

Overcoming the challenges associated with symptom management in palliative care

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Abstract: End of life (EOL) care is a topic that many families have difficulty discussing. A number of families are uncomfortable with accepting the fact that death is a part of every human's reality. Ideas and thoughts of death are interpreted differently across various cultures, and lacking to discuss disease trajectory and what to expect down the road with a physician, brings forward conflict during EOL care. Let us consider the complexities of treating Mr. X who is an 80-year-old male of Italian background with a history of advanced lung cancer with metastasis to the brain. He was recently diagnosed and his health began to rapidly decline at home. Mr. X is used in this case study to explore the challenges in providing care in a palliative care unit (PCU), and the ways in which we can overcome them.

Keywords: Palliative; symptom management; end of life (EOL); communication

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Case presentation

Upon his diagnosis, Mr. X was found to be in pain, agitated, restless, and very irritable. He was no longer able to carry a meaningful conversation. Care at home became difficult for his caregiver who felt that it was no longer possible at home. As such, the decision was made to admit Mr. X to a palliative care unit (PCU). While on the PCU, his health continued to decline despite having his symptoms pharmacologically managed. Many of his family members spent the whole day by his bedside, and felt exhausted by observing the decline in his health, and his inability to communicate in the way he was once able to. The family members stated, "*He's just not the same...*" They constantly approached the health care staff for answers regarding how they can improve the health or comfort of Mr. X and how they can make Mr. X feel better. A priest was called to provide additional support in relation to helping the patient and his family cope. Numerous family meetings with the interdisciplinary team of the PCU were held to educate the family about the prognosis, and what to expect when Mr. X

approaches end of life (EOL).

Despite understanding the nature of the illness and the unfortunate terminal outcome, the family had a hard time accepting it. Mr. X's oral intake was at a minimum, but the family continuously tried to feed him. Although he has had several onsets of aspiration already, was able to settle without antibiotics. He was at a high risk for similar onsets in the future.

Two weeks after admission, Mr. X's grandson presented the physician with new medications which was prescribed to Mr. X by his family doctor. The medication was experimental and thus was still under investigation. But, this was the last resort for the family to improve Mr. X's condition. The grandson, along with the family pleaded to give that medication a try.

As a physician, how should you approach this matter? Who will you turn to, to discuss the care of Mr. X? How would you manage caregiver and healthcare professional stress? Many of the challenges described in this care are a daily reality for physicians and healthcare staff, while

providing EOL care. This manuscript looks into the ways of how to overcome some of the challenges presented in the case.

Discussion

The influence of religion and different cultural systems

Some people view the act of suffering as something that individuals must endure and that only god will determine when and how an individual should die (1). This will have an impact on whether or not the patients and their families will accept life-sustaining therapies. For example, Saudi Arabia's whose legal system is based on Shari'a, the system of Islamic law prohibits suicide, assisted-suicide and euthanasia. Do-not-resuscitates (DNRs) are only allowed under certain circumstances, and in general, advance directives are not accepted in Islamic law, for they believe that only Allah can make choices regarding one's life (2). This may create a problem for the migrant population in choosing to live in secular societies such as Canada, where the patient or the treating staffs' expectations differ from the religious beliefs. In situations such as this where conflicts arise, social workers who are part of the interdisciplinary team, may act as mediators in arranging family meetings including religious leaders to ensure that conflict resolution is achieved.

It is important for health care providers to be aware that there is great variation within cultures. Some cultures and religions view talks about death as taboo. At this time, spiritual care is crucial for the patient and their family. Spiritual care involves religious leaders from different religions (e.g., priest, rabbi, etc.) who can especially help an orthodox family make the final decision regarding EOL care for the patient. For example, for those who are Muslim, a religious leader may be a more appropriate person to talk to about a patient's EOL care (3). The families usually follow the orders of the priest who will help both the patient and the family feel comfortable in the last days of the patient's life. The presence and assistance of the religious leader will allow them to feel that they had done everything that they could, to have the patient 'at peace in heaven'. Moreover, a religious leader who decides to take part in an EOL care discussion along with the patient and family will allow for a more open conversation. By having such conversations, a religious leader within the interdisciplinary palliative care team may also help with caregiver stress management. In countries with a more secularized society, social workers

play a crucial role in providing EOL support and alleviating caregiver stress. In the case of Mr. X, a priest was called to help the family cope with the stressful and emotional situation. Having open conversations is essential for the palliative care team, so that they are able to provide care that is accepted by both the patient and the family.

Therefore, health care providers must be open minded to the fact that their perspectives on various advanced care directives may be different from the patients and their families. Being open minded will allow both the health care providers, the patient and his/her family to communicate effectively.

Effective communication is key

Communication is essential in palliative care. It is important for the patient, families and the health care provider to discuss the wishes for EOL care. Building the relationship and trust through open communication will help the patient and families feel that their beliefs are respected and that the palliative care team is doing their best to respect the wishes and allow the patient to die with dignity. The acronym "N.U.R.S.E." can be used to ensure that we are demonstrating empathy while adequately communicating with our patients and their family. The "N" stands for "name the emotion", which shows the family that you are recognizing the way that they are feeling. "U" stands for "understanding in an open and compassionate way". "R" stands for "respect for the person experiencing the emotion". "S" stands for "communicate support". "E" stands for "explore the emotional experience of the other person" (4). This acronym serves as a guideline for demonstrating empathy which is key in a physician patient relationship, since there is in fact an association between more empathic statements and higher family satisfaction with communication (5).

Another issue may be around language and comprehension, since health care providers must be aware of how they are speaking to their patient(s) and their families. It is important for health care providers to not use code words or euphemisms while speaking (6). Vagueness must be avoided, and instead the matter must be disclosed in a manner which helps both the patient and family understand the situation. Euphemism and vagueness may result in families feeling uncomfortable and not confident about the treatment that their loved one will be receiving. In order to prevent uncertainty and promote understanding, it is best to have the patient's family and the interdisciplinary team speak in

person, face-to-face. In this situation, a family meeting with the interdisciplinary team is very important. In the case of Mr. X, meetings with both the family and interdisciplinary team were frequently held to ensure that the family was aware of his prognosis and what to expect. Having these meetings also gave Mr. X's family the opportunity to see the members involved in the care of Mr. X, and thus were able to direct their questions and concerns to whomever they wish.

Moreover, a language barrier may also be an issue between the patient and/or family, the physician, and the interdisciplinary team. This brings forward the importance of determining whether an interpreter is required for the patient and/or family. Sometimes someone from outside of the family who is trusted by the patient, or a privately hired interpreter would be helpful in discussing issues in a manner that will allow both the family and patient to understand the goals and philosophy of palliative care.

A case study about a patient in palliative care found that providing brochures and FAQ sheets about processes in palliative care and dying may not be highly beneficial (7). Due to the stress that the patient and caregiver are undergoing when approaching EOL, the written materials may be put aside since they may find themselves not having the time to read them. Another factor may be that they do not have the capacity to read and understand the material. This results in a poor understanding of the various processes involved in palliative care. So instead, the interdisciplinary team is better able to acknowledge the types of care that is needed for both the patients and families by meeting them in person, since expressions and movements can bring forward more meaning to their words.

The role of an interdisciplinary team

The idea behind an interdisciplinary team is that the collaboration of healthcare workers will result in better care for the patient and their family (6). An interdisciplinary team is the key to success in palliative care because this type of care incorporates many factors and areas of expertise to ensure the patient centered approach. Patients in palliative care usually have more than one comorbidity, and therefore require more than one healthcare provider to meet their healthcare needs. Therefore, palliative care interdisciplinary teams may include professionals involved not only in surgical interventions, radiation therapy, and symptom management, but also physiotherapy, occupational therapy, speech language pathology, social work, and recreational

therapy, among others. Moreover, the advanced and incurable disease trajectory of a loved one in palliative care may bring forward a time of worry and sorrow for the patient, family, and healthcare professionals, thus being a time of need for emotional and spiritual support.

Compassion fatigue refers to the emotional and physical exhaustion that healthcare workers may experience when caring for their patients, whereas burn out refers to the emotion, physical, and mental exhaustion due to longer involvement in an emotionally demanding situation (8). A study in the United States involving 1,357 individuals, found a burnout rate of 62%, with higher rates reported by non-physician palliative clinicians (9). Another study found that there is a strong correlation between burnout and compassion fatigue ($r=0.769$, $P<0.001$) (4). As such, in times of stress, healthcare workers are prone to both compassion fatigue and burnout. Therefore, during times of stress, the involvement of a religious provider may help with relieving stress for not only the patient and family, but also for the healthcare professionals who are also experiencing stress (10). Hence, an interdisciplinary team which involves multiple healthcare providers are very important in palliative care to ensuring that the patient, their family, and health care professionals are provided with all the available support.

Decision-making and who we are to listen to

Health care providers must be aware that while being respectful of the beliefs of the patient, it is their right to ensure that the patient is aware of and involved in the process of making decisions about his/her care. This also means that the patient is aware of both the benefits and risks associated with the discussed directives for his/her EOL care. Therefore, while discussing the perspectives of EOL care, a health care provider must make sure that the patient is aware of and has agreed with the chosen options regarding his/her care.

Although it is important for the patient to be aware of and agree with the decisions being made, sometimes cognitive impairment(s), and rapid decline in health, can result in failure to communicate and/or inability to understand and appreciate the information received. These instances may affect the patient's ability to make decisions on their own. In these situations, a power of attorney (POA) or a substitute decision maker (SDM) who is usually assigned in advance, takes on the role of making decisions on behalf of the patient.

A study using data from the Health and Retirement Study which is a biennial longitudinal survey of adults 51 years of age or older found that more than a quarter of elderly adults may need a surrogate (referred to as a POA) to make decisions at the EOL (11). Factors such as religion, inability to understand, reluctance to acknowledge incurable illness and unrealistic expectations to have life prolonged, may determine whether or not a patient can be a candidate for receiving palliative care. It's up to the patient to make a decision based on his/her wishes for EOL management. But, if the patient is not able to make his/her own decision(s), a POA or Public Guardian and Trustee (PGT) (if the patient doesn't have any family or a dedicated person/friend who can be trusted and who can take on a role of a POA) should be appointed and are expected to act in the patient's best interests. In essence, a POA or PGT is given the right to make decisions on behalf of the patient.

A POA will assess management options for the patient during circumstances where the patient does not have the cognitive ability to do so. Moreover, it has been shown that POA/proxies who understand the prognosis and expected complications reduce the likelihood that their loved one, with for example advanced dementia who are nearing the EOL will be faced with unbeneficial interventions (12). Therefore, by understanding the prognosis of the patient, the trajectory of the disease, and what to expect, a POA will ease the decision making process regarding the patient's care (13).

Conflict arises when there is a difference of opinion between the proxies and the patient, or if there is a difference of opinion between two or more individuals who are appointed to make decisions for the patient. Sometimes, a situation arises where the interdisciplinary team is finding that a POA is not acting in the patient's best interests. In this situation, the ethics committee may be involved and then a decision can be made about the possibility of PGT involvement. During such conflicts, a PGT may need to make decisions regarding the patient's health. A PGT can either authorize a qualified individual to make a decision or can act as a temporary substitute decision maker (TSDM) (14). In both circumstances, they allow for decisions to be made in times of conflict, helping to ease the decision making process for the patient. At most times, this is of last resort when the POA of the patient fail to act in the patient's best interests and/or the patient is unable to or has lost the ability to participate in the decision making process and has no one to appoint as a SDM.

Choosing to have a POA is part of an advanced directive.

The goal of advanced directives is to ensure that the patient's wishes are met during a period of time where they are no longer able to make decisions on their own. It is thus important for patients to have an advanced directive(s) in place prior to admission to a palliative or acute care facility. Having conversations about advanced directives is critical to ensuring that a patient's goals are met during their EOL. It has been found that patients who did not have an advanced directive were more likely to report concerns about physician communication and concerns about how well they were informed in terms of what to expect (15). This shows that having an advanced directive will help the patient, their family and the health care staff thoroughly discuss the diagnosis, understand the prognosis and what to expect in the future. Having the opportunity to discuss goals of care will allow conversation about what the patient can expect during their time in palliative care (13).

Once accepted into palliative care, the reality is, the patient is usually aware that he/she is terminally ill and therefore nearing EOL. As a result, many become anxious and depressed, and thus may require psychiatry, and sometimes pharmacological intervention during their stay. Additional support can be provided by social workers. Patients may also become confused and disoriented as a result of the medications they are given to control their symptoms (e.g., pain, restlessness, agitation, dyspnea, congestion, etc.) and keep them as comfortable as possible during their time approaching the EOL. In the case of Mr. X, he was experiencing pain, agitation, restlessness, and irritation. As such, symptom management was an integral component to the care he received. His proxy was the one who was able to communicate these symptoms to the health care team, and therefore, discussions with the patient/POA are crucial to ensure that they accept the care being provided prior to admission or transfer to the PCU.

Having these types of conversations in palliative care during a period where the patient's days are limited, is tough for both the patient and the family. It is therefore crucial for health care providers to discuss the disease trajectory and explain the benefits of palliative care and whether the patient may require this kind of care regardless of whether their stay is at home, in acute care or long term care setting. With regards to Mr. X, care at home became no longer possible and the decision was made to admit him to the PCU. This gives the patient more time to accept the facts and move on to palliative care, rather than have multiple admissions to acute care with hopes of recovery, but then find out that their days are limited.

Transition to palliative care

It is important for the patient and family to also understand that their loved one may not be conscious and alert as they are approaching death. Most patients find themselves in acute care if their condition is deteriorating, or in palliative care if the condition is declining at a rapid pace and EOL can be close. In acute care, health services are provided to individuals whose illness is predicted to be cured within a short period of time or remission can be achieved following exacerbation of chronic diseases. Therefore, health care providers in acute care work with the goal of discharging healthy patients and/or patients in stable condition who can be managed at home or long term care (16). In contrast, palliative care provides health services for individuals with life-threatening illnesses where remission can no longer be achieved, all attempted interventions have failed, and prognosis is short term. Health care providers in palliative care make an approach towards improving the quality of life for a patient, by make sure that the patient is kept comfortable both physically and emotionally during a period of time where they're nearing death (17).

Oral intake at the EOL

While the patient is present in palliative care, many families have a hard time grasping the fact that the appetite of their loved one is continuing to decline which will result in a low to none oral intake. In the case of Mr. X, his family was unable to accept the fact that his oral intake was at a minimum, and so were still trying to feed him. Therefore, during such times, it is important for both the patient and family to know that the body naturally forms substances called ketones which help to eliminate the feeling of hunger, thus having the patient feel more comfortable without food than with it. This natural mechanism helps the body to stay more comfortable and prevent or alleviate symptoms of congestion which are usually experienced by patients approaching EOL (18). In some instances, if the patient's wishes were to prolong the life, or the proxy has difficulties coping with lack of oral intake, the decision can be made to place a feeding tube, but, it must be understood that a feeding tube is not the solution (5). Also, the idea of a feeding tube is not easily accepted by many families, since having their loved one use a tube may be a sight that many are uncomfortable seeing. Some POAs may therefore come to believe that their loved one would have never wanted to

be kept alive if he/she was “*not recognizing, not understanding, not laughing ..., and not eating*” (18).

Therefore, healthcare providers must take the time to educate to the best of their ability, the risks and benefits in relation to the placement of a feeding tube if they wish to have their life prolonged (7).

It is important for the POA/caregiver to be aware that if their loved one has severe dementia, using a feeding tube will not prevent aspiration events, it has a low effect on improving malnutrition and in fact does not improve survival or function (18). A study involving 40 chronically tube-fed patients who had a poor functional and cognitive status were found to experience weight loss, loss of lean and fat body mass, and micronutrient deficiencies (7). It has been found that instead, patients with severe dementia will benefit from hand feeding (18). Since families may carry the assumption that a feeding tube brings health benefits to their loved one by providing them with nutrition, a physician must describe the risk-benefit ratio before a decision is made. This emphasizes the importance of education and having advanced directives in place.

Experimental drugs in palliative care

During a time where the families may feel that their options are exhausted, they may decide to have their loved one use experimental drugs. Some states in the United States have passed “right-to-try” laws which allow patients with a terminal illness(es) and with their physician's consent, to request drugs which have undergone phase 1 of clinical safe testing (19). These requests are made directly to the manufacturers, instead of the Federal Drug Administration's (FDA's) expanded access program. If a physician is asked by the families to use an experimental drug, the physician may only consider it in the circumstance where no other drug is available (20). Even so, the patient must be informed that they will be given an experimental drug and that the outcome is unpredictable and may be potentially harmful. Secondly, the patient must be able to voluntarily consent (20). If they are not able to, the patient's POA must consent on behalf of them. In the case of Mr. X, his family received permission from his family doctor to obtain experimental drugs, and the POA consents on behalf of Mr. X. The use of experimental drugs is a topic that is still under debate, but for the time being, the physician is to follow the protocol in place, ensuring that the harm associated with every decision is discussed and outweighed by the benefits (20).

Benefits of palliative care

Many transfers to palliative care take place during times of life-threatening illnesses where recovery is not expected, either due to end stages of chronic diseases or malignancy. Transitions to palliative care can be from acute care hospitals, either intensive care units or general medical wards, and occur in a situation where the patient is rapidly declining and/or the goal of care have been changed to comfort and symptom control. Some families also decide that it's time to transfer or admit their loved one to palliative care once they feel that care at home is becoming impossible due to disease progression and severity of symptoms management which requires all around 24 hr care. In the case of Mr. X, his proxy decided to admit him to a PCU after realizing that managing his care was becoming difficult at home.

A study at the Royal Melbourne Hospital which involved a review of 171 deaths in 2007 found that patients who were referred to palliative care within the hospital had resulted in key improvements in symptoms, from the care that they received. This care included appropriate EOL medical orders, cessation of futile treatment and interventions, and improved communication with families (5,7). Patients who were not referred to palliative care were found to have a lower standard in the quality of care in areas such as for example, mouth care. They also faced a lack of communication with the physicians and health care staff along with a poor degree of religious and spiritual services (15).

A randomized control trial involving patients with metastatic non-small cell lung cancer found that patients who received early palliative care integrated with standard oncologic care had a better quality of life than patients who were assigned to standard oncologic care (98/136 *vs.* 91.5/136, $P=0.03$), and fewer patients in the palliative care group had depressive symptoms than the standard care group (16% *vs.* 38%, $P=0.01$). Moreover, a median survival was longer among patients receiving early palliative care (11.6 *vs.* 8.9 months, $P=0.02$) (20). It is therefore stated that patients with metastatic non-small cell lung cancer should be offered concurrent palliative care along with oncologic care once they are first diagnosed (12).

Fostering successful integration of palliative care

It is important to note that despite the benefits, a physician may be responsible for why a patient is not transferred

to palliative care. A clinician who does not recognize the end stage of the disease and has limited knowledge about palliative care may advise the patient to continue with acute care management. As a result, many patients die without receiving the benefits of palliative care. Physicians in all sectors of health care must be aware that comprehensive palliative care services have the potential to help patients and caregivers at any stage of their illness, and thus is appropriate any time. This problem may be a result of inadequate training that medical students receive in palliative care. Professor Irene Higginson, a specialist in palliative care at King's College, London, told Members of Parliament that, "*a lot of people don't know what to do or can't recognise that people are dying*". She goes on to stating that undergraduates receive minimal training in palliative care (20 hours of tuition) in 5 years of medical school (8). These facts should be used to implement more hours of teaching in palliative care about dying in dignity. It should be enforced that if a patient is not transferred to palliative care, he/she will not receive the wide spectrum of benefits that palliative care can offer at the EOL. Medical schools must enforce the fact that palliative care should not be something reserved for patients who are expected to die within days or weeks and instead could and should be initiated at earlier stages of illness, as it provides better pain and symptom management, better satisfaction for the patient and family, in some cases increased longevity, and is also low in cost (5,7).

Caregiver burden

Despite the benefits, when asked, it has been found that most individuals would prefer to die at home surrounded by their loved ones, but statistics show that almost 70% of Canadian deaths occur in the hospital (21). Moreover, it has been found that with the use of hospice palliative care services which are known to improve symptoms and caregiver burdens while reducing costs, about 20% to 50% of patients on waiting lists for residential long-term care can safely age at their home (22). But, an issue arises regarding the number of hours that a family must spend taking care of their aging loved one, especially since the number exceeds that of a full time employee. In fact, Canadians are expected to care for a dying family member, for an average of 54.4 hours a week (23). Moreover, many of the family members who are caring for their aging loved one are of seniors who are not only untrained and unsupported, but are also trying to take care of their own health concerns. As

a result, many families choose to send their loved one to a PCU, despite the fact that through proper support, their loved one can be taken care of, at home. With regards to Mr. X, there was no support available at home that could be arranged through community resources. Palliative care seems to ease the process by having palliative care specialists and primary care workers working together to ensure that the patients and families are well aware of the timeline ahead. Health Links, for example, is a new initiative aimed to improve care for seniors and others with complex conditions by bringing together different health care providers to better coordinate care for these high-need patients (23). Helping to alleviate pain symptoms will result in less suffering, ICU admissions, non-beneficial healthcare interventions and emergency room visits. These reductions, along with the reduction in burden placed on the family including stress and finances, makes palliative care a preferred option for improving the quality of care for aging individuals. In Mr. X's case, the amount of stress placed on his caregiver and family reduced significantly after transferring Mr. X to the PCU.

Conclusions

Palliative care as with many other health care disciplines, has the primary goal of relieving and/or preventing suffering, along with making sure that the patient and their family are provided with a sufficient amount of care and support. Therefore, understanding the challenges within palliative care is the start to finding better means of overcoming the challenges. As in the case of Mr. X, patients should be provided with comfort and symptoms relief while receiving palliative care. Health care teams must therefore take the time to discuss the various challenges, and work towards finding ways to make the EOL process easier for both the patient and their family.

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Footnote

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