ospice and Palliative Care Insights this month explores how hospice care can transform the lives of patients, families, and even staff when it is tailored to the patient’s desires and wishes. In our lead article, Mary Labyak of Hospice of the Florida Suncoast introduces the Experience Model in which hospice and palliative care services are based on the unique values, end-of-life goals, and wishes/needs of each patient. This can only happen when members of the interdisciplinary team are attuned to what is important to both patient and family based on their unique values and life experiences. Interdisciplinary collaboration and service then are directed by what the patient and family define as their end-of-life goals.

The Experience Model for care, Labyak says, supports the many different dimensions – physical, interpersonal, spiritual, psychological, and emotional – of the end of life, and indeed all of life. It also can be used “whether the patient has nine hours, nine days, or nine months to live – always focusing on what is most important to the patient and family at any given moment.”

In their responses, National Council of Hospice and Palliative Professionals’ Section Leaders consider the Experience Model from the unique perspective of their individual disciplines. Certain themes emerge, such as patient choice; the importance of listening to and understanding patients, regardless of background, race, or life experience; the need to expand program and service options based on patient feedback; the benefit of staff members keeping each other “in the loop” about patients; and the necessity that all staff understand their importance to the organization and how the job they do impacts patient care.

The Experience Model is more than just putting patient and families first. It’s about transforming the end-of-life experience for patient and family, but also for staff and volunteers. It’s about knowing patients for who they are and enabling them to choose their end-of-life experiences, which, in turn, enriches the lives of staff and volunteers in so many ways.
No one would argue that every patient, family, and community member who seeks services from a hospice or palliative care provider deserves the best care available. People who need hospice services often are in the midst of a heart-wrenching journey for which they have received no preparation or guidance. End-of-life providers usually have only one opportunity to ensure that their programs meet the unique needs of the people they serve.

Hospice providers also are challenged to meet the growing expectations of people familiar with palliative care. Twenty years ago, patients and families were happy simply to receive basic pain and symptom management and to have someone acknowledge their grief. Today’s consumers are aware of the support and services that palliative care teams provide and frequently express a desire for “that medicine my neighbor had.”

Effective models of hospice and palliative care honor what hospice professionals have learned from those they have served. When staff and volunteers at all levels of the organization focus on the experiences of patients, families, and community members, they create an organizational culture in which services are based on the unique values, end-of-life goals, and wishes of each patient.

As reflected in *The Quest to Die with Dignity: An Analysis of Americans’ Values, Opinions and Attitudes Concerning End-of-Life Care*, people tend to regard the last phase of life as one of awaiting death. During this time, they desire some measure of comfort and they hope they are not a burden to others. These perceptions about the end of life can be transformed through quality palliative care that honors each individual’s values and goals. Hospice palliative care providers can create a transformative experience for patients and families that differs significantly from the experience of receiving care through a disease-focused model. A disease-focused approach involves curing the disease or restoring the patient to a previous state of health. The hospice and palliative care model is radically different. Hospice or palliative care patients and families are presented with unique opportunities to direct their own care to meet their end-of-life goals. The experience for the patient is a journey toward comfort, resolution, and life closure, rather than a forced march toward physical wellness.

The experiences of advanced illness, dying, and bereavement are much more than medical experiences. By helping to reduce all dimensions of suffering and to reframe the end-of-life experience, quality palliative care facilitates a patient’s personal growth toward a more peaceful life closure.

**A NEW MODEL FOR END-OF-LIFE CARE**

The Experience Model, which transforms end-of-life care, works best when the concept transcends all areas of hospice. *Figure 1*

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*Figure 1*

depicts the relationships of all staff and volunteers to patients, families, and community members. The center of the circle includes patients, families, and community members who direct our care and services. The next circle represents the direct service staff and volunteers who care for the patients, families, and community members in the inner circle. The outer circle represents all other staff and volunteers who support direct staff and direct volunteers in providing optimal care.

How do we transform experiences for:
- The patients, families, and community members we serve?
The staff and volunteers who provide direct services to patients, families, and the community?

Those who create and maintain systems and resources that support the other two groups?

**Transforming the Experiences of Patients and Families**

“What I appreciate about hospice is that you cared for her as the person she had always been, not the patient she had become.”

Quote from a hospice patient’s family

Hospice and palliative care are different from the care provided by other health and human service providers. In contrast to the traditional disease-focused model that addresses the physical dimensions of illness, the Experience Model is directed by the patient’s and family’s individual goals and wishes as they adapt to the effects of advancing illness, dying, or bereavement. Hospice professionals have learned from patients and families that the end-of-life experience involves not only a physical dimension but also psychological, social, emotional, and spiritual dimensions. For example, we know pain is not only a physical problem. The physical dimensions of pain affect a patient’s and family’s other dimensions, including the ability to care for oneself, the quality of interactions with others, the sense of well-being or “dis-ease,” and spirituality. The end-of-life experience is dynamic. When one dimension is affected, all other dimensions are affected. The experience not only is “multidimensional,” it is “inter-dimensional.” Therefore, quality hospice and palliative models of care must be able to support and address all these dimensions – the physical, interpersonal, spiritual, psychological, and emotional.

**Transforming the Experiences of Staff and Volunteers**

Patient and family values and life-closure goals drive care and services.

<table>
<thead>
<tr>
<th>Disease-focused Model approach</th>
<th>Palliative Experience Model Approach</th>
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<tbody>
<tr>
<td>Patient presents with symptoms of disease</td>
<td>Patient and family are affected by a life-limiting condition that cannot be reversed.</td>
</tr>
<tr>
<td>Focus is on curing or fixing the problems.</td>
<td>Facilitate a dialogue to help the patient and family define their end-of-life values, goals, and life closure wishes. These become the overriding goals of the patient and family care plan to direct our services.</td>
</tr>
<tr>
<td>Assess from the perspective of how symptoms and disease process should be different.</td>
<td>Assess from the perspective of what is helping or hindering the patient and family from reaching their end-of-life goals and wishes?</td>
</tr>
<tr>
<td>Plan and define goals of medical care for patient based on what care providers feel is best.</td>
<td>Plan how the interdisciplinary team can support the patient and family in reaching their goals, and it can reduce suffering and maximize potential toward a self-determined life closure?</td>
</tr>
<tr>
<td>Provide interventions as outlined on the plan of care to restore or reverse medical condition.</td>
<td>Help patient and family to minimize or eliminate those things that are hindering them from reaching their goals. Create opportunity for transformational experiences of growth.</td>
</tr>
<tr>
<td>Evaluate the effectiveness of disciplines’ care plan based on medical goals.</td>
<td>Evaluate effectiveness based on the patient and family’s experience of what is important to them at this time. To what degree have we helped them reach their goals?</td>
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It is a challenge to transform a professional’s approach to care of patients and families. The drivers of a traditional disease-focused model of care differ from the drivers of an Experience Model of care. Patient and family values and life-closure goals are the foundation for a patient and family Experience Model. When hospice professionals understand the inter-dimensional experience described above, their relationships with patients and families are directed by the patient’s defined end-of-life goals and values instead of by health care goals alone.

Table 1 compares and contrasts the Experience Model approach to a disease-focused approach to care. The more traditional disease-focused model of care begins with identifying the disease and its symptoms. Then, based on the discipline’s area of expertise (nurse, physician, social worker, etc.), goals are developed to help reverse or minimize the disease process. Care usually is directed by what the professionals believe is important and needed. Outcomes are based on meeting the professionals’ goals of care.

The Experience Model begins with a meeting where the patient and his or her family begin to tell their life stories. Through ongoing discussions, hospice staff members discern what is important to both patient and family based on their unique values and life experiences. Interdisciplinary collaboration and service are directed by what the patient and family wish the care experience to be and on what they define as their end-of-life goals. Staff assessment focuses on what is happening physically, emotionally, psychologically, spiritually, and interpersonally that may either be helping or hindering the patient and family to address what is important to them. The patient and family choose services, which are evaluated based on how well they have helped patients reach their end-of-life goals. This process can happen whether the patient has nine hours, nine days, or nine months to live – always focusing on what is most important to the patient and family at any given moment.

Assessment by professionals in any discipline goes beyond identifying a problem in the dimension they are most comfortable assessing (e.g., a nurse assessing physical condition). In this model of care, all disciplines approach assessment with the goal of identifying how any given issue or problem affects all dimensions. For instance, all disciplines approach patient and family-identified problems of pain with a broader vision of how it simultaneously may affect the patient’s and family’s other dimensions, including their functional abilities, interpersonal relationships, sense of well-being, and sense of spirituality. In hospice care, the disciplines don’t “own” problems or care plans. They are not ours to own. It is not the hospice team’s experience; it is the patient’s and family’s experience. All disciplines must be competent enough to address all these dimensions and collaborate as an Interdisciplinary Team (IDT) to transform the patient’s and family’s end-of-life experiences.

A comparison of how a patient and family are discussed in an interdisciplinary care plan meeting illustrates the differences between a disease-focused model and an Experience Model. In the disease-focused model, the following might be used to introduce a patient and family, usually “reported” by the nurse:

**Mr. Jones is a 78-year-old COPDer. He was on O2 prn. With his increased dyspnea at rest and bilateral congestion, he is using his oxygen on a continual basis. He is anxious at night, has trouble walking from his bed to his living room, and is demanding. The doctor changed his inhaler this week because he was not compliant with taking his other medications since he didn’t like the after-taste. The HHA visits four times a week to assist with his personal care. The patient and family are not asking for any other help at this time.**

The disease-focused model is problem-focused, identifying the patient as a disease first. The discussion may mention how the patient’s physical condition is affecting the rest of the patient’s life, but this is not of primary concern.
By contrast, the Experience Model team dialogue focuses on the patient’s and family’s values, goals, and wishes as the starting point:

Mr. and Mrs. Jones have shared their lives together for 58 years since they met and married in college. They have stated that what is most important to them at this time is for Mr. Jones’ symptoms to be controlled enough that he can spend quality time with his children and grandchildren who live close by. Mr. Jones wants to be able to communicate his thoughts and wishes to each of his grandchildren before he dies. He is also concerned about how his wife will be cared for after he is gone. Mrs. Jones is hoping that she has enough strength and endurance to stay by his side and care for him until the end. They define themselves as practicing Catholics and state that their faith has given them strength. Their usual activities, before Mr. Jones could no longer participate, included golf and travel. They now enjoy reading, movies, writing letters, and listening to old-time music.

Once the Interdisciplinary Team has been introduced to patients and families through the stories of their lives and what is important to them, the team can consider the following question: What is happening with this patient and family that is helping or hindering them in getting to what is important to them at this time?

Each IDT member approaches their assessment from the perspective of supporting those elements that help the patient and family reach their goals. In addition, staff focus on helping patients and families address those aspects that are hindering them in getting to what is important to them at this time.

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Organizational culture plays a large role in the delivery of care in an Experience Model. Organizational systems and resources that allow for individualized care while maintaining high quality standards encourage and motivate hospice staff toward excellent service. It is this culture of service excellence that transforms all interactions and experiences.

Transformative end-of-life experiences for patients and families happen when staff and volunteers understand the value of their roles in creating these experiences, even when they do not provide direct care. For instance, the finance department understands the importance of processing medical bills so that patients and families can spend more time doing what is important to them. Education staff understand that the patient and family resource materials they develop help caregivers feel confident about the care they provide and perhaps bring meaning to the caregiving experience. Administrative teams create systems that allow for bedside decision-making and flexibility without lengthy bureaucratic approvals. Leaders motivate staff review with his children, are critical aspects of service. The team also can provide additional caregiving support to Mrs. Jones so she can endure the 24-hour care required and still have energy to do the activities they enjoy together.

Each member of the IDT brings expertise on one or more of the dimensions of the patient/family experience, which makes each team member’s input and suggestions equally valuable in the Experience Model of care. The care plan problems are not nursing problems or social work problems. They are the patient’s and family’s experience – with the care plan directed by their values and end-of-life goals.

**Organizational systems and resources that allow for individualized care while maintaining high quality standards encourage and motivate hospice staff toward excellent service.**

**TRANSFORMING EXPERIENCES OF THOSE WHO SERVE DIRECT SERVICE PROVIDERS**

Excellence is the overlay of quality care and transformative experiences.

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Policies, procedures, systems, and the organizational culture must reinforce the concept that all hospice staff work to enhance the end-of-life experiences of those they serve. Figure 2 depicts a framework for mission-based policy decisions that take into account the patient’s and family’s values, goals, and wishes.

The following questions will help hospice staff assess their organization’s ability to transform its patients’ and family’s end-of-life experiences:

1. What are the organization’s systemic barriers to transforming patient and family experiences?
2. Are care delivery models flexible enough to meet the unique needs of each patient and family?
3. How does the voice of the patient and family drive interdisciplinary discussions?
4. Do IDT collaborative discussions begin with the story of the patient and family, including what is most important to them at this time?
5. Is the care planning process truly directed by the goals, values, and wishes of patients and families?
6. Are all disciplines encouraged to participate in team care discussions?
7. Is every member of the IDT competent in recognizing all dimensions of the patient and family experiences?
8. Is staff empowered to take risks that support patient and family goals?
9. Are community members asked on a regular basis about what end-of-life services they want and need?
10. Are programs and services provided based on current reimbursement mechanisms or the needs of all members of our communities?
11. What drives organizational decisions – the needs and experiences of patients and families, or regulations, reimbursement, and liability issues?

The future of end-of-life service delivery is being written every day by hospices and palliative care providers. Hospices respond by developing new, evolving models that address not only the disease but all dimensions of the patient’s experience to truly create transforming experiences. We only have one chance to support patients through a transforming experience at the end-of-life. The price of failure is not acceptable.

MARY LABYAK has been the leader of The Hospice of the Florida Suncoast since 1980, when she became its program director. Her work with the organization began in 1977, when she joined other volunteers in seeking to find better ways to care for people at the end of life. She became the agency’s president and executive director in 1983. Under her leadership, the hospice has grown from a small group of volunteers and staff into the largest not-for-profit, community-based hospice anywhere. More than 950 employees and about 2,500 volunteers care for more than 1,300 patients each day in the hospice’s Pinellas County community.

A nationally recognized expert in hospice and palliative care, Ms. Labyak is sought after as a spokeswoman and has held leadership roles in state and national hospice organizations. In recent years, she has been called upon to help shape legislative views on end-of-life issues. She was appointed to the prestigious Florida Panel on End-of-Life Care, which was established by the state legislature. She is past chair of the NHPCO Board of Directors and serves on its insurance board. In addition, she is a past president of Florida Hospices, Inc.