Palliative Care: UAE Perspective

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Palliative Care in UAE

"A Fan, an Open Door, and a Sofa"?

Are you sure that you are talking about palliative care?!

In my last article “palliative care: UAE perspective”, I talked about the difficulty of the situation, barriers faced in managing patients’ symptoms, and humble efforts from different members, trying to ease suffering; while passing on knowledge to other fellow caregivers.

This time I am going to share a story of one of the patients that I have come across while being in a clinical training rotation with my students. What provoked me to write about this case; is how holistically this patient is not being treated! Of course, not on purpose. But yet, they do receive cancer patients due to proximity of area for some patients, or due to insurance coverage issues.

I have to mention that one of the struggles we face with terminally ill patients here, is the absence of clinical pathways, or specific guidelines, that can lead health care providers towards making the best patient centered care. Though that they are one of the top priorities for the palliative care task force, but still not quite disseminated for practice, nor staff has been trained. Huge staff developments is geared towards selected primary health care centers, and as finally discussed, the health authority of Abu Dhabi will adopt now the "National Comprehensive Cancer Network” NCCN.

First heard of “Lama”, was in the morning round as they endorsed her as the metastatic lung cancer, took last chemotherapy 3 months ago, and she does not take her finger off the bell! And that regardless of what they do, her dyspnea is not getting any better though her saturation level is in 90%. I thought this is a typical case of where palliative care is desperately needed, but no one realizes that YET! One of my students jumped in, and decided to choose her, as a case to design a plan of care, and knowing how passionate I become when we come to reliving suffering of oncology patients, she decided to talk to me first.

I asked the student first to tell me Lama’s story, started repeating like a parrot what nurses said in the morning round, and added “.... currently not working, does not want to go back to home country though doctors have offered that several times”. I smiled back to her and said “NO, tell me Lama’s story….I do not want to listen to their story, I can read the file myself”, so again I plotted for her the domains of physical, psychological, social, and spiritual assessments. Though basic questions are there, but I wanted elaboration, and wanted the student to get to the stem of everything, reminding my student of holistic assessment, to give a holistic care.

Who is Lama?

Two hours later, I come back to the ward to find my student in tears and despair, wondering if we can ever help such a patient; because physicians already did their best, and it's not working…she is suffering. Again I said: “tell me Lama’s story”: Lama is a lady in her mid-forties, came to UAE 20 years ago to make a living, during which her parents have died back in Egypt 10 years ago, being an only child, with no close relatives; she started to spend even her vacation in UAE. Being a career woman, dedicated to her job, she did not get married, so did not establish a family of her own. Lama is out of her job now, but still covered by the health insurance so far. She finished all of her chemotherapy treatments, and have been admitted a month ago for severe shortness of breath, insomnia, and increased dependency in achieving activities of daily living. Her medication chart showed that she is lately receiving a 3 mg of Morphine sulfate on PRN basis for dyspnea (frequency showed she hardly takes one dose every other day), on 10 liters/minute via facial mask. And you can see in the history that several drugs have been tried here, such as: Paracetamol tablets for headaches, Alprazolam for difficult nights, and for complaints of constipation few options are there: Lactulose syrup and Dulcolax tablets when needed. Her laboratory results showed anaemia mainly.

I thought it's about time that I pay her a visit along with my student to listen more to the “unspoken” fears. We greeted her, my student took file and started repeating “she is suffering; though doctors have offered her several times….no one realizes that YET! She is out of her job now, and still covered by health insurance in UAE. She is a lady who has spent 20 years in UAE, during which her parents have died back in Egypt 20 years ago. She is an only child with no close relatives.”

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but is that all what we can do? I decided to seize the chance and have this discussion at the nurses’ rest area, with a hidden intent of letting them all hear us out and participate if possible. I opened the discussion with morphine usage for dyspnea, especially the usage of sustained release instead of PRN basis [1], moved on to her latest hemoglobin result that is definitely contributing to her dyspnea intensity [2]. And the in-charge nurse pitched in, and said: she is here for palliative reasons only, no aggressive measures...no need for blood transfusion that what the attending team said. So this comment illuminated a set of misleading perceptions regarding what does palliative care mean, and this is quite common among health care providers [3]. We all should ask ourselves: What do we mean by reversing the symptom when possible? When do we consider treatments to be futile? Also we detoured around to point out signs; which are crucially important in a chronological manner, to decide that this patient has started an active death process: the point of “we need to stop here”.

The nurses seemed interested, and started to get excited as we connected the dots. We went through Lama’s remarks. I invited them to think about the stem of such statements. They started guessing trying to voice out the unspoken concerns: The fear of dying alone, especially at time of night, when she drifts into sleep. She wanted company when possible. The agony of feeling suffocated alone in a corner room, unable to get out since a month. Having to listen to us as one.

The in-charge nurse pitched in, and said: “she is here for palliative care, and this is quite common among health care providers [3]. We all should ask ourselves: What do we mean by reversing the symptom when possible? When do we consider treatments to be futile? Also we detoured around to point out signs; which are crucially important in a chronological manner, to decide that this patient has started an active death process: the point of “we need to stop here”.

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One week later, I passed by the same ward, Lama’s room was just in front of the station, she waved hello with great passion, I could see one friend lying over the sofa with her stalk of girly magazines, the In-charge immediately greeted me, and called others: “here she comes, bring the file of Mr.(……)!” then she commented, I told them if she could stop Lama from complaining and buzzing that bell...you will sure know what to do with this patient as well!!

Conclusion

The nurses seemed to value what we have discussed together; because obviously such knowledge made them feel able to do something, for a patient whom they felt helpless about. They have seen the difference. They think that I taught them something. But in reality; I felt that they have taught me back.

It came to my mind as we were discussing that lack of a well-established palliative care services, made the multidisciplinary approach more difficult as well. The systems of providing care is still very much paternalistic, which can be a very limiting factor for nurses who are on the front line. Yes, they advocate, but at the very end, if the physician is not convinced or not preferring our suggestions, the order will not be dictated. That was obvious, in trying to get regular morphine dosing instead of PRN basis, same for laxatives, incorporating some of the respiratory therapists care despite the severe shortage. Bottom line was lots of myths that will definitely hinder an optimum interdisciplinary approach. Many people can come on board for a case like Lama: a clinical pharmacist to optimize her drug regimen, a social worker who would have been able to help with her with network of connections, a psychiatrist who can deal with the roots of her fears and final journey. So health authorities must direct efforts towards tertiary care setting as well; as patients admitted there, are sickest to manage, and trying to survive what could be their last days. As all literature supports the positive impact of an interdisciplinary team caring for such patients [5].

Being an expatriate did indeed complicate the situation, as we started to assume; that their home is where are they come from, and that their family are awaiting there. We all learnt, that despite cultural and language barriers faced, there is still one additional of the puzzle needs to be addressed. Home is where the heart is, and family can be simply the friends that we knew our whole life. We all must gear our efforts towards what the patients want, not we think that they want [6].

They made me reflect on the situation of so many other patients, who are just like Lama, spent their youth here till they feel rooted here. Built their whole career in another country, and might be deprived of any kind of health insurance if they go back. It can be painful as well, because some patients I have met do have strong family ties and connections back at their home countries, but cannot sacrifice the health services that are presented to them, especially if they come from a poorer country, which might mean a lower quality of services even. Forcing them to choose willingly, to die alone. And these patients suffer the most, as we ask them to take a decision, between going home to die among family and friends in suffering, or stay in UAE, where they will get a degree of relief, but carry their own burdens. Can the multi-ethnic workforce deal with all of this? Can we learn all together how to adjust to the need of all patients? So what did we all learn here?

The nurses have taught me that we do not need big conferences and planned workshops to have a mass effect, and spread knowledge. I do not have to be fully hired or appointed to do such a task.

This can happen anywhere, everywhere. If we simply ignite the curiosity in any given case, and then allow them to see the effect of suggested care. I always felt powerless in a hospital setting that is I am not formally employed by, and focused my efforts on patients ( considering them their own best advocates), and on my students as a force of change, who will do what is needed when they graduate.

I did not much want to the staff to feel that I am imposing myself on them or even acting superior to them with my badge of “Lecturer” on my lab coat; which is considered in culture as a more informed knowledgeable figure. I wanted more comradery relationship that can foster all kind of questions and discussions.

Through our 30 minutes of discussion in a nursing lounge, I managed to pass on knowledge on simple but yet essential pieces of knowledge in palliative care:

1. Holistic assessment: with huge focus on psychological, social, and spiritual domains.
2. The meaning of quality of life for different persons.
3. Identifying patients’ goals and desires, rather than ours.
4. The meaning of active listening, and building that rapport with the patient.
5. Importance of patient education for better compliance.
6. Ethical perspectives of: autonomy, beneficence vs. Non-maleficence; to define futility in medicine.
7. Signs and symptoms of active death.
8. The subjectivity of certain symptoms and their report, and not depending only on biophysical parameters.
9. The importance of incorporating the family and social network in our plan of care, especially when they are willing.

If someone told me earlier, that we want you to cover this in 30 minutes of discussion, my initial response would be "you need to book me a hall, these topics are a one-day workshop at least"!

Now I happily respond with "grab your cup of coffee, and that file, and let’s have a chat about this patient".

Small, simple steps, but yet can have a huge change on the performance of staff, and quality of life for patients. I have learnt my lesson as well along with my fellow nurses. As my students has said: "One life at a time", forcing me to complete the sentence…"… and one ward at a time!"

**PS:** Lama is an imaginary name for the case, for purposes of confidentiality.

**References**