

Top Ten Challenges for the Medical Oncology and Palliative Care Physicians Caring for Terminal Patients in Saudi Arabia

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Abstract

Family meetings provide an opportunity to enhance the quality of care provided to palliative care patients and their family careers [1].

It has been considered the cornerstone in the palliative care settings of our Institute. As per our policy, it is mandatory to conduct a comprehensive multidisciplinary family meeting which includes the patient's main Caregiver (assigned by the patient), Primary Treating Physician (MRP), Social Worker (the one who carries the responsibility of arranging the setting and makes sure of the presence of the right persons), the Palliative Care Nurse Coordinator, and the Palliative Care Physician (Assistant Consultant, Fellow or Consultant) in order to accept any cancer patient under palliative care. The rationale of such a meeting is to explain the goals of care, plan of management and code status (DNR).

While family meetings are promoted as a common and valuable tool within the context of specialist palliative care there is limited evidence related to how they should be conducted and indeed whether they are valuable, most evidence being extrapolated from other settings [1].

Furthermore, the agreement and signature of the assigned family member on a special meeting form which includes all the discussed points are essential requirements before accepting the transfer of care.

Similar questions, with nearly the same answers, were being repeated in most of the meetings. After collecting some data from both Medical Oncology and Palliative Care physicians, we managed to choose the 10 most common questions raised in the 100 family meetings held during the last 3 months of 2017 (from October to December 2017).

Keywords: Palliative medicine; Family meeting; End of life care; Family support.

Introduction

The process of Accepting new patients under palliative care in our hospital has to be done through official referrals of selected patients; whom with expected limited survival and no plans of further disease modifying treatments. After conducting a family meeting to discuss goals of care, and further management plans to focus on comfort only, in addition to Code status which should be changed to Do Not Resuscitate (DNR).

Our hospital internal policy states that DNR code status is considered a pure medical decision, two consultants should sign in the DNR form, and one of them should be the MRP, in addition to one assistant consultant, patient families have to be informed clearly.

The family meeting is documented in a special form, which is signed by all concerned parties, who attended the meeting, and is being kept as a part of the patient's medical record.

The palliative care team accepted 204 patients from the inpatient referral to be cared for in the inpatient palliative unit, In addition, 56 patients from the outpatient clinic referral in the year 2015. The palliative inpatient unit consists of 15 beds of specialized palliative care, with specialty trained nursing staff.

Q#1: For how long will he/she live?

This is a very common question in most of the family meetings done in our hospital. Physicians caring for patients with incurable illnesses are often asked to estimate likely survival duration for individual patients. Previous studies have established that physicians are notoriously inaccurate when estimating survival, with a consistent tendency to overestimate [2].

After discussion about the lack of disease-modifying treatment options and the need for transfer to palliative medicine for supportive care and end-of-life comfort, families try to get an estimation of the number of days remaining in the life of their dying relative so that they will know how

much time is left to spend with their beloved. Moreover, some families have tried to push the physician to give an exact date and not just a rough estimate, even though it has always been very difficult for the physician to answer them precisely.

Some families have planned to use the precious remaining time to take their patients to worship at the Holy Mosques in Makkah and Madinah. But if the patient was very close to the end, the family was discouraged from letting the patient leave the hospital as he/she needs to receive end-of-life care. Nevertheless, patients and their families were given our full support by always allowing open visits. The members of our team frequently visited the patient and functioned like a spiritual advisor, social worker and psychologist.

Q#2: Is there any chance for cure if medical advice is sought abroad? Is the patient able to travel? Where to go for medical advice?

The question about travelling abroad was not uncommon in family meetings. There were family members who were still not satisfied with the management in our hospital and have thought that by seeking medical advice abroad, they may find a way to cure the disease; hence, some families have asked for a full medical report that included the management plan and course of treatment.

Unfortunately, most of our patients were too sick to travel; therefore, another question raised was “How can the patient take a trip?” Patient transport services were normally arranged by families; physicians have nothing to do with that. Most of the time, travelling by Medivac was the only option for some families.

Affixed to the previous question is the problem of where to seek medical advice. Relatives have tried to get the names of centers either from the internet or from some friends who have experienced travelling to these centers or know of somebody who have tried the treatment centers.

Some families have insisted to take their patients to unrecognized centers in countries like India, China or Germany to be given treatment for cancer. We have seen some of these patients return in a very bad medical condition after spending money in unconventional treatments like phototherapy, laser therapy or unapproved protocols.

Q#3: There are a lot of examples of advanced cases or the medically hopeless who have been treated successfully with alternative medicine; do you think herbal medicine can cure him/her? Can you help in bringing a religious man to make Ruqyah for him/her?

When we reach the point where there is no treatment option for the Patient, the idea of traditional medicine comes as a last option for the family. Families were observed to search for people known to use traditional or Herbal medicine as a form of treatment, most especially since consumers in Saudi Arabia are familiar with the usage of herbal/traditional remedies in

curing and preventing illnesses, owing to the country’s heritage and natural resources. There are also religious reasons as the Sunnah and the Quran cite the use of some natural remedies to cure or prevent diseases and viruses, resulting in consumers favoring the use of herbal/traditional products. In most cases, the patient will be given this type of medicine involuntarily as he/she is not able to refuse the family member who brings it. This can happen at home or sometimes in the hospital, neglecting the physician’s medical opinion regarding the use of the herbal/traditional medicine. After a period of time, the family will ask to do an investigation to see the results. Even if some of those materials may be harmful or may have side effects, like affection of liver or renal function, they will totally ignore what we advise and continue on what they believe. Most of the time, the family is in control and will continue this practice till the patient is no longer able to swallow.

Some families resorted to the recitation of some specific verses from the Holy Quran or make supplication using words that are mentioned in the Hadith of Prophet Muhammad, also called Ruqyah.

Ruqyah can be described as a spiritual healing prayer taken from verses of the Holy Quran or the supplications from the Prophet. It actually provides spiritual relief for the patient and family at this time of the disease journey, most especially when the patient is close to the end. The family will ask for permission to bring their own Sheikh if the hospital cannot provide one.

Q#4: Home vs. Hospital? What is the possibility of putting the patient in a single-bed hospital room to achieve privacy?

One of most common debates encountered in family meetings is whether to allow the patient to stay at home or keep the patient in the hospital with his/her family members around.

Some families panicked and completely refused the idea of keeping the patient at home as they have to cope with the patient’s need for care in the form of giving medication, feeding, cleaning, and taking care of the patient’s wounds (especially if patient has deep bed sores). The hospital was forced to keep patients for months solely for nursing care with almost nil change of his/her ordered medication list even though, generally, it was the patient’s last wish to be at home.

Part of this problem is that we do not have hospice care. One of our palliative patients exceeded one year admission in the hospital. She was diagnosed as indolent type of lymphoma and received mainly nursing care. She also had a paid caregiver and her family came to visit her. The son however completely resisted her being discharged when we tried to send the patient as Out on Pass for one or two days upon her request. He claimed that every time she was at home, she got very sick, febrile and agitated.

On the other hand, there were also very cooperative families. They took care of the patient at home and made

use of home health care facility if they were living nearby the hospital, adjusted the pain medications, provided or performed physiotherapy and nursing care, and even gave subcutaneous fluid if needed.

Providing privacy in the hospital was not always easy to achieve. Another potential benefit of single-bed rooms is their ability to accommodate space for visitors; this could encourage friends and families to play a more active role in patient care by helping to feed the patient they are visiting [3]. We always try to provide single-bed rooms for dying patients or for those who are in need of medical isolation. Otherwise, the patient will be in a shared room even at his/her terminal stage.

Q#5: What is the form of deterioration that he/she may develop (natural history of death)?

When the patient started to deteriorate, the family also started to ask about the sequence of events. If the patient was very close to death, his/her family members asked about the patient's condition: Why is he/she not able to eat or drink? Why is the patient not talking? Why is he/she not able to communicate? Why is the patient drowsy most of the time and sleeping? Families asked about why the patient was not closely monitored.

Some families understood why no ICU transfer was done, but at same time asked about maintaining the vital signs monitoring devices to closely check on the patient's blood pressure, pulse and oxygen saturation. We always tried to explain to the family that there is no benefit of closely monitoring the patient's vitals as our focus is always on the patient's symptoms, such as being pain-free and dyspnea-free. Some patients had fever in the last few days of life which was a sign of disease progression. When the families asked about the cause of fever, we tried to explain that the fever is related to terminal illness and disease. When the patient is very close to the end, the family usually requested to have a nurse beside the patient to assess him/her every 20 or 30 minutes. This however is not practical and does not abide by the goals of end-of-life care.

Q#6: What is the rationale behind the DNR status and palliative care concept?

Do not resuscitate (DNR), allowance for natural death, is the most important item to be discussed before transfer of a patient to palliative care. CPR might appear to lack potential benefit when the patient's quality of life is so poor that no meaningful survival is expected even if CPR were successful at restoring circulatory stability [4]. Designated family members are asked to sign on the family meeting form, which includes DNR, goals of care and the plan of management. The family meeting form states clearly that the patient is not a candidate for disease-modifying agents and the plan of management will be targeted for symptom management only.

DNR status is not a familiar concept to most of the families in Saudi Arabia. In general, allowance of natural death is

confused with leaving the patient without medical care. There is an Islamic Fatwa from the highest Islamic authority in Saudi Arabia that allows a dedicated physician to decide about no resuscitation. Sometimes the designated family member understood the goals of care but he would be very hesitant to sign the family meeting form, especially due to the DNR aspect for which he might be blamed by the other members of the family. The designated family member, who should be a male as per Saudi Arabia rules, would ask for a break to discuss this issue with the others before signing the form. In situations like this, we decide to postpone the acceptance under palliative care and ask the family to come back when they have arrived at a clear agreement. It was not uncommon also that we were faced again with the question regarding ICU transfer upon further deterioration of the patient's condition.

Q#7: Does organ transplantation for terminally-ill cancer patients help save their lives?

Why is a patient not a candidate for organ transplantation, most especially if he/she has liver cancer like HCC or has liver metastasis?

The goal of most pre-transplant assessment programs is to avoid transplantation of the patient who has had a cancer or who has an occult primary or secondary cancer. The two reasons for avoiding such patients are

1. Because transplantation does not improve and may reduce the patients' prognosis.
2. To avoid placing scarce donated organs into recipients with a limited prognosis [5].

Some families had the notion that transplant was an easy solution to the patient's problem and they kept focusing on it as a valid option for the patient's advanced life-threatening illness. We always explained the uselessness of liver transplant for these patients and clarified that there are specific criteria to be met in order to proceed with that.

Q#8: Why are routine investigations discontinued?

Not doing lab tests was considered a major issue for the families of terminally-ill patients, particularly for those whose transfer of care from Oncology or Hematology Departments was just accepted since those patients were used to have very frequent labs and other investigations. Hence, they considered stopping the routine as a sign of indifference.

Doing investigations to assess disease progression is important for families. The usual approach was to explain that the investigations were unnecessary and could be exhausting to the patient, and to draw their attention towards some other radiological investigation that is needed for symptom control such as chest x-ray, US-guided paracentesis or thoracentesis. Moreover, it was explained during the family meetings that the labs can be checked only when indicated; for instance, if the patient has fever, bleeding or uncontrolled seizure.

Q#9: Do we need to feed him/her artificially?

Most terminally ill cancer patients have a reduced oral intake in the last days of life. This can be due to different causes, related to either cancer or its treatment, such as dysphasia [6], anorexia, nausea or vomiting, or mechanic problems, such as a physical obstruction in the digestive tract due to gastrointestinal or gynecologic malignancies [7,8]. Reduced oral intake may be seen as part of the natural dying process, or it may result in clinically relevant dehydration or malnutrition

How to feed the patient if he or she stops eating? Artificial feeding? Insert a nasogastric tube or gastrostomy tube? These are the common questions that we should answer competently. If the patient was not conscious or was terminally ill and cannot tolerate oral feeding, we explained to the family that feeding at this stage is not necessary and may even be harmful to the patient as he/she might aspirate while having nasogastric feeding or if forcefully fed by mouth.

On the other hand, insertion of a gastrostomy tube can be a good option if the patient has at least 6 months of life expectancy. Exposing the patient with a life expectancy of days or weeks to such a procedure will no longer be beneficial to him/her.

In special cases, for instance in patients with advanced head and neck cancer, gastrostomy tube insertion is always a valid option. However, we are not in favor of nasogastric tube insertion as it is very annoying to the patient. If we have to insert it, it will only be as a temporarily measure to give the necessary drugs. It was not easy for some families to absorb the idea that feeding is not as important as symptom control in the last days of life. They linked any deterioration with a lack of feeding. In some cases, a limited amount of intravenous fluid infusion was permitted, but excessive chest secretions were always a common drawback. Rarely, the Oncology team was pushed to start total parental nutrition, but it was stopped before the patient was transferred to the Palliative Care Team due to expected complications.

Q#10: What are the chances of a patient getting addicted to opioid use?

There is a major global fear of opioid dependence or addiction and its debilitating side effects. This concern is considered as one of the common barriers to effective opioid use in long-term pain control. There is a stigma surrounding opioids, with morphine more than others [9].

The question was always a direct one. Some families were resistant about giving their patients any kind of opioids due to their unwarranted fears of addiction, even if the patient was suffering severe agonizing pain and asked for medication to alleviate the pain. Not rarely, patients came to our clinic complaining of pain and when we probed into the details of the use of their pain relief medicines, we realized that they were not regularly using their medications. For fear of addiction, they preferred to tolerate the pain, no matter how severe it was, than take their medications.

We spent plenty of time educating the patient and his/her family about using the medication properly and close monitoring the side effects to avoid addiction. Part of patient and family education is to enlighten them that opioid medications should not be used for sleep or anxiety. Moreover, as per literature reviews, the appropriate opioid medication prescribed by a specialized physician is more effective in controlling pain with minimal possibility of addiction.

On the other hand, young patients who felt depressed might misuse opioids in order to improve their moods. For such cases, the patients were given frequent appointments in our clinic or were even admitted for close monitoring and repeated assessments. In addition to that, psychosocial assessment or even psychiatry management may be considered crucial for them.

Conclusion

Family meetings are important strategy to identify patient-centered goals, guide decision making, achieve high-quality communication and improve patients' and family's satisfaction with their care. However, family meetings can be challenging, requiring knowledge, skills, and participation. Preparing for the family meetings should include thorough review of the patient's history and current condition, along with the common questions we address to make them easier and more comfortable.

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