



Presentation of 2011 Research on Palliative Care

May 20, 2011

#11130



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What We Did

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.
- Internet bulletin board focus groups of patients with serious illness, and caregivers of patients with serious illness.
- In-person focus groups of seniors, baby boomers, and attending physicians who have patients with serious illness.

Quantitative Research:

- A national telephone survey of 800 adults age 25 or older.
- An oversample national telephone survey of 300 seniors age 65 or older.

This Presentation

This presentation builds on the qualitative phase of research. It will primarily highlight the key findings from the two national surveys. Please see the memo and PowerPoint slide deck from the qualitative phase of research for more detailed findings from that phase of research.

Perceptions and Attitudes About Patient Care

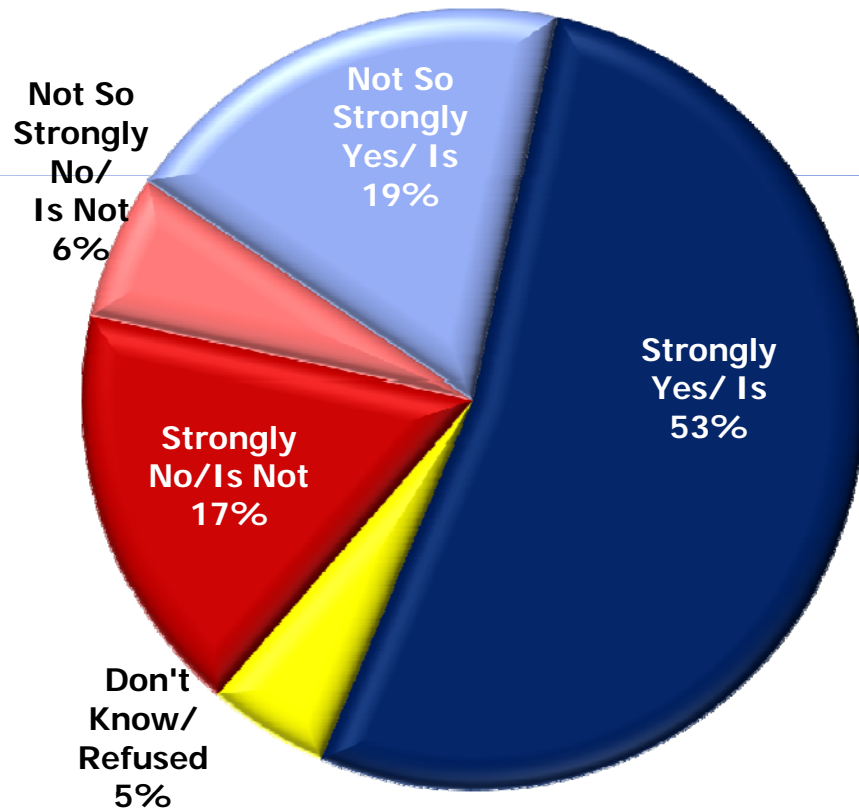
Key Finding #1

In general, respondents are content with their access to health care services and quality of health care they receive today.

Overall, respondents believe the health care system is meeting their needs. Seniors believe this more intensely.

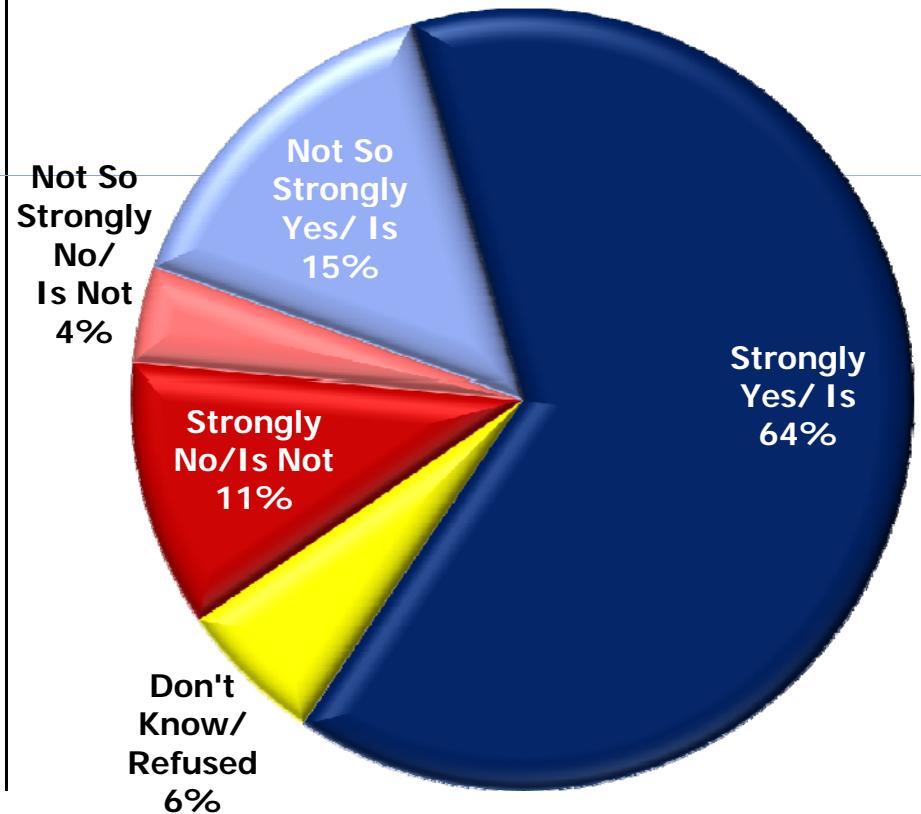
Age 25+

Total Yes/ Is	72%
Total No/ Is Not	23%



Age 65+

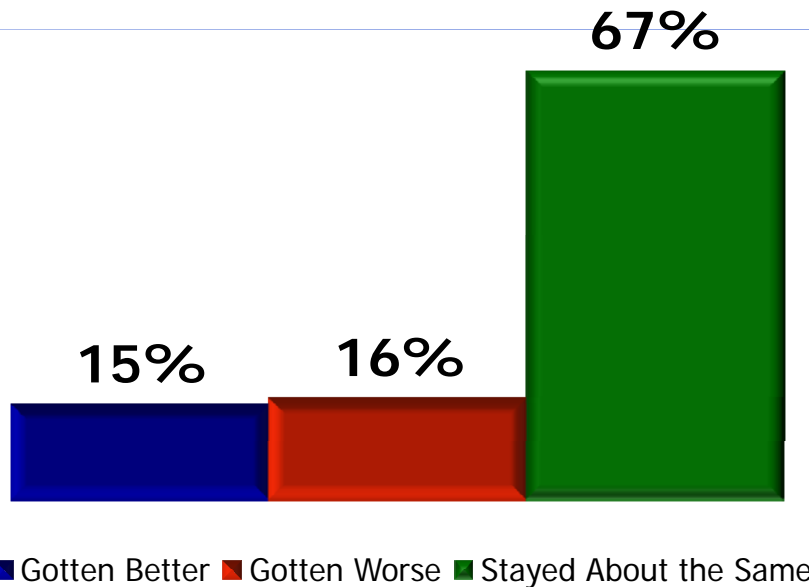
Total Yes/ Is	79%
Total No/ Is Not	15%



Generally speaking, is the current health care system meeting the needs of you and your family?

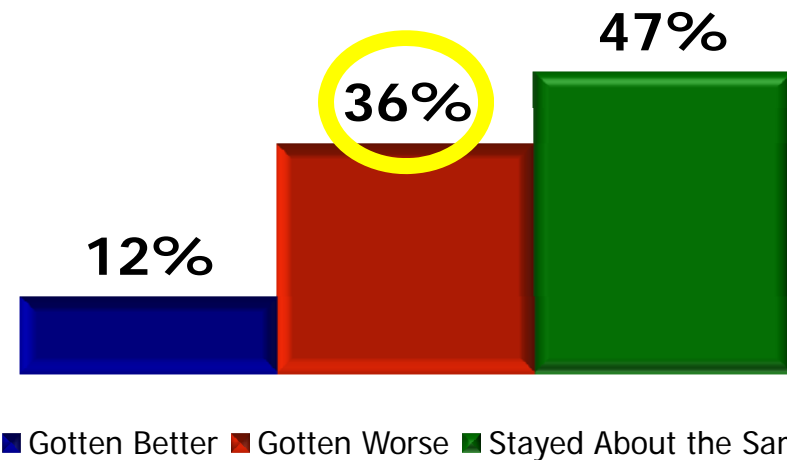
As well, roughly two-thirds of respondents believe the quality of health care they have received over the past one to two years has stayed about the same. But when asked about the quality of health care in this country more generally, one-third of respondents say it has gotten worse.

Quality of Health Care – Personally (Age 25+)



And more specifically thinking about the quality of health care you receive...in the past one or two years, do you think the quality of health care you receive has...

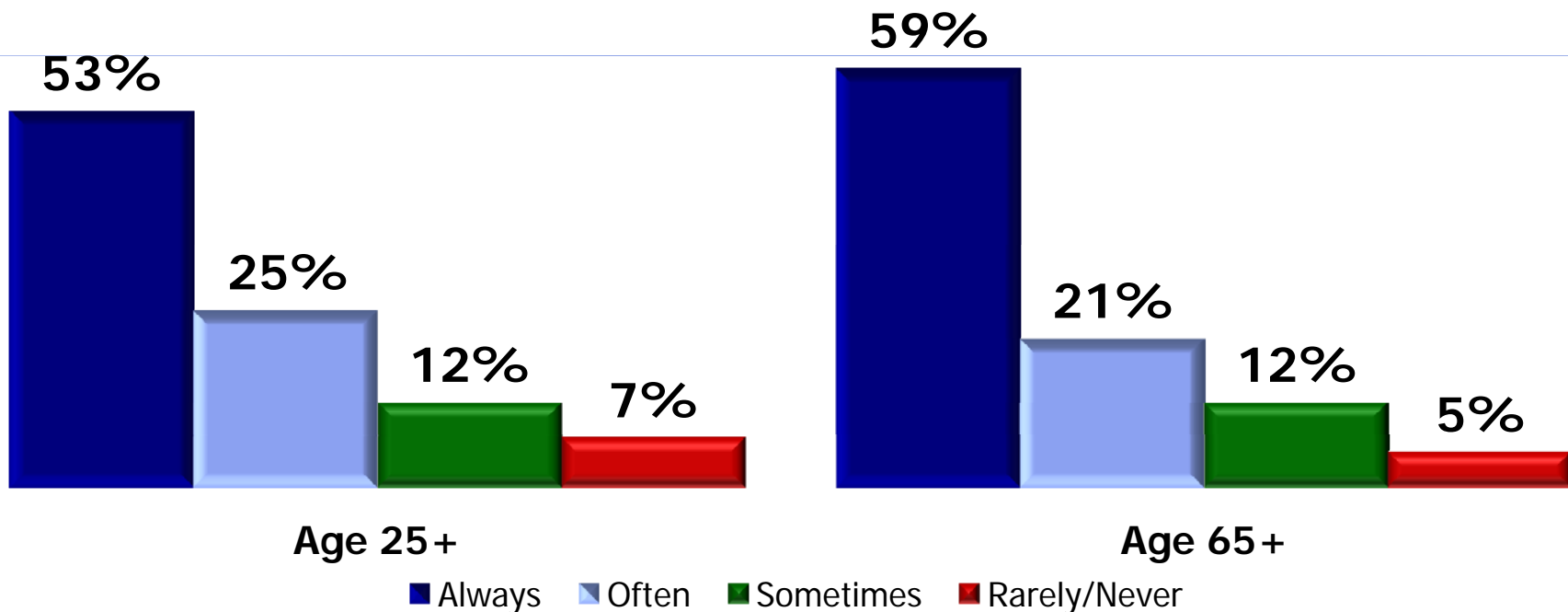
Quality of Health Care in the U.S. (Age 25+)



Thinking about the past one or two years...do you think the quality of health care in this country has...

A majority of respondents say their doctor listens to their thoughts and opinions “always” when making treatment decisions about their care.

Doctor Listens to You When Making Treatment Decisions

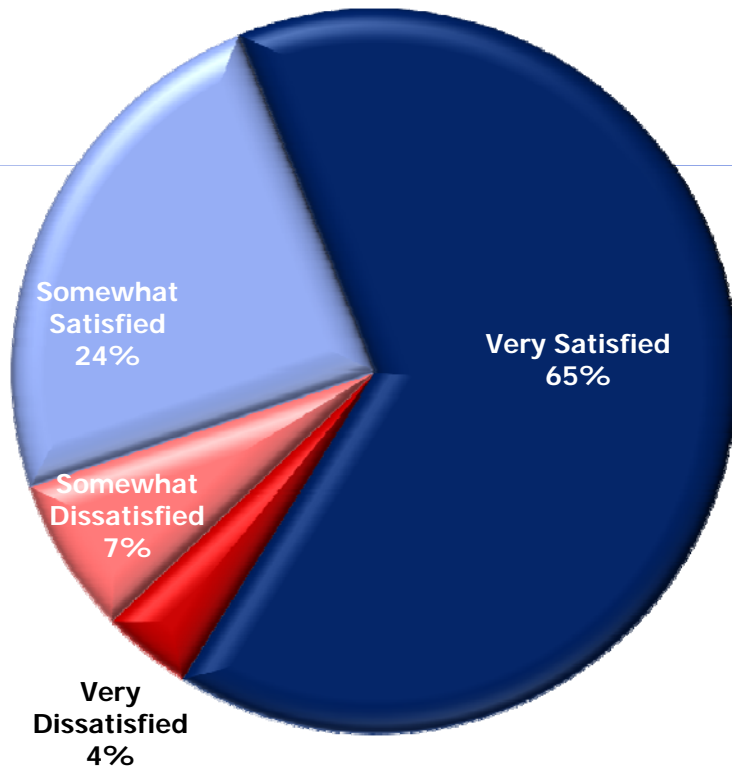


How often, if at all, does your doctor listen to your thoughts and opinions when making treatment decisions about your medical care?

Among respondents who have a doctor (98%), satisfaction levels are very high for the amount of time their doctor spends with them.

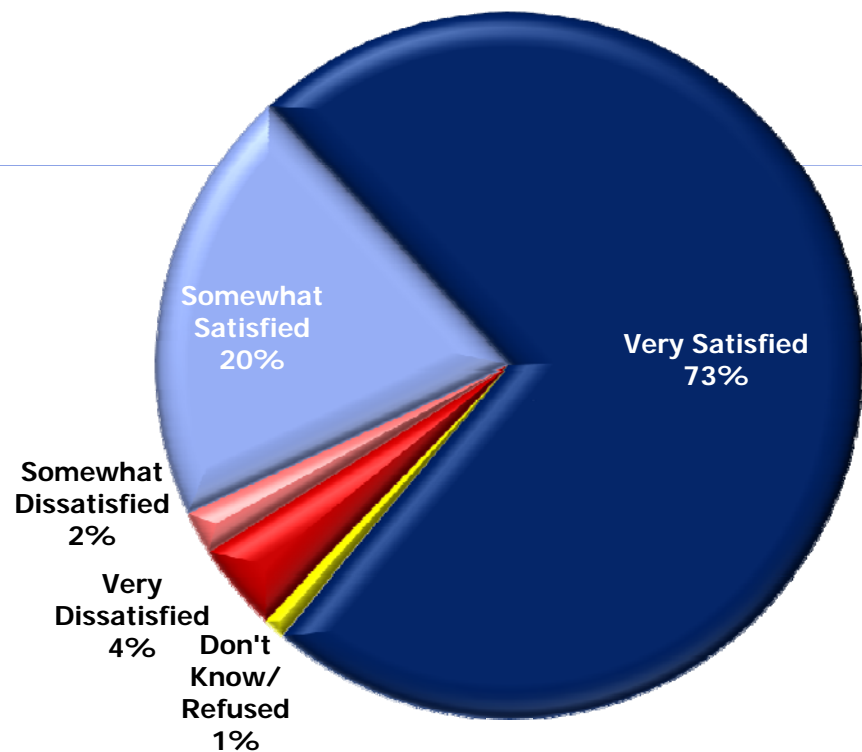
Age 25+

Total Satisfied 89%
Total Dissatisfied 11%



Age 65+

Total Satisfied 93%
Total Dissatisfied 6%



And thinking back to the most recent visit you had with a doctor, how satisfied were you with the amount of time the doctor spent with you...

Key Finding #2

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, patient control and choice, patient understanding, and quality time.

Seniors tend not to be as concerned about this issue as the population as a whole.

Biggest Concerns For Patients With Serious Illness:

%Biggest/ One of Biggest Concerns

	<u>Age 25+</u>	<u>Age 65+</u>
Doctors might not provide all of the treatment options or choices available to patients with a serious illness and their families	58%	45%
Doctors might not talk and share information with each other when treating patients with a serious illness	55%	42%
Doctors might not choose the best treatment option for a seriously ill patient's medical condition	54%	44%
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%	44%
Patients with serious illness and their families do not have enough control over their treatment options	51%	39%
Doctors do not spend enough time talking with and listening to patients with a serious illness and their families	50%	45%

Now talking some more about health care and more specifically about patients who have a serious illness... Some patients with serious illness we have talked to mention specific concerns they have when they see a doctor. I am going to read you some of these concerns mentioned and if you could just tell me for each one, whether you think it is...the biggest concern, one of the biggest concerns, a medium concern, a small concern, or whether this is not a concern when patients with serious illness receive medical care. As you respond, please keep in mind that NOT EVERY CONCERN CAN BE THE BIGGEST CONCERN.

Things that are less of a concern about the care of patients with serious illness receive:

%Biggest/ One of Biggest Concerns

	<u>Age 25+</u>	<u>Age 65+</u>
Doctors do not spend enough time reducing the pain and suffering for patients with serious illness and their families	43%	35%
Doctors might not provide personalized care to patients with serious illness	41%	35%
Doctors do not spend enough time improving the quality of life for patients with serious illness and their families	41%	34%
Doctors do not take into account the patient and family preferences for treatment for patients with a serious illness	38%	32%

Now talking some more about health care and more specifically about patients who have a serious illness... Some patients with serious illness we have talked to mention specific concerns they have when they see a doctor. I am going to read you some of these concerns mentioned and if you could just tell me for each one, whether you think it is...the biggest concern, one of the biggest concerns, a medium concern, a small concern, or whether this is not a concern when patients with serious illness receive medical care. As you respond, please keep in mind that NOT EVERY CONCERN CAN BE THE BIGGEST CONCERN.

Perceptions and Attitudes About Palliative Care

Key Finding #3

As we noted in the qualitative research analysis, this survey data also confirms palliative care is a relative unknown among consumers.

There is a clear need to define palliative care and inform consumers about palliative care.

This lack of understanding about palliative care among consumers is an important context to have as you think through messaging and language.

However once informed, consumers are extremely positive about palliative care and want to be able to have access to this care if they need it.

Key Finding #4

It matters how you define palliative care. It is about improving quality of life, providing an extra layer of support, and having a team focus to patient care. It is about how palliative care helps both the family and the patient with serious illness. It is NOT about hospice or end of life care.

A plurality of adults age 25+ and half of seniors are not able to provide a rating for how they feel about the term “palliative care.” The phrase “palliative care and supportive services” is viewed more positively than “palliative care” and a higher percentage of respondents are able to rate the term.

	<u>Age 25+</u>			<u>Age 65+</u>		
	<u>Mean Rating Score</u>	<u>%75-100</u>	<u>% Able to Rate</u>	<u>Mean Rating Score</u>	<u>%75-100</u>	<u>% Able to Rate</u>
Palliative care	57	15%	57%	62	18%	47%
Palliative care and supportive services	60	23%	69%	65	29%	68%

Now, I am going to read you some different words or phrases being used in health care today. Please pay careful attention as I read each one. Some of these might sound somewhat alike, but they are different. For each term, please rate your overall impression of the term using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of the term and one hundred means you have a very favorable opinion of the term and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression of the term.

The term palliative care receives slightly higher ratings among respondents in the Northeast region.

Palliative Care Image
By Region – Age 25+

	<u>Northeast</u>	<u>Midwest</u>	<u>South</u>	<u>West</u>
Mean Rating Score	59	55	57	55
%75-100	21%	11%	16%	12%
%Able to Rate	61%	54%	58%	54%

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Non-White respondents provide slightly lower ratings of the term palliative care.

Palliative Care Image by Ethnicity – Age 25+

	<u>White</u>	<u>Non-White</u>
Mean Rating Score	58	51
.....		
%75-100	16%	11%
.....		
%Able to Rate	56%	61%

Now, I am going to read you some different words or phrases being used in health care today. Please pay careful attention as I read each one. Some of these might sound somewhat alike, but they are different. For each term, please rate your overall impression of the term using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of the term and one hundred means you have a very favorable opinion of the term and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression of the term.

Democrats provide slightly higher ratings of the term palliative care initially.

Palliative Care Image
By Party – Age 25+

	<u>Republicans</u>	<u>Independents</u>	<u>Democrats</u>
Mean Rating Score	55	55	61
%75-100	12%	11%	20%
%Able to Rate	58%	56%	61%

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Those respondents “unable to rate” the term palliative care (42%) tend to be older adults and women, particularly with lower levels of income and education.

Top Sub-Groups – Unable to Rate Palliative Care

Adults age 75+	55%
Seniors (age 65+) with HS or less education	55%
Seniors (age 65+) with a HH income under \$40K	53%
Women living in rural areas	52%
Senior women (age 65+)	52%
Women with a HH income under \$60K	51%
Seniors (age 65+)	50%
Adults living in rural areas	47%
Silent Generation (age 67-84)	47%
Adults living in the West region	46%
Women with less than a college degree	46%
Adults with HH income under \$40K	46%
Total	42%

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In comparison, “hospice care” and “end of life care” are terms people are much more familiar with. However, the phrase “end of life care” is not perceived as positively in comparison to “hospice care.”

	<u>Age 25+</u>			<u>Age 65+</u>		
	<u>Mean Rating Score</u>	<u>%75-100</u>	<u>% Able to Rate</u>	<u>Mean Rating Score</u>	<u>%75-100</u>	<u>% Able to Rate</u>
Palliative care	57	15%	57%	62	18%	47%
End of life care	59	34%	89%	63	38%	84%
Hospice care	73	54%	92%	77	60%	91%

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Those adults who work in health care or have a family member who works in health care are more positive than the general population about these terms.

Among Those Who Work or Family Member Works in Healthcare Age 25+ (12%)

	<u>Mean Rating Score</u>	<u>%75-100</u>	<u>% Able to Rate</u>
Palliative care	66	35%	78%
End of life care	65	52%	94%
Hospice care	76	63%	96%

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The term “palliative care” does not have much meaning to consumers. Although adding “supportive services,” increases the mean positive rating, is also raises some discussion about hospice care and end of life.

Palliative Care Mean Rating Score

57

- Do not know/Not sure what it means (68 mentions);
- Relieving pain and keeping patients comfortable and taking care of a patient who is dying/terminally ill (31);
- Relieving pain and keeping patients comfortable during a serious illness (16);
- Providing supportive care to the elderly (6);
- Treating the symptoms of a disease, rather than the cause (5).

Palliative Care and Supportive Services Mean Rating Score

60

- Do not know/Not sure what it means (58 mentions);
- Relieving pain and keeping patients comfortable and taking care of a patient who is dying/terminally ill (22);
- Supportive care for the terminally ill (13);
- Hospice/in-home care (12);
- Relieving pain and keeping patients comfortable during a serious illness (11);
- Providing supportive care to the elderly(5);
- Care for the disabled (4).

Thinking about just one of these terms (Palliative Care/Hospice Care/End of Life Care/Palliative Care and Supportive Services) if a friend or neighbor asked you to describe what (Palliative Care/Hospice Care/End of Life Care/Palliative Care and Supportive Services) is and what it means, what might you tell them? What does this term refer to? Who receives this type of care?

Consumers have a better understanding of what “end of life care” and “hospice care” mean.

End of Life Care Mean Rating Score

59

- Relieving pain and keeping as comfortable as possible before one dies (62 mentions);
- Care for the terminally ill/elderly (50 mentions);
- Hospice/Someone who comes to take care of you late in life (38);
- Don't know/Not sure what it means (20);
- Medical and supportive planning for the last few days of one's life (20).

Hospice Care Mean Rating Score

73

- Relieving pain and keeping people as comfortable as possible in last days of life (81 mentions);
- Providing care for a terminally ill or dying patient (51 mentions);
- In-home care of patient (21);
- Supportive care for the families of terminally ill patients (17);
- Provides medical, emotional and spiritual care (12);
- Taking care of the elderly (11).

Thinking about just one of these terms (Palliative Care/Hospice Care/End of Life Care/Palliative Care and Supportive Services) if a friend or neighbor asked you to describe what (Palliative Care/Hospice Care/End of Life Care/Palliative Care and Supportive Services) is and what it means, what might you tell them? What does this term refer to? Who receives this type of care?

Language makes a difference. 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?

% Yes
18% Age 25+

16% Age 65+

% Yes
36% Age 25+

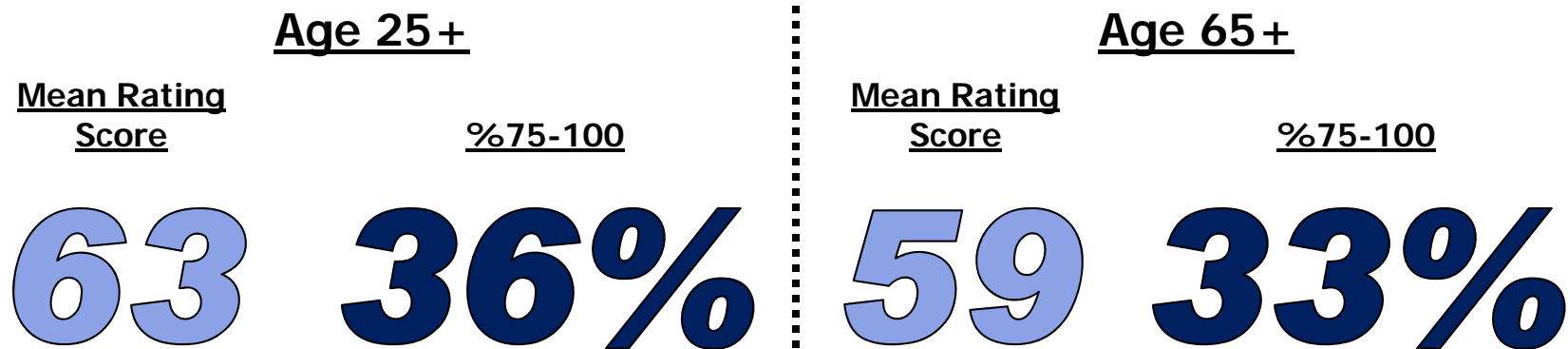
34% Age 65+

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 respondents 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**



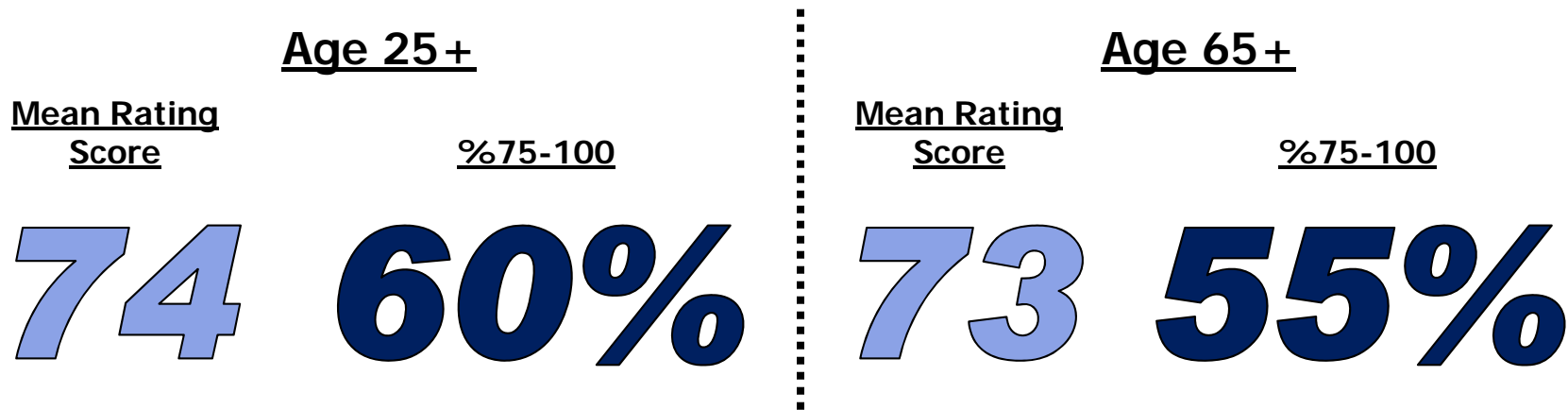
**April 2011 survey conducted of 800 registered voters*



How you define palliative care has a big impact on how people feel about palliative care. The revised definition we drafted based on the qualitative research DOES have a significant positive impact.

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.



Reasons for Positive Feelings About Palliative Care

- ✓ It is important to ease the suffering of those in pain and keep them comfortable during their illness or disease (59 mentions);
- ✓ The collaboration of doctors leads to best possible treatments (40);
- ✓ Palliative care comforts the patient physically, medically and emotionally (40);
- ✓ It improves quality of life (29);
- ✓ It provides very helpful and much needed supportive care services (29);
- ✓ It provides comfort for the family (28);
- ✓ It is important to ease the suffering of those in pain and keep them comfortable in the last days of life (21);
- ✓ My personal experience – palliative care is very beneficial for all involved (20);
- ✓ It helps all parties involved to understand the situation better (9).

Hesitations or Concerns About Palliative Care

- ✗ How much does this cost?/Is it covered by health insurance? (13 mentions);
- ✗ Does palliative care provide enough care to the patient? (4);
- ✗ The government getting involved/don't trust the government (4);
- ✗ Too many doctors/too many opinions (3);
- ✗ Palliative care is not well-known (2);
- ✗ Seems like a waste of money to involve all these doctors (2);
- ✗ Not enough is done to treat the actual problem - just treating the symptoms (1).

As noted earlier, once informed, consumers are extremely positive about palliative care.

Image of Palliative Care

	<u>Age 25+</u>		<u>Age 65+</u>	
	<u>Mean Rating Score</u>	<u>%75-100</u>	<u>Mean Rating Score</u>	<u>%75-100</u>
Initial	57	15%	62	18%
Informed	74	60%	73	55%
Net Diff.	+17	+45%	+11	+37%

Now, I am going to read you some different words or phrases being used in health care today. Please pay careful attention as I read each one. Some of these might sound somewhat alike, but they are different. For each term, please rate your overall impression of the term using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of the term and one hundred means you have a very favorable opinion of the term and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression of the term.

Once informed, respondents in the Northeast region continue to provide a slightly higher mean rating score than respondents in other regions.

Image of Palliative Care by Region Age 25+ – Mean Rating Scores

	<u>Northeast</u>	<u>Midwest</u>	<u>South</u>	<u>West</u>
Mean Rating Score	77	74	72	73
%75-100	61%	61%	60%	59%

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Once informed, there is no functional difference by ethnicity.

Image of Palliative Care by Ethnicity Age 25+ – Mean Rating

	<u>White</u>	<u>Non-White</u>
Mean Rating Score	74	72
%75-100	61%	57%

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Also, once informed, feelings about palliative care are positive across partisan lines.

Image of Palliative Care by Party Age 25+ – Mean Rating Scores

	<u>Republicans</u>	<u>Independents</u>	<u>Democrats</u>	<u>Tea Party Supporters</u>	<u>Non-Tea Party Supporters</u>
Mean Rating Score	73	69	76	72	74
% 75-100	60%	50%	63%	58%	61%

Now, I am going to read you some different words or phrases being used in health care today. Please pay careful attention as I read each one. Some of these might sound somewhat alike, but they are different. For each term, please rate your overall impression of the term using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of the term and one hundred means you have a very favorable opinion of the term and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression of the term.

Based on the definition they heard, consumers report a high likelihood of wanting to use palliative care if they or a loved one had a serious illness. They also believe it is very important for patients with serious illness to have access to this type of care at all hospitals.

Likelihood to Consider Palliative Care

Importance of Palliative Care Being Made Available At All Hospitals

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

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

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

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?



Respondents in the Northeast region have more intense feelings on both of these measures.

Likelihood to Consider Palliative Care by Region

	<u>Northeast</u>	<u>Midwest</u>	<u>South</u>	<u>West</u>
Very likely	72%	64%	57%	63%
Somewhat likely	21%	28%	34%	26%
Not too/ Not at all likely	2%	6%	6%	8%

Importance of Palliative Care Being Made Available At All Hospitals by Region

	<u>Northeast</u>	<u>Midwest</u>	<u>South</u>	<u>West</u>
Very important	78%	72%	64%	60%
Somewhat important	15%	21%	29%	30%
Not too/ Not at all important	4%	4%	6%	7%

The level of importance of making palliative care available at all hospitals is consistent regardless of ethnicity.

Likelihood to Consider Palliative Care by Ethnicity

	<u>White</u>	<u>Non-White</u>
Very likely	65%	59%
Somewhat likely	27%	34%
Not too/ Not at all likely	6%	5%

Importance of Palliative Care Being Made Available At All Hospitals by Ethnicity

	<u>White</u>	<u>Non-White</u>
Very important	68%	68%
Somewhat important	25%	21%
Not too/ Not at all important	4%	9%

Regardless of party, respondents report a high likelihood of use and see an important need for this care to be made available to patients with serious illness at all hospitals.

Likelihood to Consider Palliative Care

	<u>Republicans</u>	<u>Independents</u>	<u>Democrats</u>	<u>Tea Party Supporters</u>	<u>Non-Tea Party Supporters</u>
Very likely	61%	57%	67%	63%	62%
Somewhat likely	32%	28%	28%	29%	30%
Not too/ Not at all likely	6%	10%	3%	5%	6%

Importance of Palliative Care Being Made Available At All Hospitals

	<u>Republicans</u>	<u>Independents</u>	<u>Democrats</u>	<u>Tea Party Supporters</u>	<u>Non-Tea Party Supporters</u>
Very important	55%	63%	78%	64%	69%
Somewhat important	34%	23%	18%	27%	24%
Not too/ Not at all important	9%	10%	1%	8%	5%

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.**

Actual Verbatim Comments

“Like I said earlier the comfort level it provides and the transitions it makes for their quality of life.”

“Because it makes them more comfortable. To help patients deal with their situation; their illnesses better and to be able to get better.”

“It provides comfort in a time of chaos and it provides understanding. It usually relieves both mental and physical pain.”

“Keeping them comfortable and as pain free as possible.”

“For quality of life. Just like at any time, so that the people have more quality of life.”

“I think quality of life and end of life is just very important. I think they should be as comfortable and free of stress and pain as possible.”

“I just, I think for quality of life. Getting the care that’s needed when it’s needed. Just to give the person a better overall sense of being.”

“I just, I think for quality of life. Getting the care that’s needed when it’s needed. Just to give the person a better overall sense of being.”

“Because they devote time to you and they explain it to you and explain to your family and that’s important really in any care. Speaking with the patient and the family. I went through this with my father, my dad passed away of colon cancer and my mom passed away. So care takers are the best and they are devoting more time and consideration to that sick patient.”

“I would say one thing is because with a team of doctors working with you, your chances of getting better or being in less pain or anything like that are going to be better. The other thing is you would get more education with that type of care. Not only the patient, but the family would learn more. I would think that’s it.”

“One reason, the extra layer of support. It can never hurt having that extra support to make the person as comfortable as possible. Many different people are looking at it from different angles so you can get them together on a team and they can decide what’s the best action.”

“It just makes a transition into whatever treatment they need to do smoother or maybe get their question answer they may not remember to ask when with a physician and need support at trouble time. Well I mean if they have a serious illness and they don’t know for sure what avenue to take or a love one that I concerned that may not be getting all the options in that they can utilized people that are being provided towards them to help them get answers if the physician is not answering questions.”

Profiling Key Target Consumer Audiences' Attitudes About Palliative Care

Key Finding #5

Consumers who:

- Have experienced serious illness (12% self);
- Worry “a lot” about getting a serious illness (16%); and,
- Those who have served as caregivers for family members (49%) are much more positive about palliative care throughout this data.

Profile of People Who Have Experienced Serious Illness (Self – 12%)

Key Data

Respondents in
this sub-group
tend to:

- Be age 65+
- Have a HH income under \$40K

	<u>Overall Age 25+</u>	<u>Among the 12% Experienced Serious Illness</u>
Palliative Care Initial Mean Score	57	59
Palliative Care and Supportive Services Mean Score	60	60
Palliative Care Informed Mean Score	74	74
Very Likely to Consider Palliative Care for Loved One	63%	75%
Very Important Palliative Care is Available to All	68%	78%

Profile of People Who Worry “A Lot” About Getting a Serious Illness (16%)

Key Data

Respondents in this subgroup tend to:

- Have experienced serious illness themselves or a family member
- Be working women
- Be women age 25-44
- Be women who live in urban areas
- Be women with HH income less than \$60K
- Be people who do not have health coverage

	<u>Overall Age 25+</u>	<u>Among the 16% Worry “A Lot”</u>
Palliative Care Initial Mean Score	57	49
Palliative Care and Supportive Services Mean Score	60	52
Palliative Care Informed Mean Score	74	70
Very Likely to Consider Palliative Care for Loved One	63%	71%
Very Important Palliative Care is Available to All	68%	85%

Profile of Caregivers (49%)

Key Data

Respondents in this subgroup tend to:

- Be women
- Be age 55-64
- Be women age 45-64
- Be baby boomers
- Have Medicare coverage
- Be women with HH income \$60K+

	<u>Overall Age 25+</u>	<u>Among the 49% Caregivers</u>
Palliative Care Initial Mean Score	57	59
Palliative Care and Supportive Services Mean Score	60	62
Palliative Care Informed Mean Score	74	74
Very Likely to Consider Palliative Care for Loved One	63%	67%
Very Important Palliative Care is Available to All	68%	75%

Qualitative Research:
Physicians Attitudes About
Palliative Care

Key Finding #6

It is clear 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.

This is an important context to have as you move forward with a consumer campaign because it demonstrates a problem among referring physicians that will need to be addressed.

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 belief clearly displays the need to change the perception of palliative care among possible referring physicians from one of ‘hospice’ or ‘end of life’ care to one in which palliative care is appropriate at anytime in a patient’s care and can be provided along with curative treatment.

Palliative Care

Language and Messaging

Key Finding #7

Talking about palliative care as defined in the survey helps to clearly differentiate this type of care from hospice or end of life care. Importantly, the definition developed through this research helps to differentiate palliative care from these other types of care without having to say “palliative care is not limited to end of life care.”

After hearing the definition of palliative care, respondents disagree with the statements below that link palliative care to end of life care or hospice.

	<u>Age 25+</u>		<u>Age 65+</u>	
	<u>Strongly Disagree</u>	<u>Total Disagree</u>	<u>Strongly Disagree</u>	<u>Total Disagree</u>
Palliative care is only appropriate at the end of life	57%	82%	46%	72%
Palliative care is the same as hospice care	34%	63%	26%	51%

Now I am going to read you some statements about palliative care. For each statement please tell me whether you agree or disagree with the following statements.

Key Finding #8

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

- Should be incorporated with curative treatment;
- Is appropriate at any age and any stage in serious illness; and,
- Should be covered by insurance.

Statements About Palliative Care

	<u>Age 25+</u>		<u>Age 65+</u>	
	<u>Strongly Agree</u>	<u>Total Agree</u>	<u>Strongly Agree</u>	<u>Total Agree</u>
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%	74%	96%
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%	71%	93%

Now I am going to read you some statements about palliative care. For each statement please tell me whether you agree or disagree with the following statements.

Statements About Palliative Care

	<u>Age 25+</u>		<u>Age 65+</u>	
	<u>Strongly Agree</u>	<u>Total Agree</u>	<u>Strongly Agree</u>	<u>Total Agree</u>
Discussions about palliative care treatment options with a doctor should be fully covered by health insurance.	71%	86%	58%	83%
Discussions about palliative care treatment options with a doctor should be fully covered by Medicare.	60%	80%	70%	87%

Now I am going to read you some statements about palliative care. For each statement please tell me whether you agree or disagree with the following statements.

Key Finding #9

This survey data confirms the work we did in the qualitative research phase of developing messages.

All of the new messaging resonates very well with consumers and gives them a more favorable impression of palliative care.

The top messages reinforce for consumers the goals of palliative care:

- Providing the best quality of life;
- Providing an extra layer of support for patients and families dealing with serious illness;
- Providing a team focus to patient care; and,
- That it is appropriate at any age and any stage of illness and can be provided along with curative treatment.

FROM THE CONSUMER FOCUS GROUPS – LEARNINGS ABOUT LANGUAGE:

What Language Worked?	What Language Did Not Work?
<ul style="list-style-type: none"> ✓ Palliative care improves quality of life for both the patient and the family. ✓ Palliative care provides an extra layer of support. ✓ Palliative care is provided by a team of doctors, nurses, and other specialists. The palliative care team will spend time with a patient and their family to help them understand their treatment options and goals. ✓ The goal of palliative care is to relieve suffering and provide the best possible quality of life for a patient and their family. ✓ The goal of palliative care is to relieve the symptoms, pain, and stress of serious illness. ✓ Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment. ✓ Palliative care is medical care focused on relief of symptoms, pain, and stress of a serious illness – whatever the diagnosis. 	<ul style="list-style-type: none"> × Palliative care is symptom relief. × Palliative care is comfort care. × Palliative care is not a one-size fits all approach. × Palliative care is not limited to end of life care. × Palliative care is not limited to hospice care. × Palliative care is all about treating the patient as opposed to the disease. × Palliative care can begin right at the point when a patient is diagnosed. × Palliative care is about sharing my care.

FROM THE CONSUMER FOCUS GROUPS – LEARNINGS ABOUT LANGUAGE:

- There is a significant amount of pushback to using the term hospice at all in defining palliative care. Although people have positive feelings about hospice it equates in people's mind to death and dying. This is something to stay away from in defining palliative care as it adds to the misperception that it is synonymous with end of life care. It is critical to de-link palliative care from hospice and end-of-life care.**
- It is also important to convey palliative care is not terminal illness care but instead serious illness care (e.g. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment). This is necessary to help further differentiate palliative care from hospice and end of life care.**

TOP MESSAGES:

Age 25+

	<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%

Now I am going to read you some more statements about palliative care. For each statement please tell me whether the statement gives you a more favorable about palliative care, a less favorable about palliative care, or if it makes no difference in your opinion of palliative care one way or the other.

TOP MESSAGES:

Age 25+

% Much More Fav

% Total More Fav

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 is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

55%

82%

Palliative care makes patients feel better by treating their pain and other symptoms.

53%

82%

Now I am going to read you some more statements about palliative care. For each statement please tell me whether the statement gives you a more favorable about palliative care, a less favorable about palliative care, or if it makes no difference in your opinion of palliative care one way or the other.

Messages that also work, but not as compelling as the others we tested.

Age 25+

	<u>% Much More Fav</u>	<u>% Total More Fav</u>
Palliative care provides patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.	52%	80%
Recent studies have shown that palliative care can help patients with serious illness live longer.	50%	78%
Palliative care helps patients and family members coordinate a patient's care and navigate the medical system.	47%	79%

Now I am going to read you some more statements about palliative care. For each statement please tell me whether the statement gives you a more favorable about palliative care, a less favorable about palliative care, or if it makes no difference in your opinion of palliative care one way or the other.

After respondents heard the messages, they were asked to choose the top three things most important to convey about palliative care. The table on the following page is consistent with the qualitative research and quantitative messaging.

Most Important Thing to Convey about Palliative Care Ranked by First Choice – Age 25+

	<u>First Choice</u>	<u>Combined Choice</u>
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%

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?

After hearing the positive palliative care messages, consumers become even more favorable about this type of care.

Palliative Care Image – Initial, Informed, Final

	<u>Age 25+</u>			<u>Age 65+</u>		
	<u>Initial</u>	<u>Informed</u>	<u>Final</u>	<u>Initial</u>	<u>Informed</u>	<u>Final</u>
Mean Rating Score	57	74	79	62	73	77
%75-100	15%	60%	71%	18%	55%	66%

Now having heard more information about palliative care, please rate your overall impression of palliative care using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of this and one hundred means you have a very favorable opinion of this and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression.

Key target audiences' also become much more favorable of palliative care.

Palliative Care Mean Rating Score by Key Target Audiences Age 25+ – Initial, Informed, Final

	<u>Initial</u>	<u>Informed</u>	<u>Final</u>
People who have experienced serious illness	59	74	80
People who worry "a lot" about getting serious illness	50	70	81
Caregivers	59	74	82

Now having heard more information about palliative care, please rate your overall impression of palliative care using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of this and one hundred means you have a very favorable opinion of this and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression.

Other key demographic sub-groups whose attitudes about palliative care become much more favorable throughout the survey are:

Age 25+

Women living in rural areas	43%
Women age 25-44	42%
Women with less than a college degree	42%
Conservative Democrats	41%
Working women	39%
Adults with no health care coverage	39%
Homemakers	38%
Women with a HH income under \$60K	38%
Age 55-64	37%
Republican women	37%
Quality of HC Getting Worse	37%
<u>Attend Church Sometimes/Rarely</u>	<u>37%</u>
Total	33%

Now having heard more information about palliative care, please rate your overall impression of palliative care using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of this and one hundred means you have a very favorable opinion of this and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression.

Key Finding #10

As you move forward with a consumer education campaign, it is important to keep in mind the barriers identified you will need to combat:



Physician attitudes about palliative care.



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 frame it as end of life care.

Key Finding #10

It is important to remember: Once informed, consumers are extremely positive about palliative care and want to be able to have access to this care if they need it.



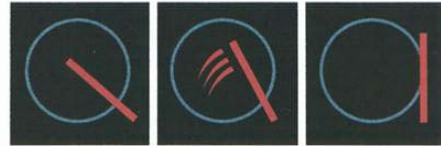
It is about improving quality of life, providing an extra layer of support, and having a team focus to patient care.



It is about how palliative care helps both the family and the patient with serious illness.



It is appropriate at any age and any stage of illness and can be provided along with curative treatment.



PUBLIC OPINION

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