



The Experience Model

By Mary J. Labyak, MSSW, LCSW

As this month's feature, NewsLine is republishing the landmark article, "The Experience Model," written by Suncoast Hospice President/CEO, Mary Labyak, who died on February 4, 2012. While written in 2001, providers still embrace this model and continue to request copies of the article—testament to Mary's lifelong impact as a hospice leader.

No one would argue that each patient, family and community member who seeks services from a hospice or palliative care provider deserves the best we can offer them. People who need our support are often in the midst of a heart-wrenching journey for which they have received no preparation or guidance. As end-of-life providers we usually have only one opportunity to ensure that the experiences of these patients and families meet their unique needs.

Palliative care providers are also challenged to meet the growing expectations of people familiar with our services. Twenty years ago patients and families were happy simply to have someone to call, and to receive basic pain and symptom management, and acknowledgement of their grief. Today's consumers know the incredible support and services that palliative care teams provide and frequently express a desire for "that medicine my neighbor had."

Successful current and future models of hospice and palliative care will honor what we have learned from those we have served. When staff and volunteers at all levels of the organization focus on the experiences of patients, families and community members, we foster an organizational culture in which our services are based on the unique values, end-of-life goals and wishes of each person we serve.

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 see the last phase of life as one of awaiting death, with the hope for some measure of comfort while not being a burden to others. These perceptions about the end of life can be transformed into a more meaningful journey through quality palliative care that honors each individual's values and goals.

Hospice and palliative care providers 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 to a previous health state. In the hospice and palliative care model, the experience for the patient becomes that of a journey toward comfort, resolution, and life closure (rather than a forced march toward physical wellness).

In reflecting on what patients and families have taught us, the experiences of advanced illness, dying and bereavement are much more than medical experiences. By helping to reduce all dimensions of suffering and reframe the end-of-life experience, quality palliative care facilitates personal growth and meaning toward a more peaceful life closure.

A Model for End-of-Life Care

The Experience Model, which transforms end-of-life care, works best when the concept transcends all areas of an organization.

Figure 1 depicts the relationships of all staff and volunteers to patients, families and community members. In the center of the



Figure 1

circle are the patients, families and community members who direct our care and services. The next circle represents the direct service staff and volunteers who provide the care and services. The outer-most circle represents all other staff and volunteers who serve and support the direct service staff and volunteers in providing optimal care.

How do we help to transform experiences for patients, families, and community members; for the staff and volunteers who provide direct service; and for those who create and maintain systems and resources that support the other two groups?

Transforming the Experiences of Patients and Families

As the family member of one patient shared: “What I appreciate about hospice is that you cared for

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her as the person she had always been, not the patient she had become.”

Hospice and palliative care are uniquely different from the care provided by other providers of health and human services. In contrast to the more 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 and bereavement.

We have learned from patients and families that this experience involves not only a physical dimension but also psychological, social, emotional, and spiritual dimensions. As an example, we know pain is not only a physical problem. The physical dimensions of pain simultaneously affect other dimensions as well, including the ability to care for oneself, the quality of interactions with others, the sense of well-being or disease, and the sense of spirituality. Like an infant’s mobile, this experience is dynamic. When one dimension is affected, all other dimensions are involved. The experience is not only “multidimensional,” it is “inter-dimensional.”

Therefore, quality hospice and palliative models of care must be able to support and address all four dimensions—the physical, interpersonal, spiritual and emotional.

Transforming the Experiences of Staff and Volunteers

Patient-and-family values and life-closure goals should drive care and services. They define what is important at this time in the patient’s and family’s life and become the focus and foundation for a patient/family Experience Model. However, it is oftentimes a challenge to transform a professional’s approach to care since the drivers of a traditional disease-focused model differ from the drivers of the Experience Model.

When we start by understanding the inter-dimensional experience described above, our relationship with the patient and family is directed by their defined end-of-life goals and values instead of a more traditional disease-focused model directed by healthcare goals alone.

Table 1 illustrates the differences between the Experience Model and disease-focused model.

In the more traditional disease-focused model, the process

begins with identifying disease and symptoms. Then, based on the discipline’s area of expertise (e.g., nurse, physician, social worker), goals are developed to help reverse or minimize the disease process. Care is usually directed by what the professionals believe is important and needed. Outcomes are based on meeting the professional’s goals of care.

The Experience Model begins with a dialog with the patient and family during which they begin to tell their life stories. Through ongoing discussions, we discern what is important to them at this time in their lives, based on their unique values and life experiences. We take their lead and our interdisciplinary collaboration and service are directed by what the patient and family wish this experience to be and on what they define as their end-of-life goals.

Our assessment focuses on what is happening in all of the dimensions that are helping or hindering the patient and family from attending to what is important to them at this time. Services are chosen by the patient and family and evaluation is based on *their perception* of how well they have reached their end-of-life goals. This process can

Table 1

Disease-Focused Model	Experience (Palliative) Model
Patient Presents with Symptoms of Disease.	Patient and Family are Affected by a Life-limited Condition that Cannot be Reversed.
	<i>Facilitate a dialog 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.</i>
Focus on Curing or Fixing the Problems.	Determine What is Helping or Hindering the Patient and Family from Reaching their End-of-Life Goals and Wishes.
<i>Assess from the perspective of how symptoms and disease process should be different.</i>	<i>Assess from the perspective of what is helping the patient and family from reaching their goals with regard to pain, family dynamics, spiritual issues, and caregiving support.</i>
<i>Plan and define goals of medical care for patient based on what care providers feel is best.</i>	<i>Plan how the interdisciplinary team can support the patient and family in reaching their goals and, in so doing, reduce suffering and maximize potential toward a self-determined life closure.</i>
<i>Provide interventions as outlined on the plan of care to restore or reverse medical condition.</i>	<i>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.</i>
<i>Evaluate the effectiveness of disciplines' care plan based on medical goals.</i>	<i>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?</i>

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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 any discipline goes beyond identifying a problem in the dimension they are most comfortable assessing, such as the physical dimension assessed by a nurse. All disciplines approach assessment from the perspective of identifying how any issue or problem is affecting all dimensions. For instance, all disciplines approach patient and family-identified problems of pain with a broader vision of how it is simultaneously affecting the patient's and family's other dimensions, including their functional abilities, interpersonal relationships, sense of well-being and sense of spirituality. In palliative care, the disciplines don't own problems or care plans—they are not ours to own. It is not our experience, it is the patient's and family's experience. All disciplines must be competent at some level to respond to all of these dimensions and adept at collaboration with an interdisciplinary team to optimally transform this end-of-life experience.

Comparing how a patient and family are discussed in an interdisciplinary care plan meeting will illustrate these differences. In a 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 patient with COPD. 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 aftertaste. The HHA visits four times a week to assist with his personal care. They are not asking for any other help at this time.

The discussion becomes problem-focused, often identifying the patient as a disease first, then perhaps mentioning how this is affecting the rest of the patient's life (although this part is often not a focus). In contrast, team dialog in the Experience Model focuses

on the patient and family's values, goals and wishes as the starting point:

Mr. and Mrs. Jones have shared 58 years together 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 to allow him to 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 story 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 the patient and family from getting to what is important to them at this time?

Each team member approaches his or her assessment from this perspective by supporting those aspects that are helping the patient and family reach their goals, reframe their hope and experiences, or by helping them meet the challenges of those aspects that are hindering them from reaching their goals. Symptoms that take away the patient's ability to focus on what is important are minimized or controlled so his energies can be used to reach his goal of spending quality time with his family. Additional activities that help the patient create and

communicate his legacy, such as life review with his children, are critical aspects of service. The team can provide additional caregiving support to his wife so she can endure the 24-hour care required and still have energy to do the activities they enjoy together. Each member of the interdisciplinary team brings expertise on one or more of the dimensions of the patient and family experience, which makes all of their input and suggestions equally valuable in the Experience Model. The care plan problems are not 'nursing problems' or 'social work problems,' but the patient's and family's experience—and their care plan is directed by their values and end-of-life goals.

The Benefits to Those Who Serve

Organizational culture plays a large role in affecting the delivery of the Experience

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Model. Systems and resources that allow for individualized care while maintaining high-quality standards encourage and motivate everyone toward service excellence. 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 value in processing medical bills so patients and families don't have the burden of that additional task and can spend more time doing what is important to them. Education staff understands that many of the resource materials they develop will help caregivers feel confident about the care they are providing and perhaps bring meaning to the caregiving experience. And administrative teams create systems that allow for decision making and flexibility at the bedside, without lengthy bureaucratic approvals. Leaders motivate staff and volunteers by helping them to see the connections

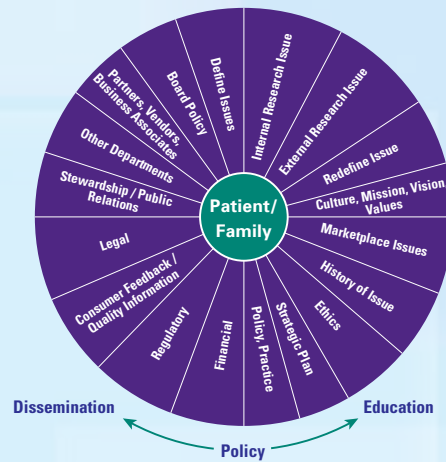


Figure 2

between their job functions and transforming the patient's and family's experiences. When we share stories about how their efforts transform end-of-life experiences, we create a passion for their roles and enhance their desire to provide service excellence in everything they do.

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

The following questions will help hospice staff members assess their organization's ability

to transform the end-of-life care experiences of their patients and families:

What are your organization's systemic barriers to transforming patient and family experiences?

Are care delivery models flexible enough to meet the unique needs of each patient and family?

How does the voice of the patient and family drive interdisciplinary discussions?

Do IDT collaborative discussions begin with the story of the patient and family, including what is most important to them at this time?

Is the care planning process truly directed by the goals, values, and wishes of patients and families?

Are all disciplines encouraged to participate in team care discussions?

Is every member of the IDT competent in recognizing all dimensions of patient and family experiences?

Is staff empowered to take risks that support patient and family goals?

Are community members asked on a regular basis what end-of-life services they want and need?

Are programs and services provided, based on current reimbursement mechanisms or the needs of all members of our communities?

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 hospice and palliative care providers. All end-of-life care models must honor the patient's and family's unique experiences and be ready to simultaneously address all dimensions. We must respond by developing new, evolving models that not only address the disease but also address *all dimensions* 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 served as the president/CEO of Suncoast Hospice (formerly The Hospice of the Florida Suncoast) from 1983 until her death on February 4, 2012. Under her leadership, the organization evolved from a small volunteer-based program to the largest nonprofit community based hospice in the nation. A nationally recognized expert in hospice and palliative care, she was the recipient of numerous accolades, including the National Hospice Foundation's prestigious Heart of Hospice Award. She was also an active member and supporter of NHPCO, serving as chair of the NHPCO board (1994), and as a member of the National Hospice Foundation's board of trustees, where she served as chair (2011-12).

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