Central patient wants [1]. This will make it harder to develop a care plan and the healthcare staff who believe that they know what the wishes of the family members (usually the healthcare proxy), having to follow their suggestions.

However, at a later time, when I returned the page, I discovered that I was speaking to the patient’s nephew. He stated that his grandmother was experiencing extrapyramidal symptoms from Methotrimeprazine, and when I had told him that I needed to get permission from the patient’s proxy- to discuss the condition of his grandmother, he had requested to listen to his concerns and agreed. The nephew became the communicator through the request that the patient’s daughters had sent. Their request was put in both verbal and written forms, allowing the healthcare staff to follow the orders of the nephew. He was not granted proxy rights, but the staffs were still required to listen to his orders, due to the fact that it was the order of the official health care proxies.

Although the patient’s daughters were the official healthcare proxy, we can still listen to family members’ concerns without having to follow their suggestions.

Conflict in Making the Decision about Medical Care

A conflict may occur if there is discordance between the wishes of the family members (usually the healthcare proxy), based on what they presume their family member would want, and the healthcare staff who believe that they know what the patient wants [1]. This will make it harder to develop a care plan for the patient. The nephew who was a psychiatrist had faxed me a letter, which requested to reassess the grandmother’s medications. The grandmother was an elderly Jewish individual who descended from a non-orthodox family. She was admitted to the Jewish Long Term Care facility Palliative Care Unit in Ontario, Canada. She had metastatic ovarian cancer, dementia with responsive behaviour and ongoing symptoms of anxiety, confusion, and visual and auditory hallucinations. She was frequently restless and agitated, in addition to having abdominal pain, dyspnea, pruritis, frequent myoclonus and constipation. The patient’s goals of care were established on admission when the patient was fully alert and able to participate in the decision making process [2].

She expressed that comfort and symptoms controls were her goals. She declined any hydration, blood transfusion, and transfer to acute care in case of acute emergency, but accepted oral antibiotics to treat infection if it was required. One of the two daughters who were present at the time of the discussion agreed with the wishes of the mother. Both daughters were shared POA [3]. The patient was given opioids and psychotropic medications including Methotrimeprazine, which were titrated carefully with consent from the patient and patient’s daughter. I contacted the patient’s daughter and told her about my conversation with the nephew. I assured the patient’s daughter that the Methotrimeprazine given to her mother was titrated to meet the patient’s needs and provide comfort. This was determined as the main goals of management during the initial consultation on admission with the patient. During my conversation with the daughter, she expressed concern about her mother’s discomfort associated with the Methotrimeprazine given to her, such as increased speech difficulties and tremor. Since the symptoms...
were not consistent, it was thought that this was a reflection of the patient's declining and her approaching end of life. A family meeting with the interdisciplinary team was suggested to clarify goals of care and the management plan, since complex situations such as this would most benefit from very intensive psychosocial interventions from all members of the team, but, this was declined by the daughters [3]. A psychiatry follow up was also arranged. Since the patient arrived at our institution, she had been burden with dyspnea, restlessness and agitation, potentially due to a combination of her breathing difficulties, anxiety, threatening visual and auditory hallucination, and ongoing confusion, in addition to abdominal pain, pruritis, repeated myoclonus and constipation. Antipsychotic medications (particularly Methotrimeprazine) had been used carefully on the unit and other Palliative Care facilities to achieve comfort of those who are at the end of life. Despite the fact that the medications were titrated carefully with consent from both the patient and daughter, the proxies' requested to decrease the amount of Methotrimeprazine.

As the Mother’s level of consciousness fluctuated, she was not deemed capable of making her own decisions at that time. As a result, we had to listen to the daughters’ requests, who were the official healthcare proxies.

If the patient had clearly expressed her wishes up front on admission and if she was competent, there may have not been a need to adhere to the surrogate decision maker's recommendations. However, clinicians often respect the family's request and try to address caregiver distress. Thus, these decisions are often highly complex.

**Request to Withdraw Medication – Legal Threat**

Two days later, we received another fax from both the daughters, indicating that the nurses and doctors no longer had their consent to treat their mother with Methotrimeprazine and other typical antipsychotics that were used prior to Methotrimeprazine to control the symptoms. The letter was also forwarded to the Ombudsperson and a family's private lawyer.

Throughout my career, I had learned that these types of threats were usually a reflection of the family's distress [4].

**Family Carries Opposing View on Palliative Care**

I had an interview with both daughters. As they described their mother’s suffering, their body language and voice showed frustration. They had stated that the staff is 'drugging' their mother with medications to ease their job, noting that these medications were making their mother unable to express herself or even handle a glass of water. We calmly explained our approach and philosophy in regards to Palliative Care, and the mother’s wishes from this regard [2], but they did not accept this. We had tried to explain that the actual amount of Methotrimeprazine given to address their mother’s agitation seemed to work fine, but the daughters continued to state that “it was not a comfort and instead a chemical restraint which was not acceptable”, further stating that the “staff were overmedicating their mother, so that she would “die faster”. I told them that discontinuing Methotrimeprazine may worsen their mother’s symptoms which will be opposed to the wishes of the mother, and suggested a private caregiver to help to avoid a possible injury as a result of uncontrolled agitation which may be secondary to discontinuation of Methotrimeprazine. But, the daughters said they could not afford one. A clinical ethics consult was also arranged to help with finding a resolution to the conflict, but both proxys declined to attend it.

In extreme cases of discordance, legal steps maybe taken to remove the healthcare proxy from that role, but this step should only be taken when the requests seem inappropriate or even harmful for the patient [5].

**Communication No Longer With Proxy**

I stayed in contact with the healthcare staff and thought the two daughters shared the status of healthcare proxy, based on their request, communication primarily occurred with the nephew after his letters were received. The daughters were comfortable with having their nephew be the primary communicator, due to the fact that he was a physician and therefore could comment based on his understanding of various medications. The Methotrimeprazine was discontinued, a private caregiver was hired, the medications were reassessed and changes were made according to the requests of the nephew, with the consent of the daughters. Olanzapine replaced Methotrimeprazine in the evening, SSRI were discontinued, and gabapentin and risperidone were titrated down. The patient’s condition stabilized, but her alertness fluctuated, similar to when she was on Methotrimeprazine. She remained confused, mildly to moderately anxious, and had a shortness of breath with conversation. The symptoms that were once controlled with Methotrimeprazine became evident again. The patient was facing ongoing threatening visual and auditory hallucinations. Abdominal pain also reappeared, which required frequent adjustment of opioids intake. But, repeated myoclonus and constipation were under control.

Over the next few days, she was able to communicate more clearly, but as time progressed, her verbal response was fluctuating. She was able to eat, but observed to be frequently congested and had a few episodes of aspiration events. Regardless of the symptoms that were once controlled with Methotrimeprazine, she appeared to be reasonably comfortable. The family became happier and made it a goal to prolong the life of their mother at least until the arrival of her great-grandchild.

**Oral intake at the end of life**

The son-in-law continued to feed the patient as much as he could, despite the fact that the patient felt terrible after each meal. She expressed her concerns after each oral intake, as she had experienced nausea and bloating at that time. Every day during the rounds she was talking about her discomfort associated with meal intake, and was more vocal when left alone by the family. The son-in-law encouraged her to finish each home made meal, along with the meal received on the unit. In the family’s view, this is how they were able to express their love and provide comfort for their mother, during the last days of her life. Although the patient continuously expressed that she felt better without eating, and the family received multiple educational sessions about absence of hunger at the end of life, and persistent risk of aspiration during the meal intake, the family couldn’t accept the situation of not feeding the Mother [6].
During such situations it is important for healthcare staff to have an intervention with the family and discuss, “When do the burdens of nutritional support outweigh the benefit to the patient?” Through the discussion, the patient, family members and healthcare staff should be open to agree upon goals of nutritional support for the patient during their Palliative Care. Despite of a clear understanding of the lack of evidence to support oral intake at the end of life [7], family had difficulties to accept it in reality.

**Thinking Twice Before Truth Disclosure**

The family was very protective about disclosing the diagnosis to the patient. They felt that revealing her fatal diagnosis would be like giving her ‘a death sentence’. Though the patient had told me to discuss everything with her daughter, as time progressed, she became very interested, in learning more about her condition [8]. The diagnosis and the severity of the patient’s condition were disclosed to her through either a nurse or social worker during the care conversation [9]. Once the information was disclosed to her, she asked me questions, as she became terrified about the diagnosis, prognosis, and approaching the end of her life. We then discussed the prognosis and after I had answered her questions, she felt relieved [10]. She had stated that she was hoping to live for another couple of months to see her to be born great-grandchild, thus indicating that she was worried that she may pass away, beforehand [11]. The family also had difficulty accepting the fact that the patient’s prognosis was poor and that death may occur prior to the arrival of her great-grandchild.

Patients trust their physicians, but at times the physician may have to think twice before disclosing information to the patient, simply because it may have a negative impact on the patient. It is therefore important to be sensitive to the patient’s ability to take in the fatal news being brought to them. As a result, sometimes it may be justified for the physician to withhold the truth from the patient.

In this case, a patient centered approach, by telling the truth and engaging the patient in the medical decision-making and care process, enhanced the patient’s trust towards the physician.

**Last Days**

The patient slowly continued to decline. She developed an episode of urosepsis, but settled for a short period of time with antibiotics. Her great-grandchild was delivered, but she was not able to see the baby due to difficult delivery and postpartum issues. Soon after the delivery of the baby, I received a call from the daughter who stated that the baby was delivered and now they wanted their mother to be comfortable and were ready to let her go. They also said they give their consent to administer all the medications that are needed to keep their mother comfortable, including the once refused typical antipsychotics. Ten days prior to her death, her pain escalated, and she developed another aspiration event. She began to vomit and became increasingly congested. Her symptoms were managed with opioids, Haldol and Methotrimeprazine. During her last days, her symptoms were stabilized and she entered a state of varying degrees of somnolence. The daughters were preparing themselves for their mother’s death, which they knew would be imminent. Despite knowing this, until near the end, they couldn’t believe that their mother was comfortable without food and being unresponsive [6]. The mother had died in comfort, two weeks after the arrival of her great-grandchild and three months after she was admitted.

**Advanced Care Planning**

Advanced Care Planning is an “ongoing process of reflection and communication” in which individuals with autonomous capacity make decisions regarding health management in the event they “becomes incapable of consenting to, or refusing treatment or other care” [2]. This allows the healthcare team to follow patients’ wishes at the end-of-life care in the case they cannot communicate their wishes directly. Research evidence demonstrates Advanced Care Planning improved patient-centered end-of-life care in the following areas: adherence to patient’s wishes, increased patient and family members’ satisfaction, and decreased stress, anxiety and depression in patients and family members [9].

There are some complex issues surrounding Advanced Care Planning, which become barriers as to why some choose to not take part in it. Data suggests that patients who have an advanced directive have a secondary or higher education, chronic medication use, higher than average number of specialist visits, a longer-term relationship with the family physician, a family history of having advanced directives and lower levels of social interaction [12]. Along with these factors, education, gender, marital status, and religious affiliation also affect end-of-life planning [13]. These results show that there are several factors, from socio-demographic situation, personal beliefs and health or functional status can play role whether or not the patient decides to formulate an advanced directive.

Beliefs play a crucial role in the decision-making process, and may interfere in decision making process, use of pain medications, and create barriers to quality of end-of-life care [14]. Negative beliefs will have such populations away from an Advanced Care Plan. Therefore, communication between the patient and physician is important to help the patient to understand the importance of an Advanced Care Plan.

Many Palliative Care patients identify the major issue as the lack of involvement in decision-making processes, and this is largely shaped by the type of patient-physician relationship they have. Patients believe a positive patient-physician relationship is characterized by the healthcare professional’s trustworthiness and the healthcare culture and setting [15]. Thus, it becomes the healthcare professional’s responsibility to create an open environment for patients to communicate their wishes. A study conducted by Wagner et al. indicated that only 53% of the participants reported that they had discussed their care preferences with their providers [16].

Realizing the complexities surrounding an Advanced Care Plan, it is important that healthcare professionals are aware of and work around these potential barriers to ensure that their patients understand the importance of having an Advanced Care Plan.

In the presented case, the mother had not planned in advance about the care that she would have wanted to receive during her last days. If Advanced Care Planning had been discussed earlier
prior to admission to the Palliative Care unit, both the mother and her proxies would have been more aware of what to expect, which could have improved the outcome for the patient and her family members/caregivers, achieved greater adherence to the patient’s goals of care and decreased caregiver burnout [17].

Due to limited knowledge of the patient’s advanced directives, we were to listen to the decisions of the proxies, and the nephew who then also became a communicator through the permission of the proxies.

Patient-centered Approach in Palliative Care

Patient-centered approach has been demonstrated to be essential in the care for patients towards their end-of-life. Although this approach has been proven to be evidence-based, physicians continue to vary in their attitudes toward engaging patients and their family in the care process [18]. In order to develop a trusting and satisfactory relationship between the patient and physician, ongoing communication and engagement in the medical decision-making process are seen to decrease the patient’s fear towards the physician and this was obvious in the described case. It has been demonstrated that insufficient patient negotiation and communication not only inhibits patient-centered care, but may also negatively influence patient adherence to advice and treatment [19]. Furthermore, a physician’s ability to correctly detect and respond to the patient’s emotional cues has also been shown to enhance patient satisfaction [10]. By engaging in patient-centered approaches, patients develop more trust in the physicians, and are more willing to accept their evidence-based recommendations in their care [20]. As a result of increased patient-centered care, there are more demands from patients for specific therapies and treatments’, leading to physician’s providing medical services to enhance “patient’s subjective functioning, appearance and health” [21].

Surrogate decision-making is commonly seen in Palliative Care. Sometimes there is a conflict between what a surrogate believes a patient would have wanted (substituted judgment) and what the surrogate believes is in the patient’s best interest. The majority of physicians believe that the surrogate should prioritize what the patient would have wanted over what they believe is in the patient’s best interest [8].

Patient-centered approach in Palliative Care has been demonstrated to enhance patient’s trust and satisfaction in the patient-physician relationship, and thus increases their willingness to adopt evidence-based recommendations from the physician.

COMMENTS

Lessons learned in overcoming dilemmas in Palliative Care

The described case shows many difficulties that may arise when a patient transitions to Palliative Care. Often, families or caregivers of the patient have different expectations of the care that will be provided, and their emotions may overpower, especially in a setting in which Advanced Care Planning didn’t take place in advance [6].

It is important to emphasize that healthcare professionals also experience distress related to caregivers. Studies identified a correlation between years of experience and burnout [22]. The existing literature acknowledged the myriad stressors that exacerbate the challenges of working in end of life care [23]. These include increased levels of job-related stress [24], compassion fatigue, secondary traumatization and burnout [25]. Sometimes professionals come across a situation where patients do not have the autonomous capacity to participate in the decision-making process due to their physical, mental or cognitive status. As a result, the decision must be made by either the family or the surrogate decision maker. Disagreements frequently arise while such decisions are being made, which may affect the quality of the end-of-life care and contribute to the distress of both the healthcare professionals and caregivers. This may be reduced through continuous professionals and psychosocial support provided to the patient and their family by the multidisciplinary team. Effective communication can help the families of the patient to better understand the patient-focused approach based on the patient’s need(s), as opposed to curative treatments and prognosis.

During this crucial period of time, it is important for the physician to work with the family members and proxies to provide the best care for the patient, keeping in mind that in certain circumstances, he must find a legal solution, beyond the orders of the proxies.

Unfortunately, healthcare providers are not always right by assuming that the families of patients have a clear idea of the type of care that will be provided. Most participants have a general knowledge of Palliative Care, which is largely influenced by experiences of their own. They often consider that this care is only needed for patients during the last days of their life [26].

Specific interventions are important in Palliative Care settings as healthcare staff would like to discuss a variety of questions, primarily about medications use, symptoms management, support services, and of what to expect approaching end of life [27]. Along with the families, the patients also have expectations of the services included, such as holistic support, symptoms control, good communication and practical support to enable choices [26].

It is also important to recognize the existing communication barriers and although question prompt sheets can be helpful in overcoming barriers in this area, not many have been developed for family caregivers [27]. Moreover, study conducted by Andrews et al., revealed that aging healthcare providers have little understanding of the information and evidence available to them to better support family members, regardless of the existence of guidelines. Therefore, it is important to educate the health care staff to provide better support family members in making decisions [28]. The family members must be educated on funeral or burial plans, and willingness to consider hospice [29]. These interventions to communicate with the health care staff providing care for the patient are essential as it is only through communication the patient, family members and healthcare providers can work together to achieve the most from the care being provided.

The goal of Palliative and hospice-based Care centers is to provide high quality patient-centered care for their patients as...
they approach the end of life and optimize outcomes for patients, especially during a time where they may lose the ability to voice their opinions [4].

In our case the family had lacked Advanced Care Planning. Had the mother prepared in advance about the care she wanted to receive, many of the issues that arose may have been solved by following the requests of the mother. As described above we received both verbal and written requests from the official health care proxies, allowing the health care staff to follow the orders of the unofficial health care proxy. In contrary situations, healthcare providers can still listen to family members’ concerns without having to follow their suggestion if the proxy rights were not granted from the official health care proxies.

CONCLUSION

The described case demonstrates the multitude of factors that need to be taken into consideration when caring for a Palliative Care patient by bringing forth the intricacies and important techniques in providing care for a Palliative Care patient. Some difficulties include the different expectations of the family members/caregivers about the type of care that will be provided and the distress experienced by healthcare professionals. During the final moments for the Palliative Care patient, it is of utmost importance for physicians in an interprofessional team to work with caregivers and proxies to enhance the patient’s quality of life and adhere to the patient’s wishes. Regardless of the various difficulties that may arise, with both sides performing their responsibilities, the patient is entitled to have the best quality of the remaining life and attain benefits of Palliative Care.

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