



2011 Public Opinion Research on Palliative Care

A Report Based on Research by Public Opinion Strategies

Research Commissioned by the Center to Advance Palliative Care

Support Provided by the American Cancer Society Cancer Action Network

Objectives

Conducted by Bill McInturff and Elizabeth Harrington of the national polling firm Public Opinion Strategies, the following research was commissioned by the Center to Advance Palliative Care (CAPC) with support from the American Cancer Society Cancer Action Network (ACS CAN). The findings below provide a roadmap for communicating with consumers and policymakers on the benefits and future direction of palliative care. This report provides an in-depth look at appropriate messages, as well as attitudes and perceptions of palliative care.

The objectives of this research were to:

- Explore key audiences' awareness and understanding of palliative care; and,
- Test language, terminology, definitions and messaging to be used in discussing palliative care with consumer audiences.

Key Finding:

Although consumers may be content with the quality of health care they receive, they have concerns about the level of care patients with serious illness receive.

The biggest concerns relate to information sharing between doctor and patient and other doctors, patient control and choice over treatment options, patient understanding about their illness and treatment, and the quality of time doctors spend with patients.

Biggest Concerns for Patients with Serious Illness

%Biggest/ One of Biggest Concerns

Doctors might not provide all of the treatment options or choices available	58%
Doctors might not talk and share information with each other	55%
Doctors might not choose the best treatment option for a seriously ill patient's medical condition	54%
Patients with serious illness and their families leave a doctor's office or hospital feeling unsure about what they are supposed to do when they get home	51%
Patients with serious illness and their families do not have enough control over their treatment options	51%
Doctors do not spend enough time talking with and listening to patients and their families	50%

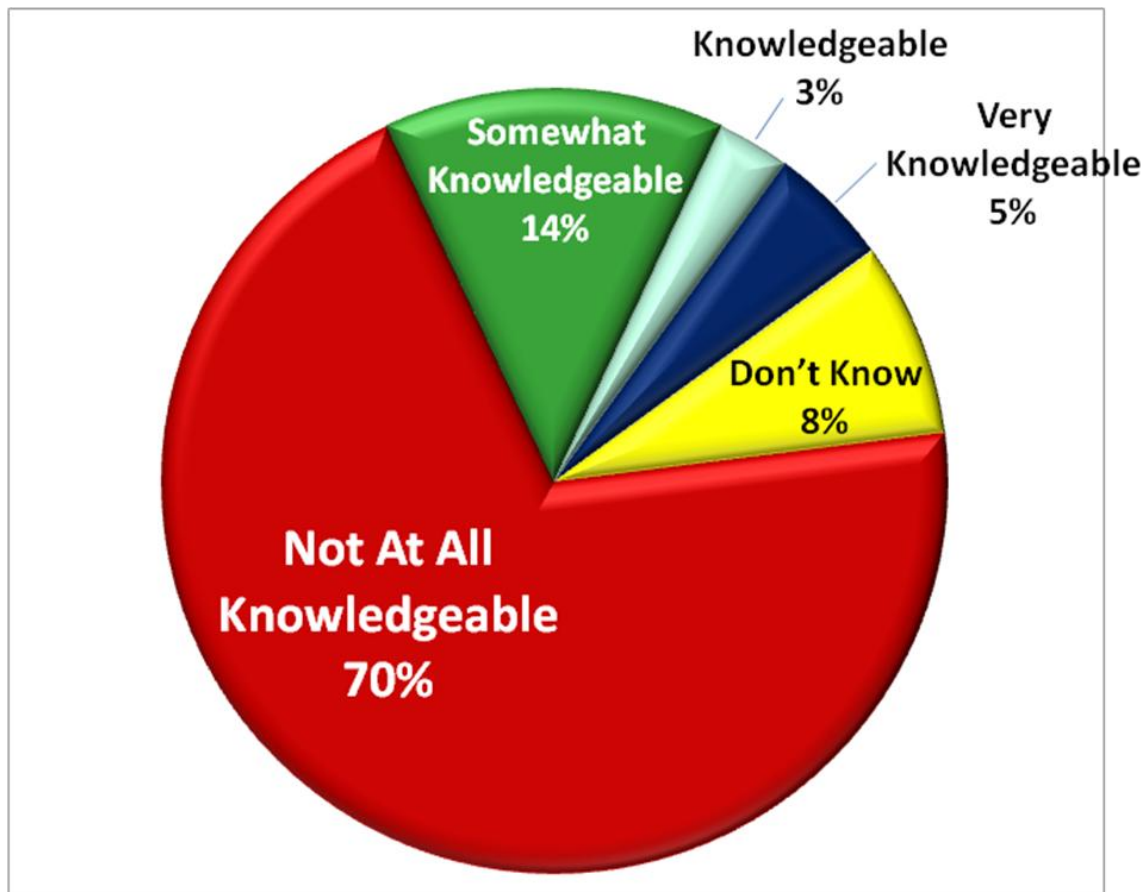
Key Finding:

This research confirms palliative care is a relative unknown among consumers.

There is a clear need to inform consumers about palliative care and provide consumers with a definition of palliative care.

Consumer Awareness About Palliative Care

How knowledgeable, if at all, are you about palliative care?



*Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.

Key Finding:

Physicians are a much more difficult audience than consumers.

- Physicians tend to either equate palliative care with “hospice” or “end of life” care, and they are very resistant to believing otherwise.
- We spoke with a total of eight physicians across the IDIs and focus groups. Although these physicians say they have referred patients to palliative care services, they admit they only do so when it is end of life care.

These physicians see palliative care as:

- *“Comfort care during one’s last few weeks or days of life to allow patients to pass in comfort and dignity.”*
- *“Make a patient’s remainder of life comfortable and pleasant, without side effects of treatment, no aggressive measures are taken.”*
- *“The overall goal is to keep a patient comfortable.”*
- *“Comfort care. The goal is to keep a patient comfortable and out of intensive medical treatment. The goal is not to cure but to treat their symptoms.”*
- *“Palliative care is helping families to give them comfort and options for what to do at their loved one’s end of life.”*

This is an important context to have because it demonstrates a problem among referring physicians that will need to be addressed.

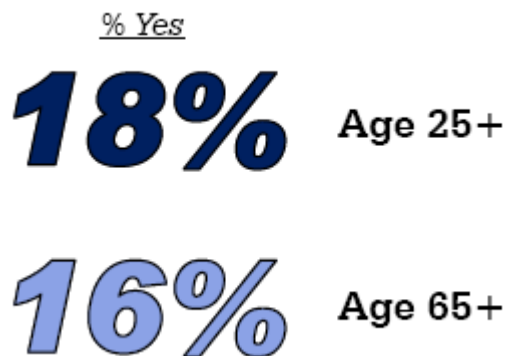
Key Finding:

Language makes a difference.

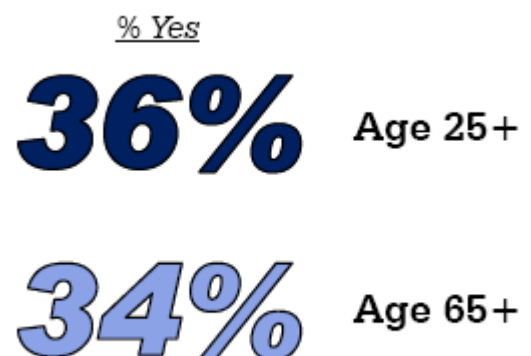
- Palliative care is about improving quality of life, providing an extra layer of support, and having a team focus to patient care.
- Palliative care is about helping both the family as well as the patient with serious illness.
- This research indicates that palliative care must be differentiated from hospice or end of life care. Focus group respondents became confused about the meaning of palliative care when the terms hospice or end of life were introduced into the definition of palliative care. It is important to avoid defining palliative care by what it is NOT.
- Once consumers understand what palliative care is, they have an extremely positive feeling about this type of care.

Serious Illness vs. Advance Illness: Palliative care should be positioned as care for patients with serious illness not advanced illness. Advanced illness is perceived to be more closely aligned with terminal illness.

When you hear the phrase **SERIOUS ILLNESS**, do you think this generally has the same meaning as terminal illness?



When you hear the phrase **ADVANCED ILLNESS**, do you think this generally has the same meaning as terminal illness?



Definition of Palliative Care: How you define palliative care has a big impact on how people feel about palliative care. The definition below does not have much positive impact on how consumers rate palliative care.

Old Language:

Palliative care is the medical specialty focused on improving the quality of life of people facing serious illness. Emphasis is placed on pain and symptom management, communication and coordinated care. Palliative care is appropriate from the time of diagnosis and can be provided along with curative treatment.

Tested on April 5-7, 2011 National*

Mean Rating Score

63

%75-100

36%

***April 2011 survey conducted of 800 registered voters**

However, the revised definition below, based on the qualitative research, had a significant positive impact. It should be used when defining or describing palliative care for consumers.

New Language:

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Mean Rating Score

74

%75-100

60%

Key Finding:

Once informed, consumers want to be able to have access to palliative care if they need it.

Once informed, consumers say they would be very likely to consider using palliative care if they or a loved one had a serious illness.

And how likely, if at all, would you be to consider palliative care for a loved one if they had a serious illness?

	Age 25+	Age 65+
Very likely	63%	62%
Somewhat likely	29%	28%
Not too/ Not at all likely	6%	6%

Once informed, consumers believe it is very important patients with serious illness to have for access to palliative care at all hospitals.

Thinking some more about palliative care...how important do you think it is that palliative care services be made available at all hospitals for patients with serious illness and their families?

	Age 25+	Age 65+
Very important	68%	69%
Somewhat important	24%	22%
Not too/Not at all important	5%	6%

Regardless of party affiliation, consumers see an important need for palliative care to be made available to patients with serious illness at all hospitals.

Thinking some more about palliative care...how important do you think it is that palliative care services be made available at all hospitals for patients with serious illness and their families?

	<u>Democrats</u>	<u>Independents</u>	<u>Republicans</u>	<u>Tea Party Supporters</u>
Very important	78%	63%	55%	64%
Somewhat important	18%	23%	34%	27%
Not too/ Not at all important	1%	10%	9%	8%

Consumers tell us in an open-ended question what they see as the importance of palliative care for patients with serious illness:

- The majority of consumers say the most important aspect of palliative care is that it makes the patient comfortable by alleviating both their stress and physical pain.
- It greatly improves the quality of their life, and it helps them and their family better understand and cope with the situation.
- By supporting all their needs – medically, physically, emotionally and spiritually – palliative care removes any suffering and brings a sense of comfort and relief into their lives.
- Additionally, by providing a team of doctors, nurses and specialists that can collaborate and evaluate the situation from multiple angles, palliative care assures that each patient receives the best possible treatment and care for their condition.

Key Finding:

After hearing the definition of palliative care, consumers strongly agree that:

- Patients with serious illness and their families be educated about palliative care.
- Palliative care is appropriate at any age and any stage in serious illness.
- Palliative care treatment options should be covered by health insurance and Medicare.

What do consumers believe to be true about palliative care?

Statements Tested	Strongly Agree	Total Agree
It is important that patients with serious illness and their families be educated about palliative care options available to them together with curative treatment.	78%	95%
Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.	73%	94%
Discussions about palliative care treatment options with a doctor should be fully covered by health insurance.	71%	86%
Discussions about palliative care treatment options with a doctor should be fully covered by Medicare.	60%	80%

Key Finding:

Palliative care's goals provide consumers with a favorable opinion of this care.

Palliative Care Positive Statements	<u>% Much More Fav</u>	<u>% Total More Fav</u>
The goal of palliative care is to relieve suffering and provide the best possible quality of life for a patient and their family.	59%	85%
The palliative care team of doctors, nurses, and other specialists spends time with a patient and their family to help them understand their treatment options and goals.	56%	83%
Palliative care doctors, nurses, and other specialists work together as a team with a patient's other doctors to provide an extra layer of support.	55%	83%
Palliative care makes patients feel better by treating their pain and other symptoms.	53%	82%

The most important things to convey about palliative care are:

Thinking more specifically about palliative care and some of the things we have discussed in the survey so far...which ONE of the following attributes do you think are most important to convey to people about palliative care?

	First Choice	Combined Choice
It helps provide the best possible quality of life for a patient and their family.	17%	27%
It helps patients and families manage the pain, symptoms, and stress of serious illness.	15%	27%
It is a partnership of patient, medical specialists, and family.	12%	21%
It is appropriate at any age and at any stage in a serious illness.	9%	19%
It provides an extra layer of support for families and patients with serious illness.	8%	20%
It is a team approach to patient care.	8%	16%
It helps coordinate a patient's care and helps them navigate the medical system.	7%	18%
It can be provided together with curative treatment.	6%	11%
It is specialized medical care for patients with serious illness.	4%	10%

Key Take-Aways:

Barriers include:

- The lack of awareness among potential consumers and patients with serious illness that palliative care services exist.
- The term palliative care having little or no meaning to consumers. Many inside the industry framing it as end of life care.
- Physician attitudes about palliative care.

But, it is important to remember that once informed, consumers are extremely positive about palliative care and want access to this care if they need it:

- ✓ **95%** of respondents agree that it is important that patients with serious illness and their families be educated about palliative care.
- ✓ **92%** of respondents say they would be likely to consider palliative care for a loved one if they had a serious illness.
- ✓ **92%** of respondents say it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.

The definition tested below had a significant positive impact and should be used when defining or describing palliative care for consumers:

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Methodology

Qualitative Research:

- One-on-one interviews with caregivers of palliative care patients, caregivers of patients with serious illness, and attending physicians with palliative care patients. Conducted 1/11/11 and 1/20/11.
- Internet bulletin board focus groups of patients with serious illness, and caregivers of patients with serious illness. Conducted 1/27/11 through 1/30/11.
- In-person focus groups of seniors, baby boomers, and attending physicians who have patients with serious illness. Conducted 2/7/11 and 2/8/11.

Quantitative Research:

- A national telephone survey of 800 adults age 25 or older. Oversample among 148 seniors age 65+ in order to have a total national sample of 300 seniors age 65+. Conducted 4/11/11 through 4/14/11.