Reframing Palliative Care: Messages Matter

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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?



Reframing can create breakthroughs.





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Some Ingredients of a Successful Social Movement

- Impassioned and motivated populace set into motion
- Language and messaging that signals consistency, reliability, and clarity

→Persuasion



The Sweet Spot of Persuasion

Audience

Benefits

Palliative Care

Differentiation



Language: What the Research Told Us

(Source: CAPC/ACS-CAN Focus Groups, Conducted by POS 2011)

"There is a significant amount of pushback to using the term hospice at all in <u>defining</u> palliative care. Although people have positive feelings about hospice, it equates in people's minds 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 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."



Evidence-Based Definition and Key Messages – Your True North

(Source: CAPC/ACS-CAN Public Opinion Research Survey, Conducted by POS2011)

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. 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.



Key Messages for Physicians

(Source: CAPC/ACS-CAN Public Opinion Research Focus Groups, Conducted by POS 2011

→ The palliative care team supports frontline physicians by devoting time to intensive family meetings and patient and family counseling.

→ It supports treating physicians by resolving questions and conflicts between families/patients and physicians on achievable goals for care.

→ It supports treating physicians by providing expertise in pain and symptom management.



"Proximity of words" can be dangerous.

So, try not to repeat the very words that lead to confusion!



Social Marketing 101

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

The Press is not the enemy. (audience remembers The Press and enemy) vs.

Actually, The Press protects the truth. (audience remembers The Press and protects truth)



The Coverage We Don't Want

(NEWS CENTER) -- Palliative care is a specialty that focuses on improving the quality of life for someone suffering from a serious, <u>life-altering illness. Hospice care falls under that umbrella, but that is specifically to deal with people who are dying</u>.



What We Learned About Imagery in 2011

"Potential consumers [patients/families] find the most compelling visuals to use in advertising and with palliative care talking points to be those which depict a patient, their family, and a palliative care doctor or nurse working together.

- ✓ Visuals should show the patient and family feeling positive and happy about their care.
- Visuals need to show that palliative care is providing support and relief for families and patients with serious illness."



What do you notice – or not notice?

Support PCHETA to help patients live better.

The PCHETA bill increases access to palliative care—a team-based approach designed to help manage pain and other symptoms, explain treatment options, and ultimately give patients more control over their care. Passing the bill could improve quality of life for millions of Americans. Learn how at **patientqualityoflife.org**.





Palliative care sees the person beyond the cancer treatment. It gives the patient control. It brings trained specialists together with doctors and nurses in a team-based approach to manage pain and other symptoms, explain treatment options, and improve quality of life during serious illness. Paliative care is all about treating the patient as well as the disease. It's a big shift in focus for health care delivery—and it works.

Cancer Action Network*

Support palliative care legislation (H.R. 1339, S. 641 & H.R. 1666). Bring quality of life and care together for the millions of families facing cancer.

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"Palliative care is all about treating the patient as well as the disease."



"Palliative care sees the person beyond the cancer treatment."

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chemotherapy

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In a Recent Study of Caregivers, These Images Tested the Best.

(Conducted by POS, 2016, Total Combined 1st, 2nd, 3rd Choice Images)



"Love, support, happiness, compassion, bonding, caring"





"Happiness, love, understanding, bonding, support, hope, familiar situation"

"Understanding, love, explaining the situation, caring, familiar situation"



Words and Messages Matter

- The field continues to use confusing language, images, and mixed messages
- Primary, generalist, specialist, advanced, serious, supportive

How meaningful are these terms to our key audiences – especially in diverse settings?



"Supportive Services" and "Advanced Illness"

(Source: CAPC/ACS-CAN Public Opinion Research, Conducted by Public Opinion Strategies, 2011

"Although adding 'supportive services,' increases the mean positive rating, it also leads to discussion about hospice and end of life."

"Language makes a difference. <u>Palliative care should be</u> <u>positioned as care for patients with serious illness *not* <u>advanced illness.</u> Advanced illness is perceived to be closely aligned with terminal illness."</u>



"Advanced Illness"

(Source: PEW Focus Groups, Conducted by Public Opinion Strategies, 2016

- Physicians have an understanding of the meaning of 'advanced illness' as "terminal, incurable, and end-stage/near death."
- → Many non-physicians are unfamiliar with the term. Some associate it with similar terms as physicians ("terminal, incurable, and end-stage/near death"). Others are just not sure what 'advanced illness' means.
- → Talk about "quality of life" instead of "death and dying."



"Advance Care Planning" Among Patients/Families

(Source: PEW Focus Groups, Conducted by Public Opinion Strategies, 2016)

- Advance Care Planning was vague and an unfamiliar term for many non-physicians. Defined as "planning ahead," "insurance," and "family involvement."
- → Not a topic they think about. Lack of awareness/knowledge even more prevalent among those under the age of 65.
- Two-thirds do not have ACPs. Reasons: procrastination, topic avoidance, healthy/young, belief that others already know their wishes, and a belief they do not need one.



To rename or not rename your program, that is often the question.







✓ Pal Care

(Only one "L" please.)



Top Positioning Opportunities

- Meetings with potential referral sources and partners
- Meetings with administration
- Media interviews and byline articles
- ✓ Journal articles/studies
- ✓ Materials
- ✓ Website
- ✓ Social Media
- Everyday conversation with non-clinicians: whenever you're asked, "What is that?" or "What do you do?"
- Progress Notes



Stay on Message!

- ✓ Know your audience
- ✓ Define/discuss palliative care in terms of what it is, not what it is <u>not</u>
- Avoid proximity to the wrong words
- ✓ Be consistent
- Repeat, Repeat, Repeat



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How to Access CAPC

→ For providers, payers, policymakers and other health care organizations: www.capc.org

- → For patients and families: www.getpalliativecare.org
- → National Palliative Care Registry: https://registry.capc.org/
- → Member organizations: Log in here at www.capc.org

