depression, cognitive disturbance, and interpersonal and spiritual crises) at the EOL. Furthermore, dying patients and their families often have to deal with complicated

“practical” issues, such as financial problems (e.g., paying for home care) and legal issues (e.g., organizing wills or healthcare proxies). These seemingly mundane concerns can cause a great deal of distress for dying patients and their families. Physicians should be aware of the possibility that these problems may contribute to patients’ distress and should be mindful of asking about them. Lastly, in those who are actively dying (i.e., the rapidly evolving process immediately preceding death, which can be recognized hours to days before death), discomfort may be heralded by shortness of breath (as a result of an accumulation of respiratory secretions).

Families involved with EOL care: Increasingly, it is recognized that “cancer is not only an individual quest; it is a family and support experience. The degree and type of family involvement, however, varies across cultures. In addition, healthcare providers’ expectations regarding the participation of patient and family members during decision-making in case of cancer, also differs among cultures. In our society, the family unit is the structural foundation of Egyptian society. The impression is that patients can cope better with a terminal illness in their home, than happens elsewhere in other countries. This is probably because of the close family bonds and their strong Islamic faith with its obligation to provide for parents in case of need, to help make their lives as comfortable as possible, and think such beliefs can help them during hard times. The family is much more implicated in the cancer experience, that it seems like family’s disease. In many situations, many families ask physicians for the patient being unaware of their disease. Therefore, physicians encounter ethical dilemmas and cannot decide easily, as they are obliged to fulfill the request of patient’ families/relatives. In this situation, physicians have to tell the truth to the first-degree relatives of patients, and give necessary information to the patient’s family. Sometimes, patients and their family tend to take their patient home to do EOL care at home, because they want their patient to die at home; they do not like death in hospital at all, this is their family belief and they won’t be happy to leave their patients in hospital. In a study reported by Alsirafy et al in 2010, described the death place of patients with advanced cancer had been referred to an Egyptian palliative care program over 1 year. Out of 79 patients, 73% died at home and 27% in hospital or ambulance. It is the authors’ impression that preferences of Egyptian patients with cancer and their caregivers and the degree of social support had contributed significantly to this relatively.²⁴

Challenges Faced by Patients and Families/Healthcare Professionals Involved with EOL Care

Preferences and practices of truth telling: Truth-telling is a central concern for staff when carers act intentionally or unintentionally to prevent staff being truthful with patients. The cultural background of our society and the families’ requests are the main obstacle for truth-telling. Some physicians cannot directly able to tell many patients about their serious condition, and cannot be able to inform them clearly and frankly in this regard.

This step is challenging as well as important for the physician because informing the patient about his problem helps him to be prepared to face it.

Patient’s capacity is the main element of autonomy-based decision-making which may be influenced by different internal factors, e.g., mental capacity, stress, and level of understanding of medical information and external factors e.g., culture, and socioeconomic class. Although family request of “do not tell” the truth and their strong resistance towards informing patients about their diseases may confuse healthcare professionals, it may also reflect divergence in patients’ interests in people.

Physicians sometimes are scared to communicate and to share bad news to the patient because they may make the patient feel hopeless and unable to cope with the problem. Words like ‘cancer’ may create a sense of death and despair in patients. Sometimes a diagnosis of a malignant disease results in the deterioration of patient’s QOL. It depends on the attitude and practice of healthcare teams about whether and how to disclose diagnoses to patients with terminal illness. Some patients will know their diagnosis without direct disclosure by the physician or their family, so not telling the truth may ruin the trust between patient and physician. Thought it is not necessary to reveal the whole truth. Thus, the patients should become aware of the required information based on their wishes. So, information about an end stage diagnosis should only be told by patients’ relatives in a longer time. Some patients prefer to receive information gradually depending on their emotional responses.

Some of our physicians think that providing patients with unnecessary information would result in loss of patients’ hope but also deviate the treatment plan. Most of our physicians are reluctant to tell the truth as they were not ready for such interaction. These providers consider sensitive communication a priority and make time to integrate communication into patient care. Usually, our physicians are likely to make full disclosure about a terminal illness to the patient’s family, who will then decide what to tell the patient about his or her condition. Our physicians emphasized that they have not been received any formal training in key communication skills, truth-telling and breaking bad news that are very essential for EOL. Physicians should know that total information disclosure is not helpful for all patients at particular times during their illness and they should take patients’ needs into account.

Physician value: It is important for a doctor to be aware of his own values and the values that drive others and their behavior. Values are pivotal to the art of medicine, and practice based on unexamined values often leads to confusion, indecision and inconsistency. Decisions regarding terminal patient care may be altered by a physician point of view and subjective attitudes toward dying patients. Physician’s anxiety towards death and their discomfort with dying patients reflect on their own past experiences, both personal and professional, impact on their

feelings regarding the treatment options available to a given patient. Some Physicians picture the situation worse than it is in order to get the patient to decide what the physician feels to be in his/her best interests. Goal is to hope for the best course of illness or for best QOL for the longest possible time

Multidisciplinary team working: Oncology is a very complicated field, which needs coordination and cooperation among multidisciplinary team working. Advanced cancer patients should be treated in a multidisciplinary approach, and a group of specialists should be involved in treating these patients. However, this approach is not possible in most of our hospitals because our centers are designed for treatment and are not appropriate for providing supportive care. Physicians and nurses are usually responsible for most of patients' needs in most of our hospital, while all of them are not in their job description. Most of our oncology hospitals are for treatment of patients, not for EOL care.

Challenges Faced by Healthcare Professionals Involved with EOL Care

Organizational responsibility: Healthcare organizations are responsible for using strategies to promote an organizational ethical climate. There is evidence that ethics protocol, guidelines and programmes may help reduce ethical conflicts.^{25,26} In this regard, having 'Do Not Resuscitate', 'Advance Care Planning' and communication policies and processes are important in EOL care. Evidence-based guidelines on transfer of patient to the intensive care unit (ICU) and use of welfare funds also take the burden of decision-making off staff and decrease the stress associated. Where the complexities of the case exceed those of the managing teams, there should be access to clinical ethics consultation and staff support schemes. Considering the investment in time often required to handle these situations compassionately, there is also a responsibility to ensure that the organization is adequately resourced.

Inadequate training: The oncologists believe that another reason, which creates contradictions for them and make them face difficult situations of decision-making, is educational constraints regarding medical care and ethical decision-making in courses of medicine, and even in residency courses that they have passed. Physicians who did not receive education in this field creates conflict itself. Education can be very effective; even educating specialists is very important.

The management of EOL care and the process of engaging in difficult conversations are topics that are frequently neglected in medical education. Many medical and surgical residents (who are often the physicians responsible for eliciting a patient's treatment preferences at the EOL and for facilitating difficult conversations with families) receives inadequate preparation for these tasks. Statistical studies revealed that there are particularly distressing when compared with similar

studies conducted on medical instruction of invasive procedures (e.g., arterial puncture, central venous line placement, and thoracocentesis). Conventional teaching methods for invasive procedural skills involve planning ahead, demonstrating the procedure, observing the learner in action, providing feedback, and encouraging the learner's self-assessment. However, certain medical specialties (e.g., oncology and intensive care) seem to offer stronger preparatory programs for EOL care and encourage the recognition of death as part of the life cycle.

Physicians often lack the skills to communicate with patients and their families. There is a need for good planning in regards with terminal cancer which requires improvement of physicians' communication skills, provision of appropriate services for EOL care, developing multidisciplinary team working and optimal health system, and to develop guidelines for ethical decision-making and set educational priorities for physician working in this field.

Insufficient compensation: An issue that receives little formal attention among clinicians who care for dying patients is the way they are compensated for their work. Physicians who care for terminally ill patients and their families are often driven by an altruistic need to ease suffering. However, for many, altruism eventually confronts financial realities. It is reasonable to assume that continuing disparities in compensation between physicians who spend much of their time talking to patients and families and those who spend much of their time performing procedures may lead physicians who currently care for dying patients to grow resentful and keep talented individuals from entering the field. It is well known that the Medicare resource-based relative value scale compensates physicians more for invasive procedures than for evaluation and management procedures. Evaluation and management procedures include the extensive discussions with patients and families that are frequently demanded of clinicians who provide EOL care.

Personal discomfort with death: Many physicians, after intensive training that focused heavily on science and technology, feel uncomfortable when directly addressing issues (particularly those concerning spiritual and emotional needs) faced by patients and families at the EOL. Attention to dying patients tends to focus on tangible questions directed toward a nurse such as "Are they eating?" or "How are they sleeping?" rather than on questions directed toward the patient like "How are you doing?" and "What would you like to do? Clinicians frequently feel uncomfortable confronting death because they relate to and identify with terminally ill patients and their families and resist doing so in the name of professionalism. Additionally, a clinician's personal anxiety about death and disease may be further incited by interactions with a dying patient. In particular, doctors often think of death as a sign of failure or as an enemy rather than as a natural and universal part of the life process. Furthermore, a patient's dying process may remind the clinician of similar losses suffered in his or her own personal life, leading the physician to

have surprisingly strong feelings toward this particular patient.

Ethical issues after death: After someone dies, loved ones may have to consider one or more of the following issues: Organ donation: when a person dies, the medical provider may consult the person's healthcare directive or their driver's license for their organ donation wishes. In the absence of these documents, the healthcare professional may ask a family member for permission to use the organs for organ donation. Solid organs and tissues may then be removed from the body and given to an ailing person. Family members may also be asked if the body of the newly deceased person may be donated to science as well.

Research with dying patients: The ethical issues around medical research conducted with terminal and palliative care patients are complex. Research review committees' opinion do not allow some researchers to access dying patients because the patient is already overburdened with a terminal disease and the approach of death. Others consider research with dying patients a necessary evil, and may consider it unfair to specially classify and distinguish dying patients from other patients. This includes demonstrating informed consent where a patient feels that participation is voluntary and fully understands what he or she is being asked to do who can present challenges to researchers when suggesting research to a review committee. These patients may be seen as particularly vulnerable because often they are reliant on the healthcare system and experience great amounts of emotional and physical stress.

CONCLUSIONS

The care of dying patients is fraught with challenges for patients, their loved ones, and their physicians. Clinicians must keep in mind the difficulties a patient faces in this process as well as their own professional and personal obstacles to performing this work to the best of their ability. Therefore, EOL care is optimized when approached as a thoughtful collaboration between patients, their loved ones, and their treatment teams. Clinicians are given a remarkable opportunity to help ease the physical and emotional suffering of patients and families confronting terminal illness and death. Culture and religion at least partially affect one's perception of palliative care and the decision-making that occurs at EOL. It is important to realize that there is an entire system at play that includes the patient, their family, their physicians, and other healthcare providers. In order to provide the best possible care to patients and families in EOL situations, it is important to understand their cultural constructs as well as their individual preferences. It is also important for each caregiver to realize that we each bring our own set of biases to these discussions based on our cultural and religious background and personal experiences.

RECOMMENDATIONS FOR HEALTHCARE PROFESSIONALS

1. Healthcare professionals need to be empowered with the capacity, skills, and knowledge to respond to the unique needs of each patient and their loved ones.

2. Proper cultural assessment of each patient for appropriate approach to assist them in their decision-making process.
3. Teaching and training in cultural competence among oncologists are lacking, and should be mandatory.
4. There is a need to develop culturally competent healthcare systems to address effectively different social, racial, and cultural realities of which they provide care.
5. Physicians must be aware of their own values, beliefs and attitudes towards life sustaining treatments as well as death and dying. Ethics education should be intensify especially for physicians routinely involved in EOL care.
6. Education about EOL care is very important and can improve physicians' practices in this area in order to apply these skills to patients care.
7. Physicians' response to patients who are non-compliant to appointments, prescriptions, and recommended medical care can be very ethically challenging.

CONFLICTS OF INTEREST

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