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

Perspective Article

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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.

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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-

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portunities for such training and skills.[5]

UAE holds a small local Emirati population, estimated as 11.5% of the total population in 2010[6] 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-Yateem[9] 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

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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-

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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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