# Section 1 Palliative Care Principles

Palliative medicine is specialized care for patients and their families who are facing serious or advanced medical conditions [1], and it can be offered to patients at any stage of their illness, even at the time of diagnosis [2, 3]. A palliative approach to care can be provided in tandem with curative or disease-directed therapies [4–6]. The provision of palliative care may be by a patient's primary care physician, neurologist, geriatrician, other care provider, or a palliative care clinician.

Palliative care interventions focus on recognizing, preventing, and alleviating suffering [7] through effective symptom management, goals-of-care conversations, support for patients and caregivers, and advance care planning. There are eight recognized domains of palliative care – Structure and Process of Care, Physical Aspects of Care, Psychological Aspects of Care, Social Aspects of Care, Spiritual Aspects of Care, Cultural Aspects of Care, Care of the Patient at the End of Life, and Ethical and Legal Aspects of Care – which collectively evaluate a person's physical, psychological, spiritual, and social circumstances [8].

1. Structure and process of care explores a person's understanding of the disease process and the role of palliative care in their care plan. The palliative interdisciplinary team, which may consist of physicians, nurses, social workers, chaplains, pharmacists, and therapists, is highlighted.
2. Physical aspects of care relates to the management of physical symptoms through pharmacologic and non-pharmacologic approaches.
3. Psychological aspects of care focuses on the psychiatric and psychological needs of patients, existential distress, coping for patients and family members, and bereavement support.
4. Social aspects of care refers to the family structure, and this domain explores how social support can be optimized to improve the quality of life for the patient and caregivers.
5. Spiritual aspects of care includes a spiritual assessment, which explores spiritual, religious, and meaning-based practices employed by the patient.
6. Cultural aspects of care broadly encompasses a person's race, ethnicity, language, nationality, socioeconomic status, and sexuality, and the impact that these factors may have on their decision-making and understanding of their disease.
7. Care of the patient at the end of life addresses the needs of patients who are in the dying process and of their family members.
8. Ethical and legal aspects of care addresses the decision-making capacity of the patient, the identification of a health care surrogate, and the completion of documents such as an advance directive that identify the care the patient desires at the end of life.

Palliative interventions have demonstrated higher satisfaction among patients and caregivers, increased quality of life, and reduced symptom burden among patients [9]. Patients with neurologic diseases that are progressive and incurable can benefit from a palliative approach to care given the expected and realized physical and cognitive decline. Neuropalliative care is a burgeoning subspecialty that focuses on the palliative needs of patients with neurologic disease and their family [10–13].

**Important Considerations at the Time of Diagnosis**

- Discussion regarding the disease
  - What does this mean for the patient/family?
- Symptom management
- Mood and coping
  - Depression, anxiety, frustration
  - Situational mood disorders
  - Support system
- Progression of disease/disease trajectory
- Advance care planning

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- Health Care Surrogate
- Living Will
- Estate/Financial Planning

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Chapter 1

# The Role of Palliative Medicine in Neuropalliative Care

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## Clinical History

Mr. L is a 63-year-old gentleman from Wisconsin with systemic mastocytosis with associated clonal hematological non-mast cell lineage disease (SM-AHNMD), a rare hematologic illness. After unsuccessful treatment with six cycles of cladribine, the patient was enrolled in a clinical trial last month. He has been married to his wife for more than 30 years and maintains a very close relationship with his father and his dog. He is a Catholic and works as a long-haul truck driver. He loves fixing up old motorcycles, spending time with his dog, and dancing to blues music with his wife. After two weeks on the clinical trial, the patient experienced a large left hemispheric stroke with a completely occluded left internal carotid artery and left cavernous sinus thrombus. A left internal carotid artery thrombectomy was unsuccessful. The patient now has profound neurologic deficits including total left eye vision loss, non-fluent aphasia, and complete right hemiparesis/hemianesthesia. The patient is currently admitted to the neurologic intensive care unit (ICU) and his hematology physician is intimately involved with his care, making daily visits while in the ICU. Palliative medicine is consulted to assist with goals of care.

## Introduction

Neurologic illnesses are often devastating and life-altering for patients, families, and medical teams. Not only do neurologic illnesses such as stroke, brain cancer, Parkinson disease, and multiple sclerosis have significant medical impacts across multiple domains of function such as gait, mobility, and eating but they also have profound impacts on nonmedical domains including self-identity and independence. The role of a palliative medicine physician includes elucidating the medical implications of neurologic illness and a patient's personal goals, preferences, and values, as well as developing an understanding of the complex interplay between the two. Although advance care planning can be done by anyone, it is a difficult task to do well, and it requires practice and training [1]. Thus, palliative medicine maintains an important role in assisting neurologic patients with clarifying the interactions between their personal values and the complexities of their current medical reality. In this chapter, we discuss the role of palliative medicine consultation in patients with neurologic illness.

## The Role of a Palliative Care Consult

A palliative care consult in general can be divided into one of two requests: assistance with complex pain and symptom management or clarification of goals of care. While palliative medicine specialists receive specialized training on complex symptom management, this chapter focuses on the role of a palliative care consultant in communication between the patient/family and the medical team. The primary goal of a palliative care consultation is to provide the patient with goal-concordant care, or care that is aligned with their personal goals, preferences, and values.

### A Understanding the Patient as a Whole Person

Effective communication about serious illness is a difficult challenge, but there is evidence that good communication improves patient and family satisfaction, improves hospice use, decreases aggressive end-of-life care, limits chemotherapy use in the last two weeks of life, and decreases depressive symptoms in both patients and their families. Patients want to know what to expect during the course of their illness, including how to plan for events that follow death. Indeed, patients fear a bad death much more than death itself [2]. Patients consistently rank nonmedical items as important in the course of serious illness, including preparation for death, achieving a sense of

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completion, decisions about treatment preferences, and being treated as a whole person [3].

Many proposed methods and models of communication regarding serious illness have emerged in the past two decades. One of the earliest discussions of the topic of physician–patient communication outlined four models of communication with a focus on the so-called deliberative model where physicians help patients to choose the best choice for them based on an exploration of their personal values while weighing the medical realities and available treatment options [4]. In the deliberative model of communication, the physician acts like a friend or teacher to help the patient make a decision. However, as can be seen in our patient scenario, many factors play into patient decision-making, and understanding the patient as a whole person is crucial in making recommendations for appropriate medical treatment.

## B Discussing Nonmedical Topics with the Patient and Family

The beginning of an effective palliative care consultation is establishing rapport and learning about who the patient is as a person. We generally begin with open-ended questions and try to cover critical areas of a patient's life such as home environment, family relationships, spiritual/religious values, and level of function with activities of daily living. Many nonmedical issues are consistently rated as important by the majority of patients with serious illness, including cleanliness, being able to say goodbye to important people, resolving unfinished business, reviewing personal accomplishments, and maintaining one's dignity [3]. As such, a traditional medical interview would be unable to identify issues that are important to patients with serious illness. For example, in our patient scenario, simply asking questions about the patient's hematologic illness or neurologic deficits would not have allowed us to identify the most important people in his life, understand his family relationships, or become familiar with some of his personal accomplishments.

## C Summarizing the Medical Situation

While most palliative medicine providers do not possess the expertise on pathophysiology, expected illness course, and treatment options for complex neurologic or neurosurgical diagnoses, they can provide value in a consultative role by communicating these things in a clear and concise manner to patients and families to allow them to make the most informed decision that would align with their goals, preferences, and values. Each palliative medicine provider has his or her own method and favored phrases, but a checklist approach that covers crucial conversation elements can be very helpful as an example of how to communicate a complex medical situation in simple terms. Preparation is the most important element before embarking on a discussion that summarizes a patient's medical situation and goals of care. Adequate preparation includes reviewing any previous advance directives on file and discussing the patient's medical situation with all relevant medical teams (in our scenario, relevant teams would be hematology and the neurology ICU teams) to get a sense of expected illness course, prognosis estimates, and treatment options. This preparation will allow for a meaningful discussion in which patients will have to make decisions based on this information.

A commonly used communication tool that highlights key elements of a goals of care discussion is the SPIKES communication tool. SPIKES is a mnemonic that stands for setting the scene, assessing the patient's perception, getting an invitation to discuss serious medical issues, providing knowledge, responding to concerns with empathy, and summarizing the conversation with a plan for what comes next [5].

## D Discussing Prognosis

One of the most important roles of a palliative care physician during the consultation process is that of a prognosticator. Modern medicine has made tremendous advancements in diagnostic tools and new treatments, but providing an accurate prognosis still presents a unique and difficult challenge. In general, patients want to know what their illness is, how bad it is, and what can be done to treat it. Most physicians are able to reach a diagnosis and offer treatment options to patients, but the discussion of prognosis is often challenging. There are many barriers to discussing prognosis, including fear of death from the patient or the physician, discomfort with strong emotions, and concern about compromising the physician–patient relationship by eliminating hope.

Discussing prognosis has the potential to empower patients and allow them to make the best decisions about their health. Patients desire to know what to expect during the course of their illness, what may happen during the process of dying, and what

**Table 1.1** The SPIKES protocol for breaking bad news

| Communication Element | Examples |
|---|---|
| **S** – Setting the scene | Put pager and cell phone on silent/vibrate mode.<br>Turn off patient television.<br>Sit down.<br>Say "There is some important information to share about your health; is everyone present that needs to be here?" |
| **P** – Patient perception | Ask "What do you understand about your illness?"<br>Ask "What have the other doctors told you so far?" |
| **I** – Invitation to share | Ask "I have some information for you; is it okay if we talk about it together?" |
| **K** – Share knowledge | Discuss medical situation and prognosis in simple terms and in straightforward language. |
| **E** – Respond with empathy | Say "I can see that this is very difficult news for you."<br>Say "This wasn't the news we were hoping for." |
| **S** – Summarize and plan for the future | Summarize the discussion in simple terms.<br>Check in with the patient for understanding.<br>Offer next steps, even if it is simply a return visit after the patient and family have had time to process difficult news. |

happens after death. Patients also want to be able to review accomplishments, say goodbye, and achieve a sense of completion during the course of serious illness. In order to allow our patients to fulfill these needs and achieve a measure of self-actualization in the face of serious illness, prognosis must be discussed, and it should be done so gracefully.

Many physicians may find it difficult to discuss prognosis, but part of the process of a palliative care consultation is to know when it is most appropriate to have these conversations. By its very nature, a discussion of prognosis is a difficult conversation that involves significant emotional content from both the physician and the patient. Most patients in the United States prefer explicit information about their prognosis, but patients always maintain the right to dictate the content and flow of information and they may not always prefer explicit prognostic information. In general, it is appropriate to discuss prognosis in cases of imminent death, patient/family inquiries about hospice, or when discussing treatment options with a very low probability of success. A discussion of prognosis is also suggested when the physician would not be surprised if the patient died in the next 6–12 months [6].

## E Negotiating Goals of Care

Understanding a patient's goals, preferences, and values is only part of the role of a palliative care consultation. The final part of a palliative care consult is the negotiation of a patient-centered plan in the context of the medical reality of serious illness. For example, most real-life medical scenarios have a very limited number of realistic treatment options, generally just two or three. In our patient with a large stroke, the realistic treatment options are limited to pursuing aggressive illness-directed therapy with a new clinical trial for his hematologic illness along with a comprehensive program of physical, occupational, and speech therapy or focusing on a comfort-directed approach to care with a focus on relief of bothersome symptoms and maximizing the patient's ability to function and accomplish his goals within a limited prognosis. However, just like anything else in medicine, the most patient-centered approach to care must be renegotiated on a regular basis as the clinical realities change. If a new experimental treatment is introduced that could potentially fit with a patient's goals of care, it is important to renegotiate the plan, as the patient's goals, preferences, and values are fluid and will change over time [7], particularly when their clinical status changes.

The process of negotiating goals of care involves many strong emotions, and several communication models are helpful in addressing situations in which strong emotions arise. A fundamental principle of addressing emotion is that patients are unable to process significant emotion and new facts at the

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**Table 1.2** The NURSE model, a tool for communicating emotions

| Emotional Communication Tool | Examples |
|---|---|
| **N** – Name the emotion | "I can see that this makes you very sad."<br>"I wonder if you might feel anger at this test result." |
| **U** – Understand the concern | "I can certainly understand why you'd be angry."<br>"Many patients feel abandoned in this situation." |
| **R** – Respect the patient's effort | "I am very impressed at your positive attitude."<br>"You have shown tremendous strength in a difficult time." |
| **S** – Support the patient | "I am here to walk with you during your suffering."<br>"I will be your doctor until the end." |
| **E** – Explore complex emotions | "You seem angry and afraid; can you tell me more about how you're feeling?"<br>"What do you mean when you say 'I can't believe this is happening after all I have done'?" |

same time. When a patient is experiencing a strong emotion (e.g., sadness), it is more helpful to stop the conversation, acknowledge the emotion, respond with empathy, and allow the patient a chance to collect themselves before trying to impart new information. We are fond of the analogy of thinking of patients like a radio that can be tuned to either an emotional channel or a factual/rational channel, and they cannot play both channels at once. It is difficult to process new information until the loop is closed with a strong emotion. A frequently used communication tool for addressing emotion is the NURSE model. NURSE is a mnemonic that stands for naming, understanding, respecting, supporting, and exploring [8].

## Conclusion

The process of doing a palliative care consult for a patient with serious neurologic illness offers many unique challenges, and thus we suggest consideration of a checklist approach to ensure that key elements of the consult are performed. One example of a comprehensive approach to a palliative care consult is the Serious Illness Communication Checklist, which integrates several communication models discussed earlier in this chapter [9]. The primary goal of a palliative care consult is to help the medical team provide goal-concordant care to the patient. Advance care planning and having difficult conversations that consider the patient as a whole person, understand nonmedical aspects of a patient's care, summarize the medical situation, discussing prognosis, and negotiating goals of care have been shown to improve the likelihood that patients' wishes are followed (that is, improving the delivery of goal-concordant care) [10].

We now return to the case of Mr. L and put everything together to discuss the role of the palliative care consult in a patient with a serious neurologic illness. What follows is a discussion that took place with the patient and the final outcome. This discussion took place with several surrogate decision makers given that the patient's neurologic deficits did not allow for him to have decision-making capacity. His wife, Mrs. L, was his primary surrogate decision maker and was named in a health care proxy form.

PHYSICIAN: Good afternoon, Mrs. L. Can you tell me a little bit about your husband before he got sick?

MRS. L: He loved dancing to blues music, playing with his dog, and repairing motorcycles. He was very independent and didn't like anyone helping him. He hasn't really been to a doctor until he got this blood problem.

PHYSICIAN: It sounds like this process has been very hard for him. I'm hearing that his ability to use his hands was very important to him?

MRS. L: That's right. Not being able to work on his motorcycles or dance to his blues music is not what he would consider quality of life.

PHYSICIAN: I have some important information about your husband's health to share with you; are you ready to discuss this?

MRS. L: Yes, that is what we have been waiting for.

PHYSICIAN: The procedure that we tried to remove the blood clot from Mr. L's artery was not successful. Unfortunately, we do not think that his neurologic problems will get better, but instead might get worse. I do not think he would be able to fix motorcycles and dance to blues music again. We are worried that his neurologic condition may get worse, and he might die from this.

Mrs. L: [Does not respond and begins to weep.]

Physician: I can see that this is very upsetting news – it was not what we were hoping for. You have been so strong through this whole process, and this is a significant setback.

Mrs. L: I knew this might happen, but I have so many emotions about this. I'm angry that the medicine for his blood problem didn't work. I'm sad that the blood clot removal wasn't successful. I'm worried about what might happen in the next few days.

Physician: I can see why you would feel that way. I wish the medicine would have worked too.

Mrs. L: What do we do next? Is he suffering?

Physician: He does not seem to be experiencing any bothersome symptoms like pain right now. I think we should discuss whether we want to focus on Mr. L's illness by discussing other medications for his blood problem and aggressive physical therapy or focus on his quality of life by taking a more comfort-focused approach to his care.

Mrs. L: I can't see that he would ever want to live this way with such a lack of mobility. I want to focus on his comfort.

The patient did not have any significant bothersome symptoms to address. We made arrangements for the patient to transition to hospice as soon as possible and discussed our conversation with the hematology team and the neurologic ICU team. Unfortunately, within the next three days, the patient became progressively unresponsive from brain herniation and died. We were at the bedside with the patient and his family and he died peacefully.

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