Key Findings on the Perceptions of Palliative Care

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Objectives

- Track awareness, perceptions, attitudes and interest in palliative care and to see how they may have shifted since our last research effort in 2011
- Explore barriers to using palliative care among patients, family caregivers and referring physicians
- Test language, terminology, definitions and messaging to be used in discussing palliative care with key audiences

2011: Public Opinion Strategies (POS) conducted a national telephone survey among adults 25+

- ➔In 2011, Public Opinion Strategies (POS) conducted a national telephone survey among 800 adults 25+ with an oversample of seniors 65+
- ➔In 2019, we added two additional groups . . .

2019: In June, Public Opinion Strategies (POS) conducted three national surveys

National telephone survey: A total of 800 adults age 25+ oversampling to reach n=347 65+ yrs

National online survey: 252 patients with a serious illness and 262 family caregivers of patients with serious illness

National online survey: 317 physicians who treat patients with serious illness (207 hospital-based /110 non-hospital-based)

Key findings

1. Public awareness has not improved since 2011.
2. Awareness among patients and families has improved.
3. Physician awareness and favorability have improved dramatically in the last 8 years, though confusion about what palliative care is persists.
4. Provision of both an audience-tested definition and messaging markedly improve favorability ratings for the public and for physicians.
5. Message discipline and alignment across our field is essential to improve both awareness and favorability of palliative care in order to build demand and access.

Adult, Patient, Caregiver Populations

KEY FINDINGS

Strong majority of the public believe the health care system *is* meeting their needs

Is the healthcare system meeting your/your family’s personal needs?

➔Patients: 84% strongly agree

➔Family caregivers: 76% strongly agree

In what ways do patients and caregivers say the current health care system is NOT meeting the needs of patients with serious illness?

- *Medicine, doctor’s visits, health insurance and out-of-pocket* ***costs*** *are* ***too expensive***
- *There needs to be* ***more affordable*** *options for home assistance/home care*
- ***The health care system is working for the for-profit/business industry and not for patients***
- ***The cost of healthcare*** *is particularly devastating to the elderly*
- ***Seriously ill patients too often receive limited care and options for their care***
- *Doctors have too many patients so can’t provide the focus and care that patients need*
- *Doctors need to better understand patients’ needs*

Top ranked concerns - both patients and family caregivers

- **Doctors might not provide all of the treatment options available**
- Patients and families not having enough control over treatment options
- Lack of understanding about what patients and families are supposed to do when they get home
- Doctors not spending enough time talking with and listening to patients and their families
- Doctors might not talk and share information with each other

Lower priority concerns

- Doctors do not spend enough time reducing the **pain and other symptoms** for patients with a serious illness and their families
- Doctors do not spend enough time improving the **quality of life** for patients with a serious illness and their families
- Doctors might not provide personalized care
- Doctors do not take into account the **patient and family preferences** for treatment

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When asked to rate their opinion of palliative care, about 40% were *unable to do so.*

	Adults Ages 25+		Adults Ages 65+	
	Palliative Care		Palliative Care	
	2011	**2019**	**2011**	**2019**
Not Able to Rate	**42%**	**38%**	**50%**	**42%**

And there has been little to no change in the general favorability perception of palliative care since 2011

	Adults Age 25+		Adults Age 65+	
	2011	2019	2011	2019
Average	57	60	62	62

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

Initial impressions of palliative care in 2019 are neutral to positive. Patients and caregivers show higher levels of familiarity than the general public.

	Adults Age 25+	Adults Age 65+	Patients	Caregivers
Average	60	62	59	57
%Not Able to Rate	38%	42%	9%	10%

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

Key Takeaway

- Public awareness has been stable from 2011-2019, though more patients and family caregivers are familiar with the term.
- Neutral public perception reflects lack of awareness.

We provided the following definition of palliative care based on audience research:

"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.

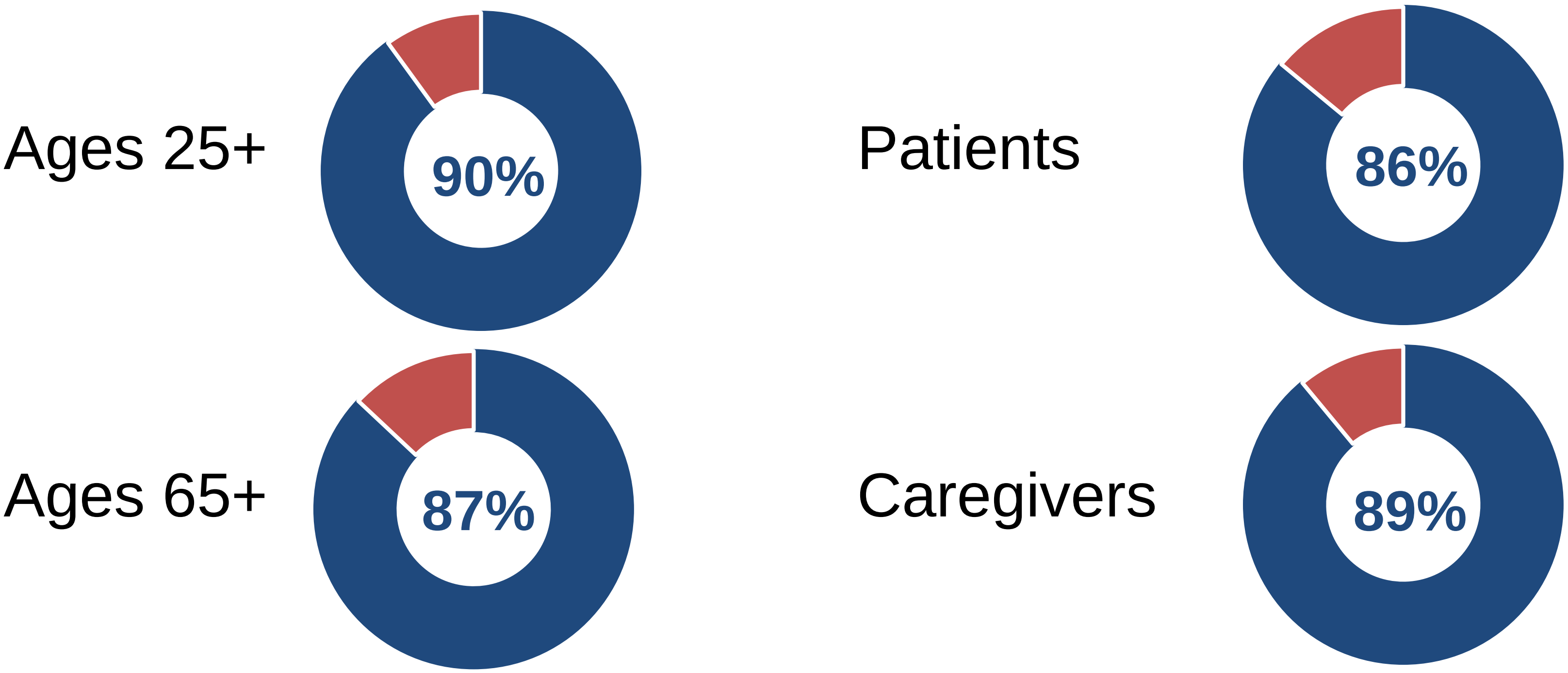
Palliative care is provided by a specially trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. This care is appropriate at any 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 positive impact on how people feel about palliative care.

	Pre-Definition (Average)	**Post-Definition** (Average)
Age 25+	60	**72**
Age 65+	62	**74**
Patients	59	**73**
Caregivers	57	**73**

After hearing the definition, more than eight in ten said they would be likely to consider palliative care for themselves or a loved one→ similar impact in 2011.

Likely to Consider Palliative Care



Palliative care messages that score well with the public:

- ➔Providing the best **quality of life**
- ➔**Relief from symptoms, pain, and stress**
- ➔Appropriate at **any age** and providing the care **alongside curative treatment**
- ➔**Matching treatment options to patient goals**
- ➔A **team approach** to care
- ➔Providing an **extra layer of support**

	Pre-Definition (Average)	Post-Definition (Average)	Post-Messages (Average)
Age 25+	60	72	**81**
Age 65+	62	74	**81**
Patients	59	73	**81**
Caregivers	57	73	**79**

[0: very unfavorable 50: neutral 100: very favorable]

Key Takeaways

- How we talk about palliative care influences perceptions about palliative care.
- Attitudes become significantly more favorable as people are educated.
- The more educated consumers become the more likely they are to say they would consider palliative care for themselves or a loved one (this is particularly true among patients and caregivers).

Key Takeaway

Language and definition/ messaging make a big difference in public attitude towards palliative care.

Physicians

KEY FINDINGS

Physicians are much more familiar and favorable towards palliative care than the general public, patients, and caregivers.

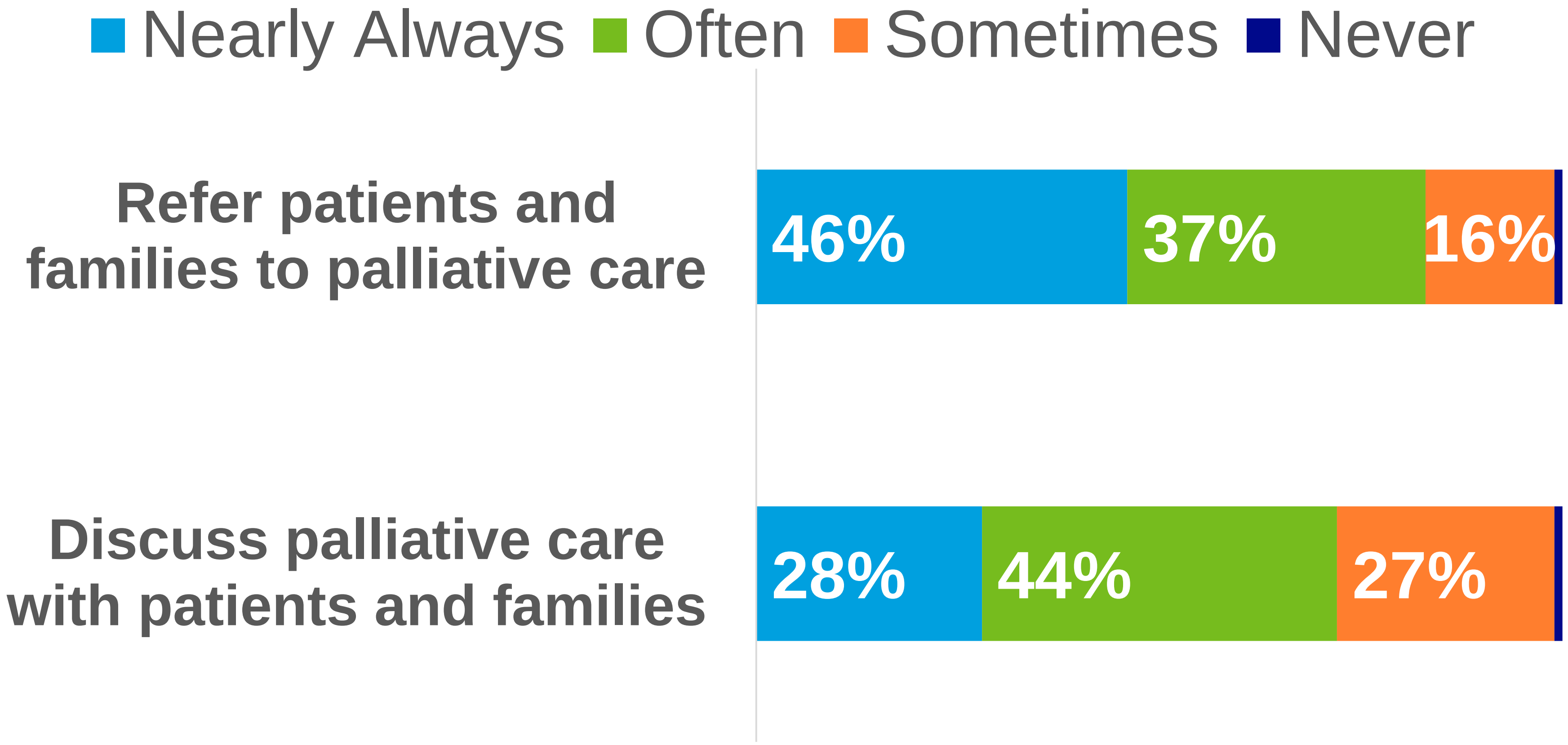
	Age 25+	Age 65+	Patients	Caregivers	Physicians
Average	60	62	59	57	**82**
Percentage that gave a score of 80-100	19%	21%	29%	24%	**72%**

[0: very unfavorable 50: neutral 100: very favorable]

Most physicians say they are very comfortable referring their patients to palliative care.

Physicians	%Very Comfortable	%Total Comfortable
Referring 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%**

Physicians report that they often or nearly always discuss with or refer their patients with serious illness to palliative care.



25

When asked about the criteria they would use to refer, however, physicians said. . .

- Illness *no longer curable*, or *no viable treatment options* available – the priority is comfort
- *Patient has a prognosis of less than six months*
- *Patient has a terminal illness*
- Patient has frequent hospitalizations or ICU stays
- If they ask for palliative care
- When pain medications are no longer effective
- When a patient has:
  - Worsening symptoms
  - Heart failure

26

When asked about the biggest barriers preventing physicians from referring appropriate patients to palliative care, they said:

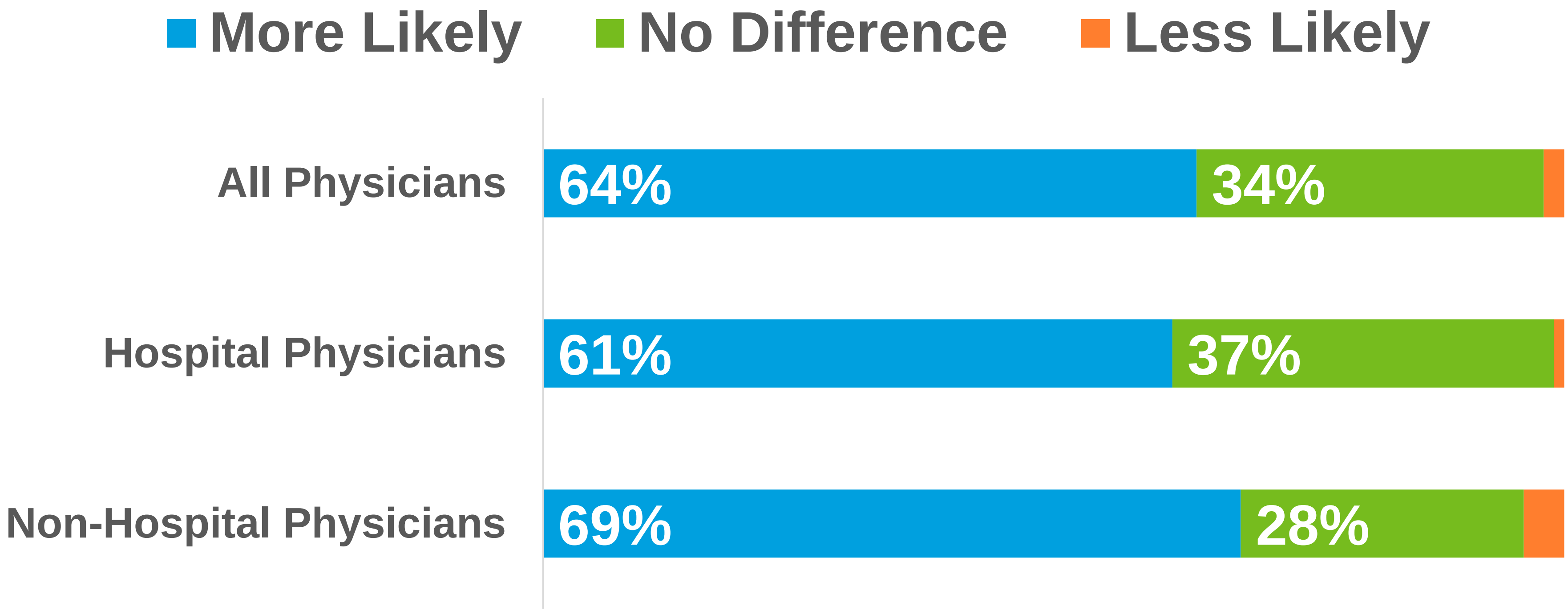
Uncomfortable talking to patients and families about palliative care
Patients do not want palliative care
Physicians view palliative care as **only end-of-life** care
Lack of availability of adequate palliative care services and practitioners
Lack of awareness about palliative care options for patients

Different barriers impacted different doctors

Differences in comfort level by physician specialty

	All Non-PCP Specialists	Oncologists	Cardiologists	Primary Care
Referring to your patients to palliative care.	81%	86%	63%	70%
Talking with your patients and their families about palliative care.	70%	77%	51%	63%
Determining when your patients need palliative care.	66%	81%	48%	57%

After reading the definition of palliative care, physicians were more likely to say they would refer.



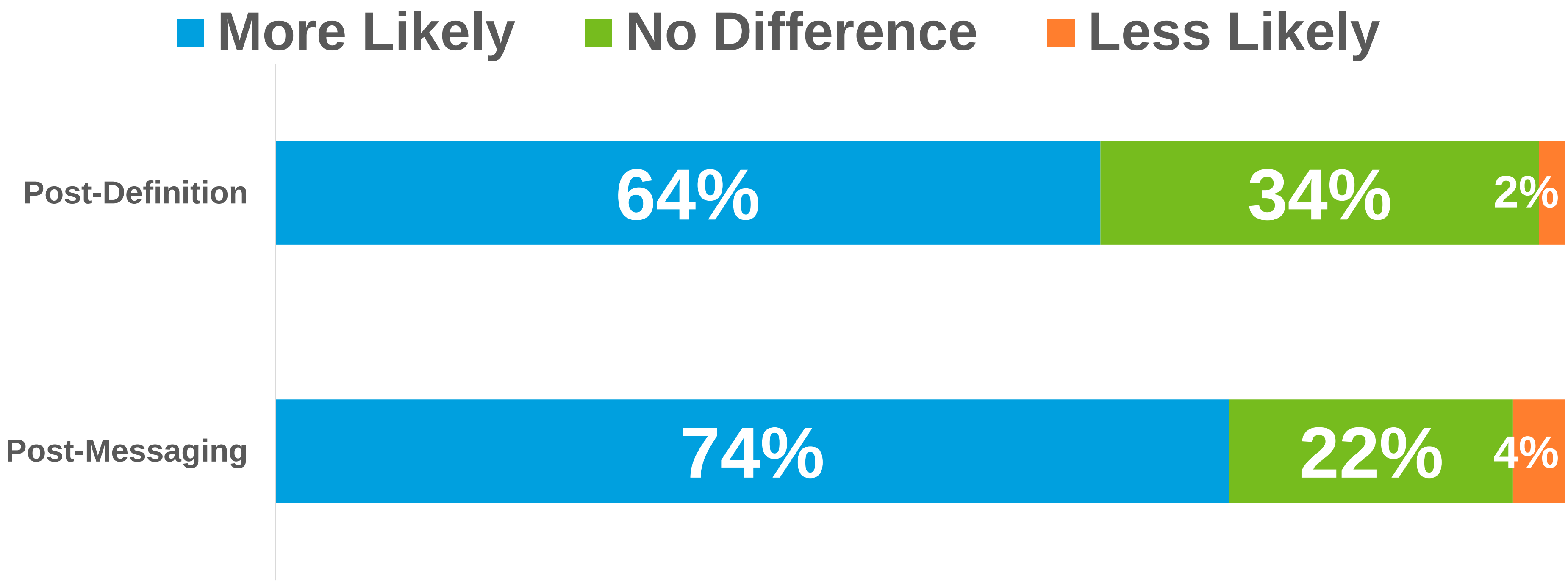
6 Messages positively influencing physician likelihood to refer (>90% more likely, >60% much more likely)

1. The palliative care team devotes *time to intensive family meetings and patient/family counseling* which helps relieve burdens on referring physicians' time.
2. 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.
3. Palliative care leads to *better outcomes* including improvement in symptoms, quality of life, patient satisfaction and reduced caregiver burden.

6 Messages positively influencing physician likelihood to refer (>90% more likely, >60% much more likely)

4. 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.
5. The palliative care team provides specialist-level *consultation* 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.
6. Palliative care *reduces ICU utilization and decreases 30-day re-admission* rates by 48% for inpatient and 50% for outpatient care.

The messages further increased their likelihood of referring patients to palliative care



Conclusion

WHAT DOES IT ALL MEAN

Consequences of message confusion

- ➔Over the last two years, how many of you been told by referral sources that their patient is not ready for palliative care, or that their patient might view it as giving up?
- ➔Why do you think this misperception is so widespread?

Proximity of words can be dangerous.

Try not to repeat the words that lead to confusion.

Social Marketing 101

Don’t define something by what it's not. The audience will remember the negative you’re trying to distinguish from:

The press is not the enemy.

(*Audience remembers press and enemy*)

vs.

Actually, the press protects the truth.

(*Audience remembers press and truth*)

What happens when we talk about palliative care and hospice in the same sentence or paragraph?

Palliative care and hospice support the patient and the family during serious illness.

➔ *Audience remembers palliative care and hospice.*

Palliative care supports the best possible quality of life for patients and their families.

➔ *Audience remembers palliative care and quality of life.*

Stay on message.

- ➔ When people are educated through use of audience-tested definition and messages, they want palliative care.
- ➔ But clinicians are the gatekeepers. It’s up to all of us and the entire field of palliative care – to correct the record.
- ➔ Use the evidence-based definition. Reinforce it by not introducing it at the same time as end of life language. Make it clear that palliative care is based on need, not prognosis.

Key Findings

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4. Provision of both an audience-tested definition and messaging markedly improve favorability ratings for the public and for physicians.
5. Message discipline and alignment is essential to improve awareness and favorability of palliative care.

Thank you.

- ➔Listen on-demand at capc.org.

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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.

Patient/Caregiver Populations Defined

Patients:

- Adults diagnosed within the past 14 years with cancer, heart failure or coronary heart disease, renal or kidney failure and on dialysis, liver failure, COPD, ALS, Stroke, and Alzheimer's disease or dementia.

Caregivers:

- Adults caring for a loved one diagnosed within the past 14 years with cancer, heart failure or coronary heart disease, renal or kidney failure and on dialysis, liver failure, COPD, ALS, Stroke, or Alzheimer's disease or dementia.
- Family caregivers who are making medical and health care decisions for their loved one, handling the paperwork and bills related to their health care, or providing physical care and assistance through the day or night. Not professional caregivers.

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Physician Population Defined

Physicians:

- Physicians who treat patients with cancer, heart failure or coronary heart disease, renal or kidney failure and on dialysis, liver failure, COPD, ALS, Stroke, and/or Alzheimer’s disease or dementia. At least 15% or higher of their patient population with at least one of these illnesses.
- Hospital-based physicians in the following specialties: hospitalists, cardiologists, oncologists (hematology, medical, and general), pulmonologists, nephrologists, critical care/intensivists, and hepatologists.
    - Hospitals with 100+ beds and have a palliative care program.
- Non-hospital-based physicians, which included the specialties above plus family/general medicine and geriatric medicine practitioners that treat patients with serious illnesses.

Demographic Profile: Adults

		Age 25+	Age 65+
Gender	Male	49%	44%
	Female	51%	56%
Age	25-44	39%	0%
	44-64	38%	0%
	65+	15%	100%
Ethnicity	White	74%	79%
	Total Non-White	26%	20%
	African American	13%	11%
	Hispanic	12%	9%
Employment	Employed	57%	15%
	Retired	27%	79%

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Demographic Profile: Adults

		Age 25+	Age 65+
Education	High School or Less	30%	35%
	Some College	27%	24%
	College +	43%	41%
Household Income	Less than $60K	33%	45%
	$60K+	57%	41%

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Demographic Profile: Adults

		Age 25+	Age 65+
Health Care Household	Total Yes	28%	26%
	Total No	72%	74%
Serious Illness Household	Total Yes	66%	67%
	Yes, Self	13%	24%
	No	33%	33%
Experience with Palliative Care	Yes	27%	26%
	No	73%	73%
Experience with Hospice Care	Yes	54%	49%
	No	46%	51%

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Demographic Profile: Patients and Caregivers

		Patients	Caregivers
Gender	Male	45%	25%
	Female	55%	75%
Age	18-44	12%	35%
	45-64	68%	52%
	65+	20%	13%
Ethnicity	White	77%	74%
	Total Non-White	22%	25%
	African American	12%	12%
	Hispanic	6%	8%
Employment	Employed	37%	49%
	Retired	49%	27%

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Demographic Profile: Patients and Caregivers

		Patients	Caregivers
Education	High School or Less	24%	25%
	Some College	35%	29%
	College +	41%	46%
Household Income	Less than $60K	57%	51%
	$60K+	42%	48%

Demographic Profile: Patients and Caregivers

		Patients	Caregivers
Health Care Household	Total Yes	2%	8%
	Total No	98%	92%
When Serious Illness Diagnosed	Less than a Year Ago	12%	14%
	1 to 5 Years Ago	52%	67%
	6 to 14 Years Ago	36%	19%
Experience with Palliative Care	Yes	14%	15%
	No	86%	85%
Experience with Hospice Care	Yes	1%	21%
	No	99%	79%

Demographic Profile: Physicians

		Physicians
Practice Setting	Hospital-Based	65%
	Non-Hospital Based	35%
Specialty	All Specialists *(hospitalist, cardiologist, oncologist, pulmonologist, nephrologist, intensivists, neurologist, heptologist)*	87%
	Primary Care Physicians	13%
Years in Practice	1 to 5 Years	23%
	6 to 10 Years	28%
	11-20 Years	30%
	More than 20 Years	19%

Demographic Profile: Physicians

		Physicians ***(Hospital Based)***
Hospital Beds	100-300	21%
	300-500	28%
	500-1,000	35%
	1,000+	16%
Employed by Hospital	Yes	89%
	No	11%
Hospital is an ACO	Yes	42%
	No	16%
	Not Sure	42%

Demographic Profile: Physicians

		Physicians
Mean % of Patients with Serious Illness		69%
Have Palliative Care training		26%
Gender	Male	69%
	Female	31%
Age	Under 45	57%
	45+	43%
Ethnicity	White	63%
	Total Non-White	29%
	Asian	22%
	African American	2%
	Hispanic	5%

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