Journal of Palliative Care & Medicine
ISSN: 2165-7386

Al-Alfi, J Palliat Care Med 2016, 6:4
DOI: 10.4172/2165-7386.1000267

Case Report Open Access

Palliative Care: UAE Perspective

Nesreen Al-Alfi*

Fatima College for Health Care Sciences, UAE

***Corresponding author:** Nesreen Al-Alfi, Nursing Lecturer, Fatima College for Health Care Sciences, UAE, Tel: 00971509750694; E-mail: Nesreen_alalfi@yahoo.com

Received date: May 25, 2016; **Accepted date:** June 08, 2016; **Published date:** June 11, 2016

Copyright: © 2016 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.

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 incomplete assessment of her case, joined with lack of simple but yet proper knowledge, placed her in that situation. And to be fair towards the staff in that hospital, there are no palliative care consultant, not to mention a multidisciplinary team. And also, it is not a designated hospital for managing oncology patients comprehensively. 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 pf 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 develop 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 permission, and I introduced myself. She started talking about her job before getting sick, and how is her whole life is built in UAE, she considers her friends, whom she made over the years as HER family, and though that she longs to her home country, but there is no one waiting for her there, and no health coverage of any kind. She talked about how tired she is, wishing if she could only sleep, and though Morphine can help, but her best friend told her that she becomes quite drowsy and difficult to arouse when she takes it, so she stopped! "I don't want to just slip into death you know…or worse, become an addict!" her best friend came to visit ,and she seemed concerned as we talked about morphine, made a comment how sleepy it can make Lama, while in reality Lama has the sharpest mind she has ever knew!" I just hate to see her sleepy and slow, that is not my fiery friend". Then excused herself to go and pick her children from school. Lama sighed saying:" I just wish if she could be more around, I know that she is a mum, and a busy one too…wish if all my friends actually would come more often, they always come together at the weekend and stay a while, but I cannot ask for more because I know that they have work"

From this point, I elaborated on how morphine actually helps patients in her case, and how addiction is the least to worry about, and being already deprived of sleep, it would be only natural if you fall asleep once you get a degree of relief from dyspnea after taking a dose. We thanked her for her time, and left her to get some rest especially that she started to be out of breathe again. We went out, and my student started to comment that patient education is really important,

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 health care providers and hospital administration, time after time, asking her to leave the only life she knew here in UAE, to go back to no one. These insights made the nurses view Lama differently. Before closing the discussion, I asked for few things if possible. I said:" can she have a fan please, and can you move her to the room that is just in front of the nurses` station when you have it available, and keep the door open". The student commented that there is central air condition, so one more piece of information, explained how dyspnoea is a subjective feeling, not necessarily related to her saturation level or how advanced is the disease [2,4] and how the feeling of an air current directed to her face can make a difference" A little bit of air when your chest feels tight" one of the nurses seemed to correlate! One last task for my student, I asked her if she would seize the chance of seeing any other friends of Lama, and ask them if they all could arrange a schedule throughout the whole week, instead of coming all together at weekends, and if any can sleep over in certain days, that would be even great.

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!"

P.S: Lama is an imaginary name for the case, for purposes of confidentiality.

References

1. DiSalvo W, Joyce M, Tyson L, Culkin A, Mackay K (2008) Putting evidence into practice: evidence-based interventions for cancer-related dyspnea. Clin J Oncol Nurs. 12: 341-352.
2. Naqvi F, Cervo F, Fields S (2009) Evidence-based review of interventions to improve palliation of pain, dyspnea, depression. Geriatrics 64: 8-14.
3. McAteer R, Wellbery C (2013) Palliative care: benefits, barriers, and best practices. Am Fam Physician 88: 807-813.
4. Clinical Practice Guidelines in Oncology TM: Palliative care.
5. Garside J, Barley T, Wellings V (2013) Collaborative services show positive outcomes for End of Life care. Nurs Manag (Harrow) 20: 16-22.
6. Balducci L (2012) Death and dying: what the patient wants. Ann Oncol 23: 356-361.