



“The privilege of caring for the dying changes the way we live, for the better.”

Kelley Clem, RN, CHPN
CHPC Nursing Education

Palliative Care Case Study

By Megan O. Farrell, M.D.
and Lita Goodman, R.N.

An elderly male with a history of bipolar disease was admitted into Hospice care with congestive heart failure from advanced ischemic cardiomyopathy and severe valvular dysfunction. The patient had a recent hospitalization for worsening lower extremity edema and cellulites. He was treated with diuretics and antibiotics. Evaluation for DVT could not be completed.

The patient was living with his primary care giver (PCG) daughter, who also had a psychiatric disorder. Shortly after his admission to the hospice home care program, the PCG expressed to the social worker that she wanted the patient to find another place to live as her father's health care needs were too demanding. A list of resources for Senior Housing and Catholic Charities was given.

Daily Hospice nursing visits for wound care were made at the patient's residence. At times the

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97% of Americans Believe Patients and Families Should be Educated about End-of-Life Care Options

Hospice care highly respected; 91% of Americans deem it a top priority

Most Americans believe that enhancing life at the end of life is more important than extending it, and they are nearly unanimous in wanting more information and education about the choices available to them in palliative care, end-of-life care, and hospice, according to a national poll released in March by *National Journal*.

As the first in a three-part series of surveys and policy summits entitled, “Living Well at the End of Life: A National Conversation,” the poll results were presented at a gathering of policy experts in the nation's capital by Brent McGoldrick, general manager and senior vice president of public affairs research at the DC offices of Financial Dynamics, the consulting firm that conducted the National Journal-commissioned survey.

Key findings include:

- 97% of respondents agree that it is important to educate patients and families about the palliative and end-of-life options available to them.
- 96% believe that issues concerning palliative and end-of-life care should be a top priority in health care.
- 71% of Americans feel it is more important to enhance quality of life for seriously ill patients than to attempt to extend life through every medical intervention possible.
- Most Americans believe that discussions with physicians about palliative and end-of-life treatment options should be covered by private insurance (86%) and Medicare (81%).

“This is not a political issue,” said McGoldrick. “People view the issues surrounding these topics primarily through the lens of personal experience.” The results were consistent across all political party affiliations, he pointed out.

“There is a sense from the two-thirds of Americans who have had direct experiences with end-of-life care that they have not been particularly well informed,” noted McGoldrick. Of the 63% of respondents who reported personal experiences with palliative and/or end-of-life care, almost half said they felt unprepared. “If the threshold question is whether or not Americans are ready and willing to have this conversation, the answer is a resounding ‘Yes,’” he concluded.

Americans support palliative care despite their lack of knowledge

When asked about the term “palliative care,” few respondents (24%) said they were familiar with it. Yet 44% of those surveyed thought it should have top priority in the nation's health care system. Similarly, while 65% said they were familiar with the

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97% of Americans Believe Patients and Families Should be Educated about End-of-Life Care Options, *continued from page 1.*

term “end-of-life care,” 86% considered it important. “Hospice care” was better known and highly respected, with 86% being familiar with the term and 91% deeming it a top priority.

Following a description of all three terms by an interviewer, 96% of respondents believed it important that these health and life issues have top priority in health care, with 72% believing this priority status to be very important.

A question of trust

Although respondents reported receiving most of their information on palliative and end-of-life care from family members, friends, and the news media, the sources they trusted most to provide this information (rated 7-10 on a 10-point scale) were physicians, followed by family and friends. Least trusted sources were news media and politicians.

Most trusted sources for end-of-life care information included:

- Physicians and other health care providers (76%)
- Family members and friends (69%)
- Clergy and spiritual leaders (46%)
- Social service agencies and programs (39%)

Financial concerns

The survey found evidence of conflicted emotions regarding expenditure at the end of life, with 79% of respondents reporting that their greatest concern would be the cost of treatment if they or a family member became seriously ill, while 55% felt that the health care system had the responsibility to spend whatever was necessary to extend their lives. Lack of trust in the health care system and desire for all life-prolonging treatments in the face of serious illness were highest among those with a lower level of education and African-American ethnicity.

Personal concerns about serious illness

Personal concerns regarding serious illness (rated 7-10 on a 10-point scale) included:

- Cost of treatment (79%)
- Lack of sufficient information with which to make decisions (73%)
- Burdens on family and friends (72%)
- Being emotionally or spiritually unprepared for death and dying (48%)

“The issues and choices surrounding health care at the end of life have huge implications for our country, on the personal level, in the health care field, and for policy-makers,” said summit moderator Ronald Brownstein, editorial director of National Journal Group. “This poll makes it clear that while Americans are wrestling with these issues in their personal lives, the public conversation simply isn’t keeping up. Americans want to learn more about options at the end of life, and it’s time our national discussion shed less heat and more light.”

The survey interviews were conducted by telephone among 1000 adults (male, 48%; Caucasian, 70%; not currently covered by health insurance, 13%) during three days in February 2011.

Results of the survey and a video of the March 2011 policy summit are available at: www.nationaljournal.com/events/event/45/.

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patient would not allow the nurse to perform the care, but visits also provided an opportunity to monitor medication compliance. Despite these frequent visits and phone call checks, the patient made numerous calls to hospice, after hours, for supplies already in the home.

The patient was non-compliant with medications for managing his edema. He attributed the non-compliance to short term memory deficits.

However, compliance with his regimen of psychiatric medications, which included a mood stabilizer and an atypical antipsychotic seemed good. Despite this, the patient exhibited other paranoid behaviors.

Approximately two weeks after admission into hospice, the patient's PCG stated that the patient "needs to be removed from the home." In light of the risk to patient care and safety, all members of the team collaborated to discuss options and coordinate a safe transfer to the hospice inpatient unit. The patient eventually agreed to the transfer after discussions and reassurances from each of the team members.

While at the inpatient unit, psychiatric consultation was obtained for the patient's worsening agitation and delirium. With regimen adjustments, both improved. Unfortunately, his heart failure worsened, as did his renal insufficiency. He died comfortably several days later.

This case illustrates some unique challenges managed by the Hospice Interdisciplinary Team (IDT) when caring for patients with a progressive chronic medical disease and a significant psychiatric illness. The situation described was unique in that both the patient and his caregiver had psychiatric illnesses, the patient with bi-polar disease, progressive delirium and paranoia.

Much of the literature of hospice and palliative care deals with psychiatric comorbidities which result from terminal illness, rather than with those which are separate pre-existing conditions. Delirium, depression and anxiety are common conditions arising during the end of life, and have received much attention in light of their frequency (> 50%) and significant impact on quality of life.

Yet, patients who have chronic psychiatric illness such as schizophrenia, bipolar disorder or major depression deserve unique consideration and a thoughtful approach during the final stages of life. Their underlying mental illness may present challenging clinical scenarios and demand management strategies which strain the capacity of the caregiving system and IDT. Consistent and careful monitoring by the homecare nursing staff and clear communication between members of the IDT can help assure compliance with the psychiatric medical regimen prescribed and identify evolving symptoms which warrant adjustments in medications. A concerted effort to discuss advance directives and get appropriate orders in place should be made when the patient is psychiatrically stable and competent to make wishes known.

Consultation with psychiatry and mental health professionals (preferably those who have been involved) is paramount to managing patients who are terminally ill. This can be particularly challenging as a patient's functional status declines and the patient becomes more and more debilitated. Establishing strong collaborative relationships early on in the patient's medical course may facilitate the maintenance of those relationships as the patient's condition deteriorates.



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Hospice Buffalo Continuum of Care

- Homes
- Palliative Care/Hospice Beds in Hospitals
- Hospice Assisted Living and Nursing Home Services in area adult homes, nursing facilities, and group homes
- Mary & Ralph Wilson, Jr. Hospice Inpatient Unit at the Mitchell Campus for short-term pain/symptom management, respite and end-stage care
- Hospice Buffalo House at the Mitchell Campus and the St. John Baptist/Hospice Buffalo House for hospice-eligible patients needing 24-hour nursing care during the final months or weeks of life.

Definition of Palliative Care:

Palliative Care is comprehensive care provided by an interdisciplinary team for patients living with a chronic, often progressive illness, and for their families. Care is focused on alleviating physical and psychosocial symptom burdens, and promoting quality of life according to the patient's goals.

Major issues addressed are:

- Pain and symptom management
- Information regarding the illness
- Advance care planning
- Psychosocial and spiritual needs
- Coordinated care with other community resources

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Calendar of Events

Wednesday Aug. 10 and
Thursday Aug. 11
Volunteer Open House

Learn about the many volunteer opportunities at Hospice to assist patients, families and staff. Both short and long-term openings are available to fit your interest, skills and availability. Refreshments and tours will be provided. Visit HospiceBuffalo.com for times and locations of the open house.



Thursday, Aug. 18
Summer Affair

Enjoy a beautiful summer evening on Buffalo's waterfront at Harry's Harbour Place Grille featuring live music from the Strictly Hip. Our 2nd annual celebration features cocktails, light fare, theme basket auction and raffles to benefit Hospice care. Tickets are \$50 per person and are available online at HospiceBuffalo.com.

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Far too often, patients who face major psychiatric conditions "fall between the cracks" and their psychiatric care, as well as their medical care, becomes the responsibility of the Hospice clinicians. Management strategies and novel therapies are probably best coordinated in consultation with psychiatric subspecialties whenever possible, but lack of supportive consultative services should not prohibit the Hospice team from addressing symptoms in a timely manner.

In urgent situations, management of patients either in an acute hospice inpatient setting with psychiatric consultation or in an inpatient psychiatric setting with palliative care consultation support may become necessary, depending on which symptoms are most pressing. The safety of the patient and comprehensive symptom management are imperative and disposition needs to be directed towards achieving those ends.

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Save the Date!

11th Annual Harvest Festival

Friday, October 14 at Adam's Mark Hotel

Wine Tasting, Gourmet Dinner, Silent & Live Auctions,
Live Music by Twilight. Details at HospiceBuffalo.com

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