

Palliative Care Research: Key Findings

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PUBLIC OPINION STRATEGIES

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Methodology:

Public Opinion Strategies conducted three national surveys in June 2019 on behalf of CAPC:

- **National telephone survey** among N=800 adults ages 25+ with an oversample of adults ages 65+ to reach an N=347 of this audience (June 8-13, 2019)
- **National online survey** among N=252 patients with serious illness and N=262 family caregivers of patients with serious illness (June 12-24, 2019)
- **National online survey** among N=317 physicians who treat patients with serious illness (N=207 hospital-based physicians/N=110 non-hospital-based physicians) (June 18-27, 2019)

Trend data is shown among adults ages 25+ and ages 65+ from a national telephone survey conducted in April 2011 on behalf of CAPC.

Key Findings: Consumer Populations

Palliative care is still relatively unknown among the general public.

	Adults Ages 25+		Adults Ages 65+	
PALLIATIVE CARE IMAGE RATING (Scale: 1=very unfavorable, 50=neutral, 100=very favorable)	Palliative Care		Palliative Care	
	<u>2011</u>	<u>2019</u>	<u>2011</u>	<u>2019</u>
Mean	57	60	62	62
Not Able to Rate	42%	38%	50%	42%

For each term, please rate your overall impression using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of it and one hundred means you have a very favorable opinion of it and fifty is neutral.

Overall initial impressions of palliative care are positive to neutral. Patients and caregivers report higher levels of familiarity than the general public audiences.

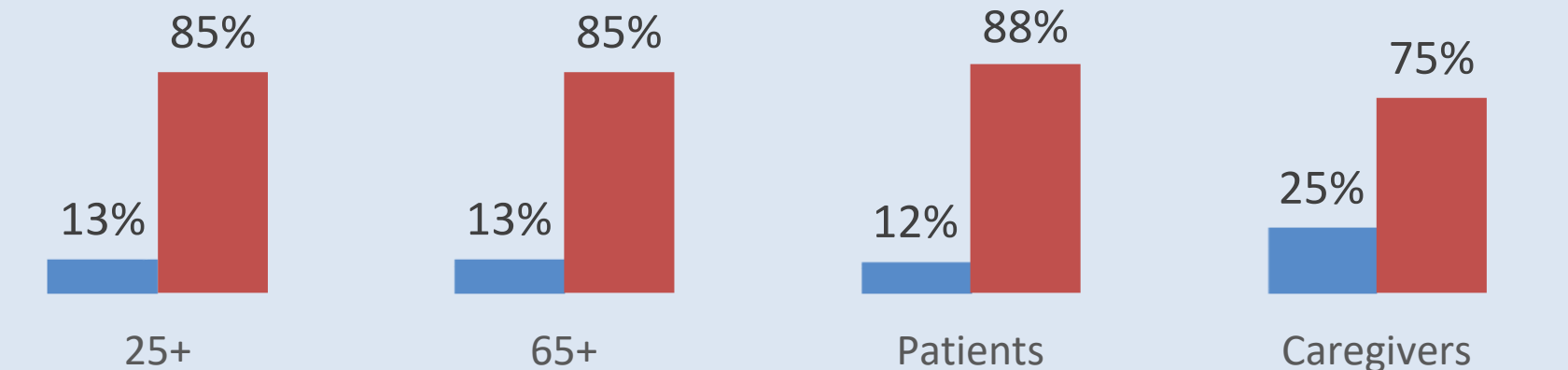
PALLIATIVE CARE IMAGE RATING (Scale: 1=very unfavorable, 50=neutral, 100=very favorable)	Adults Ages 25+	Adults Ages 65+	Patients	Caregivers
Mean	60	62	59	57
% Rating 80-100	19%	21%	29%	24%
Not Able to Rate	38%	42%	9%	10%

For each term, please rate your overall impression using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of it and one hundred means you have a very favorable opinion of it and fifty is neutral.

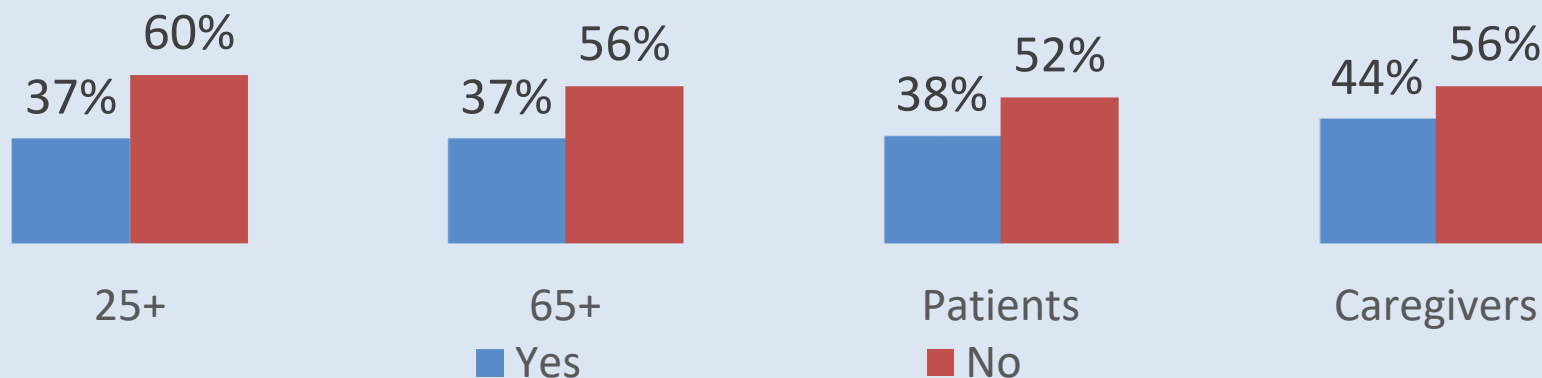


Language still makes a difference. This data continues to show that palliative care should be positioned as care for patients with serious illness but NOT advanced illness. Advanced illness is perceived to be more closely aligned with terminal illness.

Serious Illness



Advanced Illness



When you hear the phrase serious/advanced illness, do you think this generally has the same meaning as terminal illness?

We provided respondents with the following definition of palliative care:

“Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. This care is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.”

Defining palliative care in this way has a big positive impact on how people feel about palliative care. Consumers are very favorable toward palliative care based on this definition.

PALLIATIVE CARE IMAGE RATING	Adults Age 25+		Adults Age 65+		Patients		Caregivers	
	% 80-100	Mean	% 80-100	Mean	% 80-100	Mean	% 80-100	Mean
Initial	19%	60	21%	62	29%	59	24%	57
Informed	49%	72	51%	74	51%	73	51%	73
Net Difference	+30	+12	+30	+12	+22	+14	+27	+16

Now thinking about your overall opinion of palliative care based on this description, please rate your overall impression 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.

More than eight in ten consumers say they would be likely to consider palliative care for themselves or a loved one if they had a serious illness.

<u>Likely to Consider Palliative Care</u>	Adults Ages 25+	Adults Ages 65+	Patients	Caregivers
Very Likely	62%	61%	41%	51%
Total Likely	90%	87%	86%	89%
Total Not Likely	8%	8%	14%	11%

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

There is a strong belief among these consumer audiences that it is very important for palliative care services be made available at all hospitals for patients with a serious illness and their families.

<u><i>Importance of Palliative Care Services Being Available At All Hospitals</i></u>	Adults Ages 25+	Adults Ages 65+	Patients	Caregivers
Very Important	71%	71%	69%	68%
Total Important	94%	94%	94%	95%
Total Not Important	5%	5%	6%	5%

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 a serious illness and their families?



After hearing the definition of palliative care, substantial majorities of consumer audiences “strongly agree” with these premises about palliative care:

<i>%Strongly Agree – Ranked by Patients</i>	Adults Ages 25+	Adults Ages 65+	Patients	Caregivers
Palliative care treatment options should be fully covered by health insurance.	74%	77%	77%	78%
It is important that patients with a serious illness and their families be educated that palliative care is available to them together with curative treatment.	78%	80%	76%	72%
Doctors who treat patients with a serious illness should refer these patients to palliative care when the patient is experiencing difficult-to-manage pain or other symptoms	58%	62%	63%	65%
Palliative care should be available to patients with a serious illness based on a patient’s need, not based on their prognosis.	64%	70%	62%	61%

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 Findings

- **All nine of the messaging and talking points we tested regarding palliative care score well as compelling statements among consumers.**
- **Those statements that focus on improving life expectancy, providing the best quality of life, appropriate at any age and providing the care alongside curative treatment, matching treatment options to patient goals, being a team approach to care, providing an extra layer of support, and providing relief for patients.**
- **There are some modest differences in how the different consumer audiences rate these messaging statements in terms of what is most compelling to them.**

Palliative Care Messages Tested - % Much More Favorable of Palliative Care

<i>%Much More Favorable – Ranked by Patients</i>	Adults Ages 25+	Adults Ages 65+	Patients	Caregivers
Recent studies, including one published in the New England Journal of Medicine, have shown that patients with a serious illness who have received palliative care lived longer than those that did not receive this care.	56%	57%	69%	61%
The goal of palliative care is to relieve suffering and provide the best possible quality of life for a patient and their family.	58%	61%	67%	71%
Palliative care provides patients with relief from the symptoms, pain, and stress of a serious illness	49%	53%	67%	65%
Palliative care is appropriate at any age and at any stage in a serious illness and can be provided alongside curative treatment.	54%	53%	66%	56%
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.	51%	54%	64%	58%
Palliative care helps patients and family members coordinate a patient's care among health care providers and navigate the medical system.	48%	52%	63%	56%
Palliative care is available to patients with a serious illness regardless of their prognosis.	47%	52%	61%	58%
The palliative care team of doctors, nurses, and other specialists spends time with a patient and their family to help them match their treatment options to their goals.	54%	57%	60%	57%
Palliative care is about treating the patient as opposed to the disease	45%	47%	57%	56%

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 opinion about palliative care, a less favorable opinion about palliative care, or if it makes no difference in your opinion of palliative care one way or the other.

When asked to choose the two MOST important things to convey about palliative care, consumers choose relieving suffering, providing the best possible quality of life.

	25+	65+	Patients	Caregivers
The goal of palliative care is to relieve suffering and provide the best possible quality of life	29%	30%	49%	45%
The palliative care team spends time with a patient and their family to help match treatment options to their goals	23%	25%	17%	26%
It helps coordinate a patient's care and helps them navigate the medical system	19%	17%	12%	13%
Studies have shown that patients who receive it live longer	18%	11%	21%	18%
It is appropriate at any age and at any stage in a serious illness	18%	17%	15%	15%
It is about treating the patient as opposed to the disease	17%	16%	16%	21%
It provides patients with relief from symptoms, pain, and stress	16%	13%	31%	26%
It is available to patients with a serious illness regardless of their prognosis	14%	13%	16%	10%
It is a team approach to provide an extra layer of support	12%	10%	10%	11%
It can be provided together with curative treatment	9%	10%	10%	10%
None Of These	3%	3%	1%	3%

Thinking more specifically about palliative care and some of the things you have heard in the survey so far...which ONE of the following attributes do you think are most important to convey to people about palliative care?) And which is the next most important thing to convey about palliative care?

How you talk about palliative care impacts perceptions about palliative care. Attitudes about palliative care shift to become significantly more favorable throughout the course of the survey as respondents are educated about palliative care.

PALLIATIVE CARE IMAGE RATING	Adults Ages 25+		Adults Ages 65+		Patients		Caregivers	
	% 80- 100	Mean	% 80- 100	Mean	% 80- 100	Mean	% 80- 100	Mean
Initial	19%	60	21%	62	29%	59	24%	57
Informed	49%	72	51%	74	51%	73	51%	73
Post Messaging	65%	81	65%	81	66%	81	63%	79
Net Difference (Post Message-Initial)	+46	+21	+44	+19	+37	+22	+39	+22

Now having heard more information about palliative care, please rate your overall impression 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.



Key Findings: Physicians

Physicians who treat patients with serious illness are much more familiar with palliative care and have much more favorable views of palliative care than consumers.

PALLIATIVE CARE IMAGE RATING (Scale: 1=very unfavorable, 50=neutral, 100=very favorable)	Adults Ages 25+	Adults Ages 65+	Patients	Caregivers	Physicians
Mean	60	62	59	57	82
% Rating 80-100	19%	21%	29%	24%	72%
Not Able to Rate	38%	42%	9%	10%	0%

For each term, please rate your overall impression using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of it and one hundred means you have a very favorable opinion of it and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression.



In fact, these physicians' rate palliative care more favorably than hospice care and end of life care.

(Scale: 1=very unfavorable, 50=neutral, 100=very favorable)

	Physicians		
	Palliative Care	Hospice Care	End of Life Care
Mean	82	77	72
% Rating 80-100	72%	60%	58%

For each term, please rate your overall impression using a scale of zero to one hundred, where zero means you have a very unfavorable opinion of it and one hundred means you have a very favorable opinion of it and fifty is neutral. You can use any number between zero and one hundred depending on your overall feeling or impression.

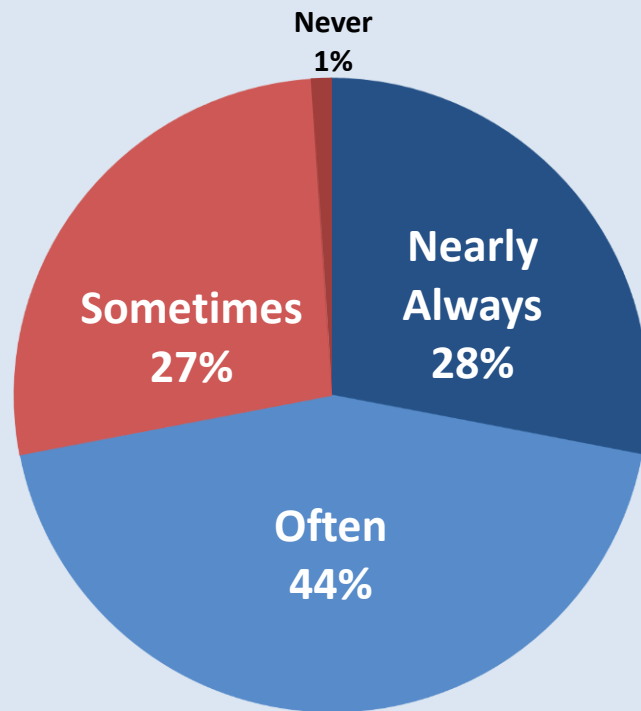
Most physicians say they are very comfortable referring their patients to palliative care. Nearly all are very or somewhat comfortable talking to their patients and families about palliative care and determining when their patients need palliative care.

<u><i>All Physicians</i></u>	Very Comfortable	Total Comfortable
Referring to your patients to palliative care.	83%	99%
Talking with your patients and their families about palliative care.	70%	98%
Determining when your patients need palliative care.	66%	98%

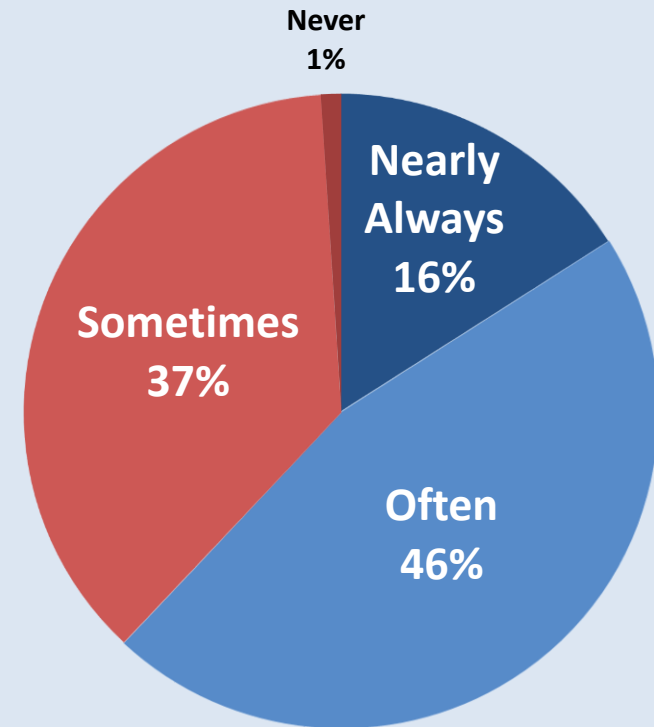
In general, please record how comfortable you are doing each of the following with your patients who have a serious illness

However, on average, physicians report that they are not always referring their patients with serious illness to palliative care or talking with their patients or their families about palliative care.

Talk with your patients and their families about palliative care



Refer your patients to Palliative Care



On average, how often, if at all, do you do each of the following with your patients who have a serious illness. Using a scale of “you nearly always do this,” “you often do this,” “you sometimes do this,” and “you never do this.”

How are these physicians saying they determine when to refer their patients with serious illness to palliative care?

Under what circumstances would you refer your patients with a serious illness to palliative care, and what would be your reasons for doing so?

- *A patient's quality of life becomes poor*
- *Patients have either chronic pain or chronic illness that needs management*
- *The family needs support or help*
- *A patient has a life-threatening diagnosis*
- *The patient would benefit from palliative care help and guidance*
- *If the patient is elderly*
- *If the patient qualifies for hospice care*

What specific criteria would you use/at what point in their illness would you typically consider referring them to palliative care?

- *No longer curable, no viable treatment options available for patient, priority is now comfort*
- *Patient has frequent hospitalizations, trips to the ICU*
- *Patient has less than six months to a year to live*
- *Terminal illness*
- *Late/end stage cancer*
- *Worsening symptoms*
- *Heart failure*
- *If they ask about palliative care*
- *When pain meds are no longer effective*

*Under what circumstances would you refer your patients with a serious illness to palliative care, and what would be your reasons for doing so?
What specific criteria would you use or at what point in their illness would you typically consider referring them to palliative care?*

When asked what the biggest barriers preventing physicians from referring their patients to palliative care are, these physicians say: physicians not being comfortable talking with patients about it, patients not wanting it, and physicians viewing palliative care as only end of life care.

<i>Ranked By First Choice</i>	1st Choice	Combined Choice
Physicians not being comfortable talking with patients and families about palliative care	17%	41%
Patients not wanting palliative care	17%	40%
Physicians view palliative care as ONLY end of life care	14%	44%
Lack of or inadequate palliative care services and professionals available	10%	31%
Lack of awareness about what palliative care options are available for patients	10%	31%
Competing treatment priorities, needing to address and treat serious illness first	9%	25%
Lack of knowledge about the criteria used to determine when to refer patients to palliative care	6%	25%
Lack of knowledge and familiarity with palliative care	6%	23%
Physicians concern that palliative care providers are not experts in all serious illnesses	4%	11%
Not sure if palliative care is covered by insurance	3%	11%
Physicians feel referring to palliative care would give up control of the patient's care	3%	17%
Other	1%	1%

From the list below, which of these would you say are the three biggest barriers preventing physicians who treat patients with a serious illness from referring their patients to palliative care?



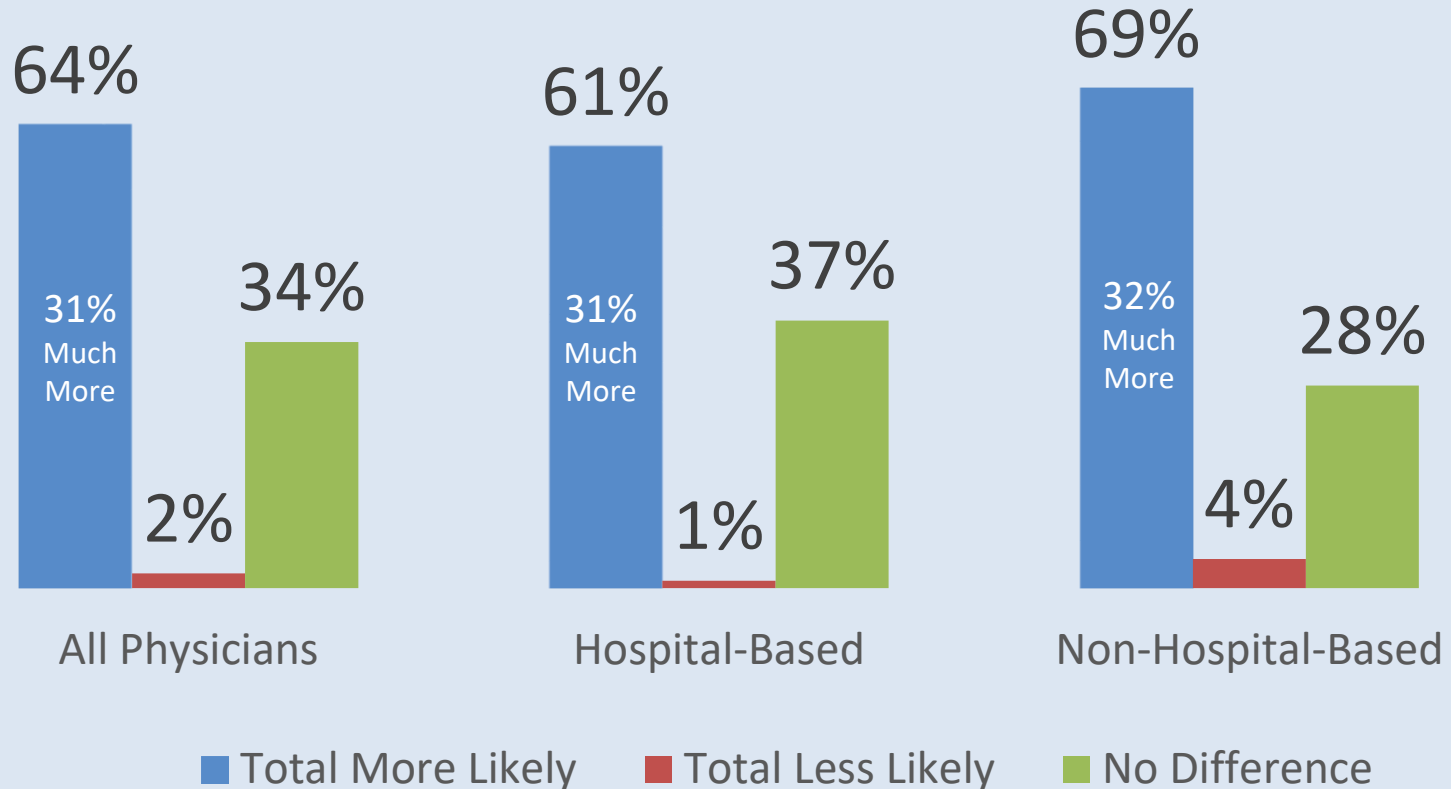
These physicians though also recognize the positive impact palliative care has for patients and their care:

<i>Ranked by %Very Positive Impact</i>	%Very Positive Impact	%Total Positive Impact
The ability to manage the pain and other symptoms for patients with a serious illness	61%	93%
The quality of life for patients with a serious illness	58%	89%
The quality of care patients with a serious illness receive	47%	85%

Please record whether you think palliative care has a very positive impact, a somewhat positive impact, a somewhat negative impact, or a very negative impact on each of the items listed below or if you think palliative care does not have an impact one way or the other.

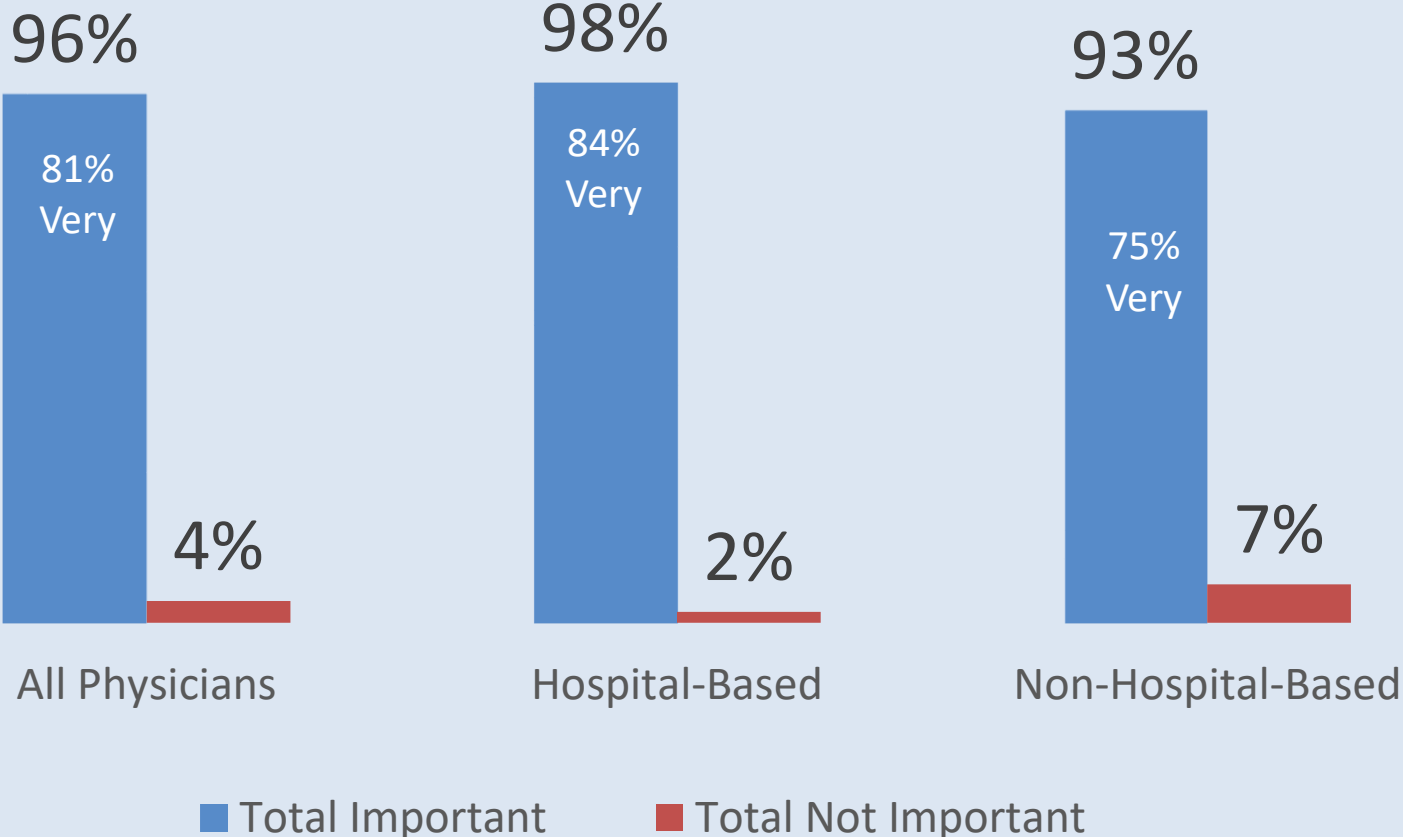


After reading the definition we provided of palliative care, more than six in ten physicians say they are more likely to consider referring patients with serious illness to palliative care.



Based on this description of palliative care are you much more likely, somewhat more likely, somewhat less likely, or much less likely to consider referring your patients with a serious illness to palliative care or does it not make a difference to you one way or the other?

And after hearing the definition of palliative care, nearly all physicians say it is important (eight in ten say it is very important) that palliative care services be made available at all hospitals for patients with serious illness and their families.



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 a serious illness and their families?

Nearly all physicians agree that:

<i>Ranked by %Strongly Agree</i>	%Strongly Agree	%Total Agree
Palliative care treatment options should be fully covered by health insurance.	80%	93%
It is important that patients with a serious illness and their families be educated that palliative care is available to them together with curative treatment.	75%	94%
Palliative care should be available to patients with a serious illness based on a patient's need, not based on their prognosis.	60%	94%
Doctors who treat patients with a serious illness should refer these patients to palliative care when the patient is experiencing difficult-to-manage pain or other symptoms.	53%	91%

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.



Top Messages: Reasons Physicians Should Refer to Palliative Care

<i>Ranked by %Much More Likely</i>	%Much More Likely	%Total More Likely
The palliative care team devotes time to intensive family meetings and patient/family counseling which helps relieve burdens on referring physicians' time.	66%	92%
Palliative care improves patient and family satisfaction with their care. Patients receiving hospital-based palliative care rate the quality of care higher than patients who do not receive palliative care.	65%	95%
Palliative care leads to better patient and caregiver health outcomes including improvement in symptoms, quality of life, patient satisfaction and reduced caregiver burden.	65%	92%
Palliative care improves the quality of life for patients and families struggling with serious illnesses that they might live with for years, including heart and lung disease, complications of diabetes, cancer, and kidney and Alzheimer's disease.	65%	91%
The palliative care team provides specialty-level assistance with the complex physical and emotional symptoms patients experience, including difficult-to-treat pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite, and difficulty sleeping.	63%	91%
Palliative care reduces ICU utilization and decreases 30-day re-admission rates by 48% for inpatient and 50% for outpatient care.	62%	92%

For each statement please indicate whether the statement makes you much more likely to refer your patients with a serious illness to palliative care, somewhat more likely, or less likely to refer your patients with a serious illness to palliative care or if it makes no difference one way or the other.



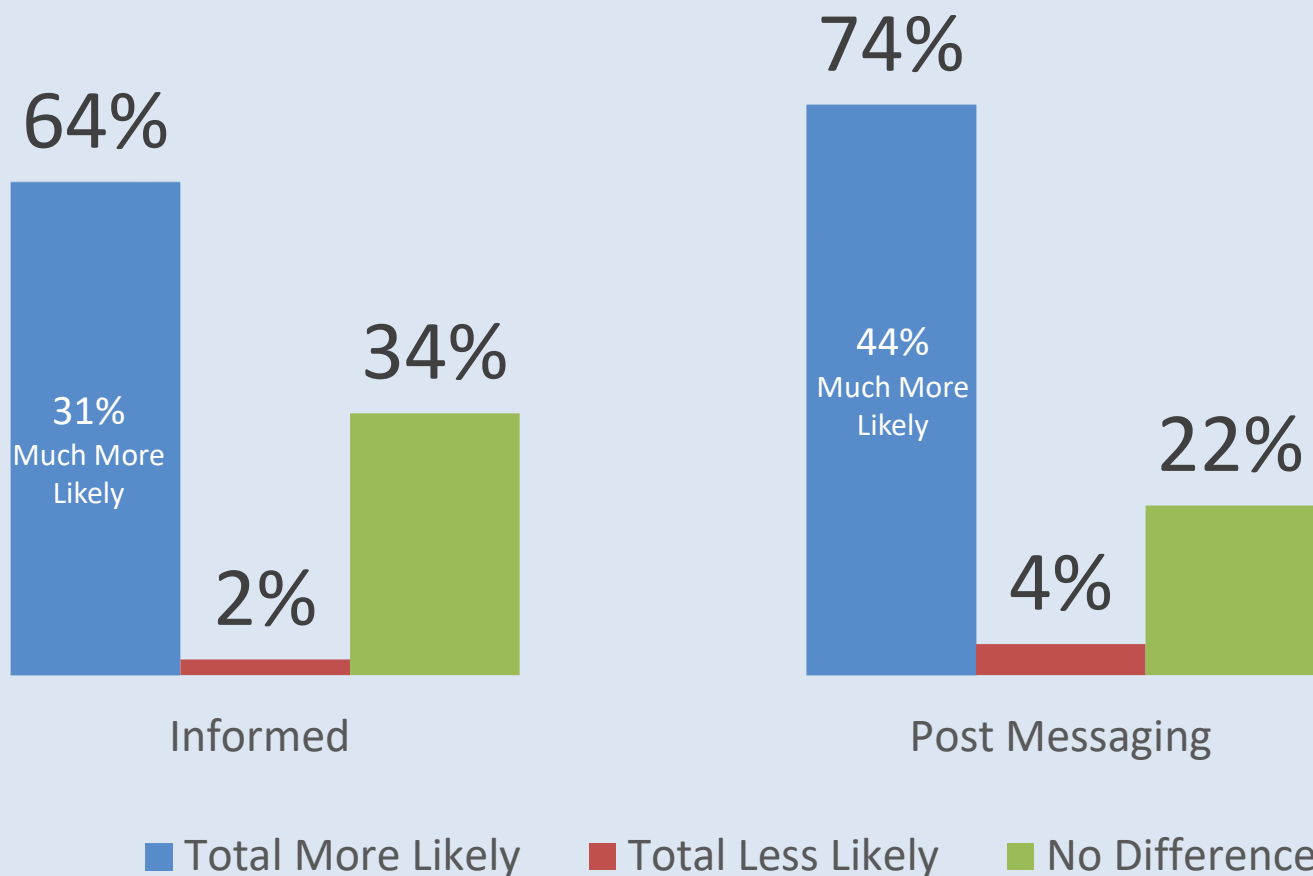
After the messages, physicians' ratings of palliative care are more positive, particularly the percentage rating palliative care a 100.

PALLIATIVE CARE IMAGE RATING	%80-100	%100	Mean
Initial	72%	29%	82
Informed	81%	29%	86
Post Messaging	86%	43%	89
Net Difference (Post Message-Initial)	+14	+14	+7

Now thinking about your overall opinion of palliative care based on this description, please rate your overall impression 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.



The messages we tested help to increase physicians' reported likelihood of referring their patients with serious illness to palliative care.



Are you much more likely, somewhat more likely, somewhat less likely, or much less likely to consider referring your patients with a serious illness to palliative care or does it not make a difference to you one way or the other?



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