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"**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 Bokovaon 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

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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, Faili 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 wants 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

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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

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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 grandmother 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.

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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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