

Palliative Care in the United Arab Emirates: A Nurse's Perspectives

Nesreen Al-Alfi*

BSN, MSN, Fatima College for Health Care Sciences, Abu Dhabi, UAE

*Corresponding author: Al-Alfi N, BSN, MSN, Fatima College for Health Care Sciences, Abu Dhabi, UAE, Tel: 00971509750694; E-mail: Nesreen_alalfi@yahoo.com

Received date: Nov 05, 2015, Accepted date: Dec 07, 2015, Published date: Dec 10, 2015

Copyright: © 2015 Al-Alfi N. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Introduction

UAE is one of the GCC countries that its population as last reported by WHO is around the 8 million, out of which only 8% are considered as nationals, the rest are expatriates. The expats are the major working force, coming from different ethnicities and backgrounds, all of which enrich the community with its variety and experiences [1].

UAE is a well-known oil-rich country. Oil is the main source of income and wealth. The UAE is always thriving, and working to be the top notch of everything. This momentum in building capacities and infrastructure has been a driving force in continuously opening eyes for the needs of the nation, and how to achieve it the best way possible. And you know what? If someone can pull it; it's definitely the people of UAE, but that is not the case always.

Palliative Care Nursing

Palliative care nowadays is receiving much attention in UAE in comparison to the last years, a huge emphasis came from the health authority to actively start bringing these services into a more structured, and standardized delivery system. The gap is noticed between the WHO report that mandate that by 2020 all countries should have palliative care services in place; to minimize the suffering of the non-communicable debilitating disease, out of which cancer sufferers to be the first to benefit from the existence of such health care services [1].

I am privileged actually to be selected as one of the experts chosen to be on a task force in the health authority of Abu Dhabi. As it made total sense that someone like Me, who come from a similar background of Arabic culture and Islam religion, would have a lot to contribute with. Is it?

I remember clearly how we started in Jordan, with a dedicated team of 3 nurses and 2 physicians, as a core group, who got together aiming to build palliative care services in King Hussein Cancer Centre (currently known as King Hussein Cancer Foundation & Center), we faced different challenges that has really tested our patience, stamina, and creativity to get around them [2]. We started in a phase when patients were told that they have a tumour, a stubborn infection, anything but to say the word cancer, even if everything around starting from the center name itself that contain the word "cancer", ending with the tissue box, that states clearly that it is a cancer center. The society we had to confront had a huge denial issue, so imagine discussing DNR or any of other end of life decisions. Even oncologists when talking to patients, would not take that plunge before referring them to palliative care!

Policies were created to overcome such practice, training on communication and breaking bad news were actively done, and then we ended being labelled as "death team", a stigma that disabled us from

taking care of those patients who are not terminal, and yet was scary enough to those who are terminal; because our service meant to them "Death", a word that is equally feared as "cancer", and even used alternatively!

Religion is another issue that needed a careful approach, as religion addresses many existential matters, so having (fatwa's) from respected Islamic authorities was a must-have to address questions and fears in our society. And as we kept overcoming obstacles, each one at a time, we were learning, growing, and reflecting on how far we are progressing. Progress was another term that we had to define for our administration, as an institution that depends largely on donations; it was crucial to demonstrate our importance and contribution in means of: lower costs, better quality of lives for our patients, and a higher level of patients and family satisfaction. Moving on to training staff who are willing to take on all of these challenges with us, and to retain them among all stressors faced. All of this in the middle of expanding services, with evolving policies and standards of care, while creating up-to-date clinical pathways guidelines. So I can say that the depth of this experience made me feel ready to take on next challenge in UAE!

Yes, Jordan and UAE are both Arabic and Islamic countries [3], we share a lot; in terms of the spoken language, and following the regulations of Islam. As a matter of fact... our king's sister is married to the ruler of Dubai! Sounds like a lot. But as we started to meet; to discuss standards of care, and possible channels of delivery, I stumbled upon many differences. First of all, the society of the UAE is quite different in relation to the Jordanian one; in terms of who constitutes the working force in the health sector, and who receives such services. The multiethnic health care providers, with patients who are also from all around the world; create a huge barrier of language, culture, and belief system [4], that directly affect the concepts of health, illness-wellness definitions, and what a good dignified death means, and just going through some case reports faced in UAE can reflect few of many challenges faced [5] What a huge challenge to address, as you are trying to build trained professionals in palliative care [6]. Not to mention that; even if you have trained a small percent, chances are quite slim in retaining them; as most of this working force is expats on fixed terms contracts, and once done, they will be heading to their home countries, leaving you trotting back to square one.

Palliative care services by a trained team (until the date of writing this article) are provided in very specific places: Tawam hospital, being UAE's nation oncology center, and in Sheikh Khalifa Medical City, where they have a home-care team, that offers such services. Now we cannot say that the other clinical settings do not provide any. Lots of symptom management is being done in oncology units, but not necessarily comprehensively, nor effectively relieving the suffering.

In my modest personal experience, as I accompany students in their clinical training, I see lots of patients who are still undertreated for pain plus other somatic symptoms, they are overlooked in

psychological anguish, and the most difficult part: Isolated in their final journey of life; due to a barrier of language, religion, and culture and sometimes...far away from home and loved ones.

The challenges are huge. Even when the language and culture barriers are down, I still see defects in caring for those patients due to lack of training and structured programs for palliative care, that equip providers with needed information and skills. Having palliative care knowledge, made me realize the huge demand for sharing such knowledge with colleagues, with a strong wish to contribute in improving the quality of life for those who are still suffering. Talking around to patients, then their attending care teams, I noticed the big difference between what is perceived as achieved, and what is actually happening in reality; my specific encounters revealed to me, that many would like to believe, that they are managing symptoms effectively, while in reality patients still in real distress.

The classical picture of under assessing symptoms [7], disregarding non-somatic ones, lack of advanced pain management options and knowledge, and loads of myths mixed with exaggerated fears of using opioids, and addiction as an end result. All what literature review can reveal as causes of inadequate symptoms relief coming as one big package, leaving you feeling intimidated on how are you ever going to fight all that, when only there is only few who knows.

Another hindrance here in UAE, is the legal system, till this moment there are no approved policies of "Do Not resuscitate" or "Allow Natural Death". So not intervening acutely and aggressively, even when it is not advised, or proven to be medically futile can be punished by the UAE law, and a health care provider can end up being on trial for malpractice, and man slaughter. So any concepts learnt of comfort care, or managing symptoms rather than trying to reverse an irreversible disease is gone out of the window; once you feel that it will compromise your legal situation and license to practice.

In UAE, to my knowledge to this date, palliative care is still not part of the formal nursing, or medical training. And even after graduation, chances are very slim to be exposed to a structured and well-planned training in this field. Bits and pieces on how to manage certain symptoms in a very general way, and orientation programs upon hiring are geared towards different tracks of general safety, cultural awareness, and skills competency in practice.

In the last two years, one could notice that more conferences are being held with the theme of palliative care as a focus. In addition to; many oncology- focused conferences have started to add palliative care workshops/topics as parallel sessions to the main event. I have participated in many in Abu Dhabi and Dubai palliative care awareness conferences, as a trial to change mentalities, spread knowledge that can affect quality of care, and raise awareness. Feedback were great regarding the topics presented, and the more I meet fellow nurses, the more emphasis I get about how much these topics are needed, and sought after; as resources are scarce in this arena. I am still thrilled to see how presentations can draw an "AHA-moment" on their faces, though the topic might be as simple as "The 6-step protocol of breaking bad news"; but it makes a huge difference in their practice.

And I have to be honest here, and admit making a final statement, to colleagues who shuddered their shoulders, in lack of interest as they

declared that: palliative care is all about pain management only, and holding hands! We know it all. " NO it is not, let's start with you fellow educators!"; and stop misleading those who really want to learn, and know more about what is it really about. Learning is a lifelong process, and palliative care is an interdisciplinary professional arena, where lots of science come together to achieve one goal only: quality of life, whatever that means to whoever patient. As Stephen Hawking said one: "the greatest enemy of knowledge, is not ignorance, but the illusion of knowledge"

Many researches are needed in palliative care, but if we are going to talk about Middle East, and Arabic countries, the field is very rich and fertile, loads of questions that need to be answered, but being realistic here, I can see that those who are on the battle field like myself, are worried about spreading basic knowledge and art of palliative care first, rather than engaging in research ventures about advanced management options. Though research is highly needed, and few activities are going on, but I would say that they are humble in comparison to our colleagues in America and Europe; as we are still in the phase of getting answers to basic questions that are stemming from an Arabic Islamic culture and mentality.

Despite all of these setbacks, I have to admit, that the progress is slower than we wish, but YES we are moving forwards. Finally in last meeting with the health authority task force, there was a blueprint, with scope of work for the multidisciplinary team members, suggested channels of services delivery, at a carefully selected primary health care centers, list of drugs needed and availability in UAE, and a request that was very dear to my heart..." can you suggest a plan for training the nurses in such health care centers on palliative care?"; confidently and happily, I replied "YES".

References

1. WHO/CCU/14.03/United Arab Emirates.
2. Stjernswärd J, Ferris F, Khleif S, Jamous W, Treish I, et al. (2007) Jordan palliative care initiative: a WHO Demonstration Project. *Journal Of Pain & Symptom Management* 33(5): 628-633.
3. Bou Khalil R (2013) Attitudes, beliefs and perceptions regarding truth disclosure of cancer-related information in the Middle East: a review. *Palliative & Supportive Care* 11(1): 69-78.
4. Harrison A, Busabir A, Al-Kaabi A, Al-Awadi H (2015) Does sharing a mother-tongue affect how closely patients and nurses agree when rating the patient's pain, worry and knowledge? *Journal Of Advanced Nursing* 24(2): 229-235.
5. Hidayatullah M, Fromme E (2013) Die in a foreign land or forgo cancer care: difficult choices faced by the expatriate workers in the United Arab Emirates. *Journal Of Pain And Symptom Management* 46(4): e8-e10.
6. Hannawi S, Al Salmi I (2015) Health workforce in the United Arab Emirates: analytic point of view. *The International Journal Of Health Planning And Management* 29(4): 332-341.
7. Laugsand E, Jakobsen G, Kaasa S, Klepstad P (2015) Inadequate symptom control in advanced cancer patients across Europe. *Supportive Care In Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer* 19(12): 2005-2014.

This article was originally published in a special issue, entitled: "**Palliative Care & Nursing**", Edited by Michael Silbermann, Middle East Cancer Consortium, Israel