

COMMUNICATION ABOUT THE TRANSITION TO HOSPICE

Hospice professionals' perspectives on communication about end-of-life care involved four types of communication: (a) patient-family communication, (b) patient-family-physician communication, (c) patient-family-hospice communication, and (d) hospice-physician communication. Each type of communication can facilitate or become a barrier to the use of hospice. Examples of both positive and negative outcomes are presented. Table 1 summarizes these results.

Patient-family communication. This communication can involve situations in which the person who is dying and the family members have a mutual understanding that the condition is terminal. A series of alternatives can also exist in which family members have different levels of understanding and awareness of the approaching death, the patient understands and family members do not, the family members understand and the patient does not, or family members have differential comprehension of the terminality of the situation. The internal family dynamics that accompany the development of a shared understanding of illness progression

include recognition of the visual signs—physical, functional, and behavioral changes together with comprehension of the information about the diagnosis and prognosis. An example illustrates a situation when family members and the person who was dying do not have a shared understanding: “The patient may be accepting of a terminal diagnosis, fatigued, and wishing for palliative comfort type care but the family is talking about electric wheelchairs and taking trips.”

Mutual understanding of the approaching death was described as an important issue to ease distress during end-of-life care and for preparing families for the approaching loss. On the other hand, a hospice social worker described families in which there was a mutual understanding this way: “Some families understand that death is approaching, cope well, and this becomes a process of bonding and strengthening.”

Patient-family-physician communication. Communication between the family and the physician(s) is important for the establishment of clear and understandable information about the prognosis. In some situations, the family members request hospice and initiate the referral either through the primary physician or by calling hospice directly. One participant described physicians who were open to families' suggestions as follows:

If a referring physician offers positive support for a family's request for a hospice referral, supports the philosophy, and works with the hospice staff, the situation as a whole is a much easier one. The families and patients feel a continuity of care and a confidence in their treatment.

However, in other situations, the physician may not address the terminal nature of the illness. An example of this is “The doctor wasn't realistic with the patient and family and they are having trouble finishing their business and coming to terms with the reality.” Thus, communication between families and physicians can facilitate or become a barrier to the transition to hospice care.

Patient-family-hospice communication. In some situations families have had prior experience with hospice and are

knowledgeable about the type of care. The dying person and the family are open to building a relationship with the hospice team. A hospice nurse describes this type of communication:

Mrs. G was admitted to hospice when her diagnosis was made because she chose not to have curative treatment. The family was very close and communicated freely about the disease progression and approaching death. Mrs. G was with hospice for 3-4 months. By the end stage, the family and I knew each other quite well and the patient had wonderful care—we trusted each other.

In other situations, either family members are not ready for the transition from a curative to palliative approach to care or hospice team members are challenged by families' wishes, questions, or dynamics. When families are not ready for hospice, either a patient or family member still desires treatment while others understand that it is futile. Overall, the family is uncomfortable with the change in approach to care and a focus on preparing for death. The example below illustrates this:

Someone who is not accepting a prognosis that is limited and still wants aggressive treatment or that perhaps someone has discomfort using medications for symptom control that are "addictive." Perhaps we as caregivers just don't think they believe in what we do or share the same goals.

Some families do not want all available hospice services, question the palliative approach, or express their responses to hospice admission in dynamics that are difficult for hospice professionals to understand. Communication is more difficult when family members are uncomfortable with the transition or when hospice teams have specific expectations about how families will feel and act toward the hospice approach to care.

Hospice-physician communication. Hospice admission requires a physician's order and therefore, clear communication about the disease progression and prognosis. In some situations, physicians refuse to give admission orders. In other situations, the physician still wants to treat the illness and is pressuring the patient to continue chemo or radiation therapy or the physician may feel threatened by hospice and think that he or she should be managing the situation.

An example illustrates the absence of open hospice-physician communication.

The doctor will have told them (a family) not to come to hospice but they're taking care of someone at home who is throwing up blood and has no bowel control and they think, you know, "I don't care what he says I've got to do something. I need help." I hear that at least once a week—the doctor didn't want me to do this.

Without hospice-physician communication, people who desire hospice care cannot receive it because there is not a mutual understanding about the person's wishes and available options for care.

Some physicians turn to hospice professionals to help patients make difficult transitions in care. A hospice nurse describes how open, collaborative physician-hospice communication can assist a patient's care transitions:

This patient had metastatic abdominal cancer and was receiving TPN [Total Parenteral Nutrition, or intravenous feeding] and chemotherapy. He made the decision to withdraw from aggressive treatments. There was an open dialogue between the physician, spouse, and family with hospice to assist them with the process of accepting, dealing with their fears and guilt. This helped set the stage for healthy family interactions and set the stage for holistic comprehensive end-of-life care.

The nature of communication between community physicians and hospice professionals depends on attitudes, knowledge, and willingness to relinquish a central role in care management as well as personal and professional preparation to help another person face life's end.

Discussion

Hospice admissions represent a transition in the progression of care for a life-limiting illness and an ideological shift from living with to dying from a terminal illness. The analysis of ethnography with 6 hospice teams generated qualitative data that were used to describe the patient-family dynamics for hospice teams as they work to alleviate symptoms and provide relief from distress as death approaches. Using focus groups, interviews, and written follow-up questions to explore 53 hospice team members' perspectives on their relationships with families and physician providers, this study's results also illustrate the sensitive and complex dynamics that accompany the development of a mutual understanding, comfortable rapport difficult

TABLE 1 Communication about the Transition to Hospice

Communication type	Presenting situations	Factors that contribute	Potential dynamics
Patient-family	<ul style="list-style-type: none"> • Patient and all family members have a mutual understanding of the terminal condition. • Patient and family members, have different levels of awareness about the terminal prognosis. 	<ul style="list-style-type: none"> • Family communication patterns • Differential involvement of family members • Individual expectations/goals for end-stage care • Level of awareness/avoidance of terminality • Knowledge/perceptions about hospice 	<ul style="list-style-type: none"> • Family is coping together; strengthened and bonded as death approaches. • Family members have uneven comprehension of the terminal prognosis and each thinks that the other is unaware. • Family grasps the approaching death but patient does not. • Patient grasps the approaching death but family does not.
Patient-family-physician	<ul style="list-style-type: none"> • Patient, family and physician have a shared understanding of the need for hospice. • Patient, family and physicians have different knowledge of the diagnosis, prognosis and available options. 	<p>Families have:</p> <ul style="list-style-type: none"> • individual perceptions of the illness • variable levels of information/knowledge about the diagnosis • different levels of comfort • discussing a terminal prognosis • professional opinions about continuing treatment • communication with other providers including specialists 	<ul style="list-style-type: none"> • Open communication: physician supports the need for hospice. • Both MD and family know but avoid discussing the approaching death. • Either the family or the doctor avoid discussing the approaching death. • Medical abandonment: patient-family need but do not get assistance or the referral for hospice.

Patient-family-

- Patient and family are ready; hospice is a relief.
- Patient meets hospice admission criteria but the hospice transition is difficult.

Families bring:

- personal, emotional, philosophical, religious perspectives about continued treatment vs. death, end-of-life and a palliative approach
- Family requests transition to hospice.
- Family finds relief with hospice care.
- Family wants to continue food/fluids.
- Family seeks cure.
- Family is uncomfortable preparing for death.

Hospice professionals bring:

- professional knowledge and expertise in palliation
- a daily focus on the dying process
- experience/expertise managing symptoms at life's end
- hospice approaches physician for transfer orders
- MD misunderstanding of hospice care or guidelines
- MD resists discussion of prognosis with the family
- Physician agrees and refers.
- Physician refuses orders; does see the person as ready for hospice.

Hospice-physician

- Family requests hospice.
- Physician suggests hospice.